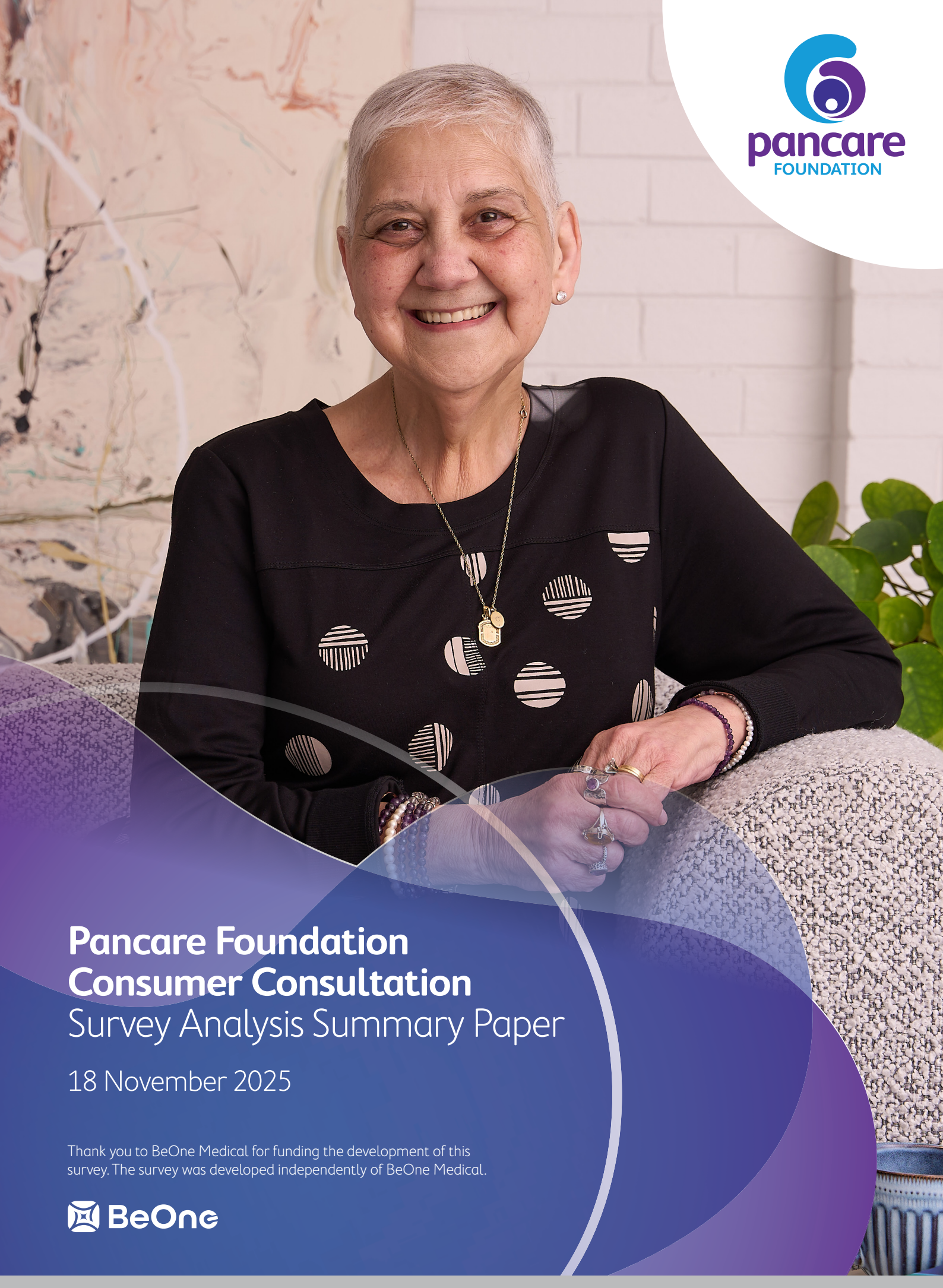

Pancare Foundation Consumer Consultation

Survey Analysis Summary Paper

18 November 2025

Thank you to BeOne Medical for funding the development of this survey. The survey was developed independently of BeOne Medical.

Pancare Foundation knowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities.

We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders both past and present.

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Abbreviations

Abbreviation	Definition
AIHW	Australian Institute of Health and Welfare
GI	Gastrointestinal
HMA	Healthcare Management Advisors
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer (or Questioning), plus
Pancare	Pancare Foundation
PBS	Pharmaceutical Benefits Scheme

1 Introduction

1.1 Background

Pancare Foundation (Pancare) has engaged Healthcare Management Advisors (HMA) to:

> *undertake a survey, interviews, and focus groups of patients with upper gastrointestinal (GI) cancers and their families/carers.*

Pancare is a national not-for-profit organisation dedicated to supporting patients with upper gastrointestinal (GI) cancers, including oesophageal, stomach, liver, biliary, and pancreatic cancers, as well as their families, friends, and carers (collectively referred to as 'carers' for the remainder of this report, unless otherwise stated). The foundation provides a range of services to raise awareness, support the physical and emotional needs of patients and families, and fund research. Current support services and resources provided by Pancare include:

- Information and resources: Pancare 'My Care KIT', website, booklets and fact sheets, and information sessions
- Community supports: online support groups for people with upper GI and their carers
- Clinical services: Telephone Helpline, one-on-one counselling, and access to as care co-ordinator and specialist upper GI cancer nurses.

Pancare has engaged HMA to conduct consumer and carer consultation (this project) to better understand the experiences and needs of those affected by upper GI cancers. The insights gathered from this project are intended to help Pancare continuously improve its existing services and develop new supports and resources that meet the needs of those with upper GI cancer and their carers.

1.2 Project Scope

The scope of the project is to deliver the following activities:

- undertake a literature scan and desktop audit of similar work in upper GI and other cancer types, both nationally and internationally, to provide a summary of consumer needs and available resources for patients and their carers
- develop a baseline survey of patients with upper GI cancer and their carers, aimed at better understanding their support needs
- obtain ethics approval for the project
- conduct the consumer and carer survey, and analyse and report on survey findings in a survey analysis summary paper (this document)
- conduct interviews and focus groups with up to 20 consumers and carers and analyse consultation outcomes
- prepare a final report triangulating findings from the survey, interviews, and focus groups.

The project commenced in April 2025 and is due to concluded in November 2025. It is being conducted through eight structured project stages:

- **Stage 1:** Project initiation (April 2025)
- **Stage 2:** Literature scan and desktop audit (May 2025)
- **Stage 3:** Development of data collection instruments (May–June 2025)
- **Stage 4:** Completion of ethics requirements (July 2025)
- **Stage 5:** Survey distribution and analysis (August–September 2025)
- **Stage 6:** Focus groups and interviews (September 2025)
- **Stage 7:** Synthesis of information (September–October 2025)
- **Stage 8:** Preparation of final report (October–November 2025).

1.3 Pancare Consumer and Carer Survey

As part of this project, HMA conducted a survey of people who have been diagnosed with an upper GI cancer within the last five years, as well as carers of people who were diagnosed with upper GI cancer in the previous five years.

The survey aimed to capture both quantitative and qualitative insights directly from people affected by upper GI cancer, including:

- their support needs in relation to upper GI cancer
- gaps in existing information and supports
- feedback on key aspects of Pancare's supports and resource offerings
- opportunities for Pancare to improve its range of resources and support services to better support people impacted by upper GI cancer and their families and carers.

The following sections provide an overview of the survey development, distribution, and analytical processes.

1.3.1 Survey development and distribution

HMA developed the survey in collaboration with Pancare, drawing on findings from the literature scan and desktop audit conducted in Stage 2 of the project. The survey was further refined for accuracy and appropriateness by an expert advisory group convened by Pancare for this project. The expert advisory group included upper GI medical specialists, nurses, allied health professionals, consumer and carer representatives, and Pancare representatives.

HMA converted the survey tool to an online survey using *SurveyManager*, an Australian-based and hosted electronic survey platform. It was then tested by six consumer and carer representatives identified via Pancare. Minor refinements were made to several survey questions based on feedback provided during testing to ensure functionality and user-friendliness.

The final online survey consisted of 59 questions for consumer participants and 35 questions for carer participants. However, due to branching logic, no participant was required to answer every question. The questions were a mix of multiple choice, single choice, Likert scale, and short-answer response options. The consent question and questions relating to the skip logic of the survey were mandatory, with the remainder voluntary.

The survey was structured as follows for both consumer and carer participants, with variations in the question wording and focus for each participant cohort:

- About you: demographic questions to help understand the representativeness of the sample
- Upper GI cancer experience: questions relating to participants' experience and support needs regarding upper GI cancer
- Pancare support and resources: knowledge, use, perceptions, and opportunities for improvement
- Future opportunities: questions to inform the development of new Pancare Foundation supports and resources.

The full survey is provided in Appendix A.

The survey was launched on 14 August 2025 and closed on 15 September 2025. It was distributed by Pancare through existing communication channels and networks, including electronic newsletters, the Pancare website, and social media (Facebook, LinkedIn, and Instagram).

1.3.2 Survey analysis

Survey data were cleaned and analysed in Microsoft Excel.

A total of 164 respondents commenced the survey, of whom 107 completed the full survey.

Nine respondents were screened out due to not meeting the survey eligibility criteria, outlined below:

- someone with a diagnosis of an upper GI cancer: liver, biliary (including cholangiocarcinoma (bile duct), gallbladder cancer or ampullary cancer), oesophageal, stomach, and pancreatic cancers; diagnosed within the last five years
- a carer of someone diagnosed with an upper GI cancer (as above) within the last five years.

Of the 48 respondents who partially completed the survey, nine were excluded due to providing insufficient data (providing only demographic details or less).

The total number of responses included in the analysis was 133. This included 48 people with upper GI cancer (referred to as consumers) and 85 carers.

Given that most questions were optional, the response rate for each question varied. The specific number of responses analysed for each survey question is indicated throughout this report.

Descriptive analysis was used for all quantitative survey questions, while thematic analysis was used to analyse qualitative survey responses.

Sub-analysis

Sub-analyses of survey responses by demographic characteristics or cancer type were not undertaken due to relatively small response rates at these levels, which limit the reliability of the data and increase the risk of re identification of respondents.

National comparator data

National comparator data in chapter 2 was based on the national **five-year prevalence** of upper GI cancers reported by the Australian Institute of Health and Welfare (AIHW). Given that the cohort surveyed were diagnosed between zero and five years ago, national five-year prevalence data for 2025 was found to be the most appropriate comparator. AIHW 2025 prevalence data is a prediction of prevalence based on actual prevalence in 2021.

Cancer types included from the AIHW prevalence data were:

- liver cancer
- pancreatic cancer
- stomach cancer
- oesophageal cancer
- biliary cancer listed as:
  - ampullary cancer
  - gallbladder and extrahepatic bile duct cancer
  - overlapping and unspecified sites in biliary tract (cancer of)

AIHW five-year prevalence data is available here.

The AIHW does not report prevalence data by jurisdiction. Therefore, national **incidence** data was used as the comparator for Figure 2.6 (which examined survey responses by jurisdiction), based on the latest complete dataset available (2021).

Cancer types included from the AIHW incidence data were:

- liver cancer
- pancreatic cancer
- stomach cancer
- oesophageal cancer
- biliary cancer listed as:
  - ampullary cancer
  - gallbladder and extrahepatic bile duct cancer

Note overlapping and unspecified sites in biliary tract (cancer of) were not recorded in the incidence data set, and therefore not included.

AIHW incidence data is available here.

1.4 Purpose and Structure of this Document

The survey analysis summary paper (this document) provides an analysis of responses to the Pancare Consumer and Carer Survey.

The remaining chapters are presented as follows:

- **Chapter 2:** Respondent profile
- **Chapter 3:** Experiences of the health system
- **Chapter 4:** Impacts of upper GI cancer
- **Chapter 5:** Upper GI cancer support
- **Chapter 6:** Next steps
- **Chapter 7:** Appendices:
  - **Appendix A:** Pancare consumer and carer survey
  - **Appendix B:** Additional survey analysis data
  - **Appendix C:** References

2 Respondent Profile

This chapter details the characteristics of respondents to both the consumer and carer surveys. Demographic characteristics of including age, gender, location, cultural and linguistic background, type of upper GI cancer and diagnosis status, as well as support network is discussed.

Key insights

- The majority of consumer respondents were aged between 50 and 79 years (91.6%). Almost half of the carer responded (48.3%) were aged 20 to 49 years.
- The majority of consumer and carer respondents were female (66.0% and 83.5%, respectively). Therefore, male perspectives may be underrepresented in the data.
- Consumer and carer respondents were most likely to live in Victoria (39.6% and 48.2%, respectively), followed by New South Wales (33.3% and 21.2%, respectively). Thus, the perspectives from health systems in non-eastern states may be limited.
- Almost 60% of consumers (58.3%) and carers (57.6%) lived in a metropolitan area, and around 30% of consumers (27.1%) and carers (35.3%) lived in a regional area. Views and additional challenges from people living in rural and remote areas may be limited.
- The majority of consumer and carer respondents were born in Australia (74.5% and 84.7%, respectively) and spoke English at home (97.4% and 95.6%, respectively). Perspectives from culturally and linguistically diverse populations may be limited.
- One consumer (2.1%) and one carer (1.2%) identified as being from an Aboriginal and Torres Strait Islander background.
- Consumers (63.5%) and carers (58.3%) were most likely to have or care for someone with pancreatic cancer, which were higher than the proportion of national prevalence at 24.8%). Therefore, responses may be skewed to the needs of pancreatic cancer patients above other upper GI cancers.
- Over half of consumers (52.1%) and carers (69.4%) were diagnosed (or caring for someone diagnosed) between one and five years ago.
- Considering the stage of their cancer journey, consumers were most likely to be receiving initial treatment (22.9%), recovering from treatment (27.1%) or in remission (18.8%). The majority of carers indicated their loved one had died (67.1%).
- Almost all consumers indicated they had a main support person (95.8%).
- Support people were most likely to be a partner or spouse (indicated by 69.6% of consumers and 32.9% of carers) or a child of the person with upper GI cancer (indicated by 17.4% of consumers and 43.5% of carers).

2.1 Age and Gender of Consumer Respondents

Figure 2.1 shows the age distribution of consumer respondents. The majority of consumer responders were aged between 50 and 79 years (n=44, 91.6%); 14 responses from people aged 50–59 years (29.2%), 16 responses from people aged 60–69 years (33.3%), and 14 responses from people aged 70–79 years (29.2%). Only 4.2% (n=2) of respondents were aged 80 or over, and only 4.2% (n=2) were aged 40–49. There were no respondents under 40 years of age.

Figure 2.2 suggests that the proportions of consumer respondents by age are consistent with the national prevalence of upper GI cancer in Australia (based on AIHW 2025, five-year national prevalence projections).

Figure 2.1: Age distribution of consumer respondents (n=48)

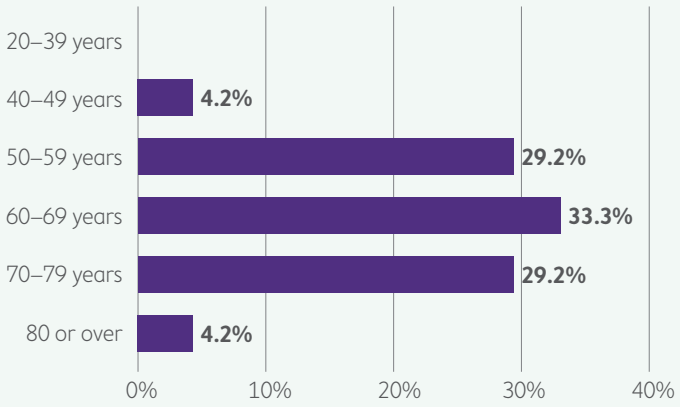
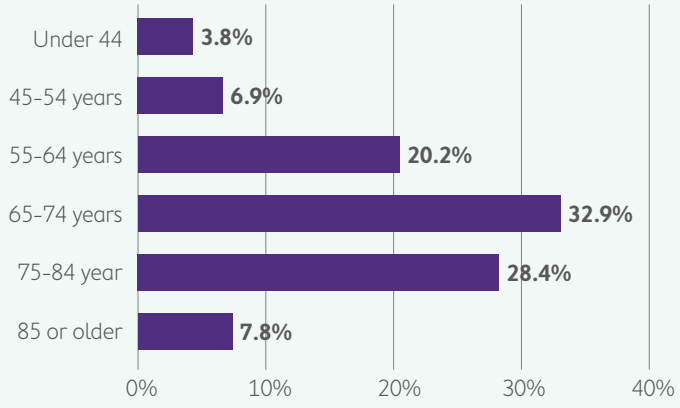


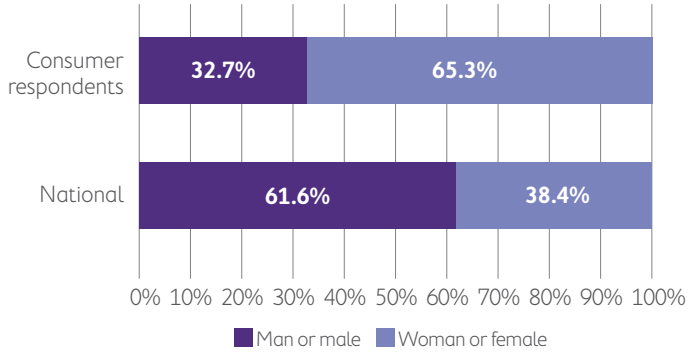
Figure 2.2: National prevalence of upper GI cancers by age group (2025)



Source: AIHW, Cancer data in Australia (2025). The 2025, five-year national prevalence projections of upper GI cancers was used as the national comparator, as detailed in section 1.3.2.

Figure 2.3 shows consumer respondents by gender compared to national proportions of upper GI cancer patients (based on AIHW 2025, five-year national prevalence predictions). The majority of consumer survey respondents were females with upper GI cancer (n=31, 66.0%), while male respondents accounted for 34.0% (n=17). National prevalence data indicate that upper GI cancer is more common among males (63%) compared to females. However, this is mostly in liver, stomach and oesophageal cancers (data not shown), which had low response rates in this survey (see section 2.5.1).

Figure 2.3: Consumer respondents by gender compared to the 2025 national prevalence of upper GI cancer by gender (2025) (n=47)



Source: AIHW, Cancer data in Australia (2025). The 2025, five-year national prevalence projections of upper GI cancers was used as the national comparator, as detailed in section 1.3.2.

2.2 Age and Gender of Carer Respondents

Figure 2.4 shows the distribution of carer respondents by age. Carers were mostly aged 25–39 (27.1%, n=23), 40–49 (21.2%, n=18), or 60–69 (20.0%, n=17), followed by 50–59 years (14.1%, n=12). Very few carer respondents were young (aged 18–24, 4% (n=3)) or elderly (aged 80 or over, 5% (n=4)).

Figure 2.4: Proportion of carer respondents by age (n=85)

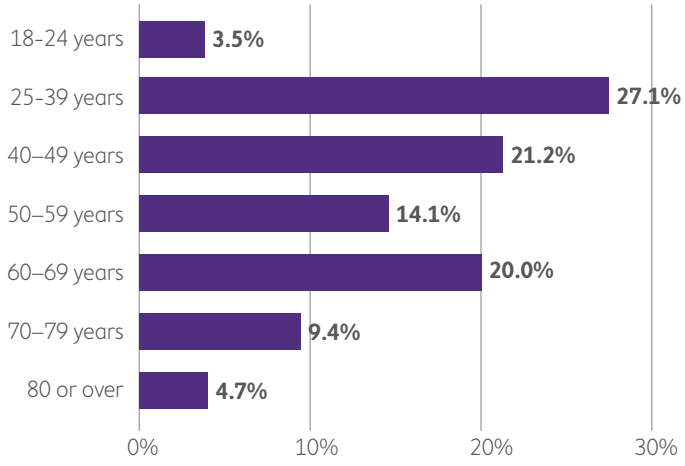
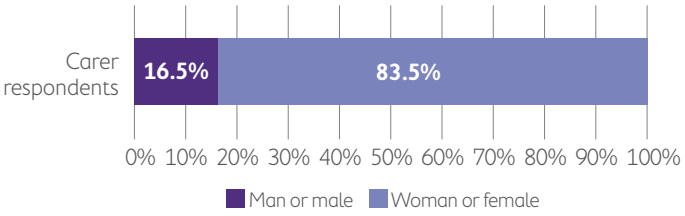


Figure 2.5 shows the gender distribution of carer respondents was predominantly female (83.5%, n=71), with male carer respondents representing 16.5% (n=14).

Figure 2.5: Proportion of carer respondents by gender (n=85)



2.3 Jurisdiction and Remoteness

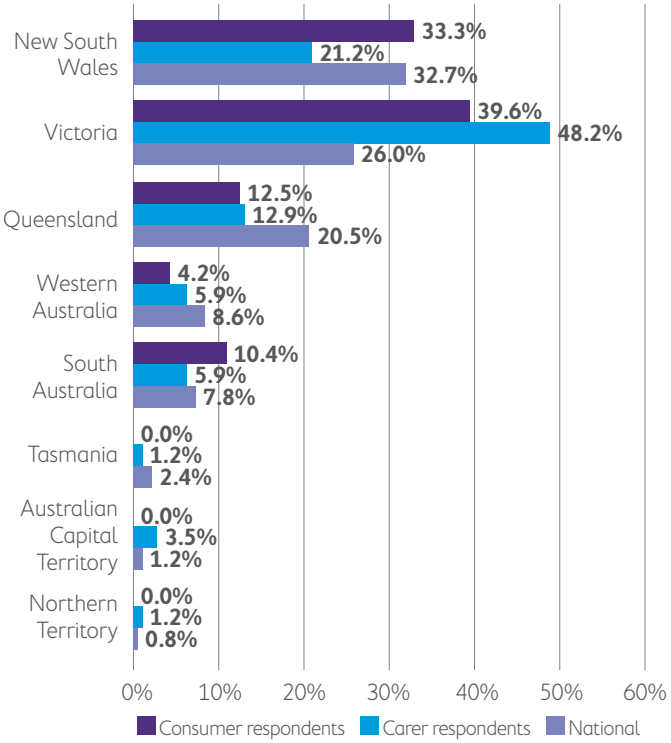
An analysis of where consumer and carer respondents lived was undertaken by jurisdiction and remoteness. Figure 2.6 shows the proportion of consumer and carer respondents by jurisdiction.

The analysis by jurisdiction showed that the highest number of **consumer respondents** lived in Victoria (39.6%, n=19), followed by New South Wales (33.3%, n=16), and Queensland (12.5%, n=6). No consumer participants were from the Australian Capital Territory, Northern Territory, or Tasmania.

The distribution of **carer respondents** mirrored that of consumer respondents, with carers from Victoria accounting for 48.2% (n=41) of the carer cohort, followed by New South Wales at 21.2% (n=18) and Queensland at 12.9% (n=11).

Comparison to the distribution of people with upper GI cancer (based on 2021 national incidence data by jurisdiction) showed that survey respondents generally reflected the national proportions of upper GI cancer incidence (see Figure 2.6, New South Wales 32.7%, Victoria 26.0% and Queensland 20.5%), although the surveys had higher-than-anticipated response rates in Victoria.

Figure 2.6: The distribution of consumer (n=48) and carer (n=85) respondents by jurisdiction compared with national incidence by jurisdiction (2021)



Source: AIHW, Cancer data in Australia (2025) The 2021 national incidence by jurisdiction was used as the national comparator, as detailed in section 1.3.2.

Table 2.1 shows the comparison of consumer and carer respondents' locations by remoteness. In both cohorts, over half of respondents were from metropolitan areas (58.3% of consumers (n=28) and 57.6% of carers (n=49)), followed by regional areas (27.1% of consumers (n=13) and 35.3% of carers (n=30)). A few responses from each cohort were from a rural location (12.5% of consumers (n=6), and 7.1% of carers (n=6). Neither cohort had respondents living in remote or very remote areas. The distribution by remoteness largely reflects the total population distribution across Australia (see AIHW data on rural and remote health available here). No response from remote or very remote locations is not unexpected given the small response size of both surveys.

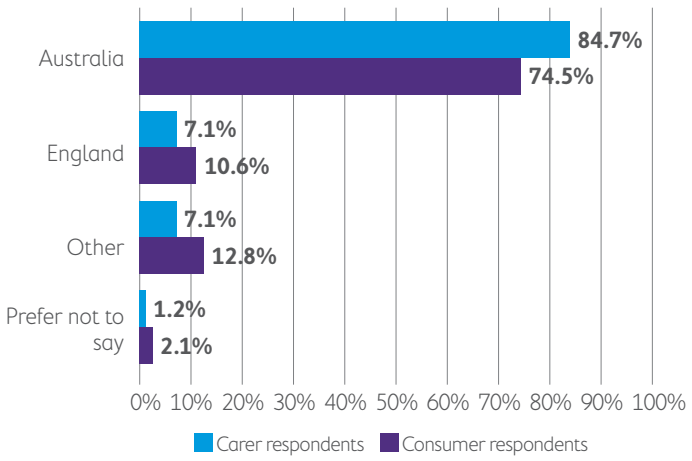
Table 2.1: Consumer (n=47) and carer (n=85) respondents by remoteness

Remoteness	Consumer Respondents N (%)	Carer Respondent N (%)
Capital city/ metropolitan area	28 (58.3%)	49 (57.6%)
Regional area	13 (27.1%)	30 (35.3%)
Rural area	6 (12.5%)	6 (7.1%)
Remote area	0 (0.0%)	0 (0.0%)
Very remote area	0 (0.0%)	0 (0.0%)
Total	**47 (100.0%)**	**85 (100.0%)**

2.4 Cultural Background

Figure 2.7 presents the proportions of consumer and carer respondents by country of birth. The majority of both cohorts were born in Australia (74.5% of consumers (n=35) and 84.7% of carers (n=72)). Approximately one-tenth of respondents were born in England (10.6% of consumers (n=5) and 7.1% of carers (n=6)). A small proportion of respondents indicated they were born in 'other' countries (12.8% of consumers (n=6) and 7.1% of carers (n=6)). *Other* countries of origin for consumers included Scotland, the Netherlands, Ireland, Malaysia, Holland, and the USA (n=1, 2.1% each). For carers, other countries of origin included two (2.4%) from New Zealand (n=2, 2.4%), and one from each of South Africa, Germany, Scotland, and Vietnam (n=1, 1.2% each).

Figure 2.7: The proportion of consumer (n=47) and carer (n=85) respondents by their country of birth



Note: One consumer responded with 'not applicable' and was excluded from the data, causing the total number of responses to be 47.

As shown in Table 2.2, English was the main language spoken at home by almost all respondents from both surveys (97.9% (n=47) of consumers, and 96.5% (n=82) of carer respondents). One consumer respondent (2.1%) said they would prefer not to say. 'Other' carer responses included one each for Polish and English, Afrikaans, or French (1.2%, n=1 each).

Table 2.2: The proportion of consumer (n=48) and carer (n=85) respondents by language spoken at home

Main Language Spoken at Home	Consumer N (%)	Carer N (%)
English	47 (97.9%)	82 (96.5%)
Other	-	3 (3.5%)
Prefer not to say	1 (2.1%)	-
Total	**48 (100.0%)**	**85 (100.0%)**

Carers and consumer respondents were also asked if they were of Aboriginal or Torres Strait Islander background. Table 2.3 shows that most respondents across both surveys did not identify as Aboriginal or Torres Strait Islander (95.8% (n=46) of consumers and 97.6% (n=83) of carers). One consumer (2.1%) and one carer respondent (1.2%) identified being both Aboriginal and Torres Strait Islander. One consumer (2.1%) preferred not to say, while one carer respondent (1.2%) did not respond to the question.

Table 2.3: The proportion of consumer (n=48) and carer (n=85) respondents by Aboriginal and Torres Strait Islander background

Aboriginal or Torres Strait Islander Background	Consumer N (%)	Carer N (%)
No	46 (95.8%)	83 (97.6%)
Yes (both)	1 (2.1%)	1 (1.2%)
Prefer not to say / no answer	1 (2.1%)	1 (1.2%)
Total	**48 (100.0%)**	**85 (100.0%)**

2.5 Upper GI Cancer Diagnosis

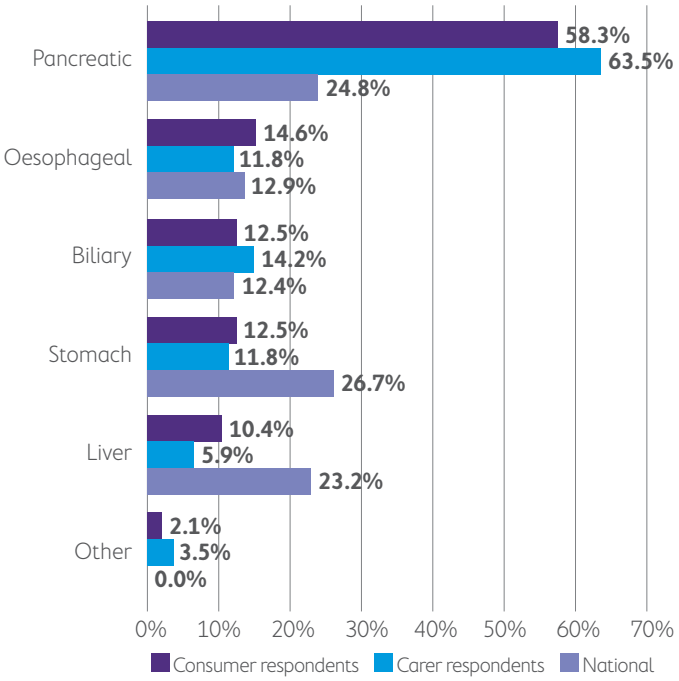
This section discusses the type of upper GI cancer diagnosis, time since diagnosis, status, and support network of the consumer respondents or the loved one of the carer respondents.

2.5.1 Type of upper GI cancer

Figure 2.8 shows the proportion of consumer and carer respondents by cancer type relative to the national proportions. Pancreatic cancer was significantly more common among consumer respondents at 58.3% (n=28) and person being cared for by carer respondents at 63.5% (n=54). Between 11.0% and 15.0% of consumer and carer respondents indicated they or their loved one had biliary (12.5% (n=6) of consumers, 14.1% (n=12) of carers), oesophageal (14.6% (n=7) of consumers and 11.8% (n=10) of carers) and/or stomach cancer (12.5% (n=6) of consumers, 11.8% (n=10) of carers). Liver cancer was the least reported cancer among both cohorts (10.4% (n=5) of consumers and 5.9% (n=5) of carers).

The proportion of pancreatic cancer among survey respondents was notably higher than the national proportion (based on AIHW 2025, five-year national prevalence projections, at 24.8%). This overrepresentation could be linked to the history of the Pancare Foundation's user base, which was a dedicated pancreatic cancer website (2019) before expanding to include other types of upper GI cancer [1]. Conversely, the proportion of liver cancer was notably lower among survey respondents than the national proportions (23.2%). The reasons for this were not explored in the survey.

Figure 2.8: The proportion of consumer (n=48) and carer (n=85) respondents by cancer type compared to the national prevalence predictions (2025)



Source: AIHW, Cancer data in Australia (2025). The 2025, five-year national prevalence projections of upper GI cancers were used as the national comparator, as detailed in section 1.3.2.

Among the 48 consumer respondents, there were five co-occurrences of upper GI cancer. Four (8.3%) had both liver and pancreatic cancer, while one (2.1%) had liver and stomach cancer. However, whether these were due to metastatic disease or two separate primaries was not explored in the survey.

Carers also identified whether the people they cared for had multiple upper GI cancers. Of the 85 carers, nine indicated co-occurrences of upper GI cancers, with the following combinations identified:

- liver and pancreatic cancer (2.4%, n=2)
- liver and biliary cancer (1.2%, n=1)
- liver and pancreatic (1.2%, n=1)
- liver, stomach and pancreatic (1.2%, n=1)
- liver and stomach (1.2%, n=1)
- biliary and pancreatic cancer (1.2%, n=1)
- oesophagus and stomach (1.2%, n=1)

Additionally, among the 'other' cancer types identified from carer respondents (3.2%, n=3) were both spleen and throat cancer, and one respondent stated they were unsure of the upper GI cancer type. Again, whether the cooccurrences were due to metastatic disease or separate primaries was not explored in the survey.

2.5.2 Time since diagnosis

Table 2.4 identifies the time proportions since the diagnosis of upper GI among consumer and carer respondents. Most consumers and patients being cared for by carers were diagnosed 1–5 years ago, accounting for 52.1% (n=25) of consumers or 69.4% (n=59) of carer responses. One-quarter of consumers (n=12) indicated they were diagnosed 6–11 months ago, and 18.8% of carers indicated their loved one was diagnosed 6–11 months ago. Slightly fewer consumers (22.9%, n=11) and patients cared for by carers (11.8%, n=1) were diagnosed within the last 6 months.

Table 2.4: Time since diagnosis for consumer (n=48) respondents and the person being cared for (n=85)

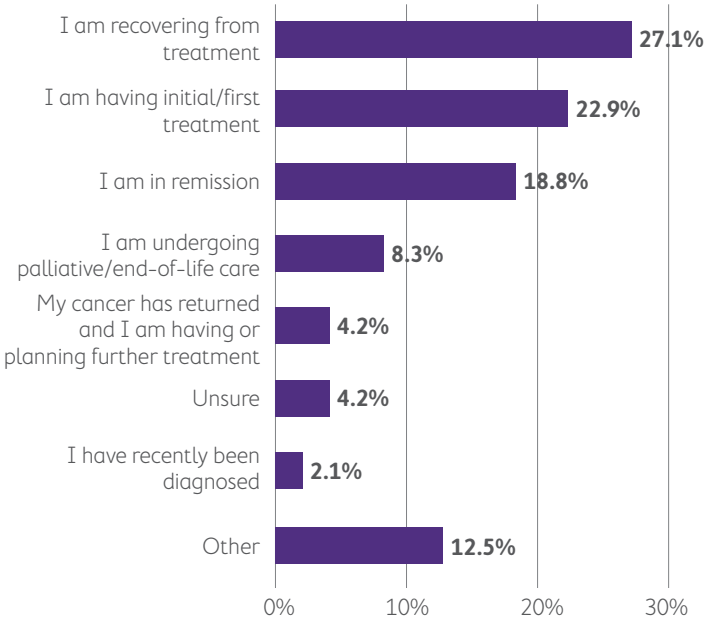
Timeframe	Consumers	Carers
Less than 6 months ago	11 (22.9%)	10 (11.8%)
6–11 months ago	12 (25.0%)	16 (18.8%)
1–5 years ago	25 (52.1%)	59 (69.4%)
Total	**48 (100.0%)**	**85 (100.0%)**

Note: Anyone diagnosed over 5 years ago was screened out to ensure the recency of data.

2.5.3 Cancer treatment status

Figure 2.9 displays the distribution of **consumer respondents** by their cancer treatment status. The largest group was consumer respondents who were recovering from treatment at 27.1% (n=13), followed by respondents undergoing their first treatment at 22.9% (n=11) and people in remission at 18.8% (n=9). Only 8.3% (n=4) reported being in end-of-life care. Additionally, 4.2% (n=2) said they were planning further treatment because their cancer had returned.

Figure 2.9: The proportion of consumer respondents by their cancer treatment status (n=48)



Of the six consumer respondents who selected 'other', responses included:

- enrolled in a clinical trial (4.2%, n=2)
- past treatment and in a monitoring stage (2.1%, n=1)
- on the second round of targeted therapy (2.1%, n=1)
- on ongoing target therapy, but did not specify how many rounds (2.1%, n=1)
- on their third round of treatment (2.1%, n=1)

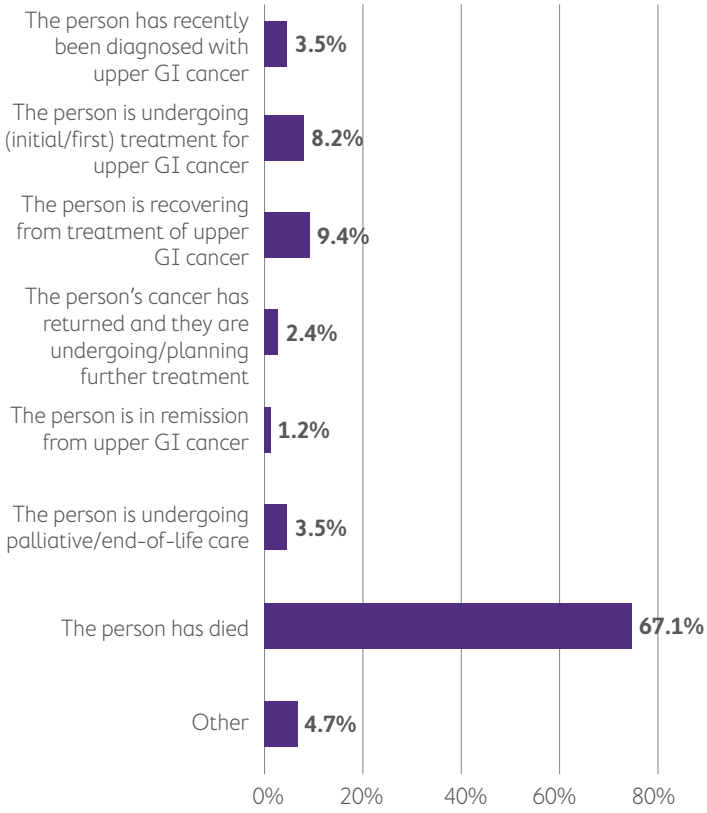
Therefore, 16 consumers (33.3%; based on responses to initial/first treatment and other) were undergoing some form of treatment (in any round of treatment, undergoing targeted therapy or participating in a clinical trial) at the time of completing the survey.

Figure 2.10 shows the cancer status among patients cared for by **carer respondents**. A significant portion of these patients had passed away, accounting for 67.1% (n=57) of the cohort. The next largest group was patients receiving treatment, comprising 9.4% (n=8), followed by those undergoing initial treatment, at 8.2% (n=7).

For the four carers who reported 'other', the cared for person's cancer treatment status was described as follows:

- participating in a clinical trial (n=1, 1.2%)
- off treatment (n=1, 1.2%)
- chemotherapy and radiation therapy for an inoperable tumour (n=1, 1.2%)
- adjuvant chemotherapy (n=1, 1.2%)

Figure 2.10: The cancer status among patients cared for by respondents (n=85)

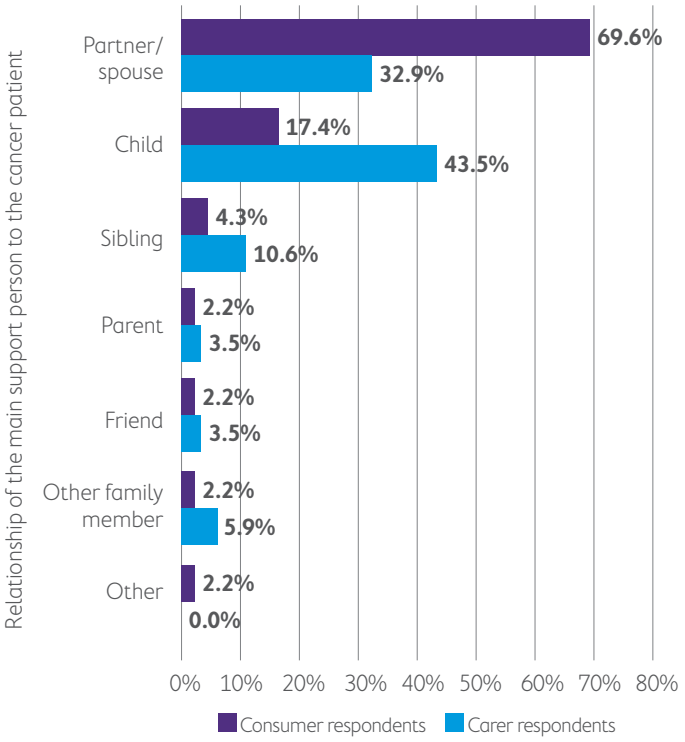


2.5.4 Support people

Of the 48 consumer respondents, 95.8% (n=46) reported having a main support person, and only 4.2% (n=2) did not. Of the 46 who had a support person, 44 specified their relationship, see Figure 2.11.

Partners or spouses were the most common main support person, accounting for 69.6% (n=32), followed by children at 17.4% (n=8) and siblings at 4.3% (n=2). Parents, friends, and other family members combined comprised only 6.5% (n=3) of the main support persons. The one respondent who chose 'other' did not provide further details.

Figure 2.11: The relationship of the main support person to the cancer patient (consumer n=46, carer n=85)



Carers were also asked about their relationship to the person they care for. Figure 2.11 shows the relationship between the carer and patient. Carer respondents were most likely to be the cancer patient's child (n=37, 43.5%), followed by the cancer patient's partner or spouse (n=28, 32.9%). Almost one-quarter of carers (23.5%, n=20) were either a friend, parent, sibling or other family member to the person with upper GI cancer.

3 Experiences of the Health System

This chapter focuses on the experiences of consumer survey respondents within the health system in relation to their upper GI cancer diagnosis.

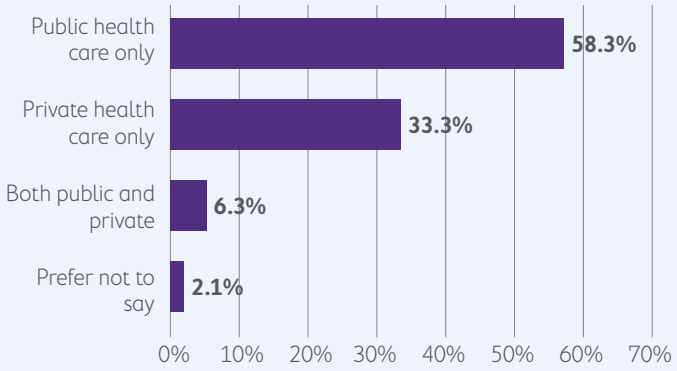
Key insights

- Almost 60% of consumers (58.3%) reported using public health services only for their cancer care, with one-third (33.3%) using private health care services only.
- Most consumers (81.3%) preferred to receive chemotherapy at a hospital/treatment centre, indicating limited demand for in-home treatment models.
- Over half of consumers (54.2%) were not offered a discussion about clinical trial options by their healthcare provider. Among consumers that did not participate in a clinical trial, the main reason was that none had been offered.
- Just over half of consumers (52.1%) reported not having accessed a specialist upper GI cancer nurse through their hospital/treatment centre. The top reasons cited were lack of referral and lack of availability at their hospital.
- Access to dietetic support is high, with 85.4% of consumers reporting having accessed a dietitian as part of their care.
- Access to exercise physiologists or physiotherapists was relatively low among consumer respondents (38.3% access), with the main barrier being that the healthcare team did not recommend it (39.3%).
- Almost 60% of consumer respondents (59.6%) did not understand the concept of molecular tumour testing, indicating a potential knowledge gap.
- Telehealth was widely used by consumer respondents (80.9%), but delivery was predominantly via telephone appointments (70.2%), with video less common (25.5%).
- The main reported barriers to using technology as part of care reported by consumers was that their health professional(s) did not offer technology options (14.9%) and a lack of confidence/comfort (12.8%).
- Among the few consumers in remission, half (50%, n=4) reported being offered supportive care after their treatment concluded.

3.1 Use of the Health System

As shown in Figure 3.1, almost 60% of consumer respondents (58.3%, n=28) reported using public health services only for their cancer care, and one-third (33.3%, n=16) used private health services only. A small minority used a mix of both private and public health services (6.3%, n=3).

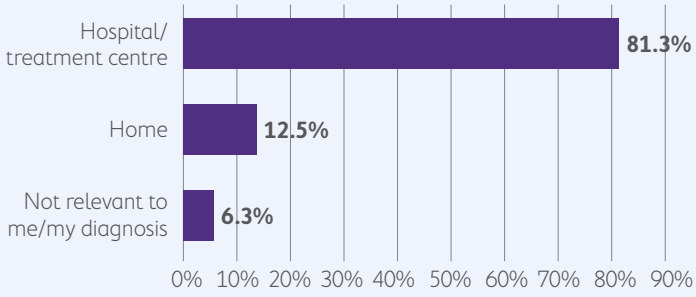
Figure 3.1: Use of public and private health care services used for cancer care (n=48)



3.2 Preferred Location for Chemotherapy

Consumer respondents were asked where they would prefer to receive chemotherapy treatment, if possible and relevant to them. The majority of consumers (81.3%, n=39) indicated they would prefer to receive chemotherapy treatment at a hospital/treatment centre (Figure 3.2). Only 12.5% (n=6) reported a preference for chemotherapy at home, while 6.3% (n=3) indicated chemotherapy was not relevant to them or their diagnosis.

Figure 3.2: Preferred location of chemotherapy (n=48)



Note: respondents were able to provide multiple responses.

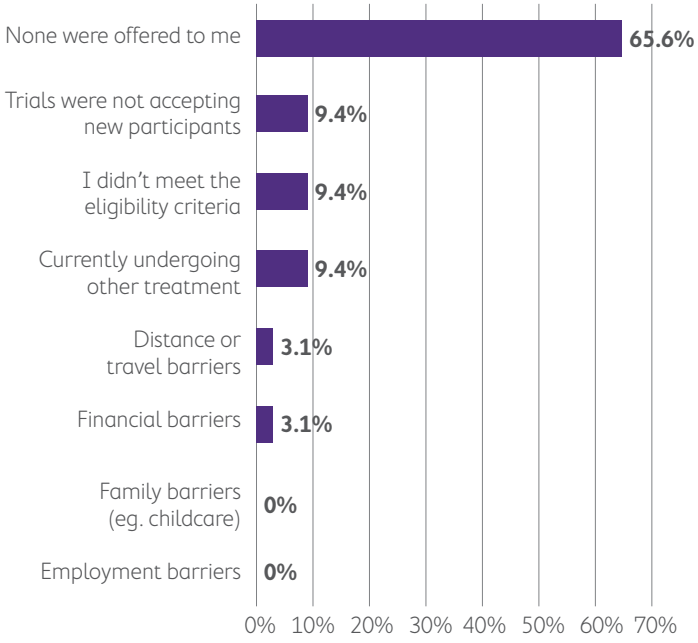
3.3 Clinical Trial Options

Consumer respondents were asked about their engagement with clinical trial options during their treatment. Just over 40% of respondents (43.8%, n=21) reported that their healthcare provider had discussed clinical trials with them, while 54.2% (n=26) indicated that this discussion did not occur. One respondent (2.1%) reported being unsure. Further analysis of where consumers lived showed that metropolitan-based patients were slightly more likely to have had clinical trials discussed with them (50.0%, n=14) compared to people in regional or rural areas (36.8%, n=7).

When asked about actual participation, 31.1% (n=15) of consumer respondents reported signing up for and/or participating in a clinical trial, with the majority (66.7%, n=32) reporting they had not participated.

Among the 32 respondents who indicated they had not signed up for or participated in a clinical trial, the main reason reported was that none had been offered to them (65.6%, n=21; Figure 3.3). Other factors, including ineligibility, trials not accepting new participants, and undergoing other treatments, were each cited by a small proportion of respondents (9.4%, n=3). Importantly, financial barriers and distance/travel barriers (3.1%, n=1 each) were rarely identified as reasons for non-participation in this cohort.

Figure 3.3: Reasons for not participating in a clinical trial (n=32)



Note: respondents were able to provide multiple responses.

3.4 Access to Health Professionals

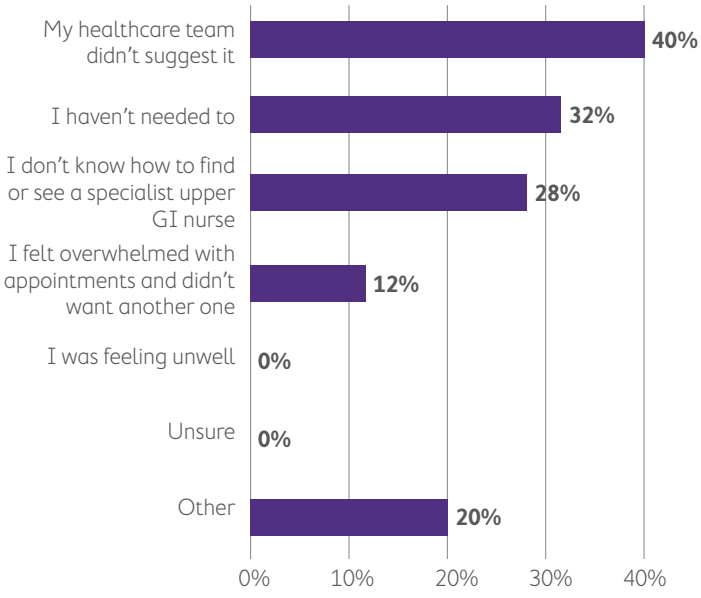
This section examines consumer respondents' reported access to specialist nurses, dietitians, exercise physiologists or physiotherapists during their cancer care. The reasons for not accessing these professionals are also outlined.

3.4.1 Access to a specialist upper GI cancer nurse

Among the 48 consumer respondents, only 43.8% (n=21) reported having access to a specialist upper GI nurse at their hospital or treatment centre. Just over half (52.1%, n=25) reported not having access to this support, while 4.2% (n=2) were unsure.

For the 25 respondents who reported not accessing support from an upper GI cancer nurse, the most common reasons cited were that their healthcare team did not suggest it (30.3%, n=10) and that they felt they did not need to (24.3%, n=8). Just over 20% (21.2%, n=7) reported being unsure where to find a specialist upper GI nurse. Of the five respondents (20.0%) who cited 'other' reasons, all indicated that their lack of access was because a specialist upper GI nurse was not available at their hospital.

Figure 3.4: Consumer respondents' reasons for not accessing a specialist upper GI nurse at their hospital or treatment centre (n=25)



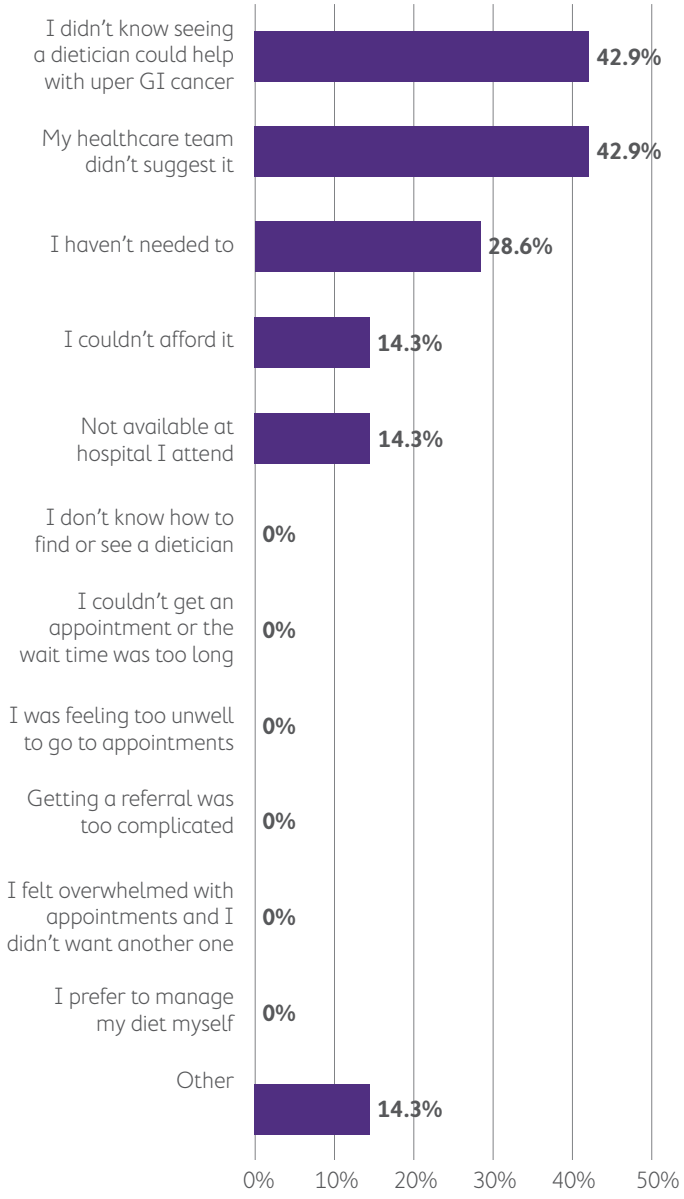
Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

3.4.2 Access to a dietitian

Reported access to dietetic support was high among consumer respondents, with 85.4% (n=41) confirming they had accessed a dietitian at their hospital/treatment centre as part of their treatment. This high rate suggests that nutritional support is generally well-integrated as a critical component of care for upper GI cancer.

Only seven respondents (14.6%) reported not having accessed a dietitian through their hospital/treatment centre. The reasons given by this small group (detailed in Figure 3.5) indicate that non-access was primarily due to information gaps or to system availability, with three respondents indicating they were either unaware that a dietitian could help with their cancer or that their healthcare team did not recommend it. Two respondents reported they did not feel they needed a dietitian. One mentioned cost as a barrier, and another noted that a dietitian was not available at their hospital.

Figure 3.5: Consumer respondents' reasons for not accessing a dietitian (n=7)



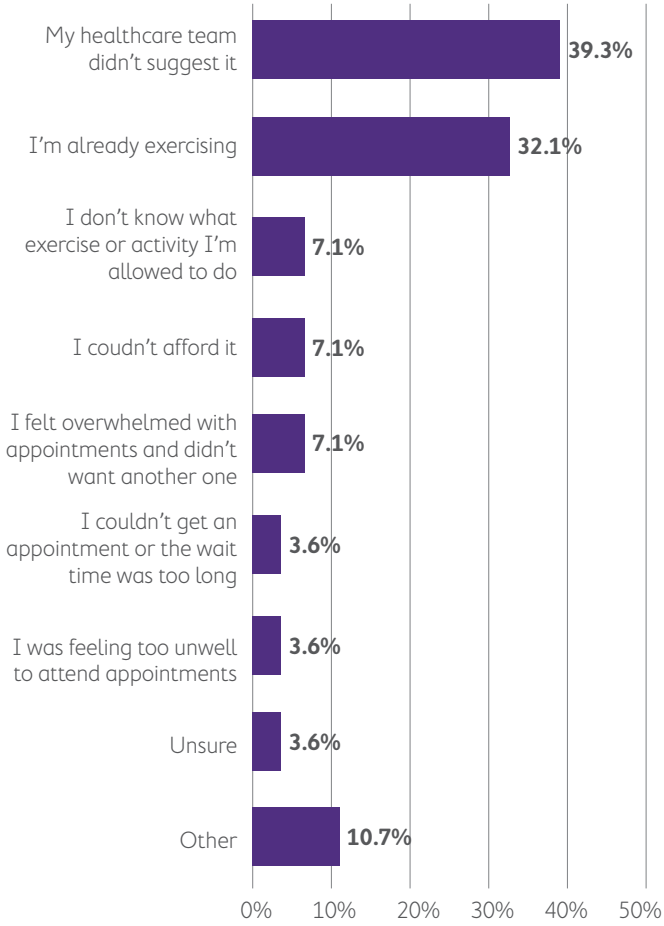
Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

3.4.3 Access to an exercise physiologist/ physiotherapist

Reported access to an exercise physiologist or physiotherapist was relatively low among consumer respondents who answered this survey question (n=47), with 38.3% (n=18) indicating they had accessed this support as part of their cancer care. Almost 60% (59.6%, n=28) had not accessed an exercise physiologist or physiotherapist, and one respondent (2.1%) was unsure.

Among the 28 consumers who reported not seeing an exercise physiologist or physiotherapist, the most common reason was that their healthcare team did not recommend it (39.3%, n=11), followed by respondents feeling they did not need this support because they were already exercising at the time (32.1%, n=9; Figure 3.6). Only a small number (7.1%, n=2) mentioned cost as a barrier. Three respondents selected 'other', with reasons including that they were either waiting to be contacted by a health physiologist or physiotherapist or had already been referred. No respondents reported not wanting to exercise or being unable to get a referral.

Figure 3.6: Reasons reported by consumers for not accessing a physiotherapist or exercise physiologist (n=28)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%. Three responses were moved from 'other' to 'I'm already exercising' as they indicated this in their open text response.

3.5 Access to Supportive Care

Consumer respondents in remission (n=8) were asked if they were offered supportive care (i.e. the information, resources, and services a person may need as part of comprehensive cancer care) after treatment. Half (50.0%, n=4) reported not being offered any supportive care. Of the four who received support, the most beneficial supports cited were counselling, yoga, cancer massage, dietitian assistance, and Pancare services.

> *"Dietitian support for a year post-treatment was beneficial. I was not offered any other support."*
>
> – Consumer respondent

3.6 Molecular Tumour Testing

Molecular tumour testing, sometimes referred to as comprehensive genomic profiling, is a technique used to uncover the specific genetic features of a cancer. It involves testing a cancer tissue sample to identify changes (biomarkers) in over 500 genes known to affect cancer growth. This information creates a 'fingerprint' for the tumour, which can then be used to inform targeted treatment options.

Consumer respondents were asked to indicate whether they understood what molecular tumour testing was. Of 47 responses to this question, 59.6% (n=28) indicated they did not understand the concept and 40.4% (n=19) reported they did.

The 19 respondents who indicated they understood what molecular tumour testing was were then asked whether they had received this testing. Just over half of these respondents (57.9%, n=11) reported having undergone molecular tumour testing, while 15.8% (n=3) had not and 26.3% (n=5) were unsure.

3.7 Technology

This section explores how consumer respondents used technology during their treatment for upper GI cancer. It examines the use of telehealth and other technologies employed in their treatment, as well as any challenges encountered.

3.7.1 Use of telehealth appointments

As shown in Table 3.1, the majority of consumer respondents (80.9%, n=38) reported using telehealth for at least one appointment with a health professional as part of their cancer care. Telephone appointments were the dominant mode, reportedly used by 70.2% (n=33) of respondents. Video appointments were considerably less common, used by approximately a quarter (25.5%, n=12) of respondents. Only 19.1% (n=9) of consumers reported having had no appointments conducted via phone or video. These findings suggest a relatively high overall uptake of telehealth among consumer respondents, primarily driven by the use of telephone consultations.

Table 3.1: Appointment modes reported by consumer respondents (n=47)

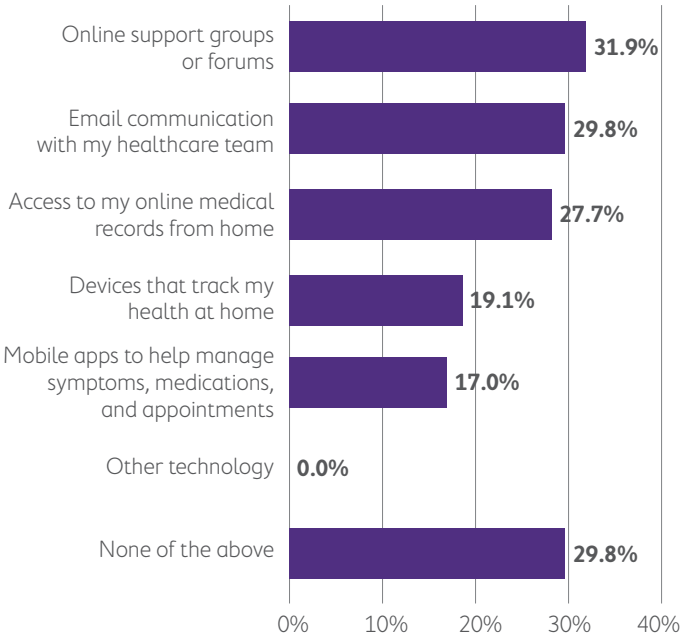
Response	Number	%
Yes, I've had at least one appointment by phone	33	70.2%
Yes, I've had at least one appointment by video	12	25.5%
No	9	19.1%
Total	**47**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

3.7.2 Technologies used as part of cancer care

Consumer engagement with various technologies for cancer care included in the survey was high, with 70.2% (n=33) of respondents reporting the use of at least one type of technology. As shown in Figure 3.7, the most frequently used technologies were those facilitating communication and information access, including online support groups or forums (31.9%, n=15), email communication with their healthcare team (29.8%, n=14), and accessing online medical records from home (27.7%, n=13).

Figure 3.7: Reported technology types used by consumer respondents as part of cancer care (n=47)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%. Three responses were moved from 'other' to 'I'm already exercising' as they indicated this in their open text response.

Consumer respondents were then asked whether they had faced, or expected to face, any challenges in relation to using technology as part of their cancer care. As shown in Table 3.2, a substantial proportion of respondents (46.8%, n=22) reported no challenges or anticipated no barriers to using technology as part of their care. Among those who did identify barriers, the most common were that their health professional did not offer technology options (14.9%, n=7), lack of confidence or comfort using technology (12.8%, n=6), and not knowing how to use the technologies (10.6%, n=5).

Notably, physical/logistical barriers such as slow internet (8.5%, n=4), lack of devices (8.5%, n=4), and cost (2.1%, n=1) were less frequently cited.

Table 3.2: Challenges consumer respondents have faced or expect to face when using technology as part of their cancer care (n=47)

Response	Number	%
I don't anticipate or haven't experienced any barriers in using technology as part of my care	22	46.8%
My health professional(s) are not offering technology options	7	14.9%
Not feeling confident or comfortable using technology	6	12.8%
Not knowing how to use technologies	5	10.6%
Slow or unreliable internet access	4	8.5%
Not having the right devices (e.g. smartphone, computer)	4	8.5%
Worries about privacy or security of online information	4	8.5%
The cost of the internet or devices	1	2.1%
Not being physically able to use technologies (e.g. the writing is too small, or my fingers are too stiff to use)	1	2.1%
Unsure	2	4.3%
Total	**47**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

4 Impacts of Upper GI Cancer

This section explores the physical, emotional, social, and financial impacts experienced by consumer respondents throughout their cancer care, as well as the emotional, social, and financial impacts reported by carers.

Key insights

- Physical symptoms that impacted consumers the most were stomach, digestion and bowel issues (affecting 65.1%), eating, taste, and dietary changes (affecting 53.5%) and fatigue (affecting 41.9%).
- Emotional and mental health challenges that impacted consumers the most were feeling down, depressed or sad (61.0%) and feeling anxious (61.0%). In addition, many consumers reported feelings of worry, fear or uncertainty, including feeling uncertain about the future (70.7%), worried about the impact of diagnosis on loved ones (68.3%) and fear that the cancer will spread or recur (65.9%). This highlights the emotional as well as physical impact of the cancer journey on patients.
- Consumers were also concerned about how they saw or felt about their body, which was cited by just over half of respondents (53.7%) and two-thirds of consumers (65.9%) reported experiencing at least one impact on their social life, including not wanting to socialise (36.6%) and feeling isolated or lonely (34.1%).
- Survey data revealed a high emotional burden among carers, with 96.5% (n=82) reporting at least one of the listed potential impacts, including worry or anxiety (83.5%), grief (75.3%) and stress (74.1%).
- A slightly higher proportion of carer respondents reported experiencing at least one form of financial impact (68.2%) compared with consumer respondents (61.0%). The most frequently cited financial impacts among carers included reduced work hours (28.2%), increased transport costs (28.2%), and loss of income (27.1%).

4.1 Experience of Physical Symptoms

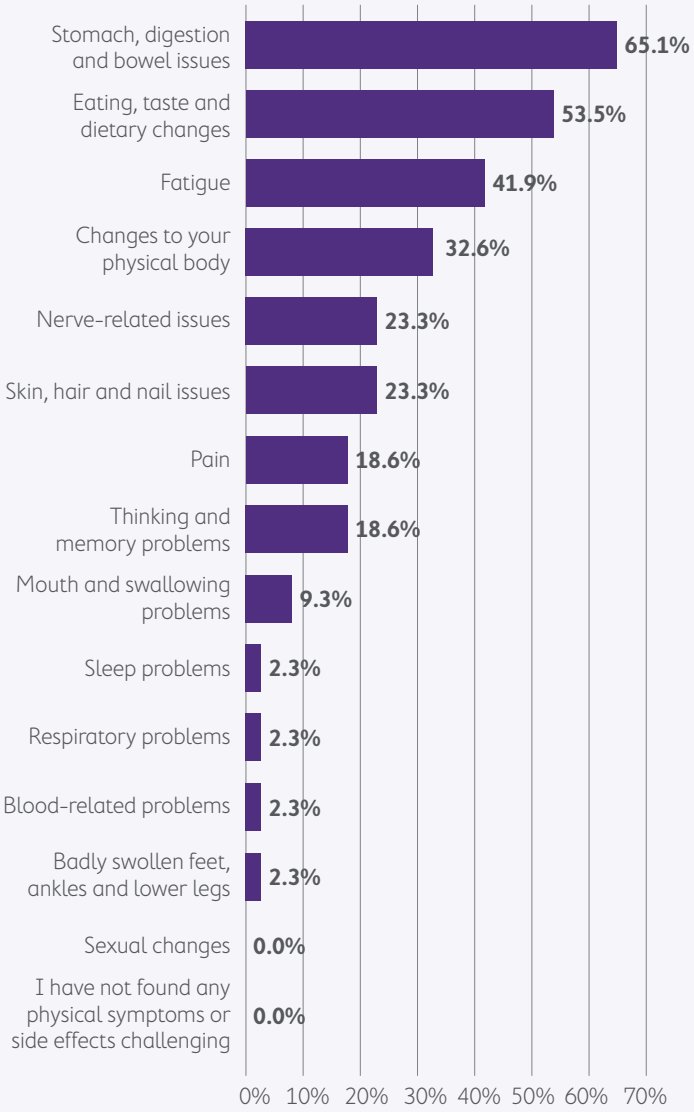
Consumer respondents were asked to select up to three physical symptoms or side effects that they found most challenging, reflecting their highest priority issues. The most commonly reported challenges were:

- stomach, digestion and bowel issues, reported by 65.1% (n=28) of consumers
- eating, taste, and dietary changes, cited by 53.5% (n=23) of consumers
- fatigue, reported by 41.9% (n=18) of consumers.

Physical changes were also a commonly identified challenge, reported by around one-third (32.6%, n=14) of respondents.

In contrast, several symptoms/side effects received almost no priority ranking from consumers (2.3%, n=1 or fewer responses). These included sleep problems, respiratory problems, blood-related issues, swollen feet/ankles, and sexual changes. This data suggests that while these symptoms may exist, they are not perceived as the highest priority burdens by consumers, relative to the dominant gastrointestinal and fatigue challenges.

Figure 4.1: Most challenging physical symptoms reported by consumer respondents (n=43)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Consumer respondents were invited to provide further detail in an open-ended response about the physical symptoms or side effects they found most challenging. The main themes arising from these qualitative responses reinforce the impact of challenges related to gastrointestinal symptoms, eating, and energy (summarised in Table 4.1).

The most common theme was challenges associated with nausea, appetite loss, and weight changes (53.6%, n=15). Some consumer respondents noted receiving valuable advice from dietitians and nurses to combat the impacts of appetite and nausea. However, this advice did not fully alleviate the burden associated with these symptoms among respondents. Fatigue and weakness (50.0%, n=14), digestive issues (39.3%, n=11), and neuropathy and pain (35.7%, n=10) were also commonly discussed.

> *"The most challenging physical symptom is the] neuropathy in feet, legs and hands following completion of chemotherapy, and the digestion and bowel movement issues after eating."*
>
> – Consumer respondent

Two (7.1%) consumers reported their difficulties dealing with isolation and limited accessibility to support services while living in rural locations.

> *"Isolation because of rural setting. Meaning there is no other people like me in our area to relate and talk to. There are limited services in a rural setting."*
>
> – Consumer respondent

Table 4.1: Primary physical challenges cited by consumer respondents (n=28)

Theme	Number	%
Nausea, appetite loss, and weight changes	15	53.6%
Fatigue and weakness	14	50.0%
Digestive issues	11	39.3%
Neuropathy and pain	10	35.7%
Challenges eating food	8	28.6%
Cognitive difficulties	6	21.4%
Emotional and psychological impact	6	21.4%
Treatment side effects	5	17.9%
Diarrhoea	3	10.7%
Tingling tongue	2	7.1%
Isolation and rural challenges	2	7.1%
Total	**28**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

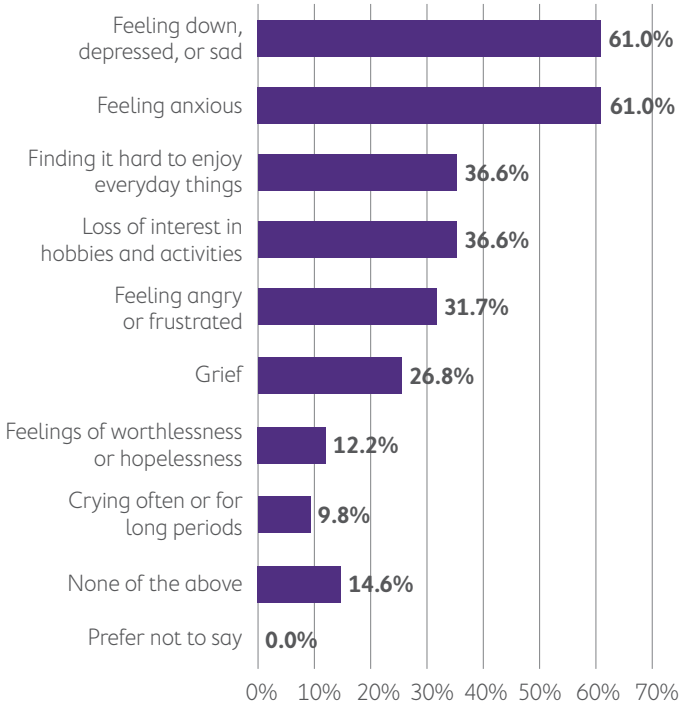
4.2 Consumer-Reported Emotional and Social Impacts

This section examines emotional and social impacts reported by consumer respondents.

4.2.1 Emotional and mental health impacts

The majority of consumer respondents (85.4%, n=35) reported experiencing at least one of the emotional or mental health impacts explored in the survey. The main challenges cited were feeling down, depressed or sad and experiencing anxiety, both reported by 61.0% (n=25) of respondents (Figure 4.2). Around a third of respondents also reported finding it hard to enjoy everyday things (36.6%, n=15), a loss of interest in hobbies and activities (36.6%, n=15), and feeling angry or frustrated (31.7%, n=13).

Figure 4.2: Consumer-reported emotional and mental health impacts (n=41)

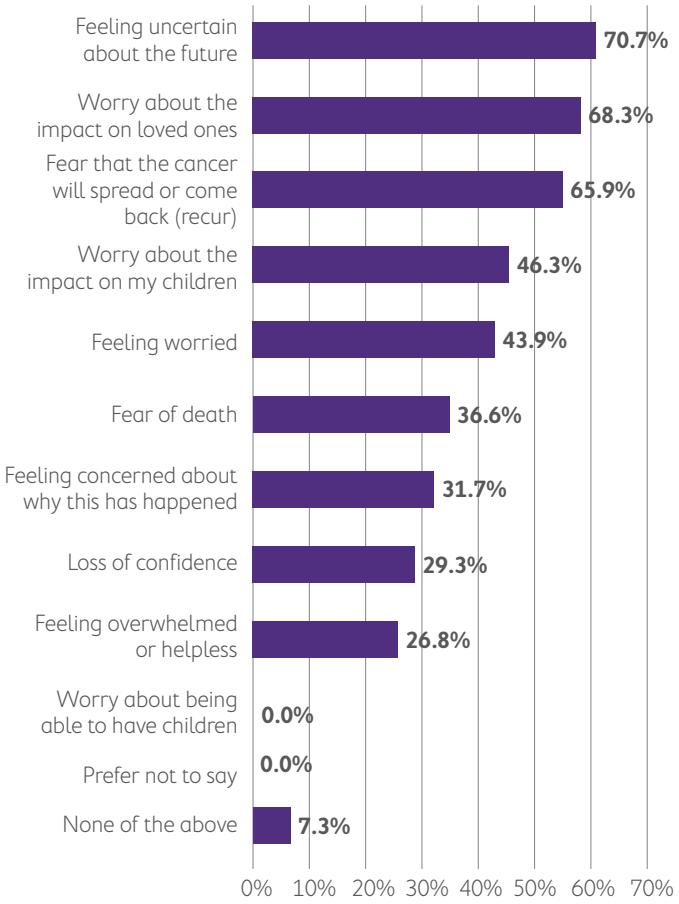


Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

4.2.2 Worry, fear, and uncertainty

Consumers were also asked whether they experienced any specific impacts related to worry, fear, or uncertainty since their diagnosis. A high proportion of consumers (92.7%, n=38) reported experiencing at least one of the listed impacts. As shown in Figure 4.3, the most pervasive concern was feeling uncertain about the future, cited by 70.7% (n=29) of respondents. This was closely followed by worries about the impact on loved ones (68.3%, n=28) and the fear that the cancer would spread or come back (65.9%, n=27).

Figure 4.3: Consumer-reported impacts related to worry, fear or uncertainty (n=41)

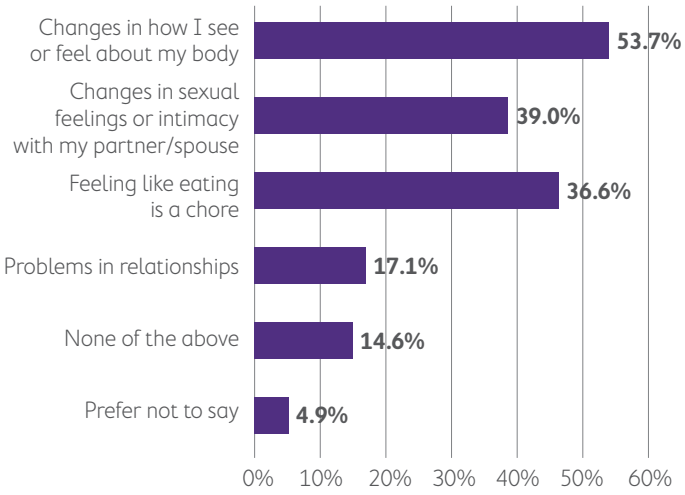


Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

4.2.3 Relationships and body image

Consumer respondents were asked whether their diagnosis had resulted in any specific impacts on their relationships or how they felt about their body. The most commonly reported impact was changes in how they saw or felt about their body, which was cited by just over half of respondents (53.7%, n=22), as shown in Figure 4.4. Almost 40% of respondents also reported changes in sexual feelings or intimacy with their partner/spouse (39.0%, n=16), and feeling like eating is a chore (36.6%, n=15). Only six (14.6%) reported not experiencing any of the potential impacts on relationships or body image identified in the survey.

Figure 4.4: Consumer-reported impact related to relationships or body image (n=41)

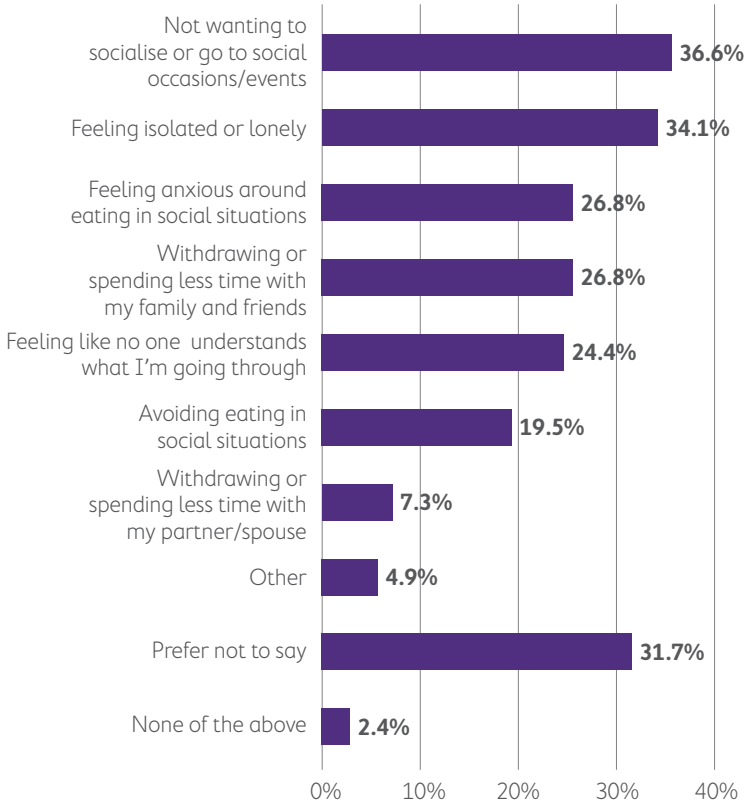


Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

4.2.4 Social impacts

Approximately two-thirds (65.9%, n=27) of consumer respondents reported experiencing at least one of the listed impacts on their social life. As shown in Figure 4.5, the most commonly reported challenge was not wanting to socialise or go to social events (36.6%, n=15). More than a third of respondents (34.1%, n=14) also reported experiencing feelings of isolation or loneliness. Approximately a quarter of respondents also reported feeling anxious around eating in social situations (26.8%, n=11), withdrawing or spending less time with family and friends (26.8%, n=11), and feeling like no one understands what they are going through (24.4%, n=10).

Figure 4.5: Consumer-reported relating to social life (n=41)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Consumers were asked to describe in further detail how upper GI cancer had impacted their feelings and social life via an open-ended question. Of the 21 responses provided, the main reported challenge was physical symptoms affecting social participation (42.9%, n=9). Consumers often mentioned that issues with digestion and the constant need to use the bathroom acted as a deterrent to entering social situations.

> *"Stomach pain and running to th toilet have halted going out for tea."*
>
> – Consumer respondent

In contrast, other respondents noted that they maintained a great social life with little negative impact from their diagnosis and treatment (38.1%, n=8).

Several consumers also cited concerns regarding the future and their family as a significant emotional burden (14.3%, n=3).

> *"The most challenging thing is the uncertainty of what will happen to me in the future and the impact this will have on my family."*
>
> – Consumer respondent

Table 4.2: Key themes reported by consumer respondents related to the emotional and social impacts of upper GI cancer (n=21)

Symptom	Number	%
Physical symptoms affecting social participation	9	42.9%
Maintaining an active social life	8	38.1%
Social Isolation and changes in social life	3	14.3%
Emotional and psychological effects	3	14.3%
Family and future concerns	3	14.3%
Coping and adaptation	2	9.5%
Support networks	1	4.8%
Food, eating, and social Anxiety	1	4.8%
Total	**21**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

4.3 Carer-Reported Emotional and Social Impacts

Carer respondents were also asked whether they had experienced specific emotional, mental health, social, or relationship impacts in relation to supporting a person with upper GI cancer.

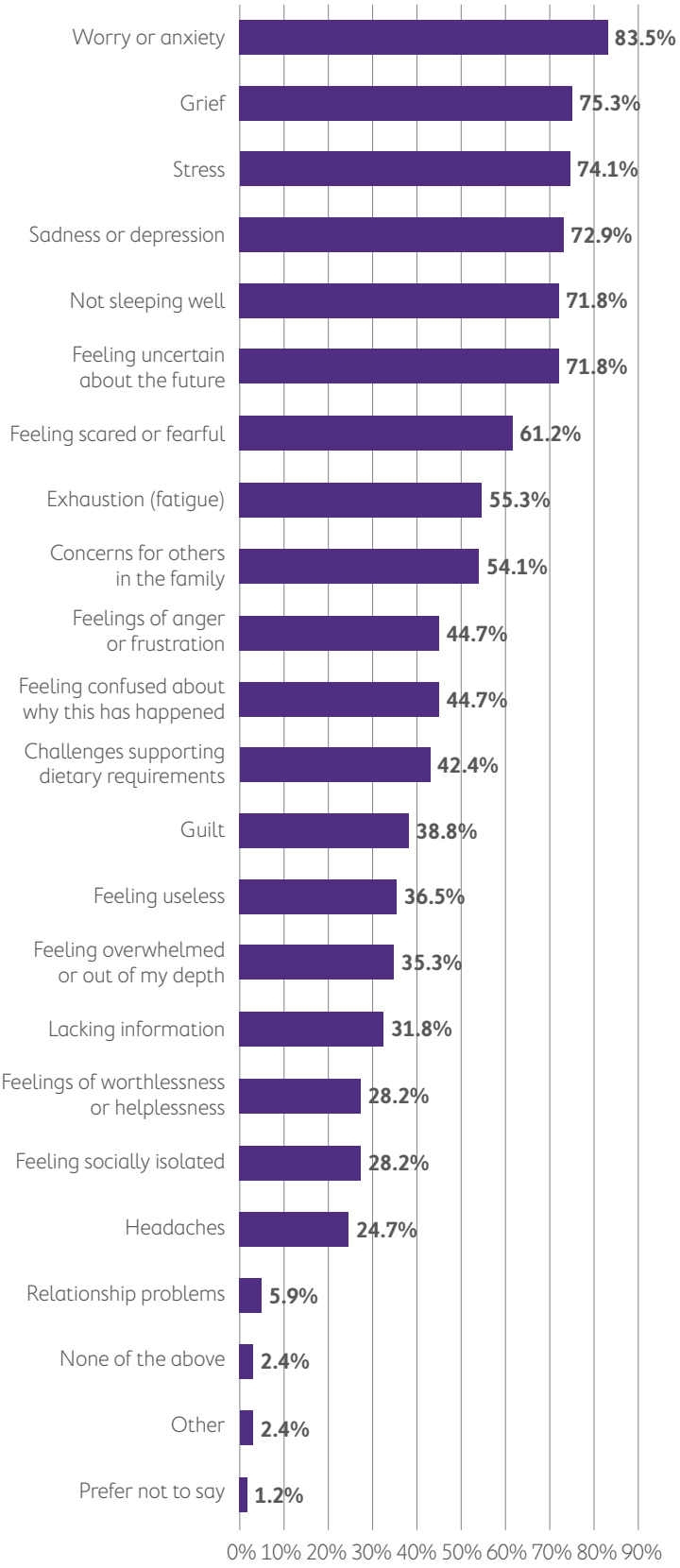
Survey data revealed a high emotional burden among carers, with 96.5% (n=82) reporting at least one of the listed potential impacts. Notably, 839 responses were recorded across the various listed impacts, indicating that carer respondents reported experiencing approximately 10 different types of emotional, mental health, social, or relationship impacts each, on average.

As presented in Figure 4.6, the most frequently reported impacts among carers were:

- worry or anxiety (83.5%, n=71)
- grief (75.3%, n=64)
- stress (74.1%, n=63).

Other commonly reported impacts included sadness or depression (72.9%, n=62), sleep disturbances (71.8%, n=61), and feelings of uncertainty about the future (71.8%, n=61).

Figure 4.6: Emotional, mental health, social, and relationship impacts reported by carer respondents in relation to supporting a person with upper GI cancer (n=85)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Carers were asked to describe, via open-ended response, the most challenging aspects of supporting someone with upper GI cancer. Responses provided by 75 carer respondents highlighted a complex intersection of emotional, informational, and systemic challenges.

The emotional burden of caring for someone with upper GI cancer – including feelings of grief and helplessness – was identified as a primary challenge, reported by 64.0% (n=48) of respondents (Table 4.3). Other key difficulties included managing pain and dealing with the person's physical decline (34.7%, n=26), along with navigating the healthcare system and advocacy responsibilities (29.3%, n=22).

A key theme was that a lack of sufficient and timely information, especially during early diagnosis, greatly heightened their emotional strain and feelings of helplessness. This gap also hindered their ability to plan, navigate the health system, and advocate for the person being cared for. Several carers noted this contributed to the patient's physical deterioration.

> *"[The main challenge was finding] advice regarding the progression of the illness, it seemed that you just waited to see how things progressed."*
>
> – Carer respondent

> *"Not getting enough information and my dad not being well informed about the outcome of his cancer, I feel that if he had known how bad it was, he may have looked for a second opinion. He didn't get to even see an oncologist until approximately five weeks from diagnosis. Dad passed eight weeks after diagnosis."*
>
> – Carer respondent

> *"Challenges included educating and finding facts on GI cancer, treatment process, and timelines. Caring for someone receiving chemotherapy and the lack of physical support and awareness of services available."*
>
> – Carer respondent

> *"The lack of information and support provided by the upper GI specialist and urologist post-surgery (12-hour Whipple surgery) and during chemotherapy and radiation treatment was appalling."*
>
> – Carer respondent

Table 4.3: Most challenging aspects of supporting someone with upper GI cancer identified by carers (n=75)

Theme	Number	%
Emotional burden, grief, and helplessness	48	64.0%
Pain management and physical deterioration	26	34.7%
Navigating the healthcare system and advocacy	22	29.3%
Coping strategies and resilience	16	21.3%
Lack of information	16	21.3%
Impact on family dynamics and relationships	15	20.0%
Symptom management and daily living	15	20.0%
Social isolation and support networks	8	10.7%
End-of-life/ death	5	6.7%
Financial challenges	4	5.3%
Total	**75**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

When asked what kind of support would have made their challenges easier to manage, the primary support identified by carers was better access to information and education about upper GI cancer and the supports available (24.3%, n=17; Table 4.4). Carers mentioned that receiving more information, especially at the point of diagnosis, could reduce the emotional strain of caregiving and make it easier to access support services when needed.

"More support up front, information packs automatically provided on diagnosis, helplines to call to ask the hard questions. There were many times I felt alone and scared when I was caring for my father, and it wasn't until he had finally given up and was ready to go to the hospital that I had access to support outside of the family, and even that felt minimal"

– Carer respondent

Carers also noted that increased advocacy and system navigation support could have helped them to access appropriate resources more easily (22.9%, n=16). This, in turn, could have reduced the burden of navigating a complex diagnosis, particularly when seeking information about clinical trial options.

"Instead of being reactive, they (oncology practitioners) need to be proactive, but the lack of will or knowledge was incredible. You have to advocate for yourself, and information about clinical trials should be available in a more understandable format."

– Carer respondent

"Need more information on [clinical] trials available and emotional support."

– Carer respondent

Table 4.4: Reported supports that would have helped carers manage challenges faced when caring for someone with upper GI cancer (n=70)

Theme	Number	%
Information and education	17	24.3%
Advocacy and system navigation	16	22.9%
Healthcare system navigation	11	15.7%
Specialist and tailored support	10	14.3%
Family and wider support	6	8.6%
Emotional and mental health support	6	8.6%
Financial and logistical support	2	2.9%
Peer and community support	2	2.9%
Palliative and practical care	1	1.4%
Total	**70**	**100.0%**

4.4 Financial Impacts

Both consumer and carer respondents were asked to indicate whether they had encountered any financial impacts in relation to upper GI cancer. Key findings for each cohort are presented in this section.

4.4.1 Consumer financial impacts

Table 4.5 presents the financial impacts reported by consumer respondents in relation to their upper GI cancer diagnosis. Approximately 60% of respondents (61.0%, n=25) reported experiencing at least one financial impact. The most commonly reported challenges included impacts on personal savings (39.0%, n=16), loss of income (34.1%, n=14), and early retirement (24.4%, n=10).

Table 4.5: Financial impacts reported by consumer respondents (n=41)

Impact	Number	%
Impacts on savings	16	39.0%
I have not experienced any financial impacts	16	39.0%
I have lost income	14	34.1%
I went into early retirement	10	24.4%
I have reduced my work hours	9	22.0%
Impacts on partner/spouse's income	7	17.1%
I have had to pay for my own medication costs	7	17.1%
I have had to pay for my own treatment costs or other cancer-related costs myself (e.g. tests, scans, equipment)	7	14.6%
Financial hardship or stress (trouble paying for things like rent/mortgage, food, or bills)	6	17.1%
I have had increased transport costs	5	12.2%
I lost my job	4	9.8%
I couldn't get specific medication(s) because of the cost	1	2.4%
I couldn't get specific foods or food supplements because of the cost	1	2.4%
I couldn't get treatment because of the cost	0	0.0%
Other	3	7.3%
Total	**41**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Out-of-pocket medication costs

Consumer respondents who reported needing to pay for their own medication costs (n=7) were asked whether they had self-funded any medication not currently covered under the Pharmaceutical Benefits Scheme (PBS). Of these respondents, five (71.4%) indicated they had paid for medications not funded under the PBS. The reported costs incurred by these respondents demonstrated a wide financial range, spanning $500–$1,000 up to more than $50,000.

Impact of PBS access

All consumer respondents were asked about the difference that listing new and effective cancer medications on the PBS would make for people managing treatment costs via an open-ended question. A total of 31 respondents provided a free-text response, with key themes presented in Table 4.6. Almost all consumers (71.0%, n=22) explicitly stated that they felt it would have a substantial impact on managing the cost of cancer treatment. Key perceived benefits included financial relief and affordability (41.9%, n=13), equity of access (29.0%, n=9), and emotional and quality-of-life impact (16.1%, n=5).

> *"Massive difference. Some cancer patients cannot have potentially lifesaving treatments as they cannot afford the huge costs. This is life changing."*
>
> – Consumer respondent

> *"The PBS will make life easier to bear through the burden and uncertainties of living with cancer."*
>
> – Consumer respondent

Table 4.6: Key themes from consumers on the impact of adding new medications to the PBS (n=31)

Theme	Number	%
Substantial impact for people managing cost of cancer treatment	22	71.0%
Financial relief and affordability	13	41.9%
Equity and access	9	29.0%
Emotional and quality of life impact	5	16.1%
System limitations and future concerns	1	3.2%
Total	**31**	**100.0%**

Note: respondents were able to provide multiple responses.

4.4.2 Carer financial impacts

The financial impacts reported by carer respondents in relation to supporting a person with upper GI cancer are presented in Table 4.7. A slightly higher proportion of carer respondents reported experiencing at least one form of financial impact (68.2%, n=58) compared with consumer respondents (61.0%). The most frequently cited financial impacts among carers included reduced work hours (28.2%, n=24), increased transport costs (28.2%, n=24), and loss of income (27.1%, n=23). Around a quarter of carer respondents also reported out-of-pocket expenses for treatment or medication costs (25.9%, n=22) or for medical equipment or supplies (24.7%, n=21).

Table 4.7: Financial impacts experienced by carer respondents (n=85)

Impact	Number	%
I have not experienced any financial impacts	26	30.6%
Reduced my work hours	24	28.2%
Increased transport costs	24	28.2%
Lost income	23	27.1%
Out-of-pocket expenses for treatment or medication costs	22	25.9%
Out-of-pocket expenses for specific medical equipment or supplies	21	24.7%
Financial hardship or stress (trouble paying for things like rent/mortgage, food, or bills)	12	14.1%
Went into early retirement	10	11.8%
Lost my job	2	2.4%
Other	4	4.7%
Prefer not to say	1	1.2%
Total	**85**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5 Upper GI Cancer Support

This section discusses the specific supports required by consumer and carer survey respondents, with a focus on emotional needs and supports and services provided by Pancare Foundation.

Key insights

- Most consumer and carer respondents (80.0% and 87.3%, respectively) reported needing at least one form of emotional support. Consumers reported the need for assistance for family, carers, or loved ones (55%) and support groups with other patients (47.5%), while carers most reported the need for support for grief and loss (53.2%).
- Approximately 80.0% of consumers and 70.9% carers reported they were able to access the information they needed.
- Approximately 70% of both consumers (70.0%) and carers (67.9%) reported a preference for digital information, although both consumers (45.0%) and carers (40.7%) also expressed a desire for hard copy information.
- Preferred sources of information for both consumers and carers were the Pancare Foundation Website (82.5% and 77.5%, respectively) specialist doctors (77.5% and 67.5%, respectively) and cancer nurses (65.0% and 58.8%, respectively).
- A lack of awareness of the Pancare Foundation, or a becoming aware late in the journey, was reported by both consumers and carers. Notably, a quarter to a third of consumers and carers who had not accessed Pancare support groups cited a lack of awareness as the reason. Similarly, 76.9% of consumer and 68.8% of carers indicated they did not know that the My Care KIT existed.
- Consumers and carers who had used the My Care KIT found it helpful/very helpful (73.1% and 60.0%, respectively). Suggestion for improvement to the kit included recipes, pages to track diet, information on chemotherapy side effects, financial support information and palliative care information, to name a few.
- The majority of consumers indicated they would be likely or very likely to access information new topics including post-treatment supports and services (92.5%), coping with the emotional impact of upper GI cancer (90%) and how to talk about genetic or hereditary risk in upper GI cancer with family members (90%).
- Carers indicated interest in new supports such as online talks or presentations on key upper GI cancer topics (78.4%), a private Facebook group designed to connect with other caregivers of upper GI cancer patients (60.0%), and in-person talks with expert guest speakers (59.4%).
- Carer respondents demonstrated a high interest in a new information booklet on caring for someone with upper GI cancer (64.5%).
- Both consumers and carers expressed interest in the information sessions on managing symptoms and treatment side effects (65.0% and 38.7%, respectively), latest developments in upper GI cancer (65.0% and 37.3%, respectively), clinical trials (60.0% and 44.0%, respectively) and diet, eating, and nutrition (60.0% and 38.7%, respectively).

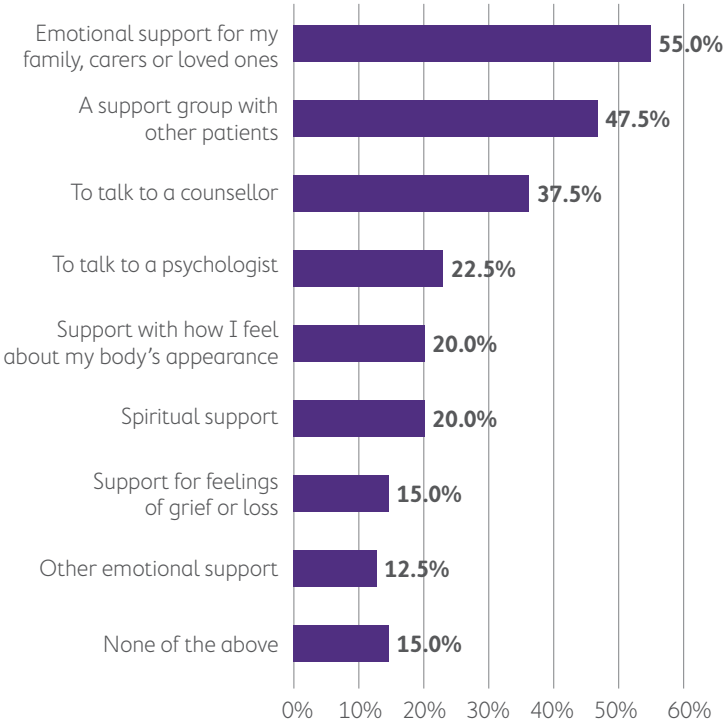
5.1 Need for Emotional Support

Consumer and carer respondents were asked to identify specific emotional supports needed in relation to living with, or caring for someone with, upper GI cancer. Survey findings for each cohort are presented in the following sections.

5.1.1 Consumer emotional support needs

Most consumer respondents (80%, n=34) reported needing at least one form of emotional support listed within the survey since their diagnosis. As shown in Figure 5.1, the supports most commonly needed included assistance for family, carers, or loved ones (55%, n=22), support groups with other patients (47.5%, n=19), and to talk to a counsellor (37.5%, n=15). The small number of 'other' responses (12.5%, n=5) included needs related to general support from family and friends, financial stress due to income loss, and specific personal issues such as marriage problems.

Figure 5.1: Emotional supports required by consumer respondents (n=40)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Consumers who identified a need for emotional support were asked whether they had been able to access all the support they needed. Of 33 consumer respondents, most (78.8%, n=26) reported being able to access the required support.

For the 21.2% (n=7) who reported unmet needs, the main missing support was access to suitable support groups (42.8%, n=3), either because available groups were not face-to-face or due to scheduling conflicts. A need for adequate counselling services (28.6%, n=2) was also noted. Individual reported challenges included feeling too embarrassed to ask for help or finding that the co-morbidity of cancer and a mental health diagnosis was a barrier to finding appropriate services.

> *"I have been abandoned by my chemo team. I am unable to be helped with co-morbidity of cancer and a mental health diagnosis."*
>
> – Consumer respondent

> *"Support groups on Zoom [are] difficult to access. There appears to be a real gap in support compared to other cancers, such as breast [cancer]."*
>
> – Consumer respondent

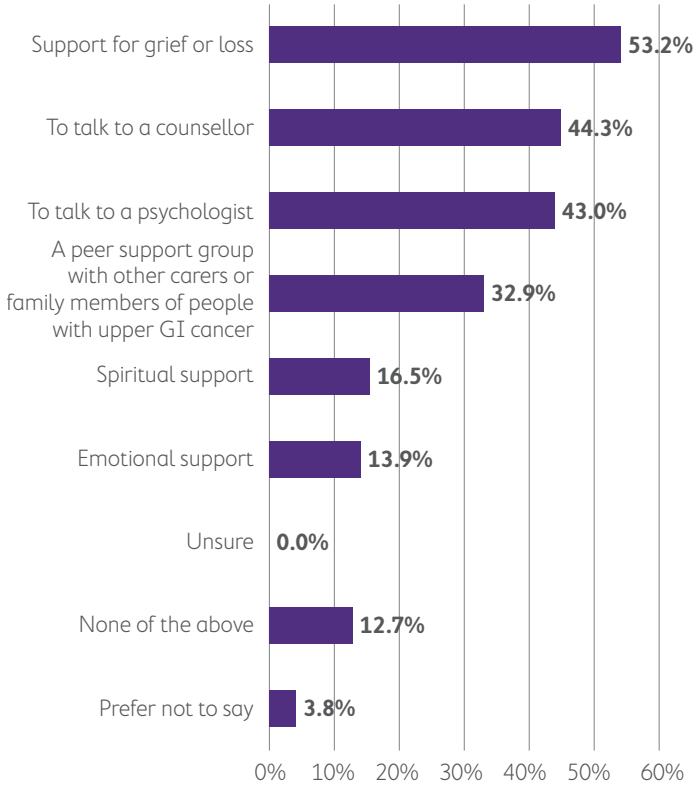
5.1.2 Carer emotional support needs

Similar to consumers, the majority of carer respondents (87.3%, n=69) reported needing at least one form of emotional support since caring for someone with upper GI cancer. As presented in Figure 5.2, the primary emotional support need cited was support for grief and loss (53.2%, n=42).

This high rate is to be expected, given the large proportion of carers for whom the person they supported had died (67.1%). Just over 40% of carer respondents also reported needing support from a counsellor (44.3%, n=35) or psychologist (43.0%, n=43), while around a third (32.9%, n=26) reported needing support from a peer support group with other carers or family members of people with upper GI cancer.

A small number of 'other' responses (13.9%, n=11) emphasised the importance of informal support from friends and family.

Figure 5.2: Emotional supports required by carer respondents (n=79)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

The majority of carer respondents with identified emotional support needs (76.9%, n=50 of 65) indicated they had been able to access the support they needed.

Among the 15 respondents who reported facing challenges accessing emotional support, the primary barrier was the timing and availability of services such as counsellors, psychologists, or grief support (40.0%, n=6; Table 5.1).

> *"The wait times for psychology are extensive; my husband often had to wait one month for appointments, which was really hard when he was dealing with bad news and needed more urgent support."*
>
> – Carer respondent

Other barriers included lack of awareness of services and difficulty navigating the support system (26.7%, n=4).

"[The main barrier was] not knowing where to go for support apart from Facebook groups."
– Carer respondent

"[The main challenges were the] brief time from diagnosis to death and the lack of knowledge that support services were hard to get."
– Carer respondent

Financial barriers were also noted by two carers (13.3%) as a factor preventing them from accessing appropriate emotional support.

Table 5.1: Reported barriers for carers accessing emotional support (n=15)

Theme	Number	%
Timing and availability of support	6	40.0%
Awareness and navigation of support services	4	26.7%
Financial	2	13.3%
Geographical isolation and access	1	6.7%
Ability to meet other carers and socialise	1	6.7%
Work	1	6.7%
Total	**15**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.2 Informational Needs

Both consumer and carer respondents were asked whether there was any information about upper GI cancer that they wanted or needed but found difficult to obtain.

5.2.1 Consumer informational needs

The majority of consumers (80.0%, n=32) reported they were able to access the information they needed regarding their cancer. However, eight (20.0%) consumers reported missing specific information or resources. These included:

- side effects from surgery and chemotherapy
- statistics and prognosis information specific to diagnosis
- diet and information on dumping syndrome
- pancreatic cancer community
- information packs
- how to approach diet when diagnosed with gallstones
- managing high cholesterol within a cancer weight loss scenario
- a single, central point to find required information.

I never knew about Pancare Foundation until 6 months post-diagnosis. No one said anything about it, even whilst in hospital. There were no information packs, and no support offered. – Consumer respondent

5.2.2 Carer informational needs

Consistent with consumers, the majority of carers (70.9%, n=56) reported being able to access the information they needed regarding upper GI cancer. However, approximately 30% (29.1%, n=23) of carers reported difficulty in finding information. Carers who encountered challenges described the types of information they struggled to access, with key themes outlined in Table 5.2.

The information carers reported being most challenging to find was information on diet, including meal plans post-surgery (30.4%, n=7), followed by information on side effects/symptoms (26.1%, n=6) and alternative therapies/clinical trials (17.4%, n=4).

"Side effects of chemotherapy and cancer development symptoms. We were only told to monitor his temperature and weight. My dad ended up developing saddle blood clots and we were not informed of the increased risk of clots. We were not checked in on and very uninformed."
– Carer respondent

Table 5.2: Reported information that carers found difficult to find (n=23)

Theme	Number	%
Dietary information/meal plans post-surgery	7	30.4%
Side effects/symptoms	6	26.1%
Alternative therapies/clinical trials	4	17.4%
Genetic studies	2	8.7%
Key signs of cancer to look out for	2	8.7%
Post-Whipple procedure information	1	4.3%
Cancer medication	1	4.3%
Information on providing first aid for low blood sugar episodes	1	4.3%
Lost my job	1	4.3%
Hospital data	1	4.3%
Patient success stories	1	4.3%
List of specialist/health professionals to go to	1	4.3%
Total	**23**	**100.0%**

Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.3 Information Preferences

Both consumer and carer respondents were asked to indicate their preferred mode(s) for written information about upper GI cancer and available support services. Respondents could select multiple options.

Both groups showed a preference for digital information (70% of consumers and 67.9% of carers). However, there was also a clear desire for hard copy or printed options, with 45.0% (n=18) of consumers and 40.7% (n=33) of carers also indicating a preference for this mode (Table 5.3). These findings suggest the need to provide information in both digital and hard copy formats.

Table 5.3: Consumer (n=40) and carer (n=81) respondents' preference for receiving upper GI cancer information

Mode of Information	Consumers	Carers
Hard copy or printed copies (like paper booklets or fact sheets)	18 (45.0%)	33 (40.7%)
Digital copies (like on websites or as online documents)	28 (70.0%)	55 (67.9%)
Total	**40 (100.0%)**	**81 (100.0%)**

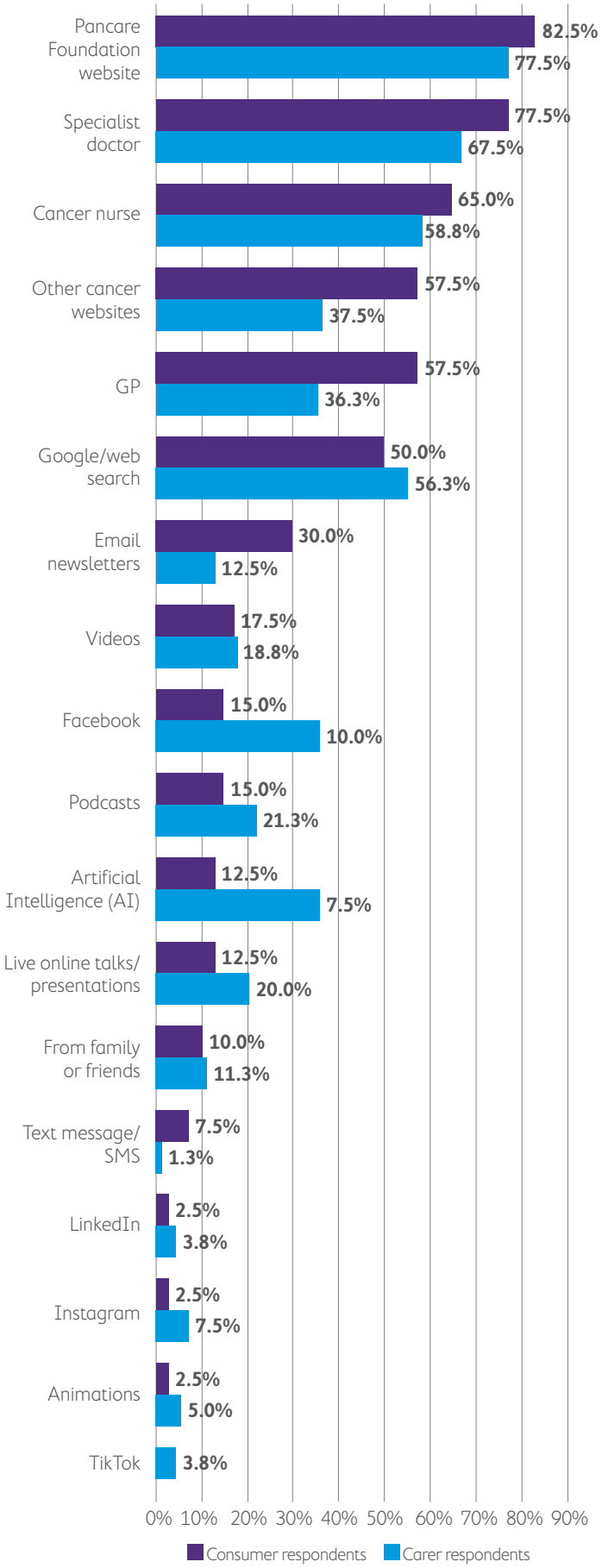
Note: While the survey question asks for which mode of receiving information respondents prefer, they were able to provide multiple answers in their responses.

Both consumer and carer respondents were asked about their preferred sources for information on upper GI cancer and available support services. Both groups were aligned on their top three choices, indicating a preference for dedicated and professional sources over general platforms (see Figure 5.3). The most preferred information sources were:

- Pancare Foundation Website: 82.5% of consumers (n=33) and 77.5% of carers (n=62)
- specialist doctor: 77.5% of consumers (n=31) and 67.5% of carers (n=54)
- cancer nurse: 65.0% of consumers (n=26) and 58.8% of carers (n=47)

In contrast, social media platforms such as Facebook, LinkedIn, and Instagram were infrequently reported as a key source of information related to upper GI cancer, with 15% or fewer consumers and carers indicating a preference to receive information via these channels.

Figure 5.3. Preferred information sources among consumer (n=40) and carer (n=80) respondents



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.4 Challenges Related to Diversity

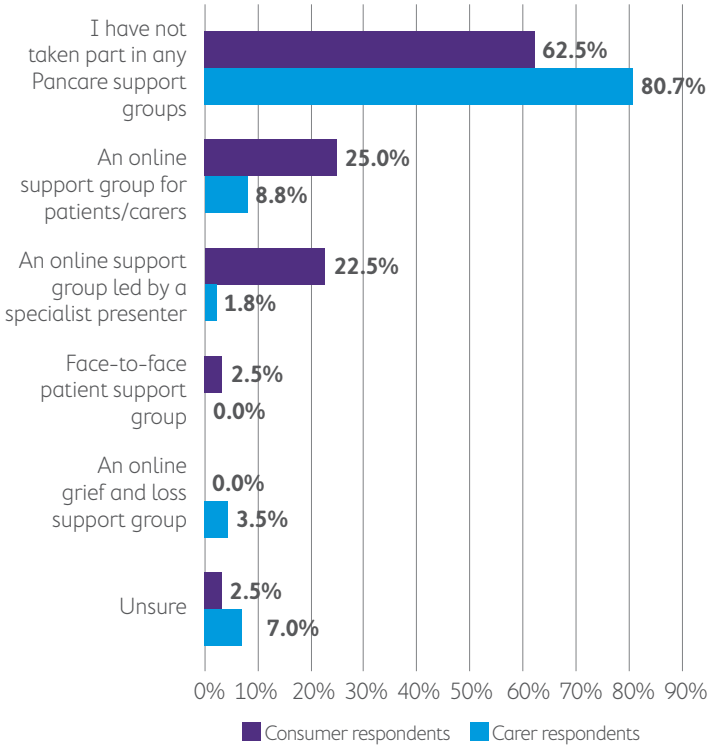
Sometimes a person's background can affect their cancer experiences and the support they receive. To understand the impacts of this, consumers were asked whether they identified with at least one of the following groups and the impact this may have had on their cancer journey:

- culturally and linguistically diverse background
- live in a regional or rural area
- lower-income background
- member of the LGBTIQ+ community
- live with a disability
- an older person
- live with a mental illness

Among the 40 consumers who responded to this question, 45.0% (n=18) identified as at least one of the listed groups; 52.5% (n=21) did not, and one (2.5%) preferred not to say.

Of the 18 consumers who identified with one or more of these groups, six (33.3%) reported challenges linked to their group identification. Challenges listed were primarily due to increased travel costs or difficulty travelling to places associated with living rurally or having a disability (66.7%, n=4). Other challenges identified were the inability to meet people going through the same treatments due to living rurally (16.7%, n=1), and the exacerbation of mental health problems (16.7%, n=1).

Figure 5.4: Pancare Foundation support groups accessed by consumer (n=40) and carer (n=57) respondents



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.5 Awareness of Pancare Support and Resources

Carer respondents were asked about their familiarity with Pancare Foundation's supports and resources. Of the 78 respondents, approximately a quarter (27%, n=21) reported being very familiar, half (46%, n=36) were somewhat familiar, and around a quarter (27%, n=21) were unfamiliar. These findings indicate there may be an opportunity to improve the visibility of available Pancare supports and resources for carers.

5.6 Pancare Support Groups

Figure 5.4 displays the range of support groups accessed by consumer and carer respondents through Pancare Foundation. Participation was generally low for both groups, with 62.5% (n=25) of consumers and 80.7% (n=46) of carers reporting they had not taken part in any groups.

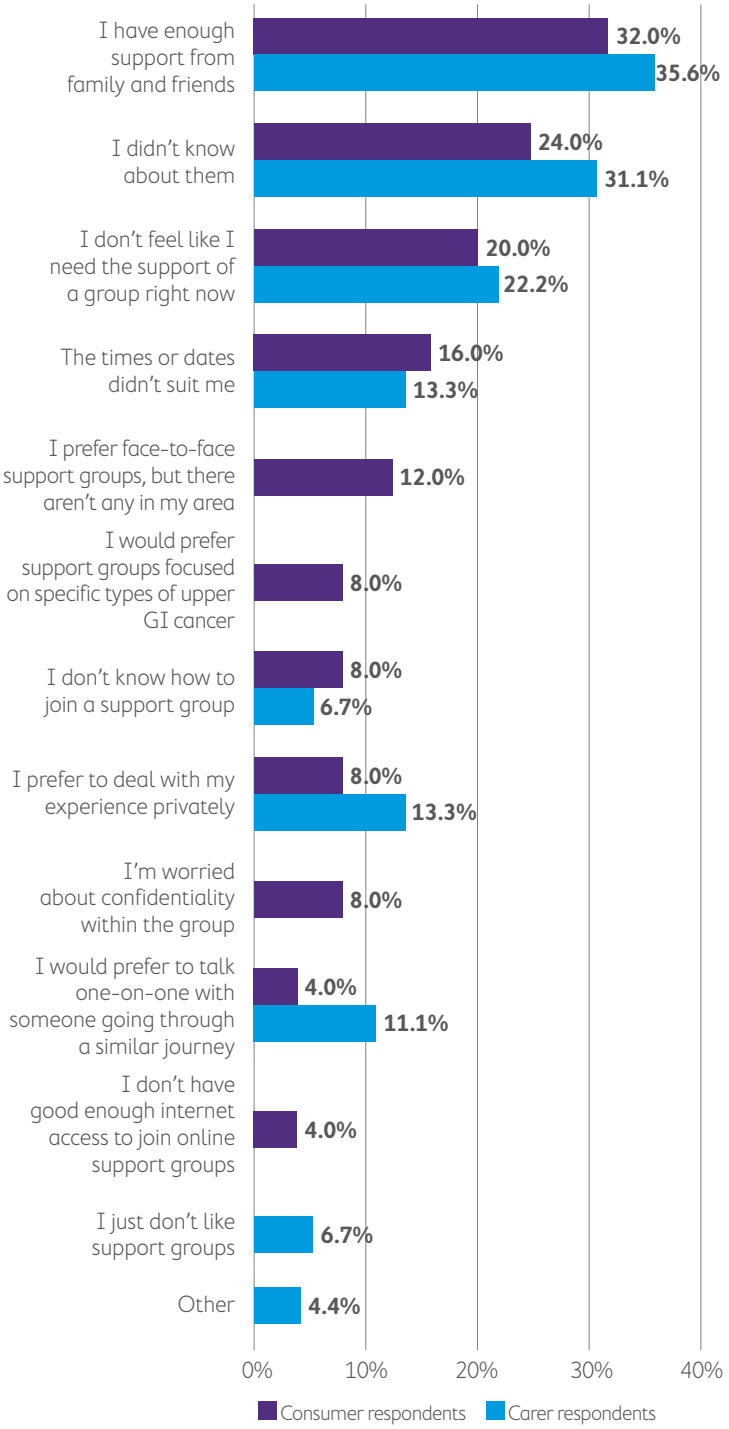
The highest engagement among consumers was for online patient support groups (25.0%, n=10) and specialist-led groups (22.5%, n=9). Among carers, 8.8% (n=5) reported participating in an online carer group. Only two carers (3.5%) had accessed a grief and loss support group.

Respondents who had not accessed a support group were asked to indicate why. As illustrated in Figure 5.5, the primary reason cited by both consumers and carers was feeling adequately supported by family and friends (32.0%, n=8 consumers and 35.6%, n=15 carers). This was followed by a lack of awareness of the support groups, reported by 24.0% (n=6) of consumers and 31.1% (n=14) of carers. Approximately 20% of both consumers (20.0%, n=5) and carers (22.2%, n=10) reported not currently requiring support from a support group.

Smaller proportions of respondents reported logistical barriers to access, including:

- inconvenient timing/date, reported by 16.0% (n=4) of consumers and 13.3% (n=6) of carers
- absence of face-to-face groups in their area, cited by 12.0% (n=3) of consumers.

Figure 5.5: Reasons for consumer (n=25) and carer (n=45) respondents not accessing Pancare Foundation support groups



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.7 Pancare My Care KIT

Consumer and carer respondents were asked about accessing a Pancare Foundation 'My Care KIT' (a hard copy folder containing a series of booklets, information sheets, and places to record information). Access rates were higher among consumers, with 65.0% (n=26) reporting they had accessed the kit, compared to 43.9% (n=32) of carers.

Among the 13 consumers (33.5%) and 32 carers (56.1%) who had not accessed a My Care KIT, the primary barrier was a lack of awareness of its existence (see Figure 5.6). This reason was reported by 76.9% (n=10) of consumers and 68.8% (n=22) of carers.

An additional 18.8% (n=6) of carers did not access the kit because they believed it was only for upper GI cancer patients, highlighting a potential lack of clarity regarding the kit's scope.

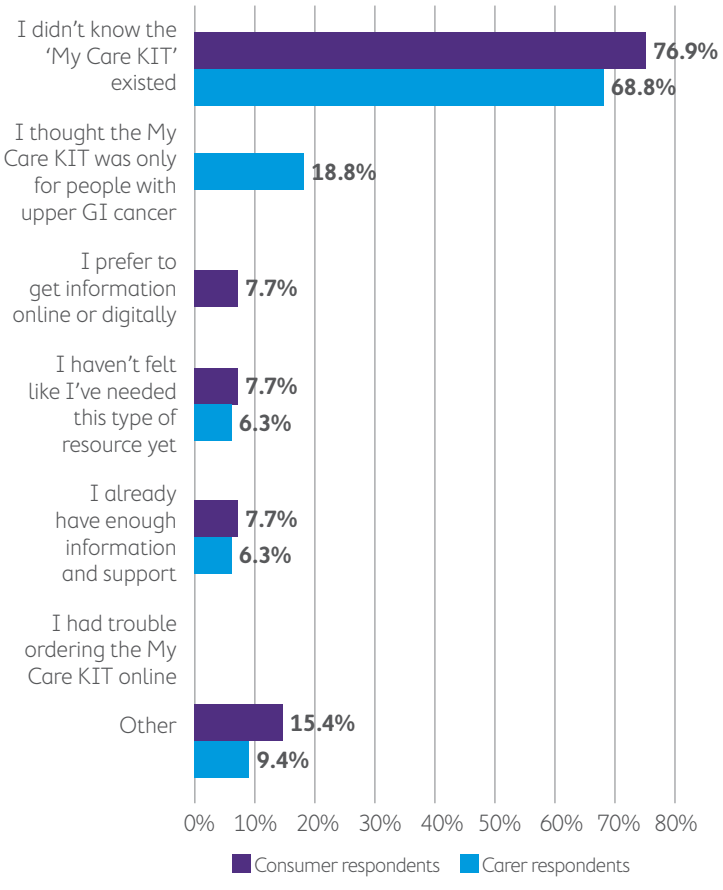
No respondents reported difficulties with the actual ordering process.

A smaller number of consumers (n=2, 15.4%) and carers (n=3, 9.4%) provided 'other' reasons for not accessing the kit:

- they were never offered it
- it was currently in transit
- their information needs were met by existing Cancer Council resources

Overall, these findings suggest that enhancing promotion of the My Care KIT and clarity regarding its scope and target audience could assist with improving uptake.

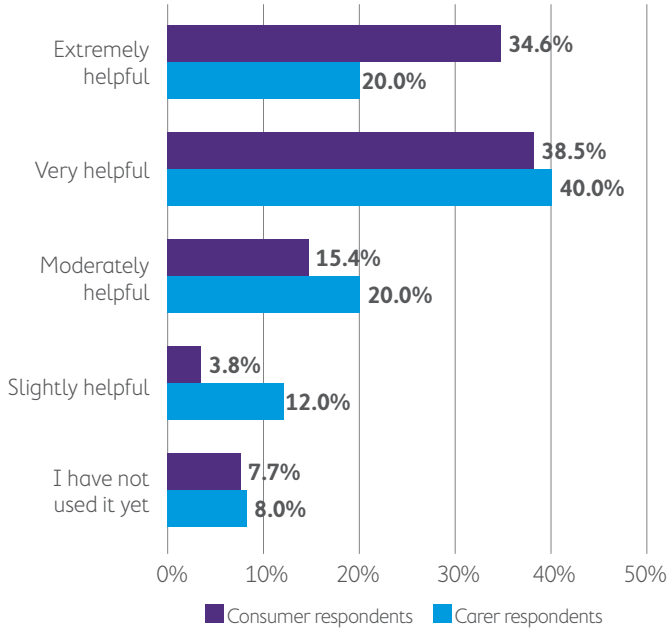
Figure 5.6: Consumer (n=13) and carer (n=32) respondents' reasons for not accessing the My Care KIT



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

Feedback on the perceived helpfulness of the My Care KIT was collected from consumers (n=26) and carers (n=25) who had accessed it (Figure 5.7). Overall, the data indicates that consumers found the kit slightly more helpful than carers, with 73.1% of consumers reporting they found it very or extremely helpful, compared to 60.0% of carers.

Figure 5.7: Extent to which consumer (n=26) and carer (n=25) respondents reported finding the My Care KIT helpful



Consumer and carer respondents were asked to provide suggestions to enhance the My Care KIT.

Consumer feedback was generally positive, with six respondents (66.7%) indicating they could not find fault with the kit. Specific suggestions for enhancement included:

- additional recipes
- sending a follow-up prompt a few months later to encourage users to revisit the kit

Carers provided a greater number of suggestions for improving the My Care KIT, as follows:

- additional pages for tracking dietary intake and Creon consumption to determine if the supplement is working
- information on side effects of chemotherapy and increased risks for cancer patients
- more information on financial support for low-income earners
- local nurse/carer numbers that can be accessed out of hours
- list of palliative care equipment and where to purchase it
- first aid for low blood sugar episodes associated with dumping syndrome
- recipes for post-operation diets
- offering an online option
- a podcast talking through the key points of the material

5.8 New Pancare Supports and Resources

This section summarises feedback from consumer and carer respondents on their likelihood of accessing a range of new potential supports and resources through Pancare, as well as suggestions for enhancing Pancare's offerings.

5.8.1 Consumer-focused supports and resources

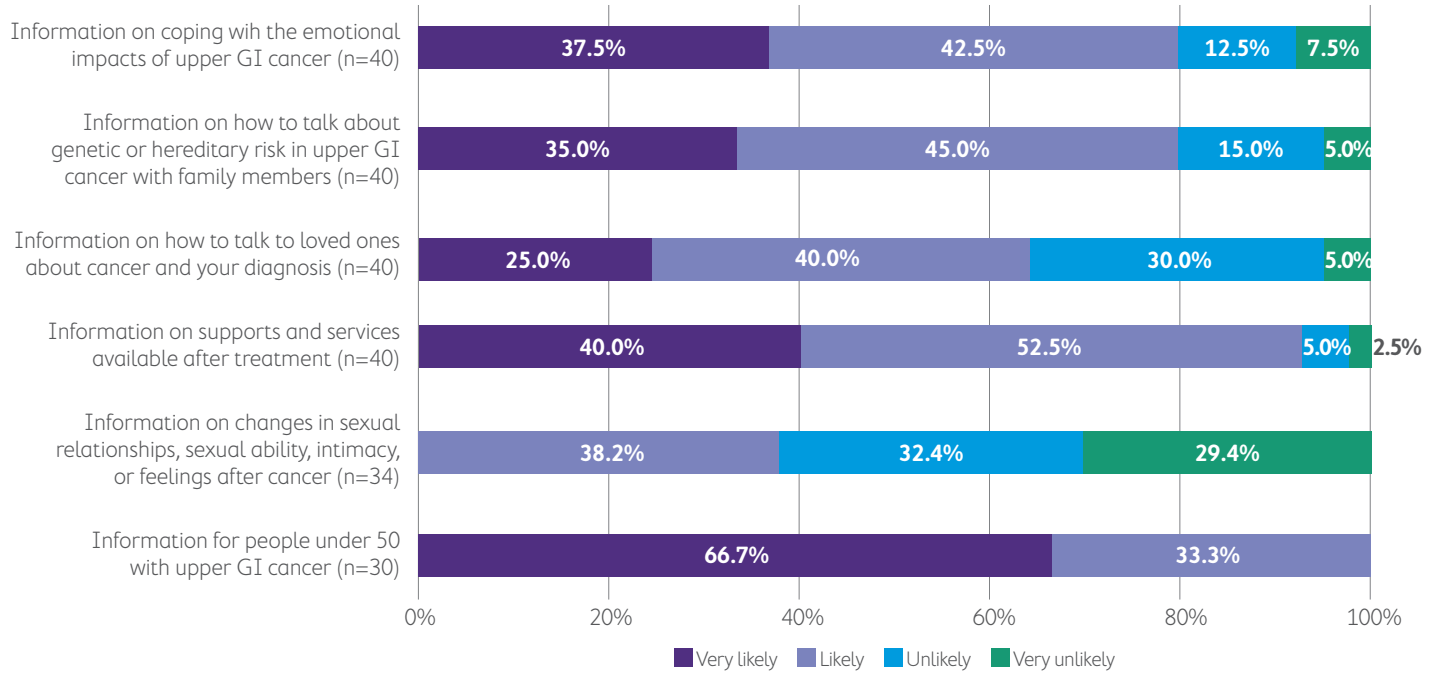
Consumer respondents were asked to indicate their likelihood of accessing information on a range of new topics through Pancare (Figure 5.8). The majority of consumers indicated they would be likely or very likely to access information on the following three topics:

- post-treatment supports and services (92.5%, n=37)
- coping with the emotional impact of upper GI cancer (90%, n=32)
- how to talk about genetic or hereditary risk in upper GI cancer with family members (90%, n=32)

In contrast, there was lower interest in information about changes in sexual relationships, sexual ability, intimacy, or feelings after cancer, with only 38.2% (n=13) of consumer respondents indicating they would access information on this topic.

While the sample size is small (n=3), all respondents under 50 years of age expressed an interest in information tailored to people under 50 with upper GI cancer.

Figure 5.8: Reported likelihood of consumer respondents accessing new resources



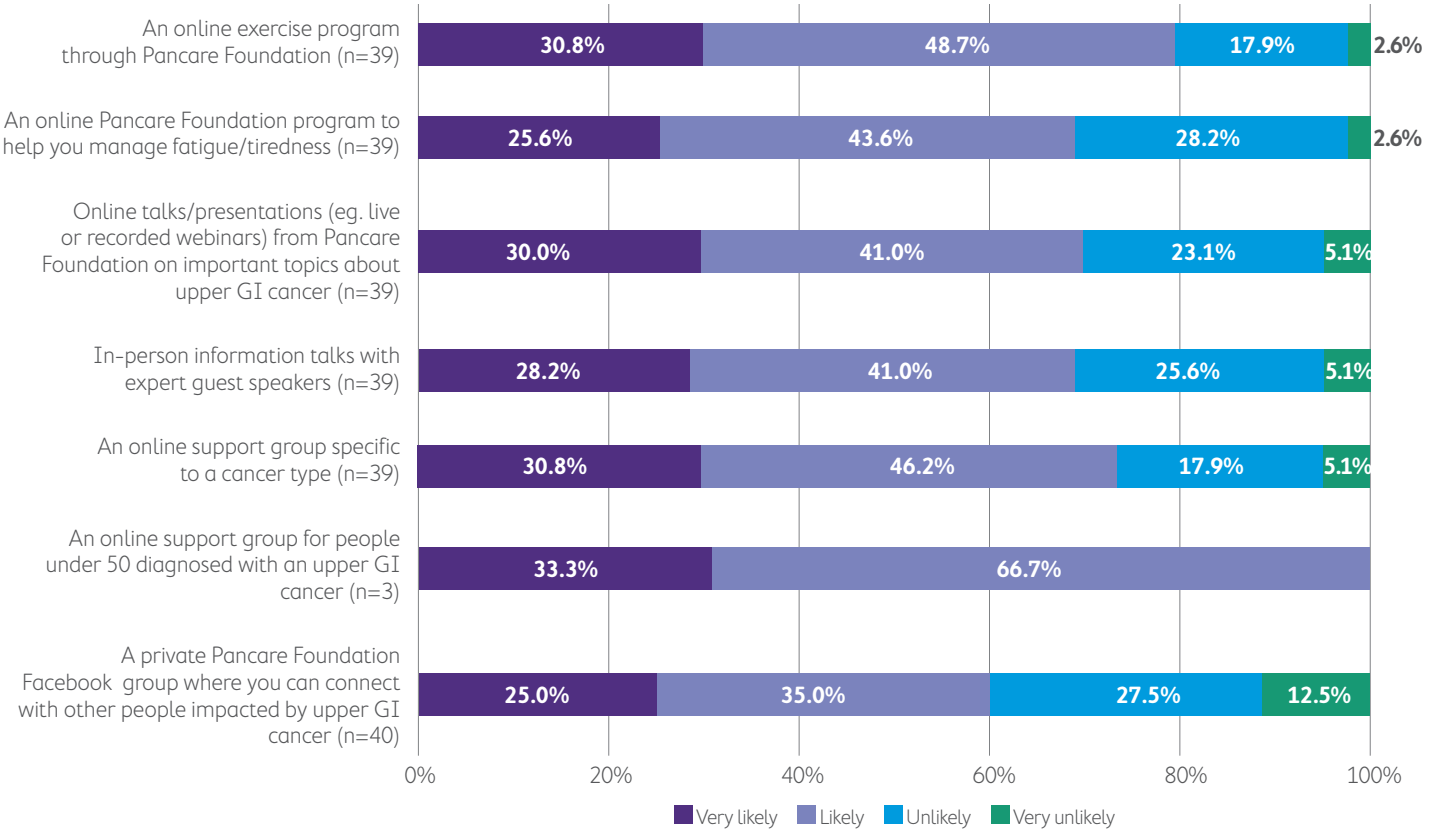
Note: The option 'information for people under 50 with upper GI cancer' was only shown to people under 50.

Consumer respondents were also asked about their likelihood of using potential new Pancare support services, as shown in Figure 5.9. There was relatively strong support for all proposed new options, with at least 60% of consumers stating they were likely or very likely to use them. The three new supports consumers reported being most likely to access were:

- online exercise program through Pancare (79.5%, n=31)
- cancer-specific online support group (77.0%, n=30)
- online talks or presentations on important upper GI cancer topics (71.8%, n=28)

Although the sample size was small (n=3), all respondents under 50 years of age expressed interest in an online support group for individuals under 50 with upper GI cancer.

Figure 5.9: Reported likelihood of consumer respondents accessing new support services



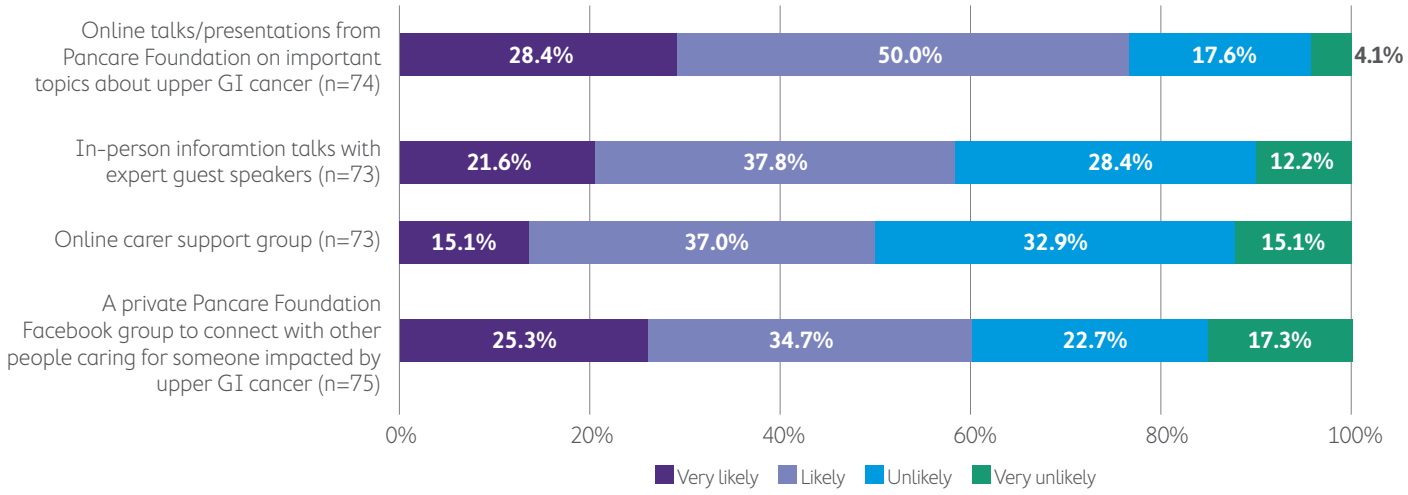
Note: Option 'information for people under 50 with upper GI cancer' was only shown to people under 50 years of age.

5.8.2 Carer-focused supports and resources

Carer respondents were also asked about their likelihood of accessing new potential support services through Pancare (Figure 5.10). There was relatively high interest in all four proposed new support options, with at least 50% of carers stating they were likely or very likely to use them. The three new supports carers reported being most likely to access were:

- online talks or presentations on key upper GI cancer topics (78.4%, n=58)
- a private Facebook group designed to connect with other caregivers of upper GI cancer patients (60.0%, n=45)
- in-person talks with expert guest speakers (59.4%, n=44)

Figure 5.10: The likelihood of carer respondents accessing new support services



Carer respondents demonstrated a high interest in a new information booklet on caring for someone with upper GI cancer. A combined 64.5% of carers reported they would be likely or very likely to use such a resource. Only seven carers (9.2%) said they are unlikely to use it, while 20 consumers (26.3%) felt it was not relevant to them.

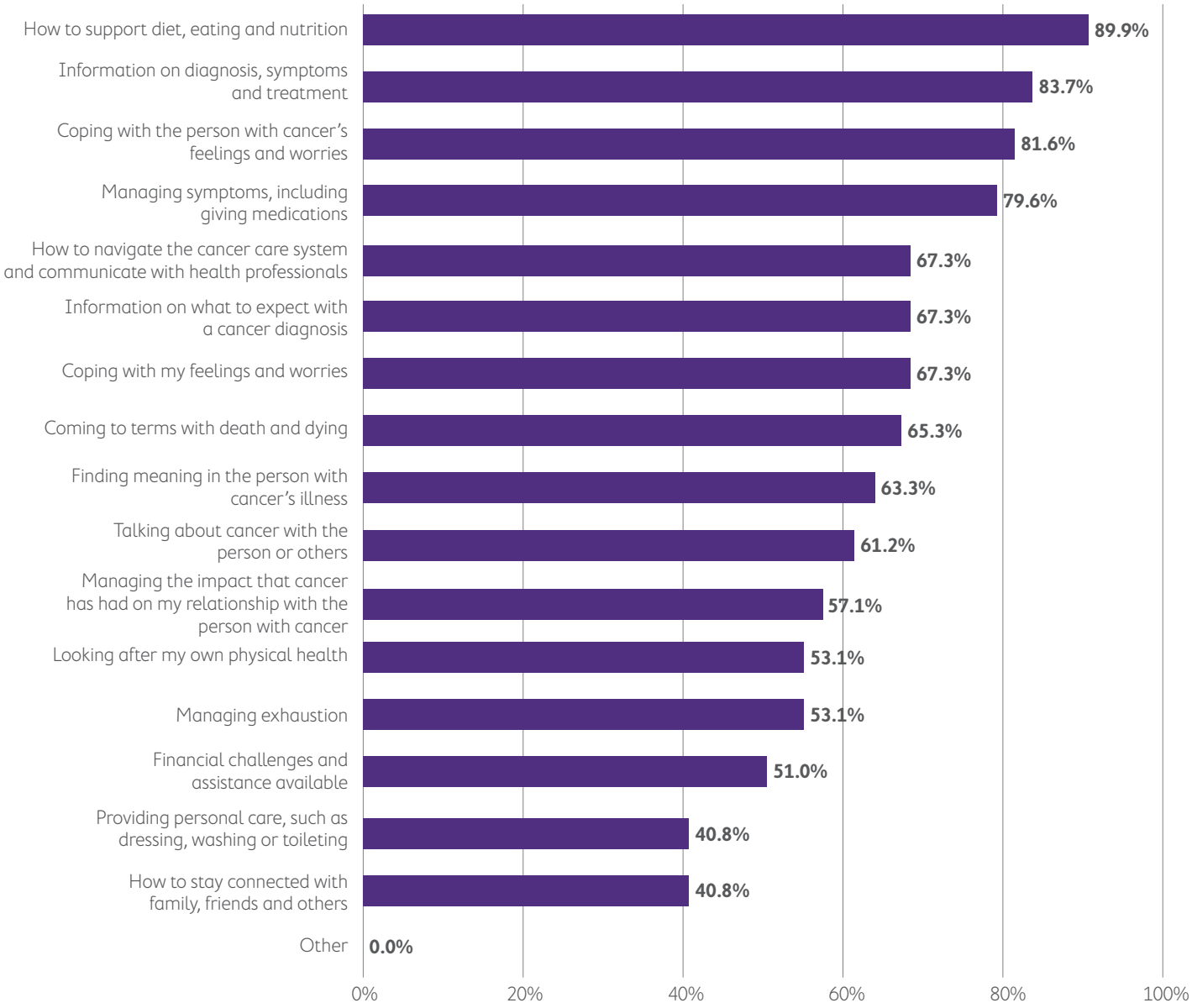
Figure 5.11 shows the specific topics that carers were most interested in seeing included in the information booklet. Notably, all proposed topics were of interest to at least 40% of respondents, suggesting a comprehensive resource covering a broad range of topics would be valued.

The topics of most interest to carers indicated a prioritisation of immediate, practical care management combined with patient-focused emotional support:

- how to support diet, eating, and nutrition (89.8%, n=44)
- information on diagnosis, symptoms, and treatment (83.7%, n=41)
- coping with the person with cancer's feelings and worries (81.6%, n=40)
- managing symptoms, including giving medication (79.6%, n=39)

The strong interest in diet and nutrition and symptom management aligns with findings on the information gaps reported by carers (Section 5.2.2), confirming these as areas where current support may be insufficient.

Figure 5.11: The topics carer respondents want in an information booklet (n=75)



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

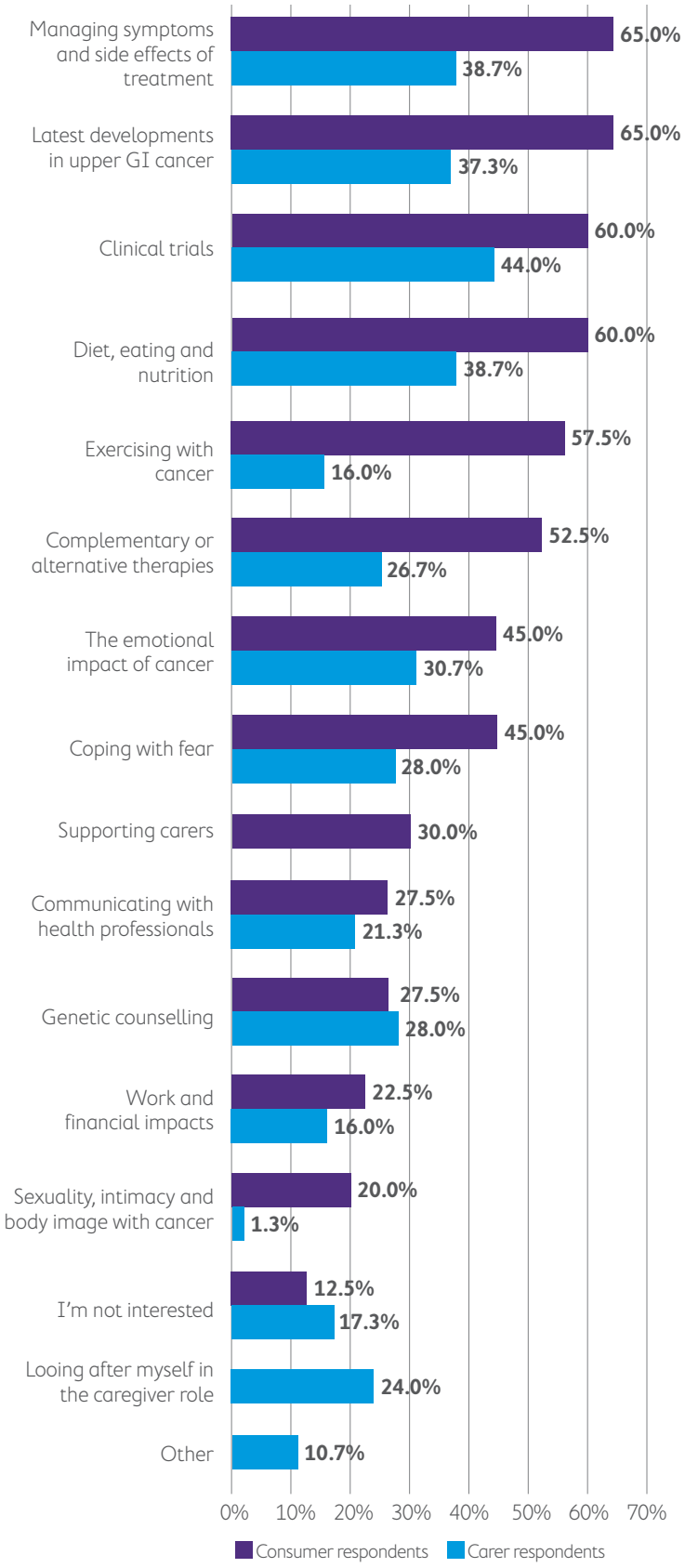
5.8.3 Preferred topics for information sessions

Figure 5.12 illustrates the topics of most interest to consumers and carers for in-person talks or webinars. Both groups showed the strongest interest in sessions about four key topics:

- managing symptoms and treatment side effects (65.0%, n=26 for consumers and 38.7%, n=29 for carers)
- latest developments in upper GI cancer (65.0%, n=26 for consumers and 37.3%, n=28 for carers)
- clinical trials (60.0%, n=24 for consumers and 44.0%, n=33 for carers)
- diet, eating, and nutrition (60.0%, n=24 for consumers and 38.7%, n=29 for carers)

Other popular topics among consumers were exercising with cancer and complementary or alternative therapies, while both consumers and carers demonstrated interest in talks or webinars about the emotional impact of cancer and coping with fear.

Figure 5.12: Topics of interest among consumers (n=40) and carers (n=75) for an in-person talk or webinar



Note: respondents were able to provide multiple responses, and therefore, the total percentage exceeds 100%.

5.8.4 Suggestions for enhancement of Pancare supports

Respondents were invited to provide open-ended suggestions for how existing Pancare support and resources could be improved, or any other resources or supports Pancare could offer. Feedback from both consumers and carers converged on improving awareness, accessibility, and the range of services offered.

Consumer respondents provided a small number of suggestions (n=5), as follows:

- expand face-to-face support group offerings
- ensure each patient is linked to a specialist nurse
- offer webinars or in-person discussions on a range of specific topics
- facilitate social days for people with upper GI cancer
- provide a Pancare card to direct patients to better and more reliable resources

A total of 27 carers provided suggestions for improving Pancare's supports, with key themes captured in Table 5.4. Feedback indicated that the primary barrier to accessing Pancare offerings stemmed from a lack of early awareness, which was attributed to limited referrals from medical professionals. A number of carers recommended that hospitals, specialists, and nurses offer information about Pancare resources and support services much earlier in the care journey. Carers noted receiving no information or only learning about Pancare after the person they cared for had passed away.

> *"I didn't know Pancare Foundation even existed until recently. Can doctors, surgeons, and hospitals more readily give out information regarding who you are, what you do and connect us to you?"*
>
> – Carer respondent

> *"I didn't find out about Pancare till after my husband's death."*
>
> – Carer respondent

> *"It would have been great to have been able to have this information booklet from Pancare provided from the specialist. We came across it on a Google search."*
>
> – Carer respondent

Carers also suggested earlier access to information about the My Care KIT and available clinical trials, as many felt they lacked sufficient information to make informed decisions.

> *"More studies regarding clinical trials and showcasing up-to-date information."*
>
> – Carer respondent

Carers also identified wanting resources to help patients, carers, and families navigate the healthcare system, face-to-face grief and loss support groups, and clinical trial information with up-to-date statistics (11.1%, n=3 each).

Table 5.4: Suggestions from carers on enhancements to existing Pancare supports and resources or new supports that could be offered (n=27)

Theme	Number	%
Facilitate earlier access to information	6	22.2%
Ensure hospitals and medical professionals refer to Pancare	6	22.2%
Provide more information about clinical trials with up-to-date statistics	3	11.1%
Provide more resources to help patients, carers, and families navigate the healthcare system	3	11.1%
Offer face-to-face grief and loss support groups	3	11.1%
Offer support groups for children who have lost their parents to cancer	2	7.4%
Provide more information about genetic mutations and upper GI cancers	1	3.7%
Share stories of people with lived experience	1	3.7%
Provide more information on how to manage diet	1	3.7%
Be more proactive in checking in with patients as the cancer progresses	1	3.7%
Total	**27**	**100.0%**

6 Next Steps

Findings from the consumer and carer survey (this document) will be triangulated with the findings from interviews with consumers and carers. This information will be used to prepare a discussion paper summarising the key themes from the survey and interviews, along with strategic options for Pancare for future service/resource delivery and development.

7 Appendices

APPENDIX A
Pancare Consumer and Carer Survey

Introduction

Pancare Foundation supports people affected by upper gastrointestinal (GI) cancers, including oesophageal, stomach, liver, biliary, and pancreatic cancer, as well as their families and carers. It does this by raising awareness, supporting research, and offering various support services, information, and resources. Pancare Foundation's goal is to improve survival rates and support patients and their families from diagnosis through treatment and beyond.

Pancare Foundation wants to learn more about the experiences and needs of people diagnosed with upper GI cancer and their families and carers. By completing this survey, you will give Pancare Foundation important information about how it can best support people affected by upper GI cancer in the future.

Healthcare Management Advisors (HMA) is running this survey on behalf of Pancare Foundation.

Your answers will be anonymous, and no identifying information will be shared with Pancare Foundation.

This project has research ethics approval from Bellberry Human Research Ethics Committee, no 2025-05-722.

Who can take part?

You can complete this survey if you are aged 18 years or over and:

- have been diagnosed with an upper GI cancer in the last five years; or
- have supported someone diagnosed with an upper GI cancer in the last five years (a family member, carer, or friend).

If you are filling out this survey for someone else, please ensure they have read the Participant Information Sheet (linked below) and provided consent for their survey answers to be collected.

What to expect

- If you are a person living with upper GI cancer, this survey will take about 20–30 minutes.
- It will take around 15 minutes if you are a family member, carer, or friend of someone with upper GI cancer.
- All your answers will be anonymous, and you will not be identifiable in any reports or papers.
- You don't have to take part if you don't want to. You can stop answering questions or close the survey at any time.

Please download and read the Participant Information Sheet for the survey by clicking <here>. It has important details about what we will ask you, how we will use the information you share with us, and any possible risks and benefits from taking part.

The survey closes at 5pm on Monday 8 September.

If you have any technical problems completing the survey, please contact HMA on (03) 8415 0936 or hma@hma.com.au.

If you need help completing this survey over the phone, or any information or support, please contact the Pancare Support team on 1300 881 698 (Monday to Friday, 9am – 5pm (AEST)) or at info@pancare.org.au.

Thank you for your time and helpful feedback.

Consent

By clicking on the "agree" button below, I confirm that I:

- have read and understood the purposes, procedures and risks of this study described in the Information Sheet attached above
- am aged 18 years or over
- consent to voluntarily taking part in the survey
- consent to the use of the information I provide (in an anonymous way) as described
- understand that I am free to withdraw at any time, noting that any data collected up until my withdrawal/exit will not be able to be removed from the study records
- understand that my involvement in this study may not be of any direct personal benefit to me.

If you do not agree to take part, please just close this window. You do not need to do anything else.

a. Agree

ABOUT YOU

1. Please select the option that best applies to you:

Please select only one item.

a. I have been diagnosed with upper GI cancer
b. I am a carer, friend, or family member of someone who has been diagnosed with upper GI cancer [skip to carer, family, and friends section on page 16]

PEOPLE DIAGNOSED WITH UPPER GI CANCER ONLY

Programming note: the following sections are only displayed for people diagnosed with upper GI cancer.

About you

2. How long ago were you first diagnosed with an upper GI cancer?

Please select only one item.

a. Less than 6 months ago
b. 6–11 months ago
c. 1–5 years ago
d. More than 5 years ago [end survey]

3. Which of the following upper GI cancers have you been diagnosed with?

Please select all that apply.

a. Liver
b. Biliary (including cholangiocarcinoma (bile duct), gallbladder cancer or ampullary cancer)
c. Oesophageal
d. Stomach
e. Pancreatic
f. Other (please specify)
g. Unsure
h. Prefer not to say

4. Please select which age range you fit into:

Please select only one item.

a. 18–24 years
b. 25–39 years
c. 40–49 years
d. 50–59 years
e. 60–69 years
f. 70–79 years
g. 80 or over

5. How do you describe your gender?

Please select only one item.

a. Man or male
b. Woman or female
c. Non-binary
d. I use a different term
e. Prefer not to say

6. In which state or territory do you live?

Please select only one item.

a. New South Wales
b. Victoria
c. Queensland
d. South Australia
e. Western Australia
f. Tasmania
g. Australian Capital Territory
h. Northern Territory

7. Which of the following best describes the area where you currently live?

Please select only one item.

a. Capital city/metropolitan area
b. Regional area
c. Rural area
d. Remote area
e. Very remote area

8. In which country were you born?

Please select only one item.

a. Australia
b. England
c. India
d. China
e. New Zealand
f. Philippines
g. Other (please specify)
h. Prefer not to say

9. Which language do you mainly speak at home?

Please select only one item.

a. English
b. Mandarin
c. Arabic
d. Cantonese
e. Vietnamese
f. Italian
g. Greek
h. Hindi
i. Spanish
j. Punjabi
k. Other (please specify)
l. Prefer not to say

10. Are you of Aboriginal and/or Torres Strait Islander origin?

Please select only one item.

a. Yes, Aboriginal
b. Yes, Torres Strait Islander
c. Yes, both Aboriginal and Torres Strait Islander
d. No
e. Prefer not to say

Experience of upper GI cancer

11. It is helpful for us to know where you are along the cancer pathway. Please select the option that best applies to you.

Please select only one item.

a. I have recently been diagnosed with upper GI cancer
b. I am having initial/first treatment for upper GI cancer
c. I am recovering from treatment of upper GI cancer
d. My cancer has returned and I am having or planning further treatment
e. I am in remission from upper GI cancer
f. I am undergoing palliative/end-of-life care
g. Unsure
h. Other (please describe)
i. Prefer not to say

12. Do you or did you have a **main support person** during your cancer care (e.g. a family member or carer)?

Please select only one item.

a. Yes
b. No

If a (Yes) selected:

What is your main support person's relationship to you?
Please select only one item.

- Partner/spouse
- Parent
- Child
- Sibling
- Other family member
- Friend
- Neighbour
- Colleague
- Other (please describe)

13. Which of the following did/do you use for your cancer care?

Please select all that apply.

a. Public health care
b. Private health care
c. Neither
d. Prefer not to say

14. If possible and relevant to you, where would you prefer to have chemotherapy treatment?

Please select only one item.

a. Hospital/treatment centre
b. Home
c. Not relevant to me/my diagnosis

Clinical trial options

15. Have any of your healthcare providers talked to you about clinical trial options?

Please select only one item.

a. Yes
b. No
c. Unsure

16. Have you signed up for and/or participated in a clinical trial?

Please select only one item.

a. Yes
b. No
c. Unsure

If b. (No) selected:

Please let us know why you have not signed up for and/or participated in a clinical trial.
Please select all that apply.

- None were offered to me
- Trials were not accepting new participants
- I didn't meet the eligibility criteria
- Distance or travel barriers
- Financial barriers
- Family barriers (e.g. childcare)
- Employment barriers
- Other (please describe)
- Unsure

Access to health professionals

17. Have you accessed support from a specialist upper GI nurse through your hospital/treatment centre?

a. Yes
b. No
c. Unsure

If b. (No) selected:

Please let us know why you have not accessed support from a specialist upper GI nurse through your hospital/treatment centre.
Please select all that apply.

- I haven't needed to
- My healthcare team didn't suggest it
- I don't know how to find or see a specialist upper GI nurse
- I was feeling too unwell to go to appointments
- I felt overwhelmed with appointments and didn't want another one
- Other (please describe)
- Unsure

18. Have you seen a dietitian at your hospital/treatment centre for your upper GI cancer?

a. Yes
b. No
c. Unsure

If b. (No) selected:

Please let us know why you haven't seen or accessed a dietitian in relation to your upper GI cancer diagnosis.
Please select all that apply.

- I haven't needed to
- I didn't know seeing a dietitian could help with upper GI cancer
- My healthcare team didn't suggest it
- I don't know how to find or see a dietitian
- I couldn't afford it
- I couldn't get an appointment, or the wait time was too long
- I was feeling too unwell to go to appointments
- Getting a referral was too complicated
- I felt overwhelmed with appointments and didn't want another one
- I preferred to manage my diet myself
- Other (please describe)
- Unsure

19. Have you seen an exercise physiologist or physiotherapist for your upper GI cancer?

a. Yes
b. No
c. Unsure

If b. (No) selected:

Please tell us why you haven't seen an exercise physiologist or physiotherapist in relation to your upper GI cancer.
Please select all that apply.

- I'm already exercising
- I don't want to exercise
- I don't know what exercise or activity I'm allowed to do
- My healthcare team didn't suggest it
- I couldn't afford it
- I couldn't get an appointment, or the wait time was too long
- I was feeling too unwell to attend appointments
- Getting a referral was too complicated
- I felt overwhelmed with appointments and didn't want another one
- Other (please describe)
- Unsure

Technology use in upper GI cancer treatment

20. Have you had any appointments with health professionals by phone or video as part of your cancer care?

Please select all that apply.

a. Yes, I've had at least one appointment by phone
b. Yes, I've had at least one appointment by video
c. No
d. Unsure

21. Have you used any of the following technologies as part of your cancer care?

Please select all that apply.

a. Mobile apps to help manage symptoms, medications, and appointments
b. Devices that track my health at home (e.g. smartwatches/ wearables, glucose monitors, blood pressure cuffs, etc.)
c. Access to my online medical records from home (e.g. through an online hospital account or portal)
d. Email communication with my healthcare team
e. Online support groups or forums
f. Other technology (please describe)
g. None of the above

22. What are some of the biggest challenges you have faced (or expect to face) in relation to using technology as part of your cancer care?

Please select all that apply.

a. Slow or unreliable internet access
b. Not having the right devices (e.g. smartphone, computer)
c. The cost of internet or devices
d. Not feeling confident or comfortable using technology
e. Not knowing how to use technologies
f. Not being physically able to use technologies (e.g. the writing is too small, or my fingers are too stiff to use)
g. My health professional(s) not offering technology options
h. Worries about privacy or security of online information
i. Other (please describe)
j. I don't anticipate or haven't experienced any barriers in using technology as part of my care
k. Unsure

Molecular tumour testing

23. Do you understand what "molecular tumour testing" is? This is sometimes also referred to as comprehensive genomic profiling.

Please select only one item.

a. Yes
b. No

If a selected:

Have you had molecular tumour testing/comprehensive genomic profiling done?
Please select only one item.

- Yes
- No
- Unsure

If b selected:

Molecular tumour testing/comprehensive genomic profiling

One way to uncover the specific genetic features of a cancer is through molecular tumour testing/comprehensive genomic profiling (CGP). This involves testing a sample of cancer tissue to look for changes in over 500 genes known to affect the growth of a cancer. These changes, called biomarkers, form a 'fingerprint' for a cancer. Doctors can then use this information to find more effective and targeted treatment options for that cancer. If you would like to know if you are eligible for molecular tumour testing/CGP please talk with your treatment team.

Experience of physical symptoms

24. Since your diagnosis, which of these types of physical symptoms or side effects (if any) have you found most challenging?

Please select up to three.

a. **Eating, taste, and dietary changes:** this could include changes in appetite, changes in taste, enjoying food less, or difficulty eating
b. **Changes to your physical body:** this could include weight loss or loss of muscle
c. **Fatigue:** feeling tired or low in energy
d. **Pain:** this could include tummy pain, back pain, shoulder pain, or headaches
e. Mouth and swallowing issues: this could include a sore mouth, mouth ulcers, pain, or trouble swallowing

f. **Stomach, digestion, and bowel issues:** this could include feeling sick, vomiting, indigestion, reflux/heartburn, feeling full quickly, bloating, wind pain, diarrhoea, constipation, or dumping syndrome
g. **Thinking and memory problems:** this could include trouble thinking clearly or focusing, or problems with memory or finding the right words
h. **Nerve-related issues:** this could include numbness, tingling, or loss of feeling in hands/feet
i. **Sleep problems:** this could include having trouble falling asleep not sleeping well, or sleeping too much
j. **Respiratory problems:** this could include shortness of breath or cough
k. **Skin, hair, and nail issues:** this could include hair thinning/loss, skin/nail changes, rashes, or itchy skin
l. **Blood-related issues:** this could include blood clots, bruising easily, or anaemia
m. **Sexual changes:** this could include loss of sexual interest or ability
n. **Other types of physical symptoms/side effects** (please describe)
o. I have not found any physical symptoms or side effects challenging

25. We would like to understand more about the symptoms or side effects that you have found most challenging. In as much or as little detail as you like, please tell us more about these challenges and how they have impacted you.

Comment box.

Emotional and social impacts

26. Since your diagnosis, have you experienced any of the following emotional or mental health impacts?

Please select all that apply.

a. Feeling down, depressed, or sad
b. Crying often or for long periods
c. Finding it hard to enjoy everyday things, like food or being with family and friends
d. Loss of interest in hobbies and activities
e. Feeling anxious
f. Grief
g. Feeling worthless or hopeless
h. Feeling angry or frustrated
i. None of the above
j. Prefer not to say

27. Since your diagnosis, have you experienced any of the following impacts related to worry, fear, or uncertainty?

Please select all that apply.

a. Loss of confidence
b. Feeling worried
c. Fear that the cancer will spread or come back (recur)
d. Fear of death
e. Feeling uncertain about the future
f. Feeling overwhelmed or helpless
g. Feeling confused about why this has happened
h. Worry about the impact on my children
i. Worry about the impact on loved ones
j. Worry about being able to have children (fertility)
k. None of the above
l. Prefer not to say

28. Since your diagnosis, have you experienced any of the following impacts on relationships or how you feel about your body?

Please select all that apply.

a. Problems in relationships
b. Changes in sexual feelings or intimacy with my partner/spouse
c. Changes in how I see or feel about my body
d. Feeling like eating is a chore
e. None of the above
f. Prefer not to say

29. Since your diagnosis, have you experienced any of the following impacts on your social life?

Please select all that apply.

a. Withdrawing or spending less time with my partner/spouse
b. Withdrawing or spending less time with my family and friends
c. Not wanting to socialise or go to social occasions/events
d. Feeling isolated or lonely
e. Feeling like no one understands what I'm going through
f. Feeling anxiety around eating in social situations
g. Avoiding eating in social situations
h. Other (please describe)
i. None of the above
j. Prefer not to say

30. We would like to understand more about how upper GI cancer has affected your feelings and social life. In as much or as little detail as you like, please tell us about the impacts you have found most challenging.

Comment box.

Financial impacts

31. Since your diagnosis, have you experienced any of the following financial impacts?

Please select all that apply.

a. Financial hardship or stress (trouble paying for things like rent/mortgage, food, or bills)
b. I lost my job
c. I have lost income
d. I have reduced my work hours
e. I went into early retirement
f. Impacts on partner/spouse's income
g. Impacts on savings
h. I have had increased transport costs
i. I have had to pay for my own treatment costs or other cancer-related costs myself (e.g. tests, scans, equipment)

j. I have had to pay for my own medication costs
k. I couldn't get treatment because of the cost
l. I couldn't get specific medication(s) because of the cost
m. I couldn't get specific foods or food supplements because of the cost
n. Other (please describe)
o. I have not experienced any financial impacts
p. Prefer not to say

If f. selected:
Have you paid for any medication yourself that wasn't covered through the government-funded Pharmaceutical Benefits Scheme (PBS)?

Please select only one item.

- Yes
- No
- Unsure

If Yes selected:
Approximately how much money have you paid yourself for these medicines each year, on average?

Please select only one item.

- Less than $500
- $500–$1,000
- $1,001–$5,000
- $5,001–$10,000
- $10,001–$50,000
- More than $50,000
- Unsure

32. When new and effective cancer medications are added to the Pharmaceutical Benefits Scheme (PBS) (meaning the government helps pay for them), what difference do you think it makes for people managing the costs of cancer treatment?

Comment box.

Your experiences and background

Sometimes a person's background can affect their cancer experience and the support they get. We want to understand if your background has made it harder or easier for you to get the care and support you need.

33. Do you identify with one or more of the following?

- From a culturally and linguistically diverse background
- A First Nations person
- Live in a regional or rural area
- From a lower income background
- A member of the LGBTIQ+ community
- Live with a disability
- An older person
- Live with a mental illness

Please select only one item.

a. Yes
b. No
c. Prefer not to say

If a. selected:
Please describe, in as much or as little detail as you like, whether you feel you have experienced any specific challenges or issues during your cancer experience as a result of identifying with any of the groups above.

Comment box.

Upper GI cancer support [programming note: this section is only displayed if 12(e) selected]

34. Were you offered any supportive care (i.e. the information, resources, and services a person may need as part of comprehensive cancer care) post-treatment?

Please select only one item.

a. Yes
b. No
c. Unsure

If a (yes) selected:
What support(s) did you find most beneficial?

Comment box.

Information about upper GI cancer

In this section, we want to learn more about how you prefer to get information about upper GI cancer and the types of information you want to be able to access.

35. How do you prefer to get written information about upper GI cancer and available support services?

Please select all that apply.

a. Hard copy or printed copies (like paper booklets or fact sheets)
b. Digital copies (like on websites or as online documents)

36. What other ways do you prefer to get information about upper GI cancer and available support services?

Please select all that apply.

a. Google/web search
b. Pancare Foundation website
c. Other cancer websites (please tell us which ones)
d. Specialist doctor
e. Cancer nurse
f. GP
g. From family or friends
h. Facebook
i. LinkedIn
j. Instagram
k. TikTok
l. Text message/SMS

m. Artificial intelligence (AI) (e.g. ChatGPT)
n. Email newsletters
o. Live online talks/presentations (e.g. webinars)
p. Podcasts
q. Videos (e.g. information videos, patient stories, or pre-recorded webinars)
r. Animations
s. Other (please describe)

37. Is there any information about upper GI cancer that you have wanted or needed but have found hard to get?

Please select only one item.

a. Yes
b. No

If a. selected:
Can you please describe the information you have wanted or needed but have found hard to get?

Comment box.

Emotional support

In this section, we want to learn more about the emotional support you have needed or wanted because of your upper GI cancer.

38. Since your diagnosis, have you felt that you needed any of the following emotional support?

Please select all that apply.

a. To talk to a counsellor
b. To talk to a psychologist (e.g. to learn new coping strategies)
c. A support group with other patients
d. Emotional support for my family, carers, or loved ones
e. Spiritual support (e.g. help to find meaning in life with a cancer diagnosis)
f. Support with how I feel about my body's appearance
g. Support for feelings of grief or loss
h. Other emotional support (please describe)
i. None of the above
j. Prefer not to say

If responses a-i selected:
Have you been able to get all the emotional support you have needed?

- Yes
- No

If No selected:
Please let us know what support you have not been able to get and what prevented you from getting this support.

Comment box.

Pancare Foundation support and information resources

Pancare Foundation offers various support, information, and resources to help people with upper GI cancer and their families and carers.

39. Have you ever accessed a Pancare Foundation 'My Care KIT' (this is a hard copy folder with booklets, information sheets, and places to record information about upper GI cancer)?

Please select only one item.

a. Yes
b. No
c. Unsure

If a. (Yes) selected:
How helpful did you find the My Care KIT?

Please select only one item.

- Extremely helpful
- Very helpful
- Moderately helpful
- Slightly helpful
- Not helpful at all
- I have not used it yet

Do you have any suggestions for how the My Care KIT could be improved?

Comment box.

If b. (No) selected:
Please tell us why you haven't accessed a Pancare Foundation My Care KIT.

Please select all that apply.

- I didn't know the 'My Care KIT' existed
- I prefer to get information online or digitally
- I haven't felt like I've needed this type of resource yet
- I already have enough information and support
- I had trouble ordering the 'My Care KIT' online
- Other (please describe)

40. Have you ever taken part in a Pancare Foundation support group?

Please select all that apply.

a. An online support group for patients
b. An online support group led by a specialist presenter
c. Face-to-face patient support group
d. An online grief and loss support group
e. I have not taken part in any Pancare support groups
f. Unsure

If e. selected:
Please tell us why you haven't participated in a Pancare Foundation support group.

Please select all that apply.

- I didn't know about them
- The times or dates didn't suit me
- I would prefer support groups focused on specific types of upper GI cancer
- I prefer face-to-face support groups, but there aren't any in my area
- I would prefer to talk one-on-one with someone going through a similar journey
- I don't know how to join a support group
- I don't have good enough internet access to join online support groups
- I prefer to deal with my experience privately
- I don't feel like I need the support of a group right now
- I have enough support from family and friends
- I'm worried about confidentiality within the group
- I just don't like support groups
- Other (please describe)

New Pancare Foundation supports and resources

Pancare Foundation is always looking to improve its current information, resources and supports, and create new ones where there is a need. The next questions are about new kinds of information resources (e.g. booklets, fact sheets, or online/digital information) that Pancare could offer.

41. If information were available on the following topics through Pancare, how likely would you be to access it?

Please select only one response per item.

	Very Unlikely	Unlikely	Likely	Very Likely
[only shown for people under 50] Information for people under 50 with upper GI cancer				
Information on changes in sexual relationships, sexual ability, intimacy, or feelings after cancer				
Information on supports and services available after treatment				
Information on how to talk to loved ones about cancer				
Information on how to talk about genetic or hereditary risk in upper GI cancer with family members				
Information on coping with the emotional impacts of upper GI cancer				

42. If the following supports were available, how likely would you be to access them?

Please select only one response per item.

	Very Unlikely	Unlikely	Likely	Very Likely
A private Pancare Foundation Facebook group to connect with other people impacted by upper GI cancer				
[only shown for people under 50] An online support group for people under 50 diagnosed with an upper GI cancer				
An online support group specific to cancer type (i.e. pancreatic cancer, liver cancer, oesophageal cancer, biliary cancer, stomach cancer)				
In-person information talks with expert guest speakers				
Online talks/presentations (e.g. live or recorded webinars) from Pancare Foundation on important topics about upper GI cancer				
An online Pancare Foundation program to help manage fatigue/ tiredness				
An online exercise program through Pancare Foundation				

43. Would you be interested in attending an in-person talk or a live online session (e.g. webinar) on any of these topics?

Please select all that apply.

a. Clinical trials
b. Sexuality, intimacy, and body image with cancer
c. Managing symptoms and side effects of treatment
d. Communicating with health professionals
e. Diet, eating and nutrition
f. The emotional impact of cancer
g. Exercising with cancer
h. Supporting carers
i. Complementary or alternative therapies
j. Coping with fear (e.g. fear of the cancer spreading or coming back, fear of death)
k. Work and financial impacts
l. Latest developments in upper GI cancer
m. Genetic counselling
n. Other topics (please describe)
o. I'm not interested

44. Do you have any suggestions for how Pancare Foundation's supports and resources could be improved, or any new resources or supports that Pancare Foundation could offer?

Comment box.

Final comments

45. Do you have any final comments or feedback you would like to share?

Comment box.

Survey end page

We're keen to speak further with people affected by upper GI cancer, including patients, families, and carers. We want to understand what support and resources would be most helpful, and what problems people face when trying to find support or information.

If you choose to take part, you'll be talking with two HMA staff members. There are two options:

- A 30-minute one-on-one video or phone call
- Joining a focus group with other people with upper GI cancer and/or family and carers for up to 90 minutes.

You will receive a $55 digital Visa gift card for your time.

46. Would you be willing to take part in an interview or focus group about your experiences?

a. Yes
b. No

Thank you for taking part in this survey.

If this survey has made you feel upset or you want to speak to someone about any issues it has raised for you, please contact the Pancare Support team on 1300 881 698 (Monday to Friday 9am–5pm (AEST)) or email info@pancare.org.au.

Please click 'Submit' to complete the survey.

If a. selected, participants will be redirected to an entirely separate form in SurveyManager to provide their contact details. This information will not be linked to survey responses in any way.

CARERS, FAMILY AND FRIENDS ONLY

Programming note: the following sections are only displayed for people who are a carer, friend, or family member of someone who has been diagnosed with upper GI cancer.

About the person diagnosed with upper GI cancer

47. How long ago was the person first diagnosed with an upper GI cancer?

Please select only one item.

a. Less than 6 months ago
b. 6–11 months ago
c. 1–5 years ago
d. More than 5 years ago [end survey]
e. Unsure

48. What type(s) of upper GI cancer does the person you have supported have?

Please select all that apply.

a. Liver
b. Biliary (including cholangiocarcinoma (bile duct), gallbladder cancer or ampullary cancer)
c. Oesophageal
d. Stomach (gastric cancer)
e. Pancreatic
f. Other (please specify)
g. Unsure
h. Prefer not to say

49. It is helpful for us to know where the person you have supported currently is along the cancer pathway. Please select the option that best applies to them.

Please select only one item.

a. The person has recently been diagnosed with upper GI cancer
b. The person is undergoing (initial/first) treatment for upper GI cancer
c. The person is recovering from treatment of upper GI cancer
d. The person's cancer has returned and they are undergoing/planning further treatment
e. The person is in remission from upper GI cancer
f. The person is undergoing palliative/end-of-life care
g. The person has died
h. Unsure
i. Other (please describe)

50. What is the person's relationship to you?

Please select only one response.

a. Partner/spouse
b. Parent
c. Child
d. Sibling
e. Other family member
f. Friend
g. Neighbour
h. Colleague
i. Other (please describe)

About you

51. Please select which age range you fit into:

Please select only one item.

a. 18–24 years
b. 25–39 years
c. 40–49 years
d. 50–59 years
e. 60–69 years
f. 70–79 years
g. 80 or over

52. How do you describe your gender?

Please select only one item.

a. Man or male
b. Woman or female
c. Non-binary
d. I use a different term
e. Prefer not to answer

53. In which state or territory do you live?

Please select only one item.

a. New South Wales
b. Victoria
c. Queensland
d. South Australia
e. Western Australia
f. Tasmania
g. Australian Capital Territory
h. Northern Territory

54. Which of the following best describes the area where you currently live?

Please select only one item.

a. Capital city/metropolitan area
b. Regional area
c. Rural area
d. Remote area
e. Very remote area

55. In which country were you born?

Please select only one item.

a. Australia
b. England
c. India
d. China
e. New Zealand
f. Philippines
g. Other (please specify)
h. Prefer not to say

56. Which language do you mainly speak at home?

Please select only one item.

i. English
j. Mandarin
k. Arabic
l. Cantonese
m. Vietnamese
n. Italian
o. Greek
p. Hindi
q. Spanish
r. Punjabi
s. Other (please specify)
t. Prefer not to say

57. Are you of Aboriginal and/or Torres Strait Islander origin?

Please select only one item.

a. Yes, Aboriginal
b. Yes, Torres Strait Islander
c. Yes, both Aboriginal and Torres Strait Islander
d. No
e. I prefer not to say

Your experience with upper GI cancer

In this section, we want to learn more about how supporting someone with upper GI cancer has impacted you.

58. Have you experienced any of the following in relation to supporting a person with upper GI cancer?

Please select all that apply.

a. Exhaustion (fatigue)
b. Not sleeping well (e.g. trouble falling asleep, staying asleep, or sleep disturbances)
c. Headaches
d. Sadness or depression
e. Worry or anxiety
f. Stress
g. Feeling scared or fearful
h. Feeling uncertain about the future
i. Grief
j. Guilt
k. Lacking information
l. Feeling overwhelmed or out of my depth
m. Feelings of anger or frustration
n. Feelings of worthlessness or hopelessness
o. Feeling confused about why this has happened
p. Feeling useless
q. Feeling socially isolated
r. Challenges supporting the person's dietary requirements
s. Relationship problems
t. Concerns for others in the family (e.g. children)
u. Other (please describe)
v. None of the above
w. Unsure
x. Prefer not to say

59. Have you experienced any of the following financial impacts in relation to supporting a person with upper GI cancer?

Please select all that apply.

a. Financial hardship or stress (trouble paying for things like rent/mortgage, food, or bills)
b. Lost income
c. Reduced my work hours
d. Lost my job
e. Went into early retirement
f. Increased transport costs
g. Out-of-pocket expenses for specific medical equipment or supplies

h. Out-of-pocket expenses for treatment or medication costs
i. Other (please describe)
j. I have not experienced any financial impacts
k. Unsure
l. Prefer not to say

60. We would like to understand more about your experience of supporting someone with upper GI cancer. In as much or as little detail as you like, please tell us about aspects you have found most challenging.

Comment box.

61. What kind of support or help do you think would have made it easier to manage any challenges you have experienced?

Comment box.

Information about upper GI cancer

In this section, we want to learn more about how you prefer to get information about upper GI cancer and the types of information you want to be able to access.

62. How do you prefer to get written information about upper GI cancer and available support services?

Please select all that apply.

a. Hard copy or printed copies (like paper booklets or fact sheets)
b. Digital copies (like on websites or as online documents)

63. What other ways do you prefer to get information about upper GI cancer and available support services?

Please select all that apply.

a. Google/web search
b. Pancare Foundation website
c. Other cancer websites (please tell us which ones)
d. Specialist doctor
e. Cancer nurse
f. GP
g. From family or friends
h. Facebook
i. LinkedIn
j. Instagram
k. TikTok
l. Text message/SMS
m. Artificial intelligence (AI) (e.g. ChatGPT)
n. Email newsletters
o. Live online talks/presentations (e.g. webinars)
p. Podcasts
q. Videos (e.g. information videos, patient stories, or pre-recorded webinars)
r. Animations
s. Other (please describe)

64. Is there any information about upper GI cancer that you have wanted or needed but have found hard to get?

Please select only one item.

a. Yes
b. No

If a. selected:
Can you please describe the information you have wanted or needed but have found hard to get?

Comment box.

Emotional support

In this section, we want to learn more about the emotional support you have needed to help you support someone with upper GI cancer.

65. Since you have been providing support to someone with upper GI cancer, have you felt that you needed any of the following?

Please select all that apply.

a. To talk to a counsellor
b. To talk to a psychologist
c. A peer support group with other carers or family members of people with upper GI cancer
d. Spiritual support (e.g. help to find meaning in the experience)
e. Support for grief or loss
f. Other emotional support (please describe)
g. None of the above
h. Unsure
i. Prefer not to say

If responses a-g selected:
Have you been able to get all the emotional support you have needed?

- Yes
- No

If No selected:
Please let us know what support you have not been able to get and what prevented you from getting this support.

Comment box.

Pancare Foundation support and resources

Pancare Foundation provides a range of supports and resources to assist people diagnosed with upper GI cancer and their families and caregivers.

66. How familiar are you with Pancare Foundation supports and resources?

a. Very familiar
b. Somewhat familiar
c. Not familiar [skip to Q69]

67. Have you ever accessed a Pancare Foundation 'My Care KIT' (a hard copy folder containing a series of booklets, information sheets, and places to record information)?

Please select only one item.

a. Yes
b. No

If a. selected:
How useful did you find the My Care KIT?

Please select only one item.

- Extremely useful
- Very useful
- Moderately useful
- Slightly useful
- Not useful at all
- I have not used it

Please provide any feedback on the My Care KIT below, including any suggestions for how it could be improved.

Comment box.

If b. selected:
Please let us know why you have not accessed a Pancare Foundation My Care KIT.

Please select all that apply.

- I didn't know the My Care KIT existed
- I thought the My Care KIT was only for people with upper GI cancer
- I prefer to get information online or digitally
- I haven't felt like I've needed this type of resource yet
- I already have enough information and support
- I had trouble ordering the My Care KIT online
- Other (please describe)

68. Have you ever participated in a Pancare Foundation support group?

Please select all that apply.

a. Online carer support group
b. Online specialist presenter led support groups
c. Online grief and loss support group
d. I have not participated in any Pancare support groups
e. Unsure

If d. selected:
Please let us know why you have not participated in a Pancare Foundation support group.

Please select all that apply.

- I didn't know about them
- The times or dates didn't suit me
- I prefer face-to-face support groups
- I would prefer to talk one-on-one with someone going through a similar experience
- I don't know how to join a support group
- I don't have good enough internet access to join online support groups
- I'm not comfortable sharing my personal experiences with others
- I don't feel like I need the support of a group right now
- I have enough support from family and friends
- I just don't like support groups
- Other (please describe)
- Unsure

New Pancare Foundation supports and resources

Pancare Foundation is always looking to improve its current information, resources and supports, and create new ones where there is a need. The next questions are about new kinds of support and information that Pancare could offer.

69. If Pancare Foundation developed a new information booklet on caring for someone with upper GI cancer, how likely would you be to use it?

Please select only one response.

a. Very likely
b. Likely
c. Unlikely
d. Very unlikely
e. Not relevant/applicable to me

If a. or b. selected:
Please tell us which topics you would like to see included in this information booklet.

- How to navigate the cancer care system and communicate with health professionals
- Information on diagnosis, symptoms, and treatment
- Managing symptoms, including giving medications
- Information on what to expect with a cancer diagnosis (e.g. potential impacts and challenges)
- How to support diet, eating, and nutrition
- Providing personal care, such as dressing, washing, or toileting
- Coping with my feelings and worries
- Coping with the person with cancer's feelings and worries
- Looking after my own physical health
- Managing exhaustion
- Financial challenges and assistance available
- Talking about cancer with the person or others
- How to stay connected with family, friends, and others
- Managing the impact that cancer has had on my relationship with the person with cancer
- Coming to terms with death and dying
- Finding meaning in the person with cancer's illness
- Other (please describe)

70. If the following supports were available, how likely would you be to access them?

Please select only one response per item.

	Very Unlikely	Unlikely	Likely	Very Likely
A private Pancare Foundation Facebook group to connect with other people caring for someone impacted by upper GI cancer				
Online carer support group				
In-person information talks with expert guest speakers				
Online talks/presentations (e.g. live or recorded webinars) from Pancare Foundation on important topics about upper GI cancer				

71. Would you be interested in attending an in-person talk or a live online session (e.g. a webinar) on any of these topics?

Please select all that apply.

a. Clinical trials
b. Looking after myself in the caregiver role
c. Sexuality and intimacy when caring for someone with cancer
d. Managing symptoms and side effects of my loved one's treatment
e. Communicating with health professionals
f. Supporting diet, eating, and nutrition for people with cancer
g. The emotional impact of cancer
h. Supporting exercising for people with cancer
i. Complementary or alternative therapies
j. Coping with fear (e.g. fear of the cancer spreading or coming back, fear of the death of the person with cancer)
k. Work and financial impacts
l. Latest developments in upper GI cancer
m. Genetic counselling
n. Other topics (please describe)
o. I'm not interested

72. Do you have any suggestions for how Pancare Foundation's supports and resources could be improved, or any new resources or supports that Pancare Foundation could offer?

Comment box.

Final comments

73. Do you have any final comments or feedback you would like to share?

Comment box.

Survey end page

We're keen to speak further with people affected by upper GI cancer, including patients, families, and carers. We want to understand what support and resources would be most helpful, and what problems people face when trying to find support or information.

If you choose to take part, you'll be talking with two HMA staff members. There are two options:

- A 30-minute one-on-one video or phone call
- Joining a focus group with other people with upper GI cancer and/or family and carers for up to 90 minutes.

You will receive a $55 digital Visa gift card for your time.

74. Would you be willing to take part in an interview or focus group about your experiences?

a. Yes
b. No

Thank you for taking part in this survey.

If this survey has made you feel upset or you want to speak to someone about any issues it has raised for you, please contact the Pancare Support team on 1300 881 698 (Monday to Friday 9am–5pm (AEST)) or email info@pancare.org.au.

Please click 'Submit' to complete the survey.

If a. selected, participants will be redirected to an entirely separate form in SurveyManager to provide their contact details. This information will not be linked to survey responses in any way.

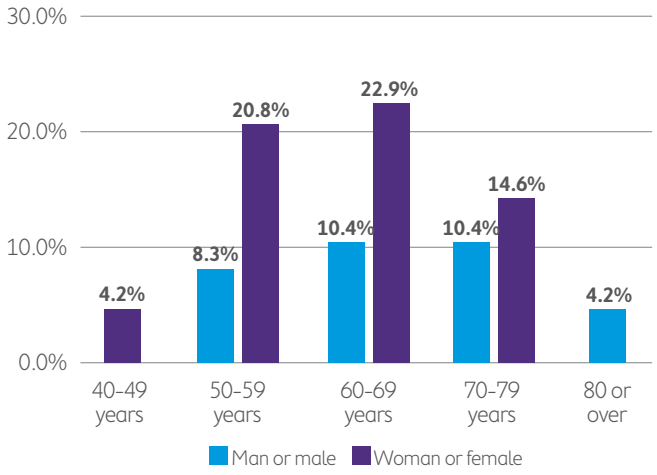
APPENDIX B
Additional Survey Analysis Data

Demographic data

Age and gender

Figure 7.1 shows that the largest proportion of **consumer respondents** with upper GI cancer were females aged between 60–69 (23.4%, n=11), followed by females aged 50–59 (21.3%, n=10), and females aged 70–79 (14.9%, n=7). There were no females aged 80 or over, and no males under 50.

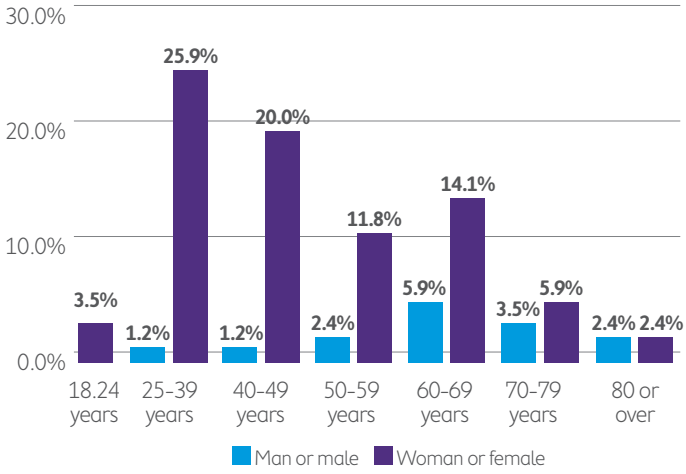
Figure 7.1: Age distribution of consumer respondents by gender (n=47)



*One respondent aged 70–79 described gender as "na" who was not represented in Figure 7.1

Figure 7.2 shows the distribution of male and female **carers** by age. The most common demographic among female respondents was those aged 25–39, representing 25.9% (n=22). Females aged 40–49 followed at 20.0% (n=17), and females aged 60–69 accounted for 14.1% (n=12). Overall, females aged 25–49 made up 45.9% (n=39) of the total cohort, whereas only 2.4% (n=2) of males fell into this age group. Within their gender groups, 55.3% of female carers are aged 25–49, compared to just 14.3% of male carers. Additionally, 71.4% of males were aged 60 years or more.

Figure 7.2: Distribution of male and female carers by age (n=85)



APPENDIX C
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