Investigating practices relating to supportive care screening in Victorian cancer services

Full technical report

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Where the term ‘Aboriginal’ is used it refers to both Aboriginal and Torres Strait Islander people.

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Contents

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Key findings

Supportive care prevalence

- The overall prevalence of supportive care screening with a validated supportive care screening tool in the study population (*n* = 643) was 63 per cent. A further 21 per cent of study participants have documented evidence of a supportive care needs discussion with a health professional.
- Supportive care screening with a validated tool was half as likely to occur in inpatients (33 per cent) compared with ambulatory chemotherapy (70 per cent) and radiotherapy patients (68 per cent).
- There was significant variation in the prevalence of supportive care screening between participating sites. The prevalence was higher at regional health services (78 per cent) compared with metropolitan health services (48 per cent) and higher at participating private health services (84 per cent) compared with public health services (61 per cent).
- The prevalence of supportive care screening was highest for participants with breast cancer (76 per cent), gynaecological cancer (75 per cent), colorectal cancer (73 per cent) and genitourinary malignancies (73 per cent). The prevalence of supportive care screening was lowest for participants with head & neck tumours (40 per cent) and haematological malignancies (39 per cent).
- The average time from the first appointment at the health service to completion of a supportive care screening tool was 21 days. More than 55 per cent of patients completed a supportive care screen before their first treatment appointment.
- Supportive care screens were most commonly administered by nursing staff (78 per cent). Nursing staff were also responsible for completing the greatest proportion of supportive care discussions in the absence of a screening tool (45 per cent), followed by social workers (27 per cent) and specialist cancer nurses (25 per cent).
- Forty-one per cent of study participants with a completed supportive care screening tool were reported to be distressed (a Distress Thermometer score of four or more). A supportive care screening tool was more likely to identify emotional and physical problems, whereas a discussion in the absence of a tool was more likely to identify family and practical issues. The majority of support issues causing distress for participants relate to physical (62 per cent of participants) and emotional needs (52 per cent of participants).
- Inpatients were more likely to report distress in each of the supportive care domains compared with ambulatory patients (emotional, family, physical, practical and spiritual). Participants with gynaecological, haematological or head & neck cancers were more likely to report distress related to practical problems compared with other tumour types. Participants with upper gastrointestinal cancers or genitourinary cancers were more likely to report distress related to physical problems compared with other tumour types.
- Twenty-one per cent of participants were formally screened for their supportive care needs on more than one occasion. Twenty-nine per cent of participants with an additional screen were found to be distressed. In repeated screening, emotional and physical problems were again most likely to be identified.
- Of all participants with evidence of a completed supportive care screening tool, 58 per cent had evidence of a supportive care intervention to address an identified issue including a discussion, provision of information or a referral to a health professional. In the absence of a supportive care screen, 90 per cent of participants who had evidence of a supportive care discussion had evidence of a supportive care intervention.
- Referrals to social work (24 per cent) and dietetic services (22 per cent) were the most common referrals made to address supportive care needs, followed by referrals to a physiotherapist/exercise physiologist and specialist cancer nurses (11 per cent each).

- Inpatients received the greatest proportion of supportive care referrals with an average of 2.8 referrals per participant. Ninety per cent of recorded referrals were made to services within the current hospital.
- Participants reported receiving significantly more supportive care than was documented in their medical record; 97 per cent of participants felt the actions they received were helpful.
- Less than half of all participants (38 per cent) reported accessing information or support independently to address their supportive care needs.
- More than 80 per cent of study participants felt it was very important or important that clinicians initiate discussions about their supportive care concerns.

Organisational practices

- Ten of the 21 participating health services have a current supportive care screening policy in place; however, very few sites have a local program of monitoring for key performance indicators relating to supportive care. Clinicians report a low awareness of supportive care policies and guidelines.
- Nineteen of the 21 participating health services (90 per cent) use the NCCN Distress Thermometer or a modified version of the tool for supportive care screening.
- Multidisciplinary clinician awareness of supportive care screening is high, with 74 per cent of those surveyed indicating that they had adequate or very good knowledge and that they routinely undertake supportive care screening of oncology patients. Screening is predominantly conducted by nursing staff.
- There is a strong agreement among clinicians that patients should have repeated supportive care screening at regular intervals during their cancer journey.
- Less than 50 per cent of clinicians surveyed agree or strongly agree that patients with supportive care needs in their health service are referred to an appropriate service in a timely manner.
- Clinicians acknowledge that the most significant barriers to administering a supportive care screen include time to administer and review the screen, and lack of knowledge and experience in supportive care screening. Other barriers include inadequate organisational support and a perceived lack of supportive care services to refer patients in need.
- Clinicians suggested that barriers to administer supportive care screening could be addressed by: improving awareness of the value and importance of supportive care screening and assessment; improving awareness of outpatient supportive care services available to patients at the health service and in the community; building supportive care screening skills and communication competencies; and integrating policies and procedures to reinforce supportive care as a key component of care.

Supportive care screening in Victorian cancer services

Introduction

The study Investigating practices relating to supportive care screening in Victorian cancer services was designed to gain an understanding of supportive care screening practices in adult Victorian cancer services.

The study has been implemented for cancer reform policymakers, Integrated Cancer Services (ICS), health services, multidisciplinary cancer clinicians and people with cancer to better understand the prevalence and outcomes of supportive care screening in cancer across Victoria and to identify areas for local improvement. This full technical report details the background, methodology and results.

Cancer in Victoria

Cancer is a leading burden of disease in Victoria, with more than 33,000 Victorians diagnosed with cancer each year. The most commonly occurring cancers in Victoria in 2016 were prostate cancer, breast cancer, colorectal cancer, melanoma and lung cancer, collectively accounting for 57 per cent of all new cancers. Almost 60 per cent of cancer diagnoses occur in people older than 65 years, with more men than women developing cancer (118 males for every 100 females). Over the past three decades, the five-year survival from cancer has increased from 48 per cent to 68 per cent (Thursfield & Farrugia, 2017).

The Victorian Admitted Episode Dataset (VAED) from the 2016–17 financial year indicates that approximately 84,397 cancer patients with malignant disease were admitted to public or private Victorian health services. These patients generated approximately 329,857 separations. More than 23,000 of these patients were admitted for chemotherapy services as part of active treatment. In addition, more than 17,000 courses of radiotherapy were provided during this period.

Supportive care in cancer

Providing comprehensive supportive care is fundamental to delivering quality cancer care (Department of Health 2009; Fitch 2008; Olver 2016). People with cancer have diverse supportive care needs including physical, emotional, social, psychological, informational, spiritual and practical needs across the care pathway (Fitch 1994). Many supportive care needs can be addressed by providing the right information at the right time; others require referral to specific services either at hospital or in the community (Fitch 2008).

Supportive care screening is the first stage of identifying needs. The purpose of screening is to identify possible risk factors and supportive care needs using a brief screening tool. The National Comprehensive Cancer Network (NCCN) Distress Thermometer and accompanying Problem List (National Comprehensive Cancer Network 2017) (Appendix 1) have been determined to be valid tools (Donovan et al. 2014) to identify those with supportive care needs. The Distress Thermometer and Problem List are the most commonly used supportive care screening tools within Victorian cancer services. It allows for patients to self-rate their level of distress on a scale from 0 to 10 and allows for open communication between patients and clinicians. A distress score of greater than 4 indicates moderate or severe levels of distress and the need for further assessment and management, which may include referral to appropriate health professionals (Cutillo et al. 2017; Holland & Bultz 2007). The accompanying Problem List identifies 35 items within the five categories of physical, emotional, practical, family and spiritual problems that may be contributing to the current distress (Vitek et al. 2007). Intervention for cancer-related distress has been shown to improve outcomes by improving quality of life

(Vitek et al. 2007). A high level of distress does not necessarily suggest that a patient is wanting a referral (Tuinman et al. 2008); however, screening is an effective way of identifying needs that may otherwise remain unidentified.

In 2009 the then Victorian Department of Human Services published *Providing optimal cancer care: Supportive care policy for Victoria* outlining four core strategic directions:

1. identify the supportive care needs of people affected by cancer
2. capacity building for optimal supportive care
3. implementing supportive care screening into routine practice
4. addressing supportive care needs – referral and linkage.

The policy aimed to use the various structures that are required for change including networks, frameworks and strategic directions that support optimal care to improve access, experience and a consistent standard of supportive care services for those affected by cancer. The Victorian ICS are responsible for implementing the policy within the health system.

Considerable investment in training, building staff capability and process-improving activities have been undertaken in Victoria since 2009 (Department of Health 2012), and regular clinical auditing is undertaken as part of the Victorian Cancer Service Performance Indicator program (CSPI). The most recent CSPI audit in 2015 showed the statewide result for documented evidence of supportive care screening was 39 per cent (Department of Health and Human Services 2016b), well below the target of 50 per cent as set in *Victoria's Cancer Action Plan 2008–2011*. These audits also demonstrate that significant variation in results between ICS and tumour streams persists. Patients and their families continue to report poor experiences regarding their informational and broader supportive care needs (Department of Health and Human Services 2016a). The *Victorian cancer plan 2016–20* provides a framework to improve cancer outcomes with a priority to strengthen supportive care and self-management including a focus on:

- ensuring implementation of systematic approaches to meet support needs through the optimal care pathways
- building and refreshing workforce skills and competency in supportive care approaches
- building self-sufficiency to enable cancer patients, their families and carers to seek information, peer support, referral and supportive care services at all stages of the pathways
- supporting approaches for priority groups that may have additional needs, including young people and older Victorians with cancer.

Objectives

The objectives of the Investigating Practices Relating to Supportive Care Screening in Victorian Cancer Services study were to:

- determine the prevalence of supportive care screening actions delivered to the Victorian cancer population across inpatient/ambulatory settings
- identify supportive care interventions for those screened and not screened
- determine how well the supportive care activity meets the population needs
- gain insight into the patient experience of having supportive care needs identified and addressed
- establish oncology clinicians' knowledge, experience and attitudes towards supportive care screening.

Funding

The Department of Health and Human Services' Cancer Strategy and Development unit invited health services in each ICS that routinely provide a significant volume of cancer care to take part in the study. The department provided non-recurrent funding to support health services to participate, specifically to complete prevalence data collection, including completion of ethics review applications, patient identification, data collection and data entry. Study expectations included some in-kind allocation of time and resources by participating health services.

Participating cancer services

Twenty-one cancer services participated in the study including the five highest volume public cancer services, three private cancer services and the eight highest volume public cancer services in the regional ICS. This included:

Barwon South Western Regional Integrated Cancer Service (BSWRICS)

- Barwon Health – Geelong, including radiotherapy services
- South West Healthcare – Warrnambool

Hume Regional Integrated Cancer Service (HumeRICS)

- Albury Wodonga Regional Cancer Centre including radiotherapy services
- Goulburn Valley Health – Shepparton
- Northeast Health – Wangaratta

Gippsland Regional Integrated Cancer Service (GRICS)

- Latrobe Regional Hospital – Traralgon, including Alfred Health Radiation Oncology

Grampians Integrated Cancer Service (GICS)

- Ballarat Health Services – including Ballarat Austin Radiation Oncology Centre
- St John of God – Ballarat
- Wimmera Health Care Group – Wimmera Base Hospital Horsham

Loddon Mallee Integrated Cancer Service (LMICS)

- Bendigo Health – Bendigo Hospital, including Peter Mac radiotherapy services
- Mildura Base Hospital
- St John of God – Bendigo

North Eastern Melbourne Integrated Cancer Service (NEMICS)

- Austin Health – Austin Hospital including radiotherapy services
- Eastern Health – Box Hill and Maroondah

Southern Melbourne Integrated Cancer Service (SMICS)

- Alfred Health – The Alfred including radiotherapy services
- Cabrini Health – Malvern
- Monash Health – Moorabbin
- Peninsula Health – Frankston

Western and Central Melbourne Integrated Cancer Service (WCMICS)

- Melbourne Health – City Campus
- Peter MacCallum Cancer Centre – Parkville, including radiotherapy services
- St Vincent's Hospital – Melbourne.

Project management

The project team, consisting of a study lead, project sponsor and advisor based at the Department of Health and Human Services, was responsible for the day-to-day management of the project. The study was planned and implemented using the department’s project management framework.

Study expert reference group

The Supportive Care in Cancer Prevalence Expert Reference Group provided expert opinion to guide the development and implementation of the study.

The role of the reference group was to provide guidance on:

- study design, development and implementation
- communication processes at the local and statewide levels
- stakeholder engagement
- issue and risk identification and management
- project reporting and evaluation.

Membership of the group included representation from the following:

- executive sponsor
- Department of Health and Human Services representatives
- consumer representatives
- ICS Information Management Group representative
- ICS Supportive Care Collaborative Group representative
- ICS program managers
- Supportive Care Refresh Project study lead (The University of Melbourne)
- director of quality in a participating health service.

The reference group convened six meetings over the span of the study.

Methodology

The study included the following elements:

1. supportive care screening prevalence study
    - (a) medical record audit with follow-up at 60 days, and
    - (b) consumer experience survey, or
    - (c) consumer experience interview.
2. audit of organisational supportive care screening policies and procedures
3. survey of multidisciplinary oncology clinicians.

The study methodology and tools were developed in consultation with the reference group and the Integrated Cancer Services Information Management Group.

Participants were not screened for their supportive care needs or distress as part of this study, only asked about their experiences in relation to this.

Part 1: Supportive care screening prevalence study

Objectives

1. To determine the prevalence of supportive care screening delivered to the cancer population across inpatient and ambulatory settings.
2. To identify the resulting actions (referral, assessment, outcome) for those screened and not screened.
3. To determine how well the resulting actions meet the population needs.
4. To gain insight into the patient experience of having supportive care needs identified and addressed.

Study tools

Medical record audit data collection tool and guidelines

(see Appendix 4)

The key points captured were:

- patient demographics
- cancer diagnosis and treatment
- evidence of completed supportive care screen
- evidence of supportive care discussion in absence of a screen
- documented actions to address supportive care needs.

Guidance for approaching participants for consumer survey and consumer interview

(see Appendix 5)

Supportive care screening consumer survey and interview tools

(see Appendices 6 and 7)

The key points captured were:

- patients’ experience of having their supportive care needs identified
- patients’ experience of having their supportive care needs addressed
- patients’ opinion of the importance of supportive care screening.

Follow-up medical record audit and guidelines

(see Appendix 8)

A follow-up audit of the study population was completed at 60 days after the original audit. The purpose of the follow-up audit was to determine whether each patient was (re)screened and to assess referral trends or to capture any new actions generated from screening having occurred or not.

It was expected that a proportion of participants would cease care or have their care transferred to a different hospital during the follow-up period. Every attempt was made to collect follow-up data for participants who transferred to another participating hospital during the follow-up period.

The key points captured were:

- evidence of completed supportive care screen occurring in 60 days post audit
- evidence of supportive care discussion occurring in absence of screen in 60 days post audit
- documented actions to address supportive care needs occurring in 60 days post audit.

Study criteria

Inclusions:

- All consenting adults with a cancer diagnosis of six months or less
- Admitted to an acute ward (inpatient) of the health service for cancer treatment or related management
- Attending the health service for chemotherapy administration
- Attending the health service for radiotherapy

Exclusions:

- Paediatric cancer patients, 17 years and younger
- Patients admitted to subacute, rehabilitation or hospice care
- Ambulatory patients attending for nursing or medical review only, including blood, radiological or other diagnostic tests, dressings and related care
- Patients for whom participation is considered too burdensome
- Patients unable to consent due to non-English speaking (in absence of interpreter), cognitive impairment or sedation
- Patients unaware of diagnosis of malignancy at admission
- Patients who have already participated in the study at another health service

Population

The 21 participating health services represent almost half of all annual cancer patient separations throughout Victoria. Each site was provided with a target number of participants to recruit from each treatment area (inpatient, chemotherapy day unit, radiotherapy) over a two-week period between August 2017 and February 2018. The target numbers were calculated to represent relative proportions of the current volume of patients treated in each of the participating health services (as reported to the VAED) and the types of treatments they received, with a maximum of 50 participants per site.

Each study participant had their medical record audited using the data collection tool and also completed either a written survey (75 per cent of participants) or face-to-face survey (25 per cent).

To minimise over-representation of cancer types, sites were advised to restrict participants from any one tumour stream to no more than 30 per cent of total participants recruited at each site. Once this number was reached, any further patients from the same tumour stream were excluded.

The statewide target participant population was 790, including 480 chemotherapy patients, 160 radiotherapy patients and 150 inpatients.

Ethical considerations

The study was classified as low and negligible risk because there was no foreseeable risk of harm or discomfort to study participants. A multi-site research application was submitted to and approved by the Peter MacCallum Cancer Centre Human Research Ethics Committee (HREC/17/PMCC/127). Individual health service organisations that participate in the National Mutual Acceptance scheme were also required to complete Site Specific Assessment forms before beginning the study locally. Health service organisations that do not participate in the National Mutual Acceptance scheme were responsible for identifying and meeting the requirements of site ethics committees before beginning the study.

All participants were provided with an information sheet explaining the purpose of the study and the methods and requirements of participants. Participants were required to sign a consent form before participating (see Appendix 9). Participant privacy and dignity was a priority at all times during data collection. Interviews were completed in a private and confidential space by staff trained in bedside audits and interviews. An exclusion criteria was in place to minimise emotional distress or unnecessary burden for those with end-of-life disease or for whom it was considered that participation was too burdensome.

Training

Site auditors were identified and nominated by each health service as having appropriate skills and experience to undertake the role. Predominantly, site auditors were senior nursing staff, allied health clinicians or quality consultants employed by the participating health service. A required one-day training session was attended by all site auditors before beginning the study. The training session included a review of data collection tools, guidance for approaching patients and information about gaining consent. Site auditors were also provided with training in responding to participants’ concerns or distress. Additional training covering ethical requirements and follow-up data collection was provided by teleconference as required.

Participant recruitment

Two weeks before the study began, posters were displayed in the treatment and waiting areas of participating health services to inform patients and clinicians that the study would be taking place. Potential participants who met the inclusion criteria for the study were identified by site auditors from treatment appointment lists and inpatient ward lists. During the designated study period, site auditors approached eligible patients to gain consent as per the study tool *Guidance for approaching participants for consumer survey and consumer interview* (see Appendix 5). Where necessary (and if possible) interpreters were used to facilitate communication between site auditors and participants.

Patients were recruited to participate in the study at each participating health service until the target number for each treatment area was reached (chemotherapy, radiotherapy, inpatient). In some smaller health services or health services with lower than expected patient activity, the period of recruitment was extended from two to four weeks to enable sites to reach target participant numbers.

A proportion of participants (25 per cent) were asked the survey questions in a face-to-face discussion in place of the written survey. Participants were selected for interview based on their hospital registration number, with those ending in an even number approached for interview.

Data management

Unique study numbers were assigned to each participant to facilitate de-identification of participant data. Each site maintained a centralised list linking the study number and patient unit record number. All data collection sheets that contained re-identifiable data were stored securely until the end of the study. Site auditors were responsible for secure storage and disposal of re-identifiable patient information in line with normal administrative practices at each site. Only de-identified patient information was forwarded to the project team for analysis. Health services were also de-identified and assigned numbers M (metropolitan) 1–9 and R (regional) 1–12 to ensure results remained anonymous.

The department purchased a SurveyMonkey® subscription for the study, which was managed by the study lead and advisor. The medical record audit, supportive care screening consumer survey and interview, and follow-up medical record audit data collection tools were reproduced in a SurveyMonkey template. Site auditors were provided with a unique link to enter de-identified study data into each online survey. Site auditors were unable to view or change entries once submitted but were unable to view entries completed by other sites.

At the end of the study, all survey responses were exported from SurveyMonkey into an electronic database (Microsoft Excel) for confirmation and analysis. Each individual health service was provided with a consolidated file containing all data collected at their site. The department's Cancer Strategy and Development unit remains custodian of the complete de-identified electronic dataset.

Data analysis

Descriptive statistics were presented as odds ratio, mean or median, with range as appropriate. The analysis was conducted using the chi-square test for equal proportion or non-parametric tests where appropriate. When comparing groups, a two-sided *p*-value of 0.05 was considered to be statistically significant.

All quantitative data was analysed using STATA®. Data was assessed for normality and log-transformed where appropriate.

Qualitative data from interviews and surveys were quantified in Microsoft Excel. Responses were coded and themed to identify common trends.

Part 2: Organisational audit

Objectives

The organisational audit was administered to identify and understand supportive care screening policy and tools currently in place at participating health services, information on supportive care referral practices, and to identify performance targets for screening in each participating health service.

Audit tool

A seven-question audit tool to identify supportive care screening policies was completed by each participating service and reviewed by their local ICS (see Appendix 2).

Protocol

All site auditors at participating health services were asked to complete the audit template document and return via email.

Data analysis

Responses were analysed in a Microsoft Excel database. Descriptive statistics were applied to identify trends and benchmark services, where appropriate.

Ethical considerations

Results from individual health services were de-identified for publication. Site numbers were consistent with the numbering used in the prevalence study results.

Part 3: Clinician survey

Objectives

1. To identify oncology clinicians' knowledge of supportive care screening tools and the use of these within their health service.
2. To understand oncology clinicians' attitudes, beliefs and expectations regarding the screening process.
3. To identify barriers and enablers among oncology clinicians for conducting supportive care screening and related actions.

Survey tool

A 16-question survey was administered to identify and understand the attitudes, knowledge and practices of oncology clinicians relating to supportive care screening (see Appendix 3).

Protocol

All hospital-based oncology clinicians in the participating health services were invited to complete the survey via email with a link to the online survey. Site auditors and executive sponsors at each participating health service circulated the emails. Participation was voluntary. Respondents completed the questionnaire via a web-based electronic survey (SurveyMonkey).

Data analysis

Responses were analysed in a Microsoft Excel database. Descriptive statistics were applied to identify trends and benchmark services, where appropriate.

Ethical considerations

Results from individual clinicians and health services were de-identified for publication.

Limitations

The following limitations of this study are noted:

Participation in the study was restricted to patients undergoing active cancer treatments and attending selected health services; there is no representation of cancer patients in other care settings where supportive care needs may still be significant. Data was not collected on general outpatients, therefore no information is available on patients who have recently completed ambulatory treatments, those discharged following surgery, pre-operative patients or those receiving community-based palliative care. There were limited numbers of patients diagnosed with less common cancers included in the study.

The validity of data relies on the quality and completeness of documentation in the participants' medical record, the design of the audit and the accuracy of site auditors in completing data collection and data entry.

Bias due to reduced inter-rater reliability is possible due to multiple site auditors, variability in sampling and multiple data collection time points across health services. There was no opportunity for reliability testing to be conducted between sites. Training was provided to all site auditors to ensure the understanding of all data elements at all sites to strengthen the reliability of results.

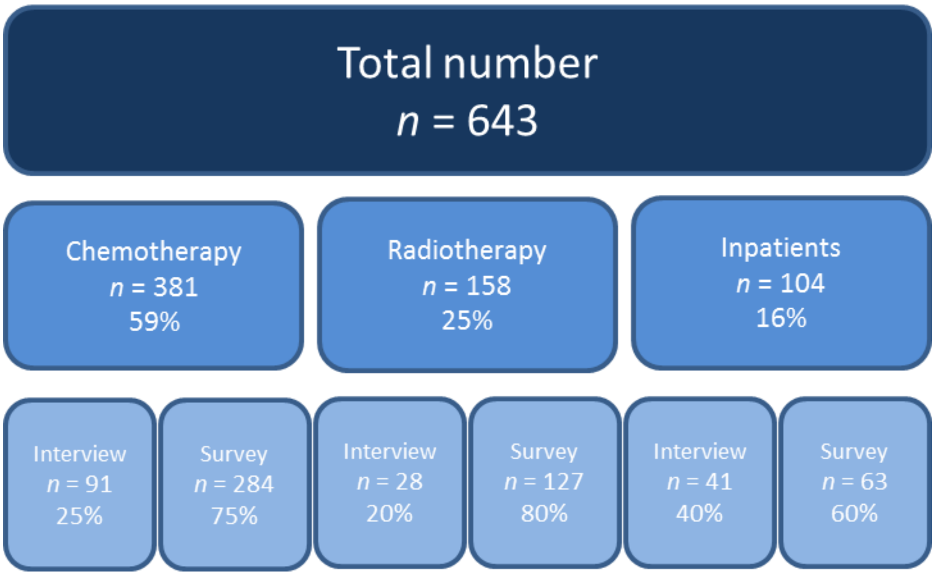
Victorian patients may receive care in another state, which is not captured in Victorian datasets. This particularly affects the data for patients in the Hume Regional Integrated Cancer Service area who regularly undergo their treatment in Albury, New South Wales.

Results

Part 1: Supportive care screening prevalence study

A total of 643 oncology patients were recruited and consented to participate in the supportive care screening prevalence study. All participants were included in the medical record audit, and 99 per cent of participants (*n* = 634) completed the consumer survey or interview. Of the participants who did not complete the survey or interview (*n* = 9), six were chemotherapy patients and three were radiotherapy patients. One hundred and sixty participants (25 per cent) completed an interview.

Figure 1.1: Outline of study participant numbers



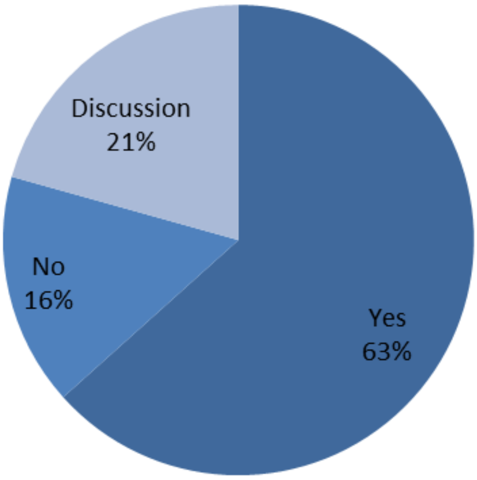
Prevalence of supportive care screening

The medical records were audited for documented evidence of a completed supportive care screening tool (NCCN Distress Thermometer and Problem List or other validated tool). In the absence of a documented supportive care screening tool, the medical records were audited for documented evidence of a discussion with a health professional regarding the patient’s supportive care needs relating to physical, practical, family, emotional or spiritual/religious concerns. Notably, supportive care screening using a validated tool is the recommended best practice to identify unmet support needs for patients. In most cases a supportive care discussion in the absence of a screening tool will focus on one or more apparent supportive care needs rather than identify sources of distress across all five domains of supportive care.

- Documented evidence of a supportive care screening tool (SCST): 408 participants (63 per cent)
- Documented evidence of participants declining an SCST: two participants (0.3 per cent)
- Documented evidence of a supportive care discussion (SCD) conducted in the absence of an SCST: 130 participants (21 per cent)
- No documented evidence of an SCST or SCD: 103 participants (16 per cent).

The overall prevalence of supportive care screening with a screening tool was 63 per cent. An additional 21 per cent of participants had evidence of a discussion of their supportive care needs in their medical record.

Figure 1.2: Percentage of total study participants with documented supportive care screening



Supportive care screening prevalence by treatment location

Evidence of supportive care screening completion was compared for inpatients and ambulatory patients. Ambulatory patients were twice as likely to be screened for supportive care needs using a validated SCST compared with patients receiving inpatient care (Table 1.1). Although the focus of this study was to determine the usage of an SCST as the recommended best practice for identifying and addressing patients' support needs, results for proportions of participants with evidence of an SCD in the absence of SCST are included in both the tables and graphs for comparison purposes.

Table 1.1: Victorian cancer services statewide supportive care screening prevalence

Variable	**Total number of participants [*n* (%)]**	**Participants with an SCST completed [*n* (%)]**	**Odds ratio (95% CI)**	***p*-value**	**Participants with discussion in the absence of SCST [*n* (%)]**
Inpatient	104 (16.2%)	34 (32.7%)	**0.21** (0.1–0.3)	**< 0.001**	41 (39.4%)
Chemotherapy	381 (59.3%)	266 (69.8%)	*Ref. value*	*Ref. value*	46 (12.1%)
Radiotherapy	158 (24.6%)	108 (67.9%)	0.93 (0.6–1.4)	0.74	43 (27.2%)
Total	643 (–)	408 (63.4%)	–	–	130 (20.2%)

Supportive care screening with a validated tool was twice as likely to occur for chemotherapy and radiotherapy patients compared with inpatients.

Supportive care screening prevalence by participating health service

The prevalence of supportive care screening with a validated SCST at each of the health services ranged from 0 to 95 per cent. Four of the nine metropolitan health services and 10 of 12 regional health services reported SCST rates above the average rate of SCST for all participating health services. Five of the metropolitan health services reported use of SCST at less than 30 per cent (see Figure 1.3 and Table 1.2).

Figure 1.3: Supportive care screening prevalence by health service

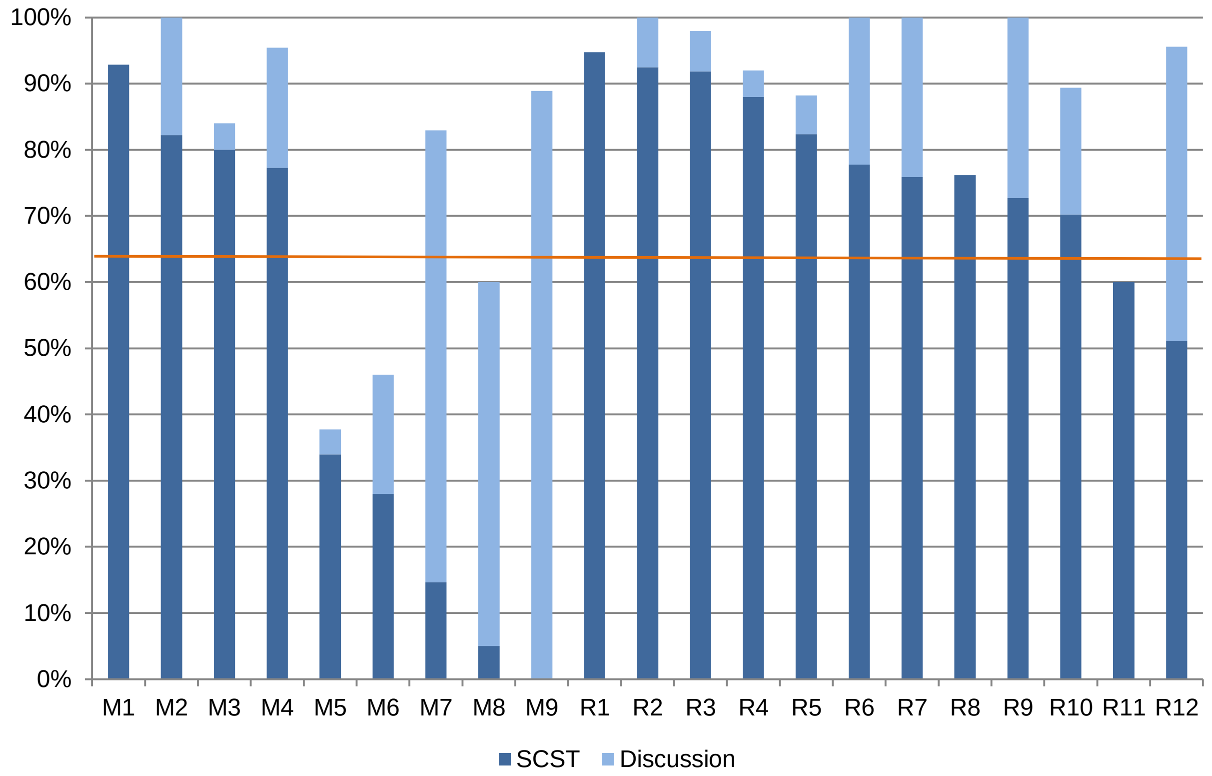


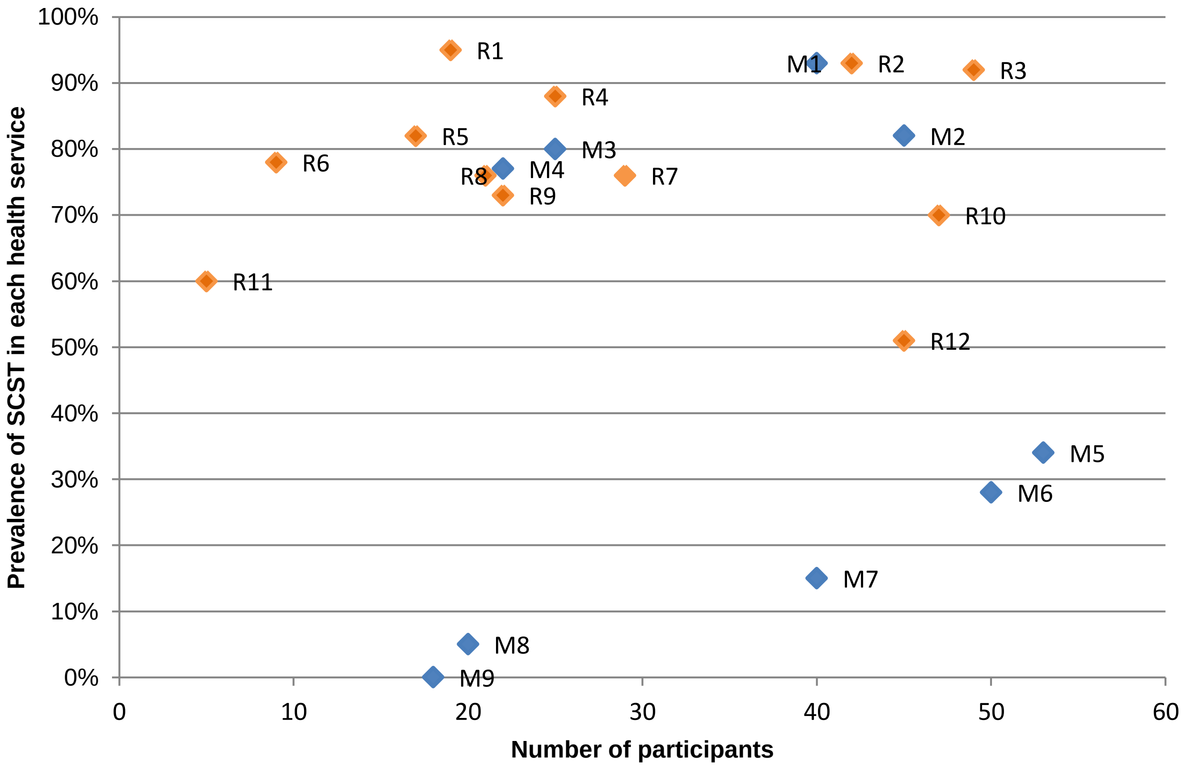
Table 1.2: Comparison of rates of supportive care screening prevalence by health service

Site	Total number of participants [*n* (%)]	Participants with an SCST completed [*n* (%)]	Odds ratio (95% CI)	*p*-value	Participants with discussion in the absence of SCST [*n* (%)]
M1	42 (6.5%)	39 (93%)	4.1 (0.9–19.0)	0.08	0 (–)
M2	45 (7.0%)	37 (82%)	1.4 (0.4–5.1)	0.57	8 (17.8%)
M3	25 (3.8%)	20 (80%)	1.3 (0.3–5.1)	0.31	1 (4%)
M4	22 (3.4%)	17 (77%)	1.1 (0.3–4.4)	0.93	4 (18.2%)
M5	53 (8.2%)	18 **(34%)**	**0.2** (0.05–0.5)	**0.002**	2 (3.8%)
M6	50 (7.8%)	14 **(28%)**	**0.1** (0.04–0.4)	**0.000**	9 (18%)
M7	40 (6.2%)	6 **(15%)**	**0.06** (0.01–0.2)	**0.000**	27 (67.5%)
M8	20 (3.1%)	1 **(5%)**	**0.02** (0.00–0.16)	**0.000**	11 (55%)
M9	18 (2.8%)	0 (0%)	*Reference value*	–	16 (88.9%)
R1	19 (2.9%)	18 (95%)	5.6 (0.6–53.4)	0.13	0 (–)
R2	40 (6.2%)	37 (93%)	3.8 (0.8–18.1)	0.09	3 (7.5%)
R3	49 (7.6%)	45 (92%)	3.5 (0.8–14.7)	0.09	3 (6.1%)
R4	25 (3.9%)	22 (88%)	2.2 (0.5–11.0)	0.3	1 (4%)
R5	17 (2.6%)	14 (82%)	1.5 (0.3–7.2)	0.64	1 (5.9%)
R6	9 (1.4%)	7 (78%)	1.1 (0.2–7.1)	0.93	2 (22.2%)

Site	Total number of participants [*n* (%)]	Participants with an SCST completed [*n* (%)]	Odds ratio (95% CI)	*p*-value	Participants with discussion in the absence of SCST [*n* (%)]
R7	29 (4.5%)	22 (76%)	1.0 (0.3–3.7)	0.98	7 (24.1%)
R8	21 (3.3%)	16 (76%)	0.5 (0.06–3.6)	0.47	0 (–)
R9	22 (3.4%)	16 (73%)	0.8 (0.2–3.3)	0.79	6 (27.3%)
R10	47 (7.3%)	33 (70%)	0.7 (0.2–2.4)	0.61	9 (19.1%)
R11	5 (0.8%)	3 (60%)	*Omitted due to small proportion*	–	–
R12	45 (7.0%)	23 **(51%)**	**0.3 (0.1–1.0)**	**0.06**	20 (44.4%)

Figure 1.4 shows that some of the sites with higher participant numbers had some of the lowest rates of screening. These sites were public metropolitan health services that treated high volumes of cancer patients.

Figure 1.4: Prevalence of supportive care screening (with SCST) by number of participants at each health service



The SCST prevalence rates were compared for a number of health service related variables including the hospital cancer volume, location, type and governance practices (Table 1.3).

As expected by the previous table and graphs, there was a statistically significant lower rate of SCST in metropolitan hospitals (OR 0.26, 95% CI 0.18–0.37, $p < 0.001$). There was also a statistically significant lower rate of SCST prevalence in public hospitals (OR 0.3, 95% CI 0.14–0.86, $p < 0.001$); however, given the limited representation of private hospitals in the study ($n = 3$) this result cannot be generalised to other private hospitals. When comparing hospitals based on the cancer volume, those sites treating the highest volume of patients had the lowest screening rates but were also most likely to be affected by variation in sampling.

There was significant variability in supportive care screening prevalence by health service with a lower rate of screening documented in metropolitan health services.

Table 1.3: Supportive care screening prevalence by health service variables

Variable	Detailed variable	Proportion of total study population [*n* (%)]	Participants with an SCST completed [*n* (%)]	Odds ratio (95% CI)	*p*-value	Participants with discussion in the absence of SCST [*n* (%)]
Hospital location	Metropolitan	315 (49%)	152 **(48.0%)**	**0.26** (0.18–0.37)	**0.000**	78 (24.8%)
	Regional/ rural	328 (51%)	256 (78.1%)	–	–	52 (15.8%)
Public/ private	Public	574 (89.3%)	350 **(61.0%)**	**0.3** (0.14–0.86)	**0.000**	124 (21.6%)
	Private	69 (10.7%)	58 (84.1%)	–	–	6 (8.7%)
Hospital cancer volume (cancer separations/ year)	≥ 10,000	259 (40.3%)	136 (52.5%)	–	–	53 (20.5%)
	10,000–5,000	203 (31.5%)	153 (75.4%)	**2.8** (1.9–4.1)	**0.000**	31 (15.3%)
	< 5,000	181 (28.2%)	119 (65.7%)	**1.7** (1.2–2.6)	**0.006**	46 (25.4%)
Supportive care screening policy	Yes	321 (50%)	212 (66.0%)	1.25 (0.89–1.75)	0.1731	66 (20.6%)
	No	322 (50%)	196 (60.9%)	–	–	64 (19.9%)

Supportive care screening prevalence by diagnosis/tumour type

Participants were grouped according to tumour streams based on the type and location of the malignancy. These tumour stream groups were based on the Victorian Cancer Registry tumour grouping. Supportive care screening prevalence by tumour stream ranged from 20 to 88 per cent depending on tumour type (Table 1.4 and Figure 1.5).

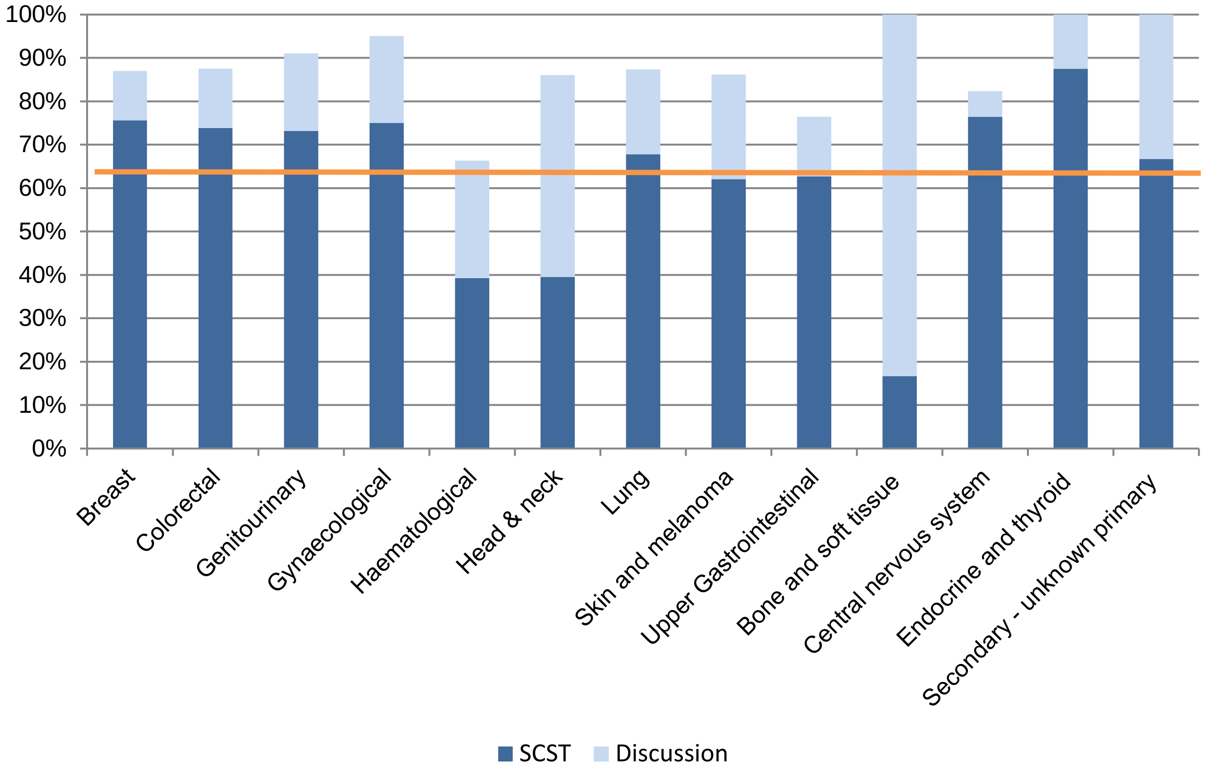
The tumour streams with the highest prevalence of SCST were participants with breast (76 per cent), gynaecological (75 per cent), colorectal (73 per cent) and genitourinary (73 per cent) malignancies. Those with the lowest evidence of SCST were head & neck tumours (40 per cent) and haematological (39.3 per cent) malignancies; this was a statistically significant result.

Table 1.4: Supportive care screening prevalence by tumour type

Tumour type	Proportion of participants [*n* (%)]	Participants with an SCST completed [*n* (%)]	Odds ratio (95% CI)	*p*-value	Participants with discussion in the absence of SCST [*n* (%)]
Breast	115 (17.9%)	87 (75.6%)	*Ref. value*	*Ref. value*	13 (11.3%)
Colorectal	88 (13.7%)	65 (73.4%)	0.91 (0.5–1.7)	0.77	12 (13.6%)
Genitourinary	56 (8.7%)	41 (73.2%)	0.88 (0.4–1.8)	0.73	10 (17.8%)
Gynaecological	20 (3.1%)	15 (75.0%)	0.96 (0.3–2.9)	0.95	4 (20%)
Haematological	107 (16.6%)	42 (39.3%)	**0.21** (0.1–0.4)	**< 0.001**	29 (27.1%)
Head & neck	43 (6.7%)	17 (39.5%)	**0.21** (0.1–0.4)	**< 0.001**	20 (46.5%)
Lung	87 (13.5%)	59 (67.8%)	0.67 (0.4–1.3)	0.22	17 (19.5%)
Skin and melanoma	29 (4.5%)	18 (62.1%)	0.52 (0.2–1.2)	0.15	7 (24.1%)
Upper GI	51 (7.9%)	32 (62.7%)	0.54 (0.3–1.1)	0.09	7 (13.7%)
Other (total)	47 (7.3%)	32 (68.1%)	0.7 (0.3–1.4)	0.32	11 (23.4%)
Other: Bone and soft tissue	5 (0.8%)	1 (16.7%)	–	–	4 (80%)
Other: Central nervous system	17 (2.6%)	13 (76.5%)	–	–	1 (5.9%)
Other: Endocrine and thyroid	8 (1.2%)	7 (87.5%)	–	–	1 (12.5%)
Other: Secondary – unknown primary	12 (1.9%)	8 (66.7%)	–	–	4 (33.3%)
Other: Unknown – not reported	5 (0.8%)	3 (60.0%)	–	–	1

The tumour types associated with the highest prevalence of supportive care screening were breast, gynaecological, colorectal and genitourinary malignancies.

Figure 1.5: Supportive care screening prevalence by tumour type



Supportive care screening prevalence by cancer stage

Cancer stage was recorded for 61 per cent of the study population, and rates of screening were reported by cancer stage. Although there was a trend for less SCST use in those with more advanced cancer, this did not reach statistical significance (Table 1.5).

Table 1.5: Supportive care screening by cancer stage

Cancer stage	**Total [*n* (%)]**	**Participants with an SCST [*n* (%)]**	**Odds ratio (95% CI)**	***p*-value**	**Participants with discussion in the absence of SCST [*n* (%)]**
Stage 1	38 (6%)	28 (73.7%)	–	–	7 (18.4%)
Stage 2	84 (13%)	65 (77.4%)	1.2 (0.5–5.7)	0.66	14 (16.7%)
Stage 3	130 (20%)	96 (73.8%)	1.0 (0.4–2.3)	0.98	20 (15.4%)
Stage 4	139 (22%)	82 (58.9%)	0.51 (0.2–1.1)	0.1	35 (25.2%)
Not reported	252 (39%)	136 (54.4%)	**0.42** (0.2–0.9)	**0.03**	55 (21.8%)

Supportive care screening prevalence by treatment modality

The prevalence of supportive care screening using an SCST was determined based on treatment type and treatment intent. Possible treatments included chemotherapy, radiotherapy, chemoradiation therapy, immunotherapy (*n* = 5), past surgery (*n* = 74) for ambulatory patients and additional treatments requiring inpatient admission including surgery (*n* = 22), stem-cell transplant (*n* = 2) and no cancer-modulating treatments/palliative care (*n* = 7). A total of 774 treatments were reported for the 643 participants because participants may have experienced more than one treatment type (Table 1.6).

Treatments were identified from the medical history to be either active/curative (where the aim of treatment was to achieve remission or a period free of cancer) or palliative (where the treatment was for symptom management). No difference was observed in the prevalence of an SCST based on treatment intent.

Data were not collected on general outpatients, therefore no information is available on patients who have recently completed ambulatory treatments, those discharged following surgery, pre-operative patients or those receiving community-based palliative care.

Table 1.6: Supportive care screening prevalence by treatment modality

Measure	Treatment	Total [*n* (%)]	Participants with an SCST completed [*n* (%)]	Odds ratio (95% CI)	*p*-value	Participants with discussion in the absence of SCST [*n* (%)]
By treatment type* (*n* = 774)	Chemotherapy	423 (54.6%)	279 (65.9%)	1.4 (1.0–1.9)	0.07	68 (16.1%)
	Radiotherapy	161 (20.8%)	97 (60.2%)	0.8 (0.6–1.2)	0.33	42 (26.1%)
	Chemo-radiotherapy	81 (10.5%)	58 (71.6%)	1.5 (0.9 –2.7)	0.1	15 (18.5%)
	Surgery	96 (12.4%)	62 (64.6%)	1.1 (0.7–1.7)	0.8	15 (15.6%)
	Other	12 (1.6%)	5 (41.6%)	–	–	2 (16.7%)
By treatment intent (*n* = 642)	Active	370 (57.6%)	248 (67.0%)	1.3 (0.9–2.0)	0.15	69 (18.7%)
	Palliative	146 (22.7%)	88 (60.3%)	–	–	30 (20.5%)
	Unknown	126 (19.7%)	72 (57.1%)	–	–	30 (23.8%)

** More than one treatment type per person possible*

Supportive care screening prevalence by demographic variables

Supportive care screening prevalence was determined by sex, age, social situation and location of usual residence (Table 1.7).

Sex: 52 per cent of the study population were male (*n* = 334). There was a trend for more females than males to have documented evidence of an SCST (OR 1.3, 95% CI 0.97–1.9, $p = 0.06$). A further 14 per cent of females (*n* = 44) and 18 per cent of males (*n* = 59) had documented evidence of an SCD in the absence of an SCST.

Age: The average age of participants was 63 years (IQR 55–72). There was no statistically significant difference between age groups in the proportion with documented evidence of an SCST.

Social situation: The majority of participants lived with others, with 18.4 per cent living alone. Thirteen per cent of participants (60/468) were identified as having a primary carer role (174 participants had an unknown primary carer role).

Location of usual residence: Location of usual residence was characterised using the Australian Standard Geographical Classification – Remoteness Area (ASGC-RA 2006). Forty-five per cent of participants lived in metropolitan Melbourne, with 38 per cent living in inner regional areas and 10 per cent in outer regional areas. There was a statistically significant difference in the rate of SCST based on location of usual residence, with those living in regional areas more likely to have an SCST (OR 2.3, 95% CI 1.7–3.3, $p < 0.001$).

Cultural background: Culturally diverse background was determined by country of birth and usual language spoken. Thirteen per cent of participants were identified as having a non-English-speaking background, with only 33 per cent (29/86) identifying a language other than English as their primary language; 55 per cent of this group (12/29) reported that they require an interpreter.

Despite this small representation of culturally diverse participants, results point to a lower rate of SCST completion among those from a non-English-speaking background (38 per cent) compared with those from an English-speaking background (65 per cent) (OR 0.33, 95% CI 0.1–0.8, *p* = 0.003). There was also an increase in the rate of SCD, with 32 per cent of culturally diverse patients having evidence of an SCD compared with 18 per cent of English-speaking participants (OR 2.1, 95% CI 1.2–3.5, *p* = 0.004).

Aboriginal and Torres Strait Islander heritage was obtained from the medical records, with six participants identified as having an Aboriginal heritage. Unfortunately this small number makes it difficult to determine differences in practice related to SCST use in this population with any confidence, but an SCST was used less frequently for those with an identified Aboriginal heritage (three of six had documented evidence of a supportive care screen).

Table 1.7: Supportive care screening prevalence by demographic variable

Variable	Detailed variable	Total number	Number with SCST completed	% prevalence SCST	95% confidence interval	*p*-value
Sex	Male	334	200	60.2	54.8–65.3	
	Female	309	207	67.0	61.5–72.0	0.06
Age	18–34 years	25	17	68.0	46.3–83.9	
	35–49 years	68	39	57.4	45.1–68.8	
	50–64 years	220	144	65.5	58.9–71.4	
	65–80 years	276	176	64.1	58.2–69.6	0.80*
	≥ 80 years	53	30	56.6	42.7–69.5	0.29^
Social situation	Lives alone	118	78	66.1	56.9–74.1	
	Lives with others	481	307	63.9	59.4–68.1	0.65
	Lives in residential care	1	1	–	–	
	Role as primary carer	60	40	66.7	53.5–77.6	0.82
Location of usual residence	Metropolitan	292	153	52.7	47.0–58.5	< 0.001[§]
	Inner regional	247	183	74.1	68.2–79.2	
	Outer regional	62	43	69.4	56.5–79.8	
	Remote	–	–	–	–	
	Interstate	33	22	66.7	48.2–81.2	
Cultural background	English speaking	550	369	67.0	62.1–70.0	
	Non-English speaking	86	39	45.3	35.0–56.1	< 0.001
	Aboriginal heritage	6	3	50	–	

[*] *< 64 years compared with ≥ 65 years*

[^] *< 80 years compared with ≥ 80 years*

[§] *Metropolitan compared with regional and rural/remote*

Timing and location of screening completion

The date of cancer diagnosis and first appointment at the health service was recorded for each participant, as was the date of SCST completion (Table 1.8). The mean time from cancer diagnosis to SCST was 42 days (IQR 17–58 days) (reported for 375/407 participants). Information for 18 participants was excluded in this calculation because the date provided for completion of the SCST was before the date of cancer diagnosis.

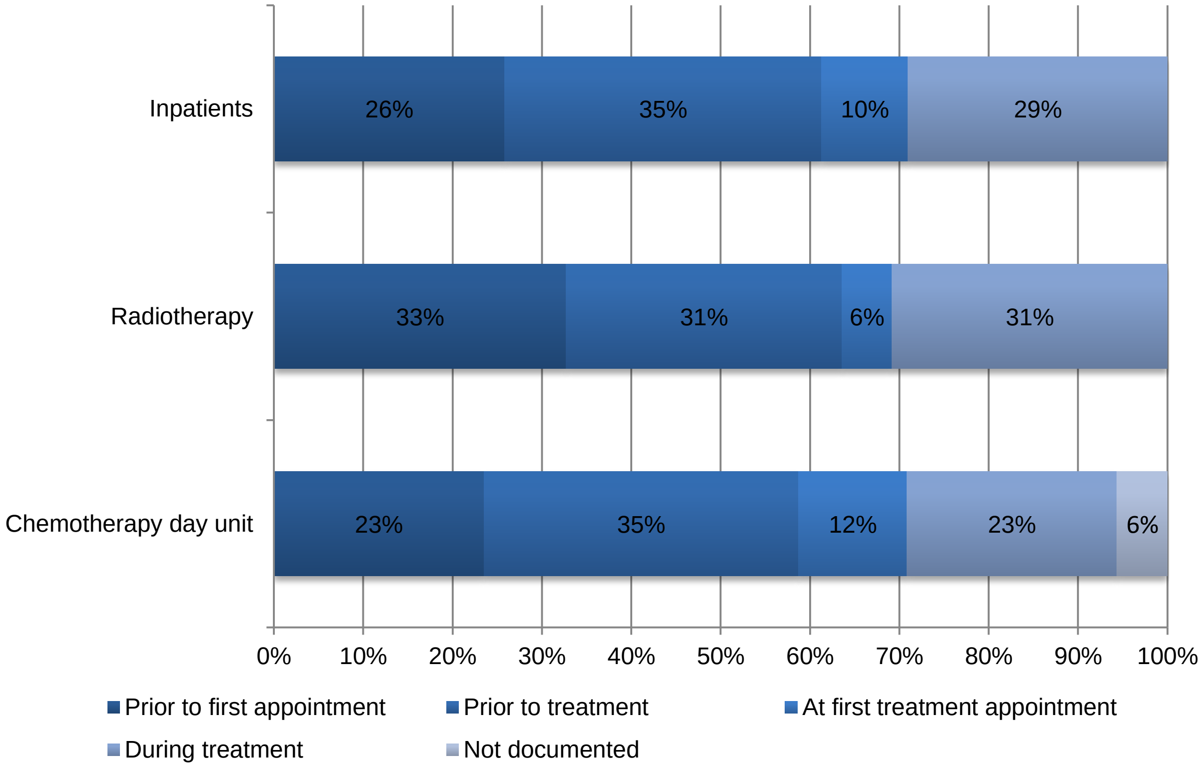
The mean time from first appointment at the health service to completion of an SCST was 21 days (IQR 0–37 days) as reported for 369 of 407 participants (Figure 1.6).

60 per cent of participants were screened for their supportive care needs before their treatment.

Table 1.8: Timing of SCST completion

Timing of SCST	Number included (*n* = 369)	%
Prior to first appointment at health service	105	25.8
Prior to commencement of treatment	137	33.7
During first appointment at health service	41	10.1
During treatment	104	25.6
At the conclusion of active treatment	1	0.25
During palliative care	1	0.25
Not documented	20	4.4

Figure 1.6: Timing of SCST by treatment unit



The location of where the patient was treated when they completed the SCST was compared with the unit where they were recruited for the study. This demonstrates that the majority of radiotherapy patients

(93 per cent) and chemotherapy patients (76 per cent) completed SCST in these units (Table 1.9). However, there is some crossover between units because inpatients were more likely to complete an SCST in another location.

Table 1.9: Location of completion of supportive care screening tool by treatment unit

Location of SCST completion	**Chemotherapy [*n* (%)]**	**Radiotherapy [*n* (%)]**	**Inpatients [*n* (%)]**
Chemotherapy day unit	202 (76%)	14	15 (44%)
Radiotherapy	11	99 (93%)	0
Inpatients	7	0	9 (26%)
Outpatients	39 (15%)	3	7
Not documented	0	2	3
Total	**266**	**107**	**34**

Discussions following a supportive care screening tool

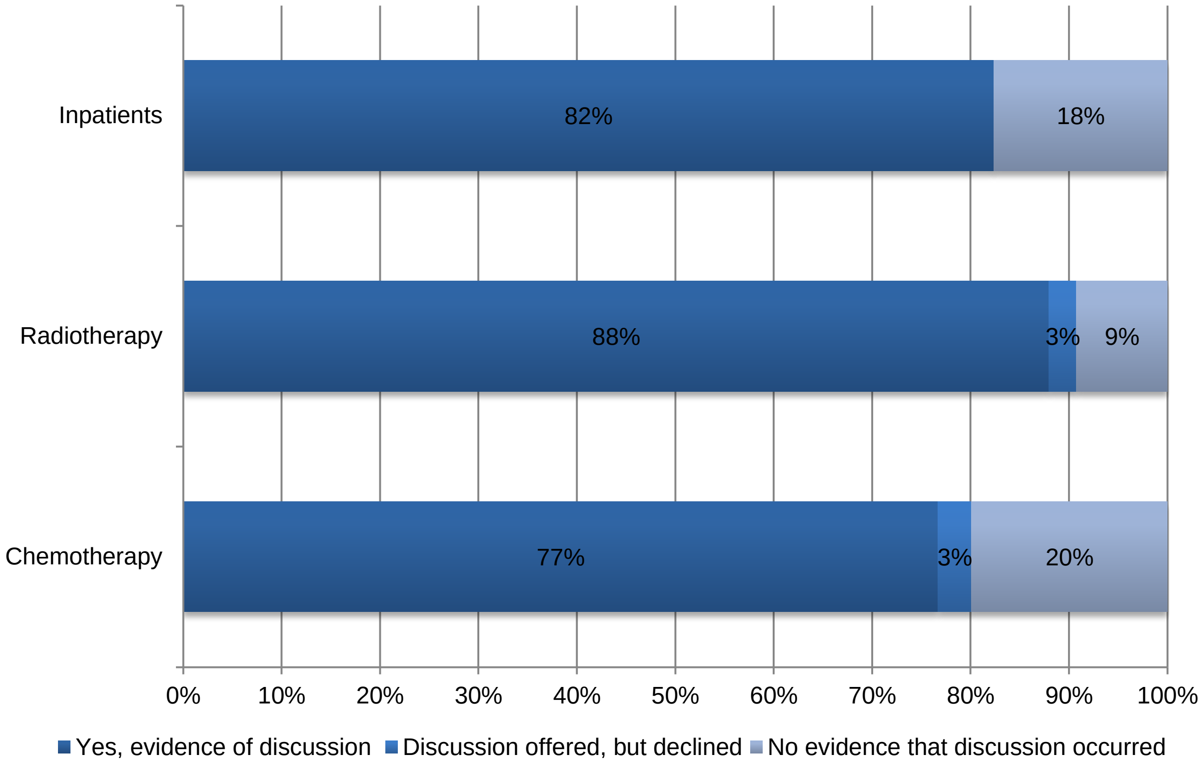
The use of a validated screening tool must be integrated within the context of a clinical discussion about the responses to the screen (Department of Health 2009). In this way, the screening tool is an important mechanism to open up channels of communication between the person with cancer and their health professional (Richardson et al. 2007). If specific issues are raised, an assessment is required, either by the initial practitioner or through referral to other service providers.

Of the participants with a documented SCST, 80 per cent (327/408) had documented evidence of a discussion with a health professional about their SCST responses, 3 per cent of participants declined a discussion about their SCST responses and 17 per cent of participants with a documented SCST (69/408) did not have documented evidence of a discussion regarding the screen (Figure 1.7). The overall prevalence of supportive care screening with an SCST followed up with a documented discussion about the responses to the screen was 53 per cent.

Participants receiving radiotherapy were statistically significantly more likely to have evidence of a follow-up discussion with their clinician on completion of a supportive care screen.

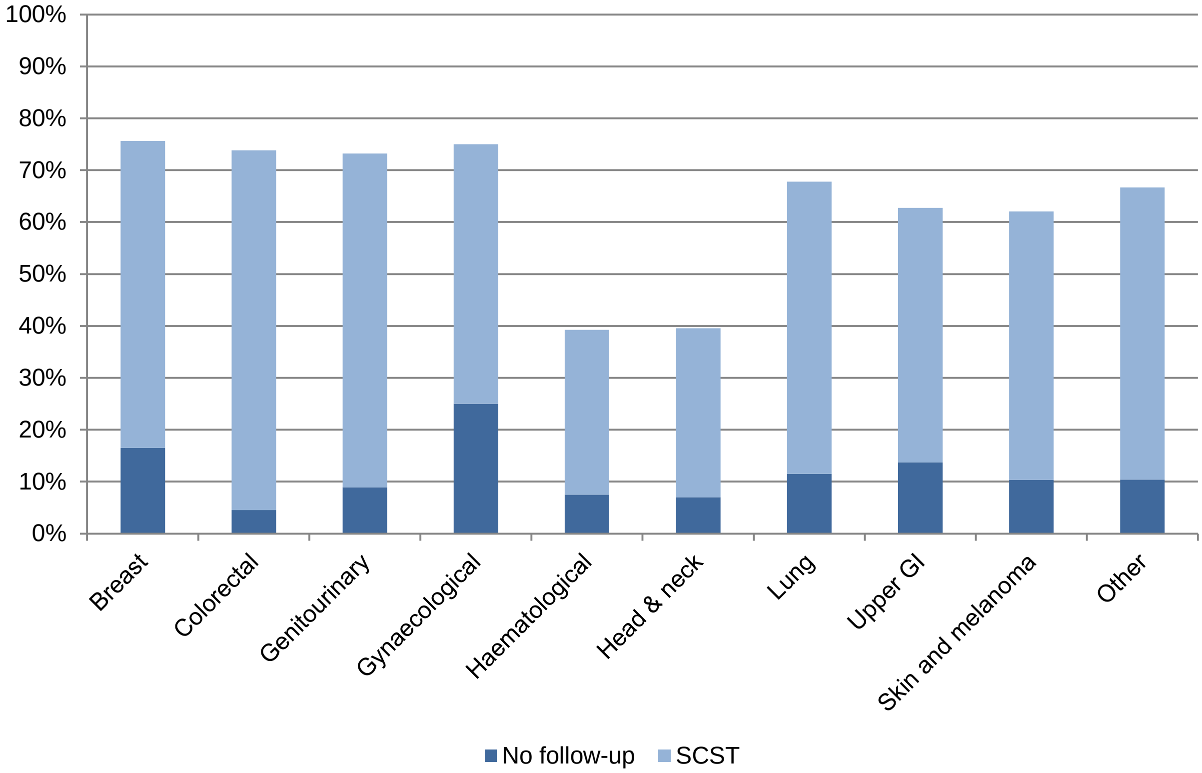
> One in six patients who completed a screening tool did not have documented evidence of a follow-up discussion with a health professional.

Figure 1.7: Evidence of a discussion following completion of SCST by treatment unit



When comparing rates of SCST follow-up by tumour type (Figure 1.8), participants with colorectal tumours were statistically significantly more likely to have a documented discussion about the completed SCST (93 per cent, OR 3.9, 95% CI 1.3–12.3, *p* = 0.02). Those with a gynaecological cancer were less likely to have this documented in their record (66 per cent), although the small numbers (*n* = 15) make it difficult to draw conclusions and the result is not statistically significant (OR 0.6, 95% CI 0.2–1.9, *p* = 0.363).

Figure 1.8: Evidence of discussion following completion of an SCST by tumour type



When comparing rates of documented SCST discussion by health service (Figure 1.9), four regional sites had rates of documented discussions that were significantly less than other sites (R3, R6, R10 and R12). This reduced the overall documented supportive care screening with a tool and follow-up discussion to less than 50 per cent of participants at these sites (Figure 1.10).

Figure 1.9: Evidence of follow-up discussion following supportive care screening by health service

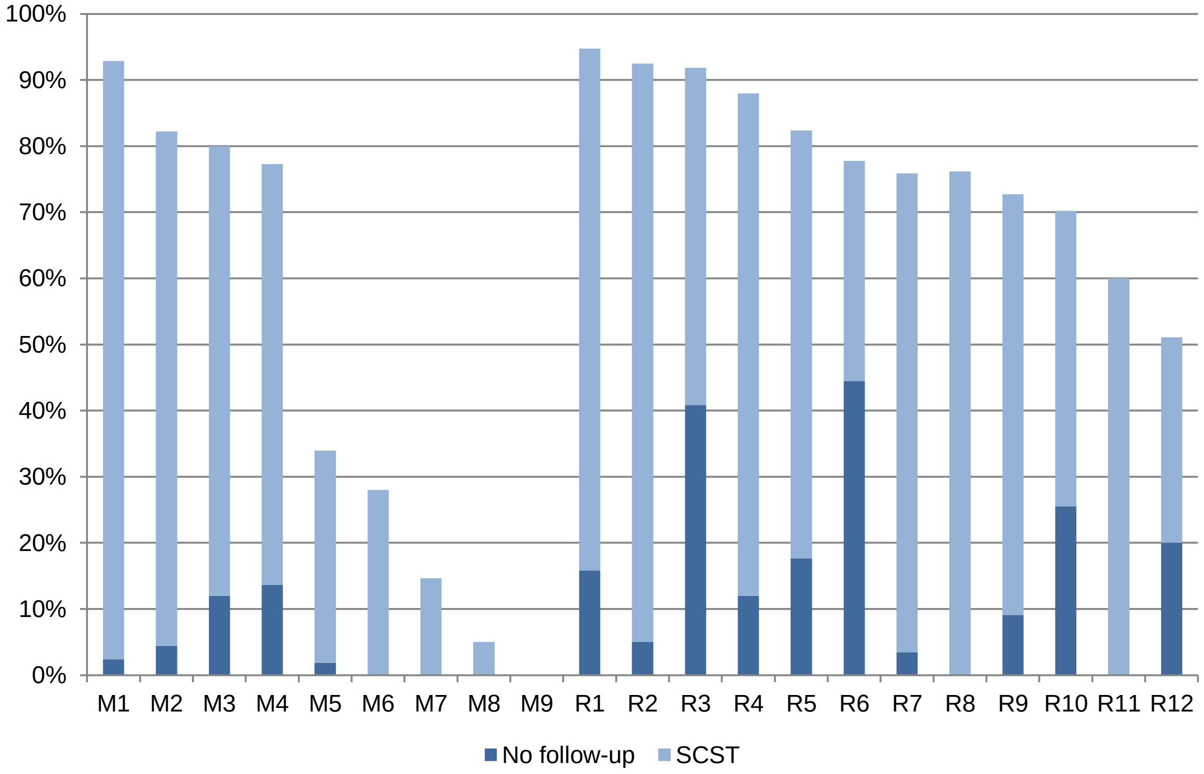
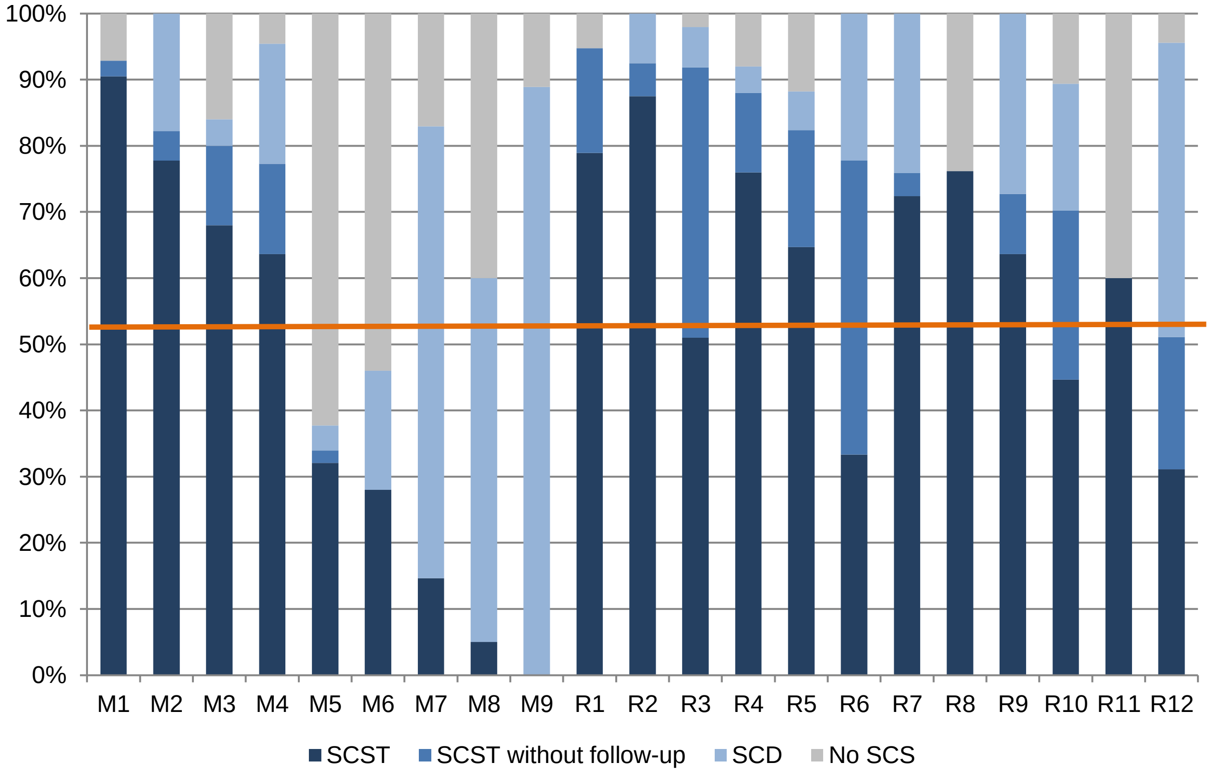


Figure 1.10: Overall prevalence of supportive care screening and follow-up discussion by health service



Documented evidence of discussions about supportive care needs identified that most commonly ward or unit nursing staff completed these discussions; they were responsible for 78 per cent of discussions following the completion of an SCST and 45 per cent of SCD that occurred in the absence of SCST. See Table 1.10. Specialist cancer nurses and social workers were also frequently involved in discussions in the absence of an SCST.

Table 1.10: Staff conducting supportive care discussions

Health professional	Discussion following an SCST (*n* = 339) [*n* (%)]	Discussion in absence of an SCST (*n* = 118) [*n* (%)]	Odds ratio	95% CI	*p*-value
Nursing staff	**264 (77.9%)**	53 (44.9%)	4.3	2.7–6.9	< 0.001
Specialist cancer nurse / clinical nurse consultant	39 (11.5%)	**25 (21.2%)**	2.1	1.1–3.7	< 0.01
Medical staff	21 (6.2%)	6 (5.1%)	-	-	-
Social worker	5 (1.5%)	**32 (27.1%)**	24.8	9.1–83	< 0.001
Other staff member	10 (3.9%)	2 (1.7%)	-	-	-

Supportive care screens and discussions were most commonly conducted by nursing staff.

Problem identification from supportive care screening

The data collected from the medical record audit captured problems/issues of concern for both participants with an SCST and those who received an SCD in the absence of a screening tool. Problems have been categorised using the problem groups defined in the NCCN Supportive Screening Tool.

Table 1.11 outlines the proportions of participants reporting problems and those with problems identified via an SCST or SCD.

Participants with a completed screening tool were more likely to report emotional and physical problems. A discussion alone was more likely to identify family and practical issues.

Table 1.11: Problems identified by SCST or SCD

Problem	Reporting problems [*n* (%)]	SCST completed [*n* (%)]	Discussion in absence of an SCST [*n* (%)]	Odds ratio (95% CI)	*p*-value
Emotional	280 (52.1%)	228 **(55.9%)**	52 (40.0%)	1.9 (1.2–2.9)	**0.0016**
Family	68 (12.7%)	44 (10.8%)	24 **(18.5%)**	0.53	**0.02**
Physical	333 (62.0%)	272 **(66.8%)**	61 (46.9%)	2.3 (1.5–3.5)	**0.001**
Practical	165 (30.7%)	98 (24.2%)	67 **(51.5%)**	0.3 (0.2–0.5)	**0.001**
Spiritual	19 (3.6%)	14 (3.4%)	5 (3.8%)	-	-

Differences in problems identified by unit

The following analysis compares the types of problems that were identified through either an SCST or an SCD (see also Figure 1.11). This result is confounded by the fact that fewer inpatients had evidence of an SCST and for these participants results relied on discussion in absence of SCST.

Emotional: Statistically significantly fewer radiotherapy participants identifying emotional concerns (OR 0.6, 95% CI 0.4–0.9, *p* = 0.02). There was a trend for inpatients to identify more emotional problems (OR 1.6, 95% CI 1.0-1.4, *p* = 0.07).

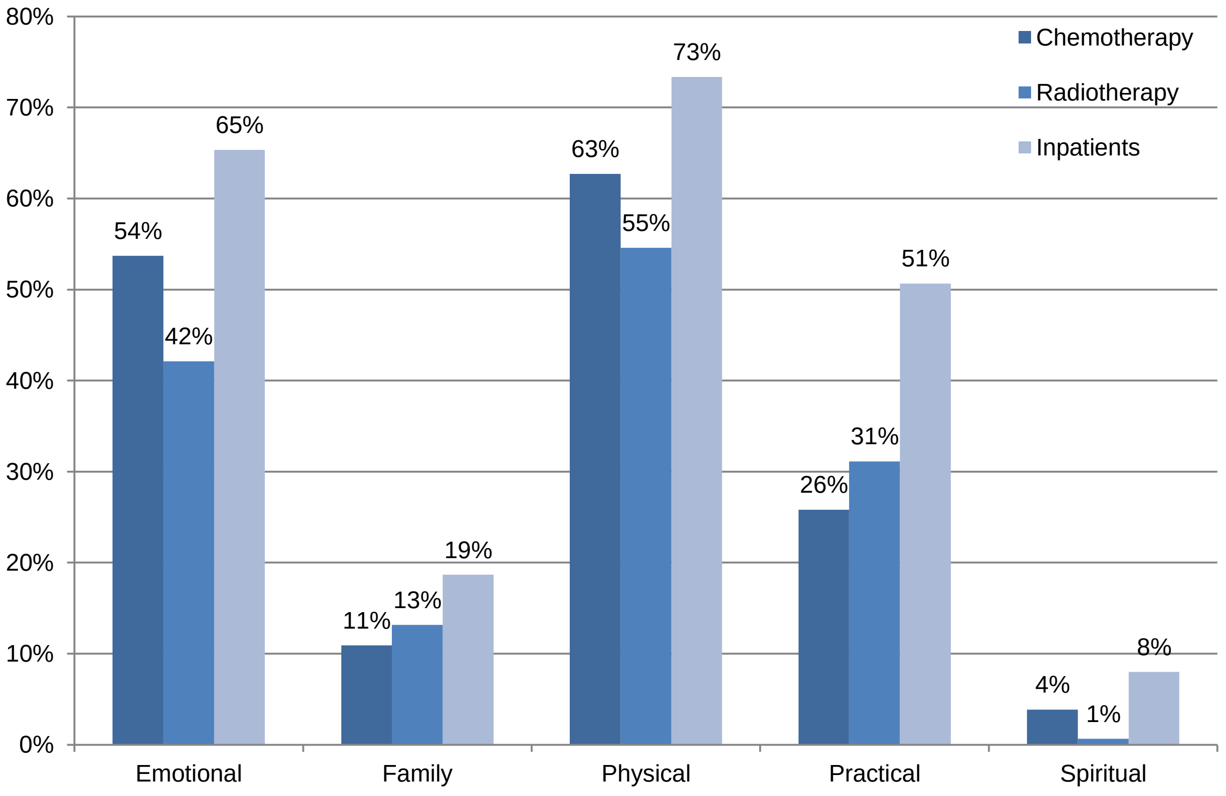
Family: There was a trend for inpatients to identify more family problems (OR 1.9, 95% CI 0.9–3.7, *p* = 0.07).

Physical: There was a trend for inpatients to identify more physical problems (OR 1.6, 95% CI 0.9–2.8, *p* = 0.09).

Practical: Statistically significantly more inpatients identified practical problems (OR 2.9, 95% CI 1.8–5.0, *p* < 0.001).

Spiritual: Small numbers limit the ability to show statistically significant difference. There was a trend for inpatients to identify more spiritual concerns (OR 2.2, 95% CI 0.8–6.0, *p* = 0.135).

Figure 1.11: Problems identified by unit



Differences in problems identified by stage

The following analysis compares the types of problems that were identified through either an SCST or an SCD by stage (see also Figure 1.12). There were no statistically significant differences in problems identified by cancer stage.

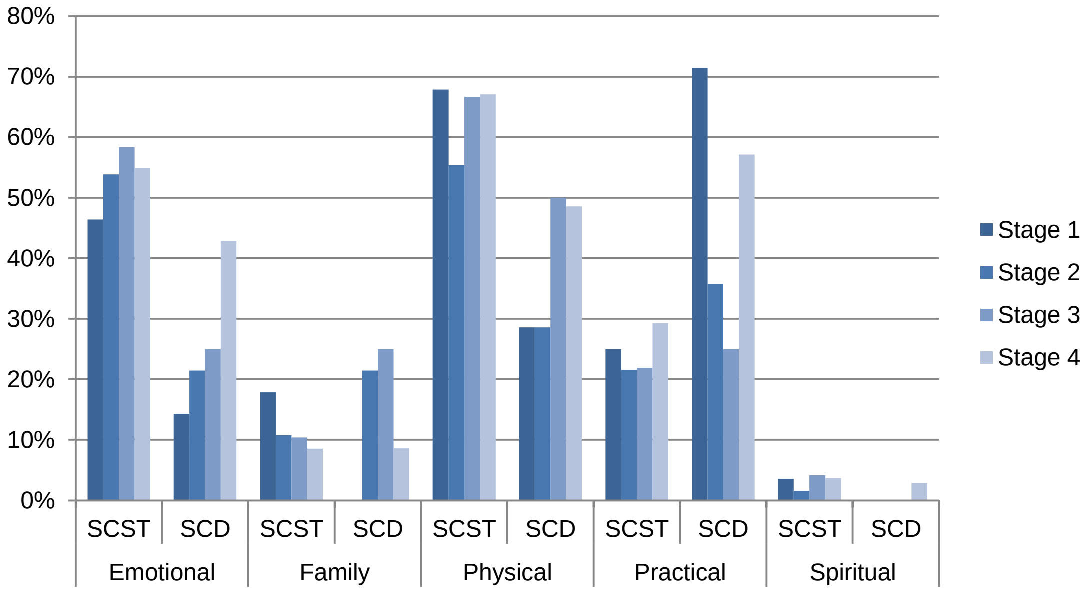
Emotional: There was a trend for participants to identify more emotional concerns through discussion at cancer stage 4 compared with earlier stages; this was not statistically significant. There was no difference observed by stage for participants who identified emotional concerns through SCST.

Physical: A higher proportion of stage 3 and stage 4 participants identified physical problems through discussion compared with earlier stages; this was not statistically significant. There was no difference observed by stage for participants who identified physical concerns through an SCST.

Practical: A higher proportion of stage 1 participants identified practical problems through discussion compared with later stages; this was not statistically significant. There was no difference observed by stage for participants who identified practical concerns through an SCST.

Spiritual: There was a trend for participants to identify more spiritual concerns through discussion at stage 4 compared with earlier stages; this was not statistically significant. There was no difference observed by stage for participants who identified spiritual concerns through an SCST.

Figure 1.12: Problems identified by stage



Differences in problems identified by tumour type

Figures 1.13a–e outline the rates of problems identified by tumour stream.

Differences in the rate of emotional, family or spiritual concerns did not reach statistical significance for any tumour type.

The only statistically significant results in the rates of problems identified by tumour type were:

- more practical problems identified by participants with gynaecological cancers (OR 3.3, 95% CI 1.2–9.0, *p* = 0.02), haematological cancers (OR 2.4, 95% CI 1.3–4.8, *p* = 0.006) and head & neck tumours (OR 2.3, 95% CI 1.0–5.0, *p* = 0.004)
- more physical problems identified by participants with upper gastrointestinal cancers (OR 3.0, 95% CI 1.2–7.6, *p* = 0.016) and those with genitourinary cancers (OR 1.9, 95% CI 0.9–4.1, *p* = 0.08).

Figure 1.13a: Proportion of participants identifying emotional problems by tumour type

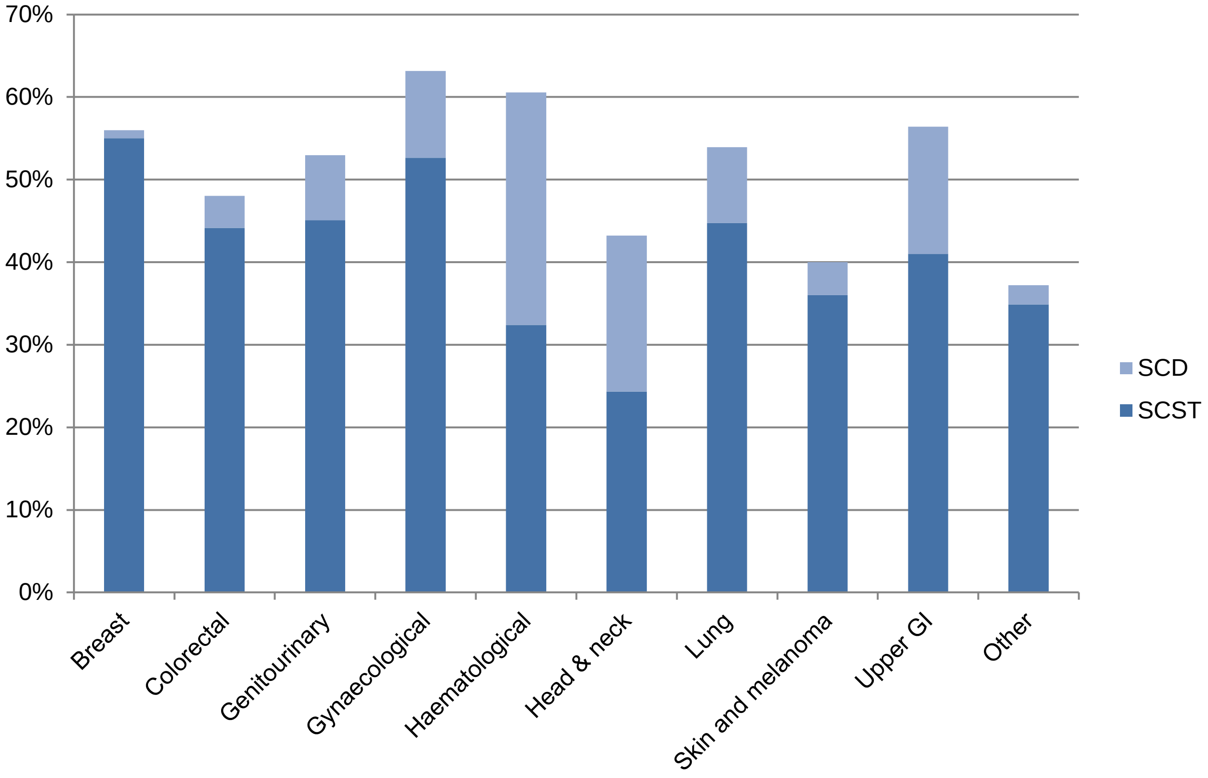


Figure 1.13b: Proportion of participants identifying family problems by tumour type

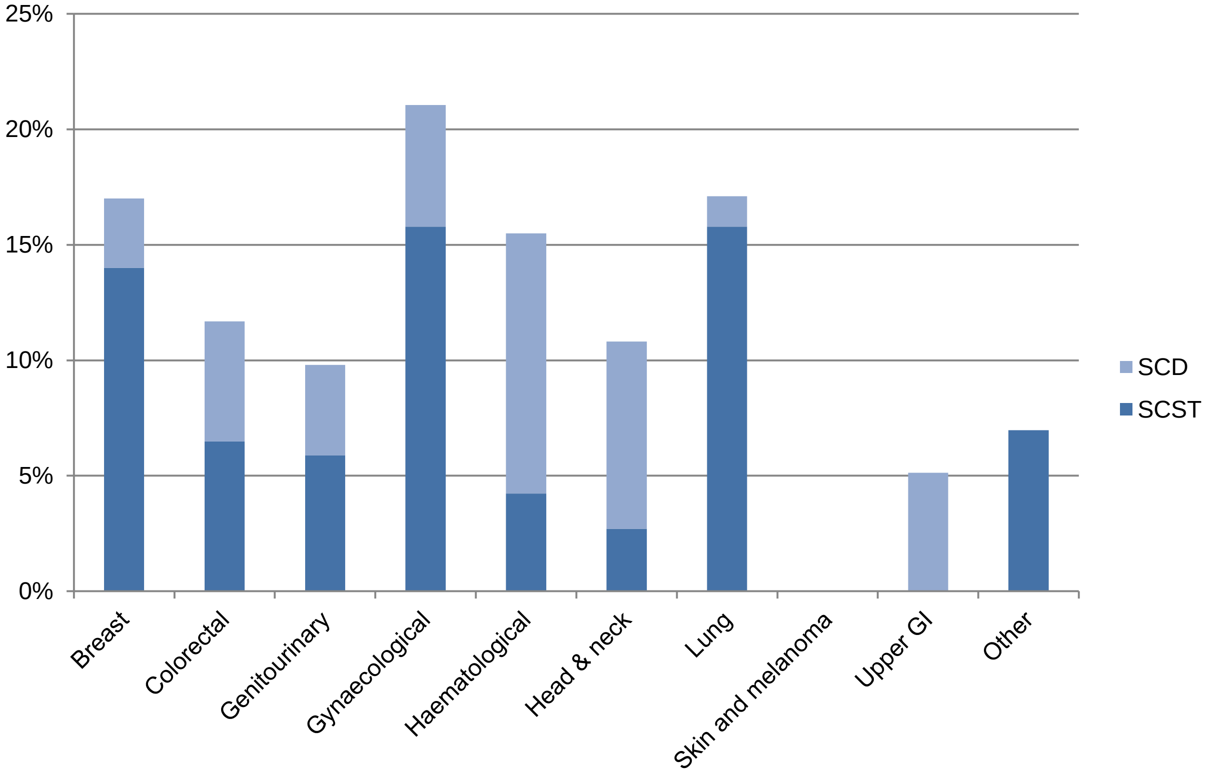


Figure 1.13c: Proportion of participants identifying physical problems by tumour type

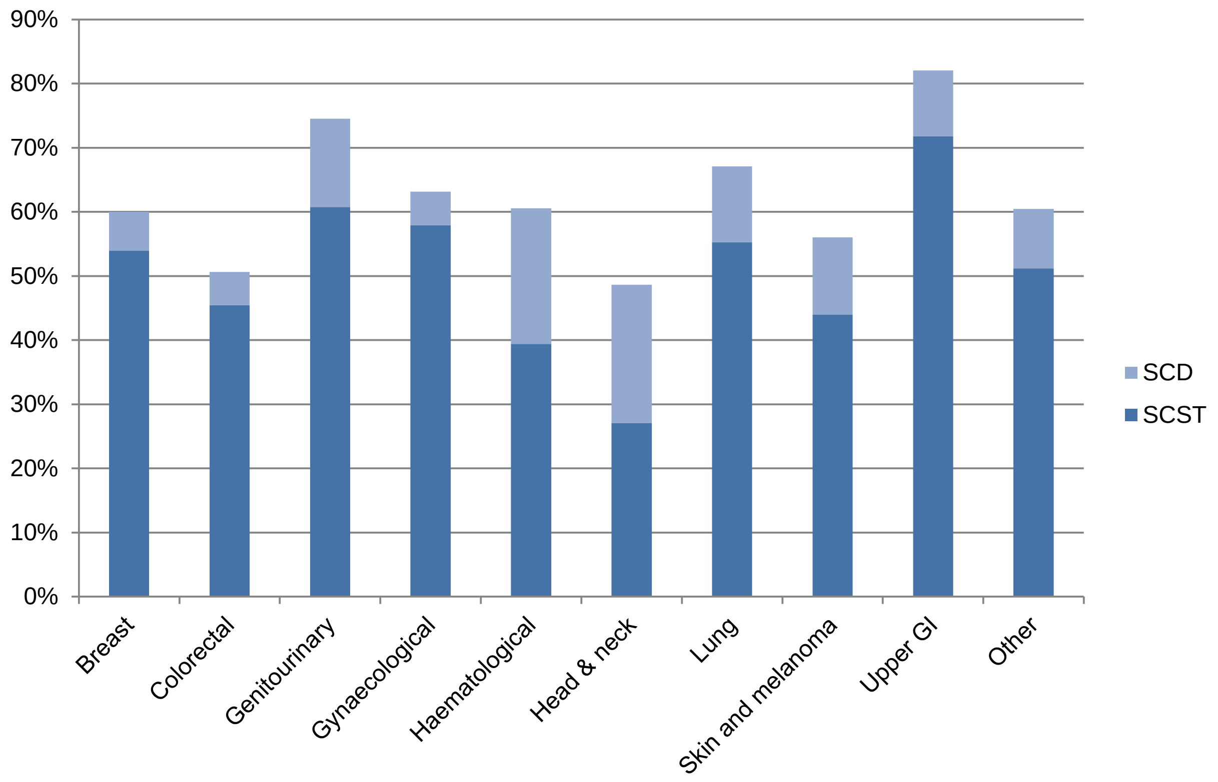


Figure 1.13d: Proportion of participants identifying practical problems by tumour type

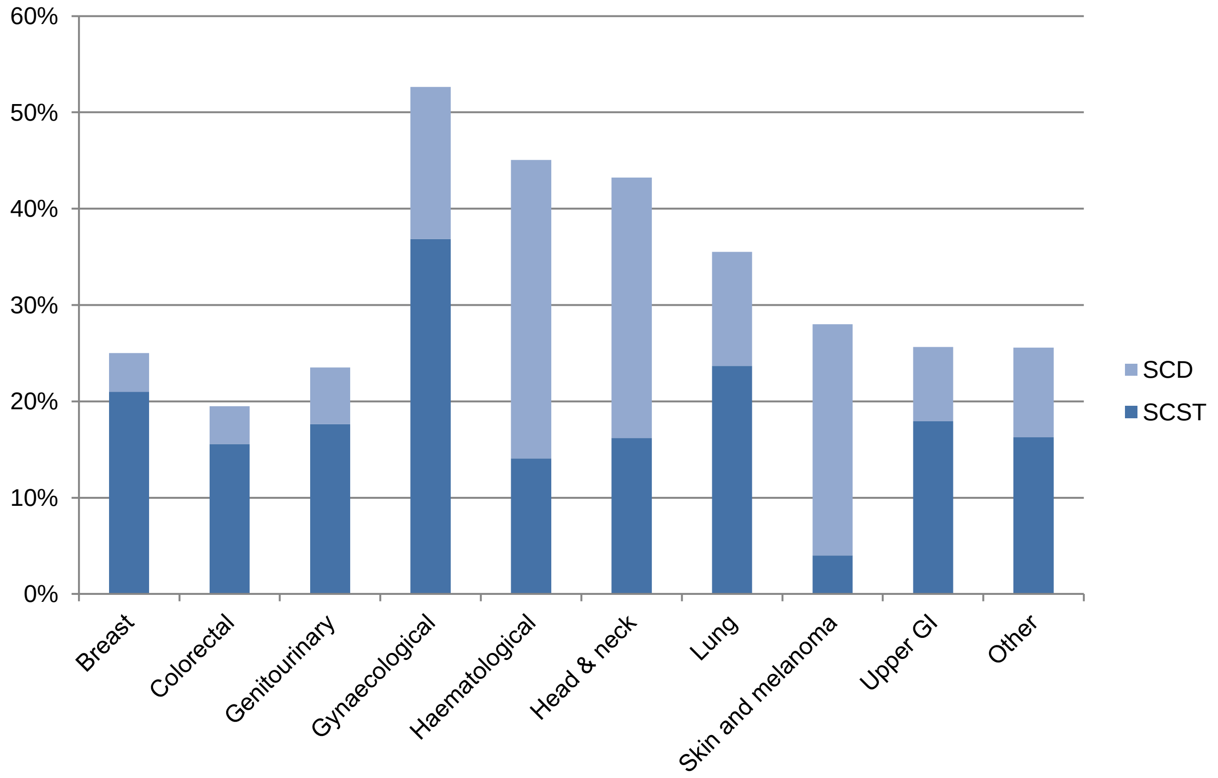
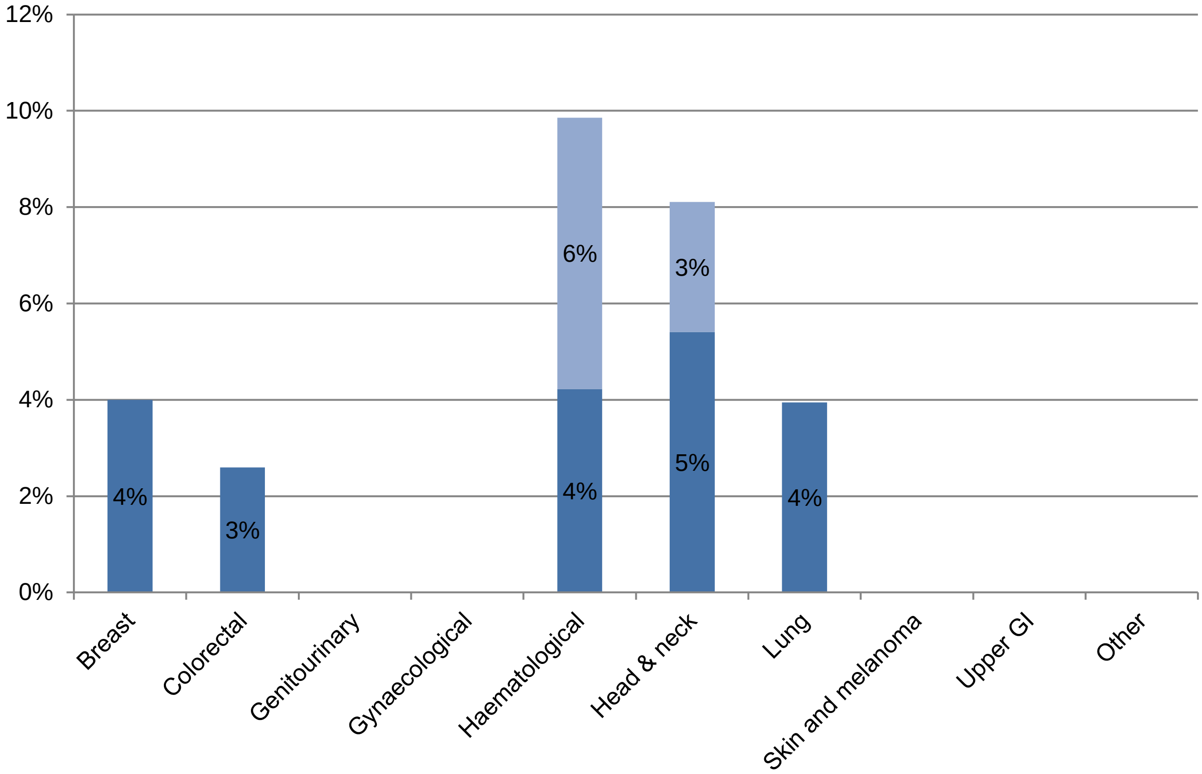


Figure 1.13e: Proportion of participants identifying spiritual problems by tumour type



Differences in problems identified by demographic variables

The following analysis compares the types of problems that participants identified through an SCST and/or SCD.

Men were more likely to identify practical problems (OR 1.7, 95% CI 1.2–2.5, *p* = 0.007) and less likely to identify emotional problems (OR 0.62, 95% CI 0.43–0.9, *p* = 0.013).

Participants who were aged 64 years or older were less likely to identify emotional (OR 0.52, 95% CI 0.35–0.75, *p* = 0.001) or family problems (OR 0.53, 95% CI 0.3–0.93, *p* = 0.03).

No statistically significant difference was observed when comparing problems reported by participants living alone or with others. Those with primary carer roles were more likely to identify practical (OR 1.9, 95% CI 1.0–3.7, *p* = 0.03) and family problems (OR 2.8, 95% 1.4–5.8, *p* = 0.006).

Participants living in metropolitan areas were more likely to identify family problems (OR 2.2, 95% CI 1.2–3.8, *p* = 0.006).

Distress identified through supportive care screening

Forty-one per cent (158/386) of the study participants with evidence of a completed Distress Thermometer were reported to be distressed, where a score of 4 or higher indicates moderate-to-severe distress.

There was no observed significant difference in distress identified by cancer stage (not shown) or timing of SCST (Table 1.12).

Table 1.12: Timing of SCST and prevalence of distress

Timing of SCST	Number of participants reporting distress	Prevalence of distress (%)	95% CI	Odds ratio
Prior to first appointment at health service	46	46.7%	37.1–56.9	1.3
Prior to treatment	50	39.7%	31.4–48.6	–
At first appointment at health service	21	53.8%	37.6–64.3	1.8
During treatment	33	32.4%	23.9–42.2	0.7

Participants reporting distress represented the highest proportion of the participants identifying all problems. Practical and emotional problems were independently associated with distress when all problems were compared (Table 1.13).

Table 1.13: Distress and problems identified by SCST

Problem	Proportion reporting distress [*n* (%)]	Proportion without distress [*n* (%)]	Odds ratio	95% CI	*p*-value
Emotional	135 (85.4%)	89 (39.0%)	**7.1**	**4.1–12.2**	**< 0.001**
Family	26 (16.5%)	18 (8.0%)	1.0	0.5–2.1	0.94
Physical	127 (80.4%)	131 (57.7%)	1.7	0.9–2.9	0.08
Practical	56 (35%)	37 (16.3%)	**2.2**	**1.2–3.8**	**0.005**
Spiritual	9 (5.7%)	4 (1.8%)	1.3	0.4–4.6	0.64

Distress was not compared by tumour type or treatment location given the limited results for some cancers and for inpatients.

Distress and screening tool follow-up discussion

There was no difference in the rate of recorded discussions following an SCST based on the level of participant distress. Eighty-five per cent of distressed participants had evidence of a discussion about their SCST compared with 81 per cent of those not reporting distress (OR 1.4, 95% CI 0.76–2.5, p = 0.27). One-third of participants (23/66) who completed an SCST and did not have evidence of a discussion about it in their medical record were identified as distressed.

Interventions to address supportive care concerns

Supportive care interventions were recorded for study participants who had evidence of a supportive care SCST and for those with evidence of an SCD in the absence of an SCST. It was possible for more than one intervention to be reported per participant (Table 1.14 and Figure 1.14).

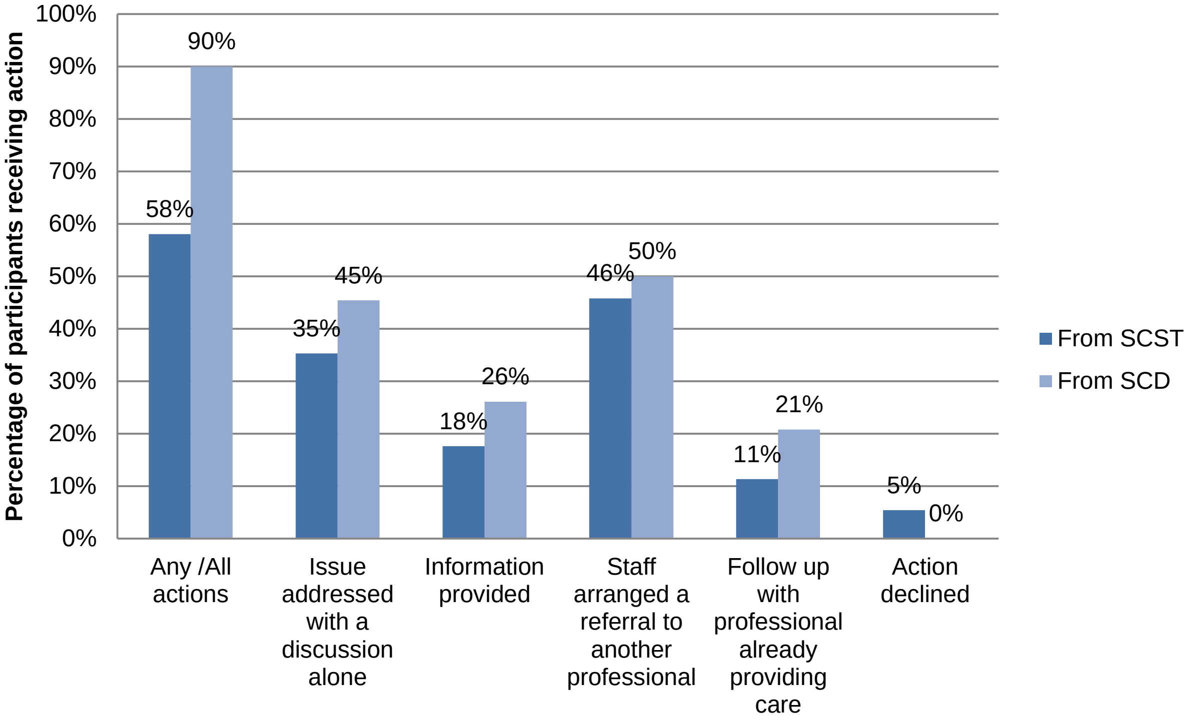
Evidence of a supportive care intervention in the medical record was likely to trigger the site auditor to identify a discussion in the absence of a supportive care screen. It is likely that SCDs occurred that were not documented in the absence of an action occurring. The proportion of participants receiving supportive care activity occurring as a result of a discussion is likely to be an underestimate.

Table 1.14: Supportive care actions reported in medical record audit

Action	Total number = 538 [*n* (%)]	Participants with an SCST completed (*n* = 408) [*n* (%)]	Participants with discussion in the absence of an SCST (*n* = 130) [*n* (%)]	Odds ratio (95% CI)	*p*-value
Any/all actions	352 (65.8%)	235 (58.0%)	117 (90.0%)	**6.5** (3.5–13.0)	**< 0.0001**
Issue addressed with a discussion	203 (37.7%)	144 (35.3%)	59 (45.4%)	**1.5** (1.0–2.3)	**0.04**
Information provided	106 (19.7%)	72 (17.6%)	34 (26.1%)	**1.6** (1.0–2.7)	**0.04**
Staff arranged a referral to another professional	252 (46.8%)	187 (45.8%)	65 (50%)	1.2 (0.8–1.8)	**0.41**
Follow-up with professional already providing care	73 (13.6%)	46 (11.3%)	27 (20.8%)	**2.1** (1.2–3.6)	**0.006**
Actions declined	22 (4.1%)	22 (5.4%)	–	–	–

Fifty-eight per cent of participants with a completed screening tool had evidence of a supportive care intervention.

Figure 1.14: Supportive care actions resulting from an SCST compared with SCD



Figures 1.15a–d show the percentages of actions following an SCST and SCD by site.

Figure 1.15a: Percentage of participants receiving any documented supportive care action following SCST and SCD by site

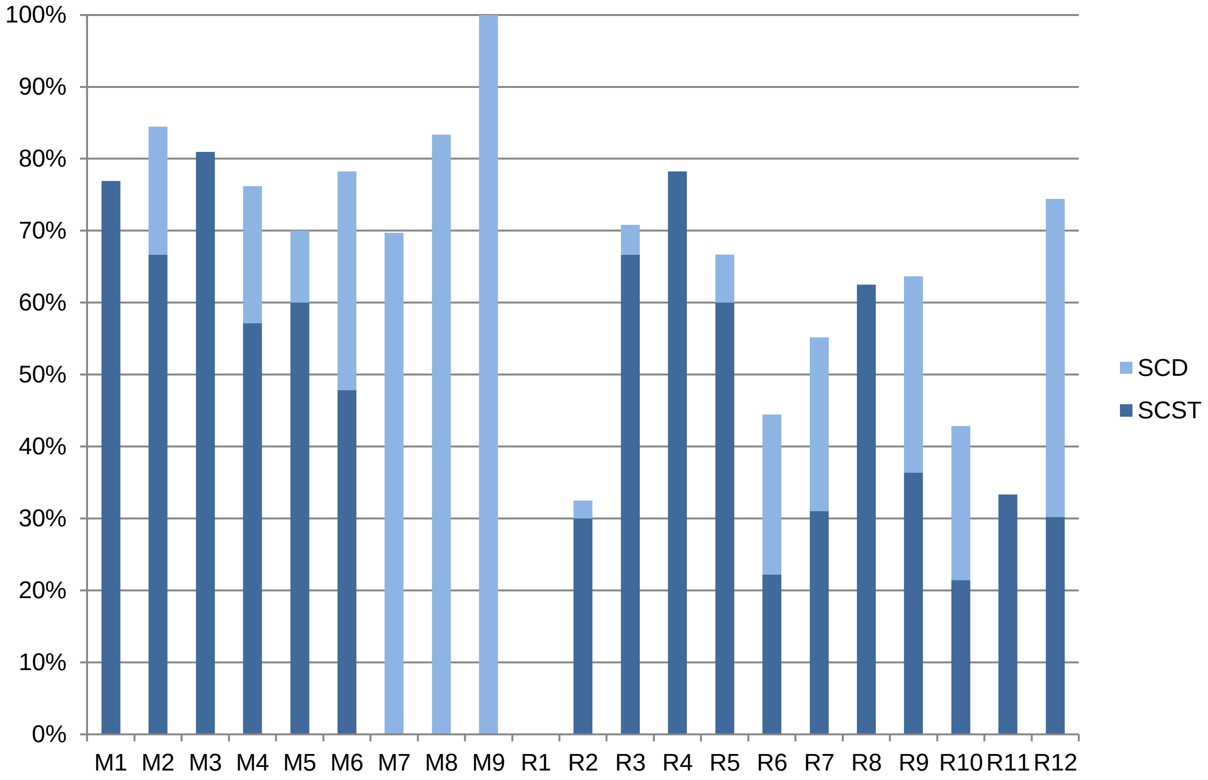


Figure 1.15b: Percentage of participants receiving discussion to address supportive care needs following SCST and SCD by site

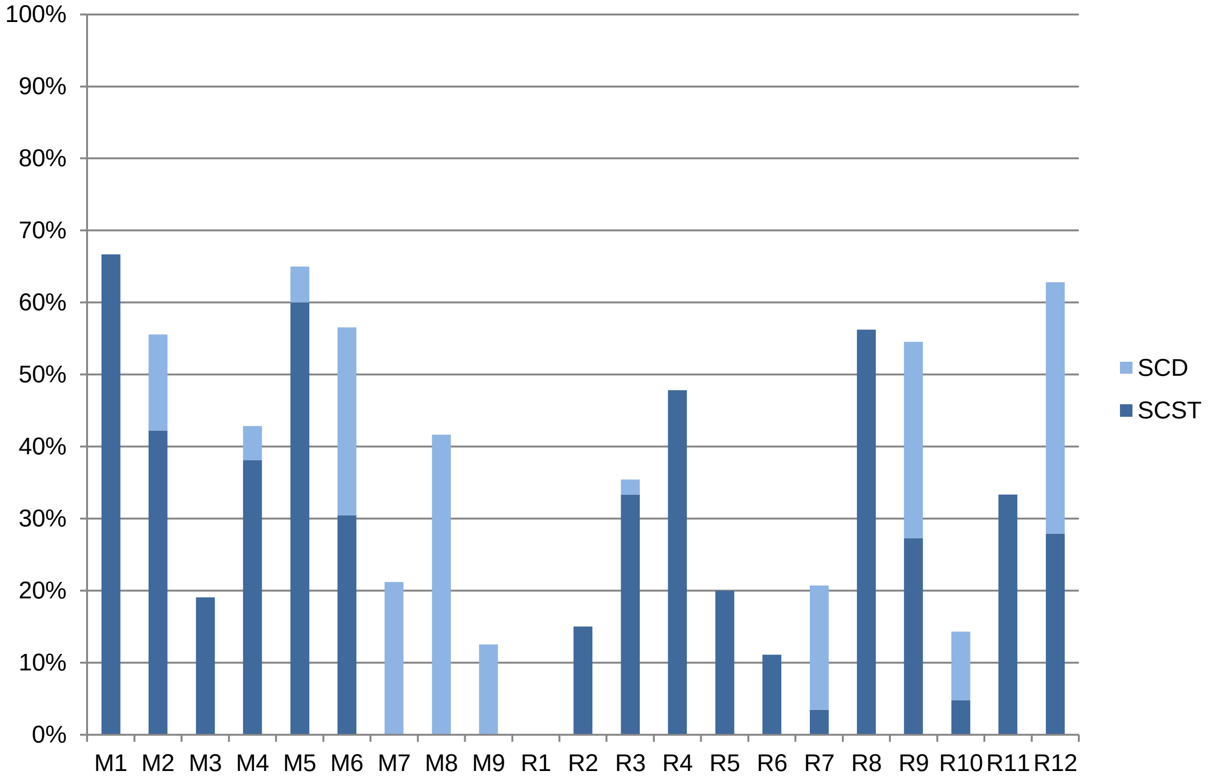


Figure 1.15c: Percentage of participants receiving information to address supportive care needs following SCST and SCD by site

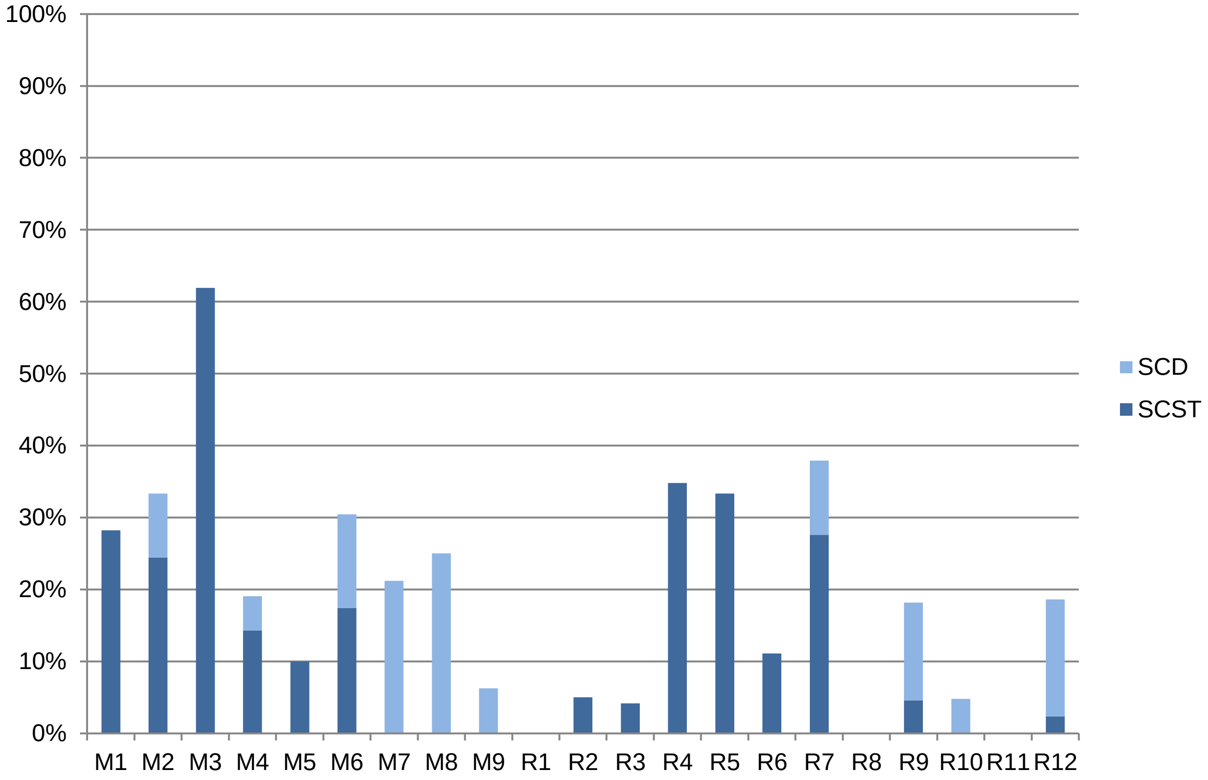
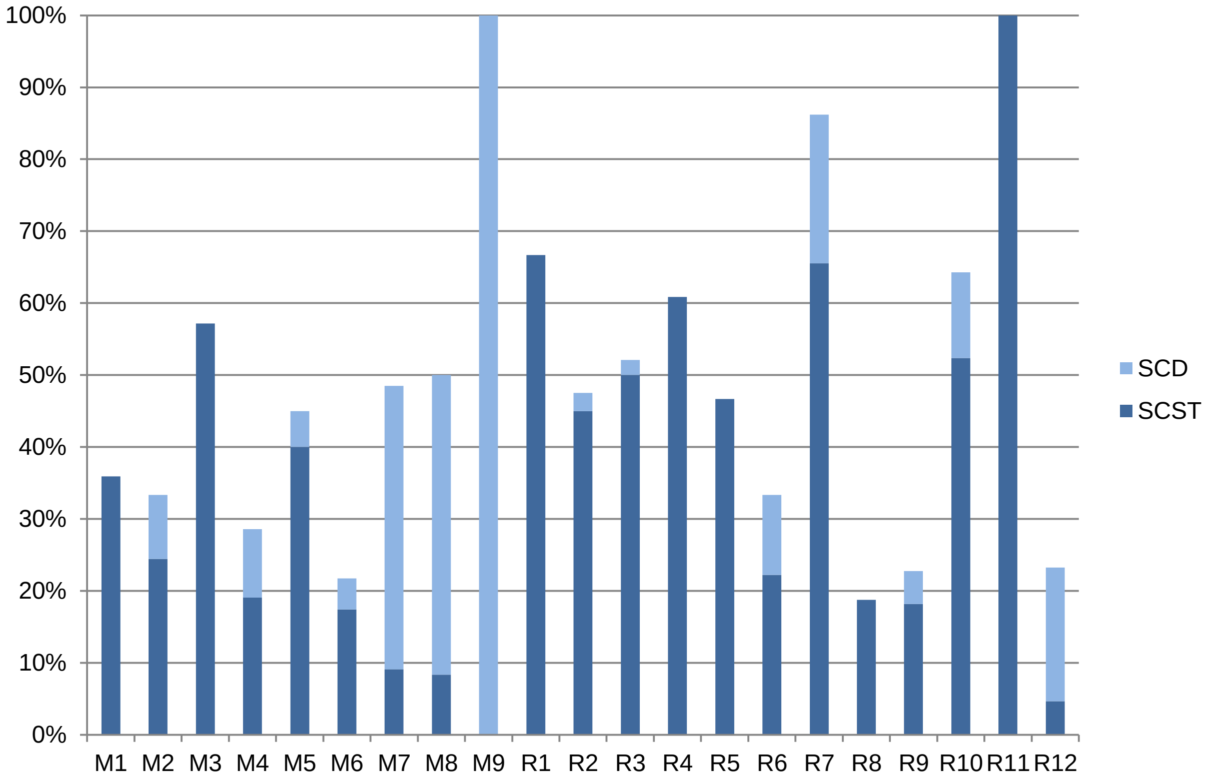


Figure 1.15d: Percentage of participants receiving a referral to address supportive care needs following SCST or SCD by site



Supportive care referrals

Overall, 54 per cent of participants had at least one documented supportive care referral in their medical record (Table 1.15). On average there were 1.9 referrals per participant associated with an SCST and 2.5 referrals per participant associated with an SCD. Additional details were collected for each supportive care referral from the medical record audit including documented reasons for referrals. Reasons for referral were categorised according to the NCCN Distress Thermometer and Problem List.

Table 1.15: Number and percentage of referrals and referral reasons

Supportive care activity	Number	Participants with at least one referral recorded [*n* (%)]	Number of referrals	Number of reasons for referrals
SCST	408	252 (61.7%)	480	648
SCD	130	83 (63.8%)	209	313
Referrals for participants without evidence of an SCST or SCD	103	14 (13.5%)	30	42
Total	641	349 (54.4%)	719	1,003

** Two participants declined an SCST.*

When compared with the actions reported in Table 1.14, 16 per cent of participants with evidence of an SCST (*n* = 65) and 14 per cent of participants with evidence of an SCD (*n* = 18) had at least one documented referral to address supportive care needs where the referral was not also recorded as an action (Figure 1.16 and Table 1.16). This finding highlights variability in the data collection and indicates an underestimate of supportive care interventions identified in Table 1.14.

Figure 1.16: Number of referrals resulting from an SCST and SCD

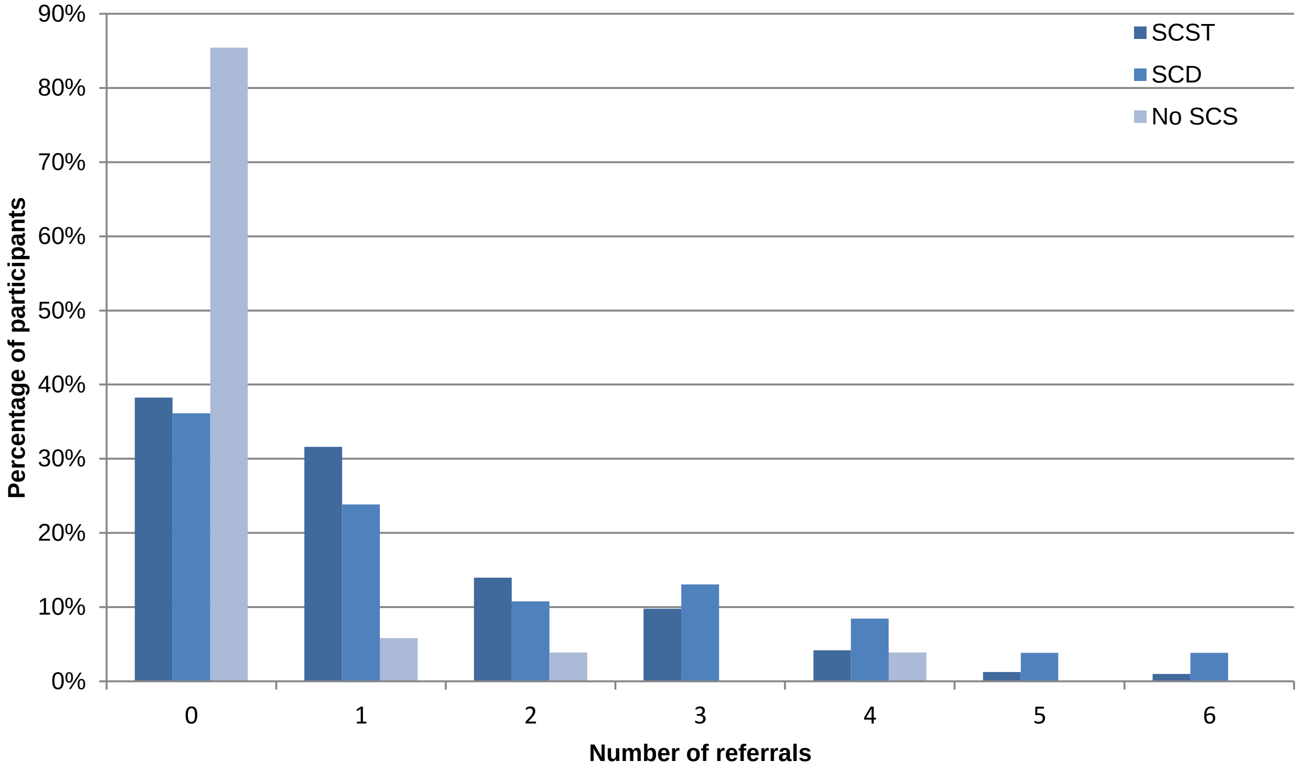


Table 1.16: Number of referrals resulting from an SCST and SCD

Number of referrals for each participant	Participants *n* = 552* [*n* (%)]	Participants with an SCST *n* = 408 [*n* (%)]	Participants with an SCD *n* = 130 [*n* (%)]	Odds ratio (95% CI)	*p*-value
0	203 (37.7%)	156 (38%)	48 (37%)	1.1 (0.7–1.7)	0.67
1	166 (25.8%)	129 (32%)	31 (24%)	1.5 (0.9–2.4)	0.08
2	75 (11.5%)	57 (14%)	14 (11%)	1.3 (0.7–2.7)	0.35
3	57 (10.6%)	40 (10%)	17 (13%)	0.7 (0.4–1.4)	0.29
4	32 (5.0%)	17 (4%)	11 (8%)	0.5 (0.2–1.1)	0.06
5	9 (1.6%)	5 (1%)	4 (3%)	0.3 (0.1–1.4)	0.05
6	9 (1.4%)	4 (1%)	5 (4%)	0.2 (0.0–1.2)	0.03

** Includes 14 participants with supportive care referrals that didn't have evidence of SCST or SCD in medical record*

Reasons for supportive care referrals

The reasons for supportive care referrals were reported against the NCCN Problem List category that they were to address (Figure 1.17 and Table 1.17). Multiple reasons were frequently recorded for a single referral, where a referral to one health professional was to address a number of issues of concern; for example, a referral may have been made to a social worker to address emotional, family and practical concerns. It was also possible for a participant to have multiple referrals to a range of different health professionals to address a single issue of concern; for example, emotional concerns may have resulted in referrals to social work and psychology professionals.

Figure 1.17: Documented reasons for supportive care referrals

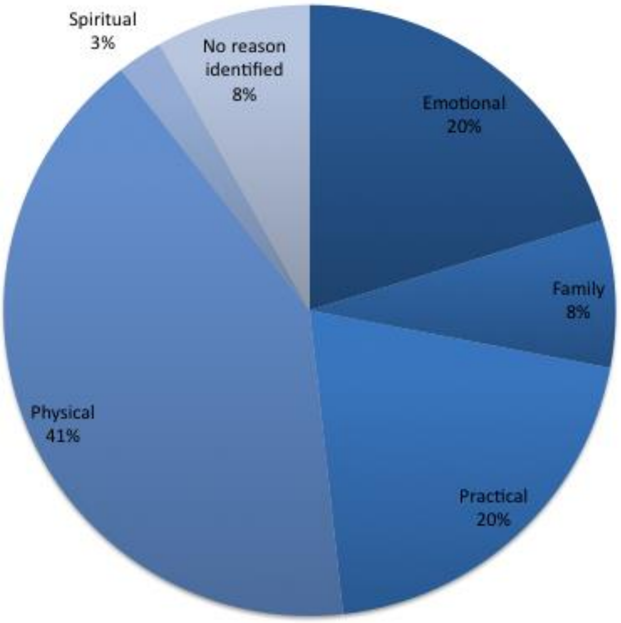


Table 1.17: Reasons for supportive care referrals

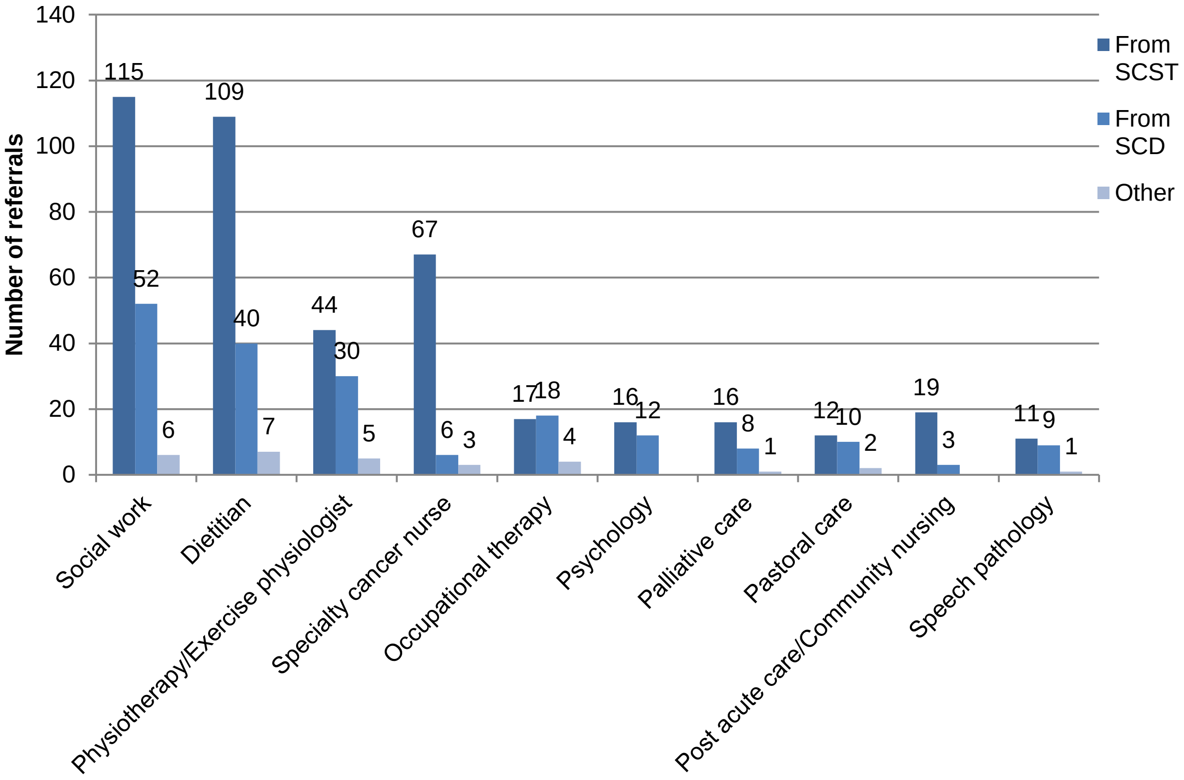
Problem	Number of referrals	Reasons for referral from SCST [*n* (%)]	Reasons for referral in absence of SCST* [*n* (%)]	Odds ratio
Emotional	203	133 (21%)	70 (19%)	–
Family	78	33 (5%)	45 (13%)	–
Physical	413	266 (41%)	147 (41%)	–
Practical	203	132 (20%)	71 (20%)	1.04
Spiritual	24	12 (2%)	12 (3%)	–
No reason identified	82	72 (11%)	10 (3%)	**4.4**
Total	1,003	648	355	–

***** *Includes both referrals for participants from an SCD and referrals made for participants without any evidence of an SCST or SCD*

Supportive care referrals by health professional

The greatest proportion of supportive care referrals were made to a social worker (24 per cent), dietitian (22 per cent), physiotherapist / exercise physiologist (11 per cent) and to a specialist cancer nurse or clinical nurse consultant (11 per cent). Figure 1.18 outlines the number of referrals to the top 10 health professionals. There were a small number of referrals to ‘other’ professionals including support groups (*n* = 19), diabetes educator (*n* = 8), pain services (*n* = 7), Hospital in the Home (*n* = 7), transport services (*n* = 6), stomal therapy (*n* = 6), continence services (*n* = 5), general practice (*n* = 5), dental (*n* = 4), music therapy (*n* = 3), smoking cessation nurse (*n* = 2), familial cancer services (*n* = 1), pharmacist (*n* = 1), fertility (*n* = 1) and Aboriginal support worker (*n* = 1).

Figure 1.18: Supportive care referrals by health professional



> Referrals to social work and dietetic services were the most common referrals made to address supportive care needs

Table 1.18a: Health professional referrals by problem – emotional

Health professional	**Number and proportion (*n* = 203)** **[*n* (%)]**	**SCST completed (*n* = 133)** **[*n* (%)]**	**Completed in absence of an SCST (*n* = 70)** **[*n* (%)]**	**Odds ratio**
Social work	76 (37%)	47 (35%)	29 (41%)	–
Specialist cancer nurse	33 (16%)	31 (23%)	2 (3%)	–
Psychology	23 (11%)	11 (8%)	12 (17%)	–
Pastoral care	18 (9%)	12 (9%)	6 (9%)	–
Dietitian	16 (8%)	10 (8%)	6 (9%)	–
Other	37 (18%)	22 (17%)	15 (21%)	–

Table 1.18b: Health professional referrals by problem – family

Health professional	**Number and proportion (*n* = 278)** **[*n* (%)]**	**SCST completed (*n* = 33)** **[*n* (%)]**	**Completed in absence of an SCST (*n* = 45)** **[*n* (%)]**	**Odds ratio** **(*p*-value)**

Health professional	**Number and proportion (*n* = 278) [*n* (%)]**	**SCST completed (*n* = 33) [*n* (%)]**	**Completed in absence of an SCST (*n* = 45) [*n* (%)]**	**Odds ratio (*p*-value)**
Social work	34 (44%)	14 (42%)	20 (44%)	0.9
Specialist cancer nurse	8 (10%)	7 (21%)	1 (2%)	**11.8 (0.006)**
Psychology	8 (10%)	1 (3%)	7 (16%)	**0.1 (0.045)**
Dietitian	8 (10%)	3 (9%)	5 (11%)	0.8
Other	20 (26%)	8 (24%)	12 (27%)	0.9

Table 1.18c: Health professional referrals by problem – physical

Health professional	**Number and proportion (*n* = 413) [*n* (%)]**	**SCST completed (*n* = 266) [*n* (%)]**	**Completed in absence of an SCST (*n* = 147) [*n* (%)]**	**Odds ratio (*p*-value)**
Dietitian	135 (33%)	93 (35%)	42 (29%)	–
Physiotherapy	71 (17%)	38 (14%)	34 (22%)	–
Specialist cancer nurse	37 (9%)	33 (12%)	4 (3%)	–
Occupational therapy	30 (7%)	10 (3%)	20 (14%)	–
Social work	29 (7%)	21 (9%)	8 (5%)	–
Other	111 (27%)	71 (27%)	40 (27%)	–

Table 1.18d: Health professional referrals by problem – practical

Health professional	**Number and proportion (*n* = 203) [*n* (%)]**	**SCST completed (*n* = 132) [*n* (%)]**	**Completed in absence of an SCST (*n* = 71) [*n* (%)]**	**Odds ratio (*p*-value)**
Social work	103 (51%)	64 (48%)	43 (55%)	0.77
Specialist cancer nurse	25 (12%)	23 (17%)	2 (3%)	**7.3 (0.002)**
Dietitian	17 (8%)	13 (10%)	4 (6%)	1.8
Occupational therapy	14 (7%)	7 (5%)	7 (10%)	0.5
Other	37 (20%)	25 (19%)	19 (27%)	0.6

Table 1.18e: Health professional referrals by problem – spiritual/religious

Health professional	Number and proportion (*n* = 24) [*n* (%)]	SCST completed (*n* = 12) [*n* (%)]	Completed in absence of an SCST (*n* = 12) [*n* (%)]	Odds ratio
Pastoral care	14 (59%)	8 (67%)	6 (50%)	–
Other	10 (41%)	4 (33%)	6 (50%)	–

Table 1.18f: Health professional referrals by problem – no reason identified

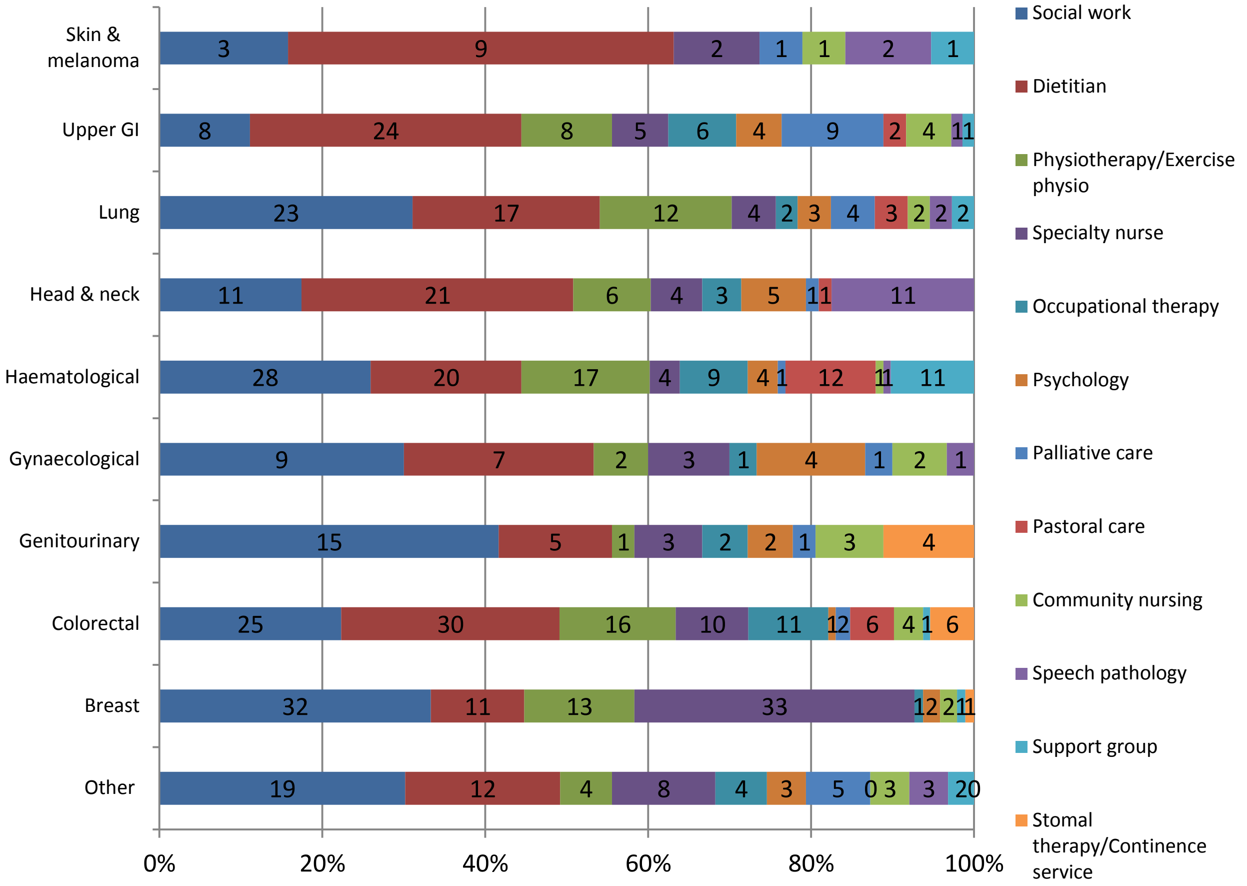
Health professional	Number and proportion (*n* = 82) [*n* (%)]	SCST completed (*n* = 72) [*n* (%)]	Completed in absence of an SCST (*n* = 10) [*n* (%)]	Odds ratio
Specialist cancer nurse	–	23 (0%)	3 (0%)	–
Social work	–	11 (0%)	3 (0%)	–
Dietitian	–	10 (0%)	1 (0%)	–
Post-acute care/HARP	–	7 (0%)	–	–
Physiotherapy	–	6 (0%)	1 (0%)	–
Other	–	–	2 (0%)	–

Supportive care referrals by tumour stream

The proportion of supportive care referrals made to each health professional were compared by tumour stream (Figure 1.19). The greatest proportion of supportive care referrals for participants with skin cancer or melanoma (47.3 per cent), upper gastrointestinal cancers (33.3 per cent), head & neck cancers (33.3 per cent) and colorectal cancers (26.7 per cent) were for dietitian services. Participants with breast cancer received the highest proportion of referrals to a specialty nurse (34.4 per cent). Participants with genitourinary cancer received the highest proportion of referrals to a social worker (41.6 per cent). Participants with head & neck cancer also received the greatest proportion of referrals to a speech pathologist (57.8 per cent).

Blanket referrals to a dietitian for head & neck cancers and upper gastrointestinal cancers were reported by more than one health service and may contribute to the prevalence of documented referrals for this group.

Figure 1.19: Supportive care referrals by tumour stream

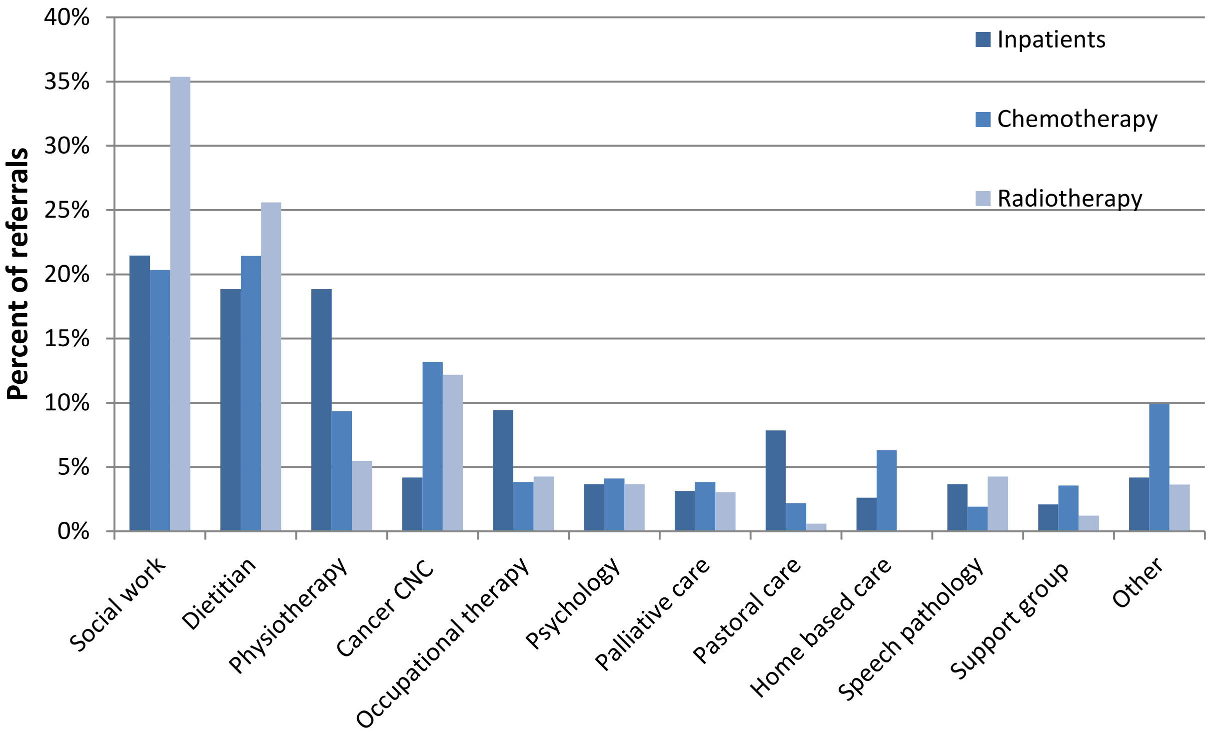


Supportive care referrals by unit

Of 719 supportive care referrals made, 51 per cent were for participants receiving chemotherapy (*n* = 177), 23 per cent were for those receiving radiotherapy (*n* = 105) and 27 per cent were for inpatients (*n* = 67) (Figure 1.20):

- 46.5 per cent of all **chemotherapy** participants received at least one referral with an average of 2.1 referrals per participant
- 66.5 per cent of all **radiotherapy** participants received at least one referral with an average of 1.6 referrals per participant
- 64 per cent of all **inpatient** participants received at least one referral with an average of 2.8 referrals per participant.

Figure 1.20: Supportive care referrals by unit



Supportive care referrals by health service

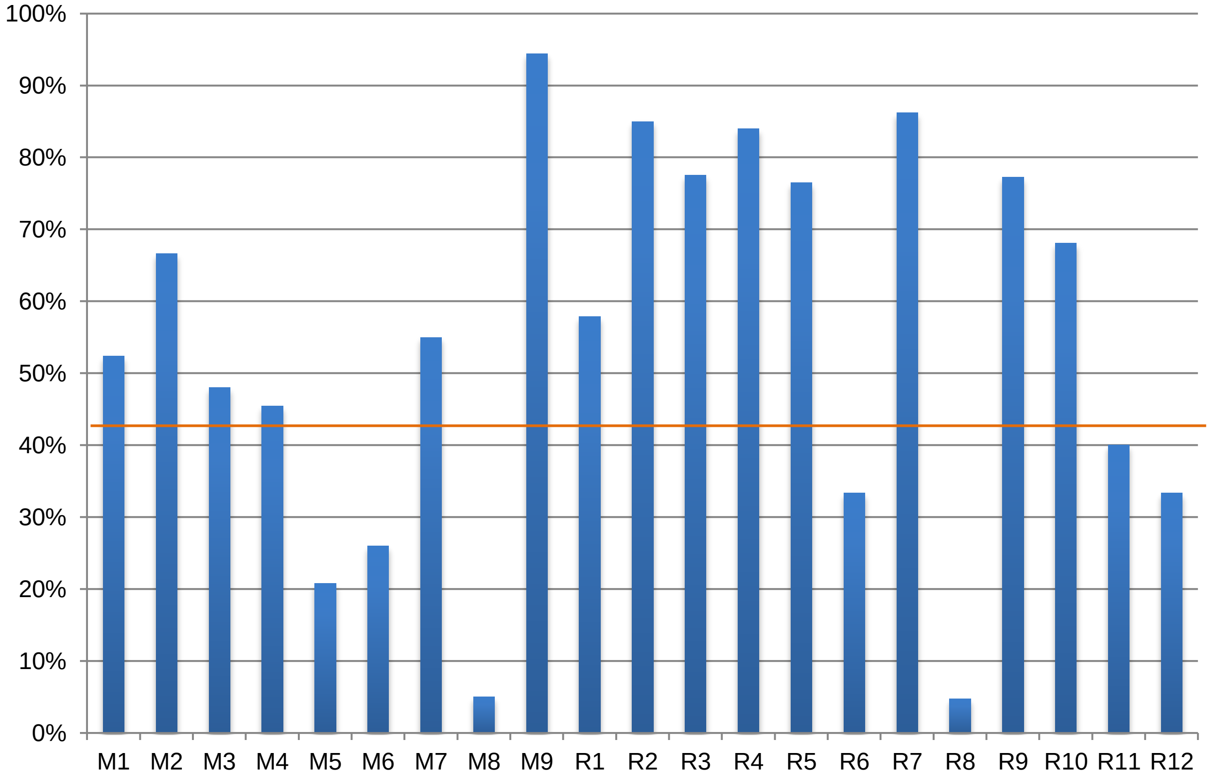
The proportion of participants with supportive care referrals and the number of referrals per participant was compared between health services (Table 1.19 and Figure 1.21). Health service M9 had the highest percentage of participants with supportive care referrals and the most referrals per participant. Notably this health service also had the lowest supportive care screening rate (0 per cent) and the highest proportion of participants with a documented SCD (89 per cent). Health services M8 and R8 had the lowest percentage of participants with supportive care referrals (5 per cent). Health service M8 had the second lowest supportive care screening rate (5 per cent) and a large proportion of participants with a documented SCD (55 per cent), while health service R8 had an above average screening rate (76 per cent) and no participants with a documented SCD.

Table 1.19: Supportive care referrals by health service

Site	Number included	Number of participants with a referral	% of participants with a referral	Total referrals	Average referrals per participant
M1	42	22	52%	44	2.0
M2	45	30	67%	63	2.1
M3	25	12	48%	23	1.9
M4	22	10	45%	26	2.6
M5	53	11	21%	14	1.3
M6	50	13	26%	20	1.5
M7	40	22	55%	61	2.8

Site	Number included	Number of participants with a referral	% of participants with a referral	Total referrals	Average referrals per participant
M8	20	1	5%	1	1.0
M9	18	17	94%	63	3.7
R1	19	11	58%	22	2.0
R2	40	34	85%	56	1.6
R3	49	38	78%	74	1.9
R4	25	21	84%	38	1.8
R5	17	13	76%	46	3.5
R6	9	3	33%	3	1.0
R7	29	25	86%	51	2.0
R8	21	1	5%	1	1.0
R9	22	17	77%	36	2.1
R10	47	32	68%	54	1.7
R11	5	2	40%	3	1.5
R12	45	15	33%	20	1.3

Figure 1.21: Percentage of participants with referrals by site



Location of referrals

Table 1.20 shows that the majority of all documented supportive care referrals (90 per cent, *n* = 642) were made to services within the current hospital.

Table 1.20: Location of referral

Location of referral	Total number	Number with an SCST completed	Number in absence of an SCST
Within current hospital	642	422	220
Other hospital	11	9	2
Community-based service	48	41	7
General practice	4	3	1
Other	7	0	7
Not reported	7	5	2

Uptake of referrals

Referral uptake was determined by documented evidence in the medical record of the participant's attendance or evidence of an assessment or intervention being provided. There was evidence of uptake for the majority of referrals (84 per cent). A statistically significant difference was observed in the uptake of referrals based on the type of supportive care screening, with a lower rate of uptake for referrals initiated by an SCST (Table 1.21). Documented evidence of referral uptake may not be available for attendance at external services, resulting in an underestimate of uptake.

Table 1.21: Uptake of supportive care referrals

Origin of referral	Total number	Yes, evidence of referral uptake [*n* (%)]	No evidence of referral uptake [*n* (%)]	Odds ratio	*p*-value
Referral from an SCST	480	390 (81.2%)	90 (18.8%)	0.4	–
Referral from an SCD or other	239	216 (91.4%)	23 (8.6%)	0.3–0.8	**0.0015**
Total	719	606 (84.3%)	113 (0%)	–	–

Rates of referral uptake were compared by:

- Type of problem: There was no significant difference based on the type of problem identified – emotional (86.2 per cent), family (87.2 per cent), physical (84.2 per cent), practical (83.7 per cent) and spiritual (79.2 per cent).
- Unit: Inpatients (94.8 per cent) were compared with ambulatory patients (80.4 per cent) (OR 4.4, 95% CI 2.2–9.6, $p < 0.001$).
- Location of referral: Uptake for referrals at the current hospital (87.2 per cent) were compared with other referrals (59.7 per cent) (OR 4.4, 95% CI 2.6–7.9, $p < 0.001$).

Additional supportive care screening with a supportive care screening tool

Forty-six participants (11.3 per cent) had a second SCST identified at the time of the initial audit. The mean number of days between the first and second screen was 35 days (IQR 17–43 days) and 62 days (IQR 37–88 days) from cancer diagnosis (see Table 1.22 for the breakdown).

Of these participants, 12 (26 per cent) had a third SCST identified at the time of the initial audit. The mean number of days between the second and third screen was 48 days (IQR 34–63 days) and 103 days (IQR 61–140 days) from cancer diagnosis.

Thirty-one participants with a second documented SCST and 10 of those with a third documented SCST did not have another documented SCST in the 60-day follow-up audit period. For analysis purposes, the details of all additional supportive care screens reported in the initial medical record audit have been incorporated into the 60-day follow-up medical record audit results.

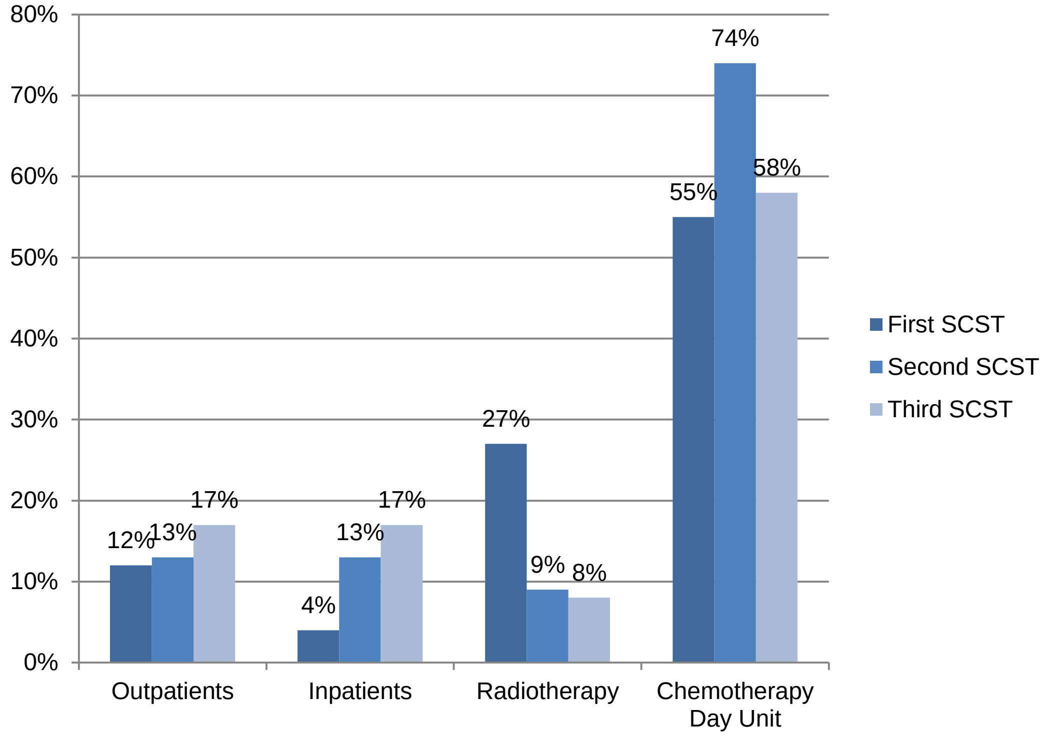
Information was not collected for additional SCDs occurring in the initial audit period.

Table 1.22: Health services reporting more than one documented SCST per participant during initial audit

Site	Participants with one SCST (*n*)	Participants with second SCST [*n* (%)]	Participants with third SCST [*n* (%)]
M1	39	20 (47.6%)	7 (16.7%)
M5	18	1 (1.8%)	–
M6	14	4 (8.0%)	1 (2.0%)
R2	37	1 (2.5%)	1 (2.5%)
R3	45	14 (28.6%)	3 (6.1%)
R5	14	2 (11.8%)	1 (1%)
R9	16	4 (18%)	–

Figure 1.22 shows the breakdown of location of additional SCSTs.

Figure 1.22: Location of additional SCST



Follow-up medical record audit

A total of 632 participants (98 per cent) were included in the follow-up medical record audit. Of these, 15 participants had two additional SCST screens and two participants had three screens in the follow-up period. Each SCST screen was recorded as a separate patient event, and these participants were recorded twice or three times in the follow-up analysis, resulting in 651 participants in the follow-up.

Eleven participants were not captured in the follow-up audit, including five from one site that did not complete the follow-up audit (R11).

Twenty participants were transferred to another health service during the follow-up period. Of these, 11 were transferred to a participating health service during the follow-up period, allowing the collection of information regarding ongoing supportive care activity occurring at the new health service. This was not possible for nine participants who were transferred to non-participating health services. Twenty-three participants died during the follow-up period.

Prevalence of additional supportive care screening during follow-up period

- Documented evidence of an SCST: 131 participants (including 20 participants with no previous SCST)
- Documented evidence of participants declining an SCST or SCD: 23 participants
- Documented evidence of an SCD conducted in the absence of an SCST: 271 participants (46 per cent)
- Documented evidence of an SCD conducted when the participant had declined SCST: 21 participants
- No documented evidence of supportive care: 199 participants

Twenty-one per cent of participants were screened for their supportive care needs on more than one occasion

Table 1.23: Prevalence of SCST and SCD during follow-up period by health service

Site	**Included [*n* (%)]**	**Participants with additional SCST completed [*n* (%)]**	**Participants with discussion in the absence of additional SCST [*n* (%)]**
M1	45* (6.5%)	34 (76%)	2 (4%)
M2	45 (7.0%)	2 (4%)	41 (91%)
M3	28* (3.8%)	12 (43%)	13 (46%)
M4	22 (3.4%)	3 (14%)	4 (18%)
M5	53 (8.2%)	4 (8%)	30 (57%)
M6	50 (7.8%)	3 (6%)	37 (74%)
M7	40 (6.2%)	2 (5%)	27 (68%)
M8	20 (3.1%)	0 (0%)	14 (70%)
M9	18 (2.8%)	0 (0%)	5 (28%)
R1	19 (2.9%)	2 (11%)	12 (63%)
R2	40 (6.2%)	11 (28%)	8 (20%)
R3	49 (7.6%)	17 (35%)	5 (10%)
R4	25 (3.9%)	5 (20%)	16 (64%)
R5	17 (2.6%)	7 (41%)	3 (18%)
R6	9 (1.4%)	1 (11%)	8 (89%)
R7	29 (4.5%)	5 (17%)	12 (41%)
R8	21 (3.3%)	4 (19%)	3 (14%)
R9	22 (3.4%)	1 (5%)	16 (73%)
R10	47 (7.3%)	6 (13%)	17 (36%)
R11	5 (0.8%)	-	-
R12	57* (7.0%)	12 (21%)	24 (42%)

** Increase in denominator due to some participants having multiple additional SCST screens*

Figure 1.23: SCST and SCD prevalence by health service during follow-up period

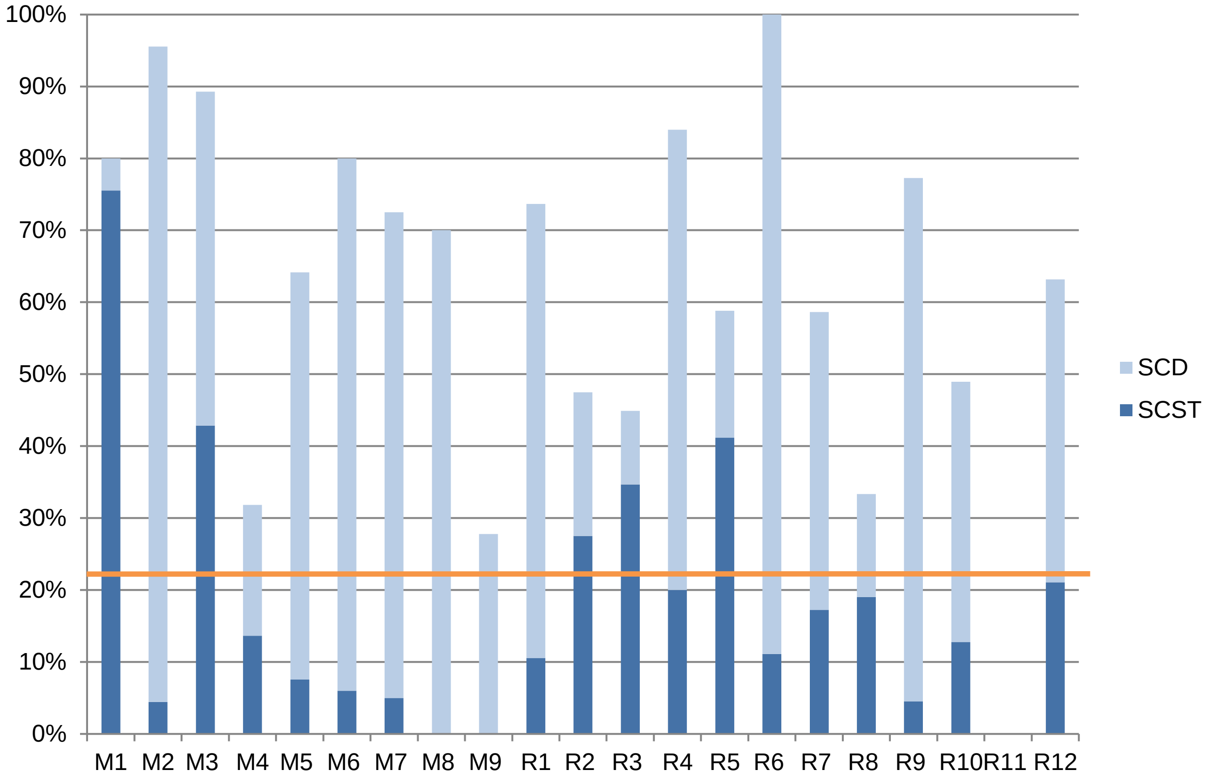


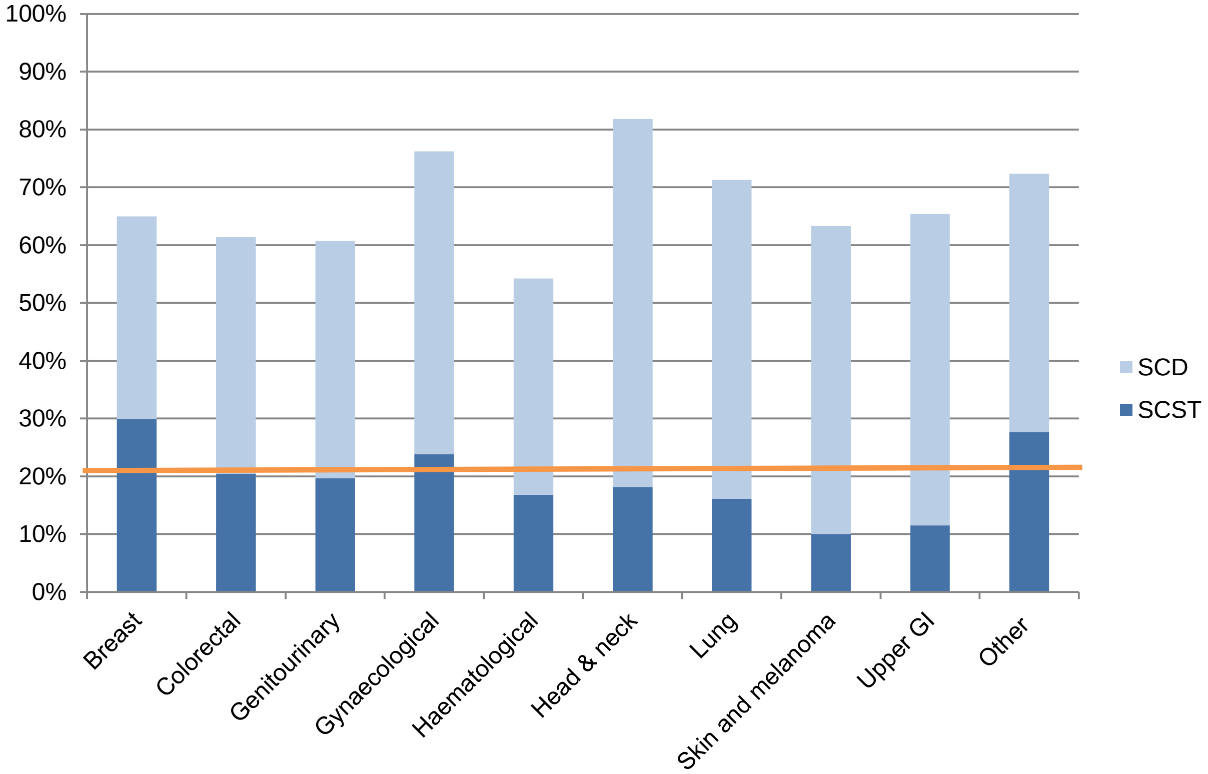
Table 1.24 and Figure 1.24 show SCST and SCD prevalence by tumour type during follow-up period.

Table 1.24: SCST and SCD prevalence by tumour type during follow-up period

Tumour type	**Total included [*n* (%)]**	**Participants with SCST completed [*n* (%)]**	**Participants with discussion in the absence of SCST [*n* (%)]**
Breast	117* (17.9%)	35 (30%)	41 (35%)
Colorectal	88 (13.7%)	18 (20%)	36 (41%)
Genitourinary	56 (8.7%)	11 (20%)	23 (41%)
Gynaecological	21* (3.1%)	5 (24%)	11 (52%)
Haematological	107 (16.6%)	18 (17%)	40 (37%)
Head & neck	44* (6.7%)	8 (18%)	28 (64%)
Lung	87 (13.5%)	14 (16%)	48 (55%)
Skin and melanoma	30* (4.5%)	3 (10%)	16 (53%)
Upper gastrointestinal	52* (7.9%)	6 (12%)	28 (54%)
Other (total)	47 (7.3%)	13 (28%)	21 (45%)
Other: Bone and soft tissue	5 (0.8%)	0 (0%)	3 (60%)
Other: Central nervous system	17 (2.6%)	2 (12%)	11 (65%)
Other: Endocrine and thyroid	8 (1.2%)	7 (87%)	1 (13%)

Tumour type	Total included [*n* (%)]	Participants with SCST completed [*n* (%)]	Participants with discussion in the absence of SCST [*n* (%)]
Other: Secondary – unknown primary	12 (1.9%)	4 (33%)	4 (33%)
Unknown – not reported	5 (0.8%)	0 (0%)	2 (40%)

Figure 1.24: SCST and SCD prevalence by tumour type during follow-up period



Participant distress reported during follow-up period

Twenty-nine per cent of participants (37 of 131) with an additional SCST were found to be distressed. This is significantly lower than the rate of distress reported at the time of the initial SCST (41 per cent) (OR 0.57, 95% CI 0.36–0.9, *p* = 0.01).

Of the participants reporting distress, 17 (46 per cent) had not reported distress at the initial screen. Twenty-six participants previously reporting distress did not report distress during the follow-up period.

Levels and causes of distress change over time and with changes in circumstances. A proportion of participants who did not report distress initially were found to be distressed in a follow-up screen.

Health professional identifying supportive care needs during follow-up period

During the follow-up period there was a reported increase in the proportion of staff other than nursing staff conducting SCDs in the absence of an SCST (Table 1.25). This suggests that the prevalence of SCD during the follow-up period was potentially over-reported as discussions may have been a result of previous referrals or developed relationships and not necessarily to identify new supportive care needs.

Table 1.25: Health professionals identifying supportive care needs during follow-up period

Health professional	Discussion following SCST (*n* = 114) [*n* (%)]	Discussion in absence of SCST (*n* = 287) [*n* (%)]	Odds ratio (95% CI)	*p*-value
Nursing staff	93 (81.6%)	129 (44.9%)	5.4 (3.1–9.7)	**< 0.001**
Specialist cancer nurse	14 (12.2%)	36 (12.5%)	0.98 (0.5–1.9)	0.94
Medical staff	2 (1.8%)	64 (22.3%)	0.06 (0.0–0.3)	**< 0.001**
Social worker	2 (1.8%)	23 (8.0%)	0.2 (0.0–0.9)	**< 0.02**
Other staff member	3 (2.6%)	35 (12.2%)	0.2 (0.0–0.6)	**< 0.003**

Problems identified during follow-up period by SCST or SCD

During the follow-up period, emotional problems remained statistically significantly more likely to be identified through completing an SCST. In addition, spiritual concerns were also more likely to be identified through an SCST, and there was a trend for more physical problems to be identified during an SCD (Table 1.26).

Table 1.26: Problems identified during follow-up period by SCST or SCD

Problem	Total number reporting problems *n* = 423 [*n* (%)]	SCST completed *n* = 131 [*n* (%)]	Discussion in absence of SCST *n* = 292 [*n* (%)]	Odd ratio (95% CI)	*p*-value
Emotional	115 (27%)	**54 (41%)**	61 (21%)	**2.7 (1.7–4.3)**	**< 0.001**
Family	40 (9%)	17 (13%)	23 (8%)	1.7 (0.8–3.6)	0.1
Physical	301 (71%)	85 (65%)	216 (74%)	0.7 (0.4–1.0)	0.06
Practical	87 (21%)	23 (18%)	64 (22%)	0.8 (0.4–1.3)	0.31
Spiritual	14 (3%)	**8 (6%)**	6 (2%)	**2.8 (0.9–10.6)**	**0.04**

When comparing problems identified by participants in the initial audit and the follow-up audit, participants were more likely to report the same problems in any follow-up screen. This observation was statistically significant for emotional, family and spiritual concerns (Table 1.27).

Table 1.27: Comparison of problems identified through follow-up screen with previously identified problems

Problem	Participants reporting problem in initial audit and follow-up audit [*n* (%)]	Total participants not reporting problems in initial audit [*n* (%)]	Odds ratio (95% CI)	*p*-value
Emotional	59 (69.4%)	126 (48.6%)	**2.4 (1.4–4.2)**	**< 0.001**
Family	9 (19.6%)	18 (5.9%)	**3.9 (1.4–9.8)**	**< 0.001**

Problem	Participants reporting problem in initial audit and follow-up audit [*n* (%)]	Total participants not reporting problems in initial audit [*n* (%)]	Odds ratio (95% CI)	*p*-value
Physical	154 (65.2%)	64 (56.6%)	1.4 (0.9–2.3)	0.12
Practical	28 (40.6%)	84 (30.2%)	1.6 (0.9–2.8)	0.1
Spiritual	4 (44%)	8 (2%)	**33.2 (5–182)**	**< 0.001**

Supportive care actions to address needs identified during follow-up period

Table 1.28 shows that 21 per cent of participants had at least one documented referral to address supportive care needs during the follow-up period. Of these referrals, 27 were the result of an SCST, 105 referrals resulted from an SCD and six referrals were documented for participants without a record of an SCST or SCD. A significant proportion of participants had evidence of a follow-up with a health professional already providing supportive care as a result of an SCD (38 per cent).

Table 1.28: Supportive care actions during follow-up period

Problem	Total number (*n* = 423) [*n* (%)]	Participants with documented SCST (*n* = 131) [*n* (%)]	Participants with documented SCD (*n* = 292) [*n* (%)]	Odds ratio (95% CI)	*p*-value
Any/all actions	370 (87%)	108 (82%)	**262 (90%)**	0.5 (0.3–1.0)	**0.04**
Issue addressed with a discussion	131 (31%)	61 (47%)	148 (51%)	0.85 (0.5–1.3)	0.43
Information provided	67 (16%)	16 (12%)	51 (18%)	0.66 (0.3–1.2)	0.17
Staff arranged a referral to another professional	90 (21%)	21 (16%)	69 (24%)	0.6 (0.3–1.1)	0.08
Follow-up with professional already providing care	138 (33%)	26 (22%)	**112 (38%)**	0.4 (0.3–0.7)	**0.001**
Actions declined	16 (4%)	3 (2%)	13 (4%)	0.5 (0.1–2.0)	0.311

Table 1.29 shows that participants without a previous referral were more likely to receive a referral during the follow-up period (24 per cent vs 17.4 per cent) (OR 1.5, 95% CI 1.0 – 2.3, $p = 0.03$). Referrals made during the follow-up period were more likely to address emotional or physical problems.

Table 1.29: Supportive care referrals to address problems identified during follow-up period

Problem identified	**Total referrals in initial audit (*n* = 1,003) [*n* (%)]**	**Total referrals in follow-up audit (*n* = 232) [*n* (%)]**	**Odds ratio (95% CI)**	***p*-value**
Emotional	203 (20%)	62 (27%)	1.4 (1.0–2.0)	**0.03**
Family	78 (7.8%)	17 (7.3%)	0.94 (0.5–1.6)	0.82
Physical	413 (41%)	176 (76%)	4.4 (3.2–6.3)	**< 0.001**
Practical	203 (20%)	58 (25%)	1.3 (0.9–1.9)	0.11
Spiritual concerns	24 (2.4%)	3 (1.3%)	0.5 (0.1–1.8)	0.302
No reason identified	82 (8.2%)	17 (7.3%)	0.9 (0.5–1.5)	0.668

The health professionals with the highest proportion of referrals during the follow-up period were dietitians (26 per cent), physiotherapists / exercise physiologists (16 per cent), social workers (14 per cent), palliative care workers (10 per cent) and occupational therapists (8 per cent). This corresponds to an increase in the proportion of referrals to social work and palliative care and a decrease in the proportion of referrals to specialty cancer nurses compared with the initial review.

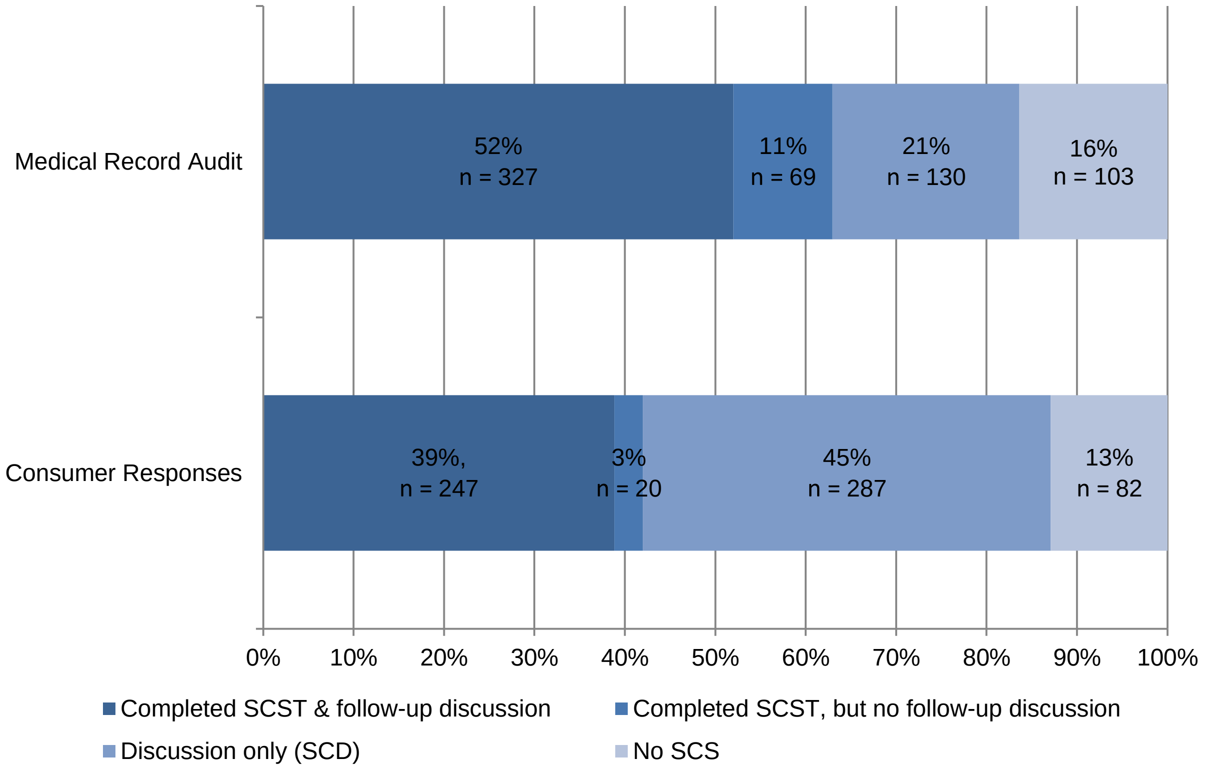
At follow-up, there were a small number of referrals to other disciplines including stomal therapy (*n* = 4), general practice (*n* = 4), diabetes education (*n* = 3), pastoral care (*n* = 2), HITH (*n* = 2), dental (*n* = 2), support groups (*n* = 1), music therapy (*n* = 1) and familial cancer services (*n* = 1).

Consumer experience of supportive care

Ninety-nine per cent of participants (*n* = 636) included in the medical record audit completed the consumer survey or interview, with 161 participants (25 per cent) completing an interview. A higher proportion of participants (66 per cent compared with 54 per cent) completing the survey had evidence of a completed SCST in their medical record (OR 1.6, 95% CI 1.1–2.3, $p = 0.008$).

From interview or survey, 42 per cent of participants (*n* = 267) reported completing an SCST, with 8 per cent (*n* = 20) reporting that they did not recall discussing their SCST responses with a health professional. Of the participants who did not recall completing an SCST, 45 per cent (*n* = 287) recalled a discussion with staff about their supportive care problems or concerns (Figure 1.25).

Figure 1.25: Comparison of participant recollection of supportive care screening compared with medical record audit documentation



Study participants were asked to identify the health professional(s) that discussed their supportive care needs with them (Table 1.30). A direct comparison with the results from the medical record audit cannot be made because participants were provided with an opportunity to identify more than one health professional involved in discussions, whereas the medical record identified a single professional who undertook supportive care screening discussion.

Table 1.30: Participant recollection of health professional involved in supportive care discussions

Health professional	**Discussion following SCST (*n* = 247) [*n* (%)]**	**Discussion in absence of SCST (*n* = 287) [*n* (%)]**	**Odds ratio (95% CI)**	***p*-value**
Nursing staff	176 (71.2%)	163 (56.8%)	1.8 (1.3–2.7)	**< 0.001**
Specialist cancer nurse	92 (37.2%)	116 (40.4%)	0.87 (0.6–1.3)	0.45
Medical staff	77 (31.1%)	109 (38.0%)	0.74 (0.5–1.1)	0.1
Social worker	59 (23.9%)	90 (31.3%)	0.7 (0.5–1.0)	**0.05**
Other staff member	6 (2%)	32 (11%)	0.2 (0.07–0.5)	**< 0.001**

Study participants were asked to identify the actions that were taken to address their supportive care needs. The results are shown in Table 1.31.

Table 1.31: Supportive care actions as reported by study participants

Action	Total number of participants (*n* = 545) [*n* (%)]	Number (%) with SCS completed [*n* (%)]	Number (%) in absence of SCS [*n* (%)]	Odds ratio (95% CI)	*p*-value
Any/all actions	529 (97%)	285 (96.4%)	244 (99.3%)	0.19	–
Issue addressed with a discussion alone	182 (33.4%)	101 (39.9%)	81 (28.2%)	**1.7** (1.2–2.5)	**0.004**
Information provided (total)	270 (50%)	131 (49.1%)	139 (51.6%)	0.9 (0.64–1.2)	0.56
Information provided about organisation	232 (42.6%)	106 (42%)	126 (44%)	0.92 (0.64–1.3)	0.64
Information provided about professional person	183 (33.6%)	92 (36.4%)	91 (31.7%)	1.2 (0.85–1.8)	0.25
Staff arranged a referral to another professional	164 (30.1%)	84 (33.2%)	80 (27.9%)	1.3 (0.9–1.9)	0.18
No actions	11 (2%)	9 (0%)	2 (0%)	–	–

Participant-reported actions were compared with the actions identified in the medical record audit. Statistically significant differences were observed, with participants reporting more actions overall and more information provision, whereas the medical record audit identified more documented SCDs and referrals to health professionals (Figure 1.26).

Figure 1.26: Comparison of supportive care actions as reported by participants and identified by the medical record audit

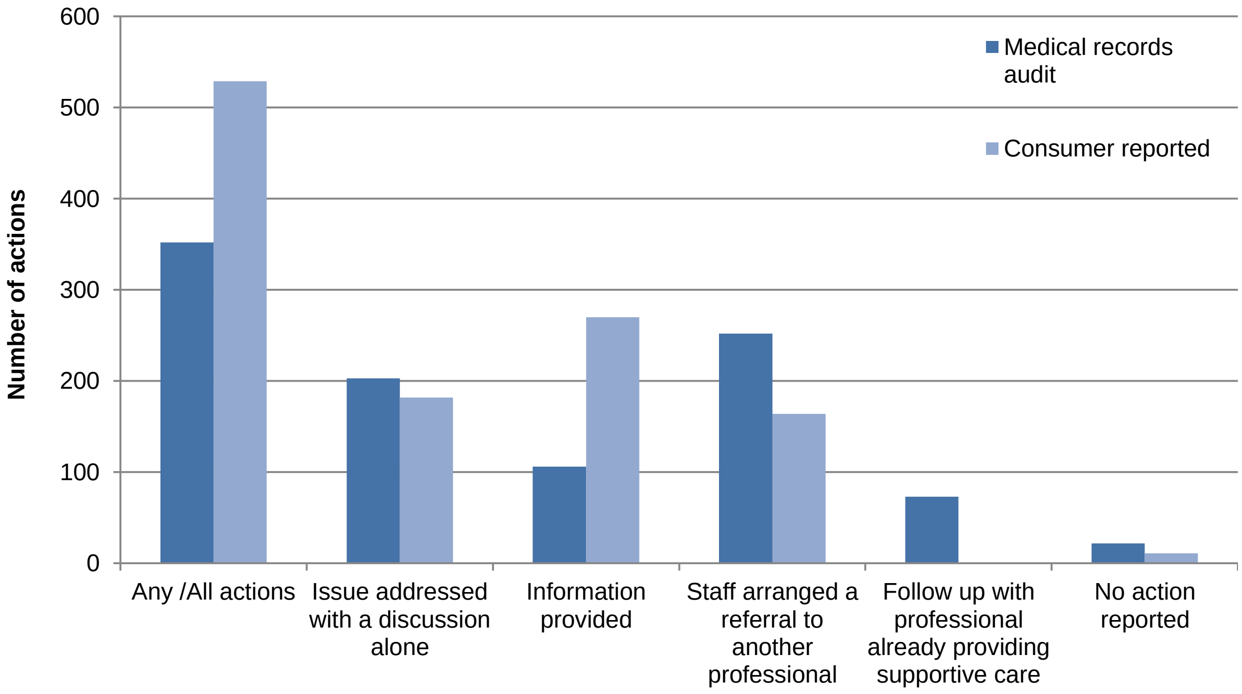


Table 1.32 shows that participants recalled more total actions than those identified through the medical records audit, with 97 per cent of participants recalling a supportive care action compared with evidence of a supportive care action in the medical record for 65 per cent of participants. Participants were more likely to report being provided with information, and the medical records audit identified a higher proportion of participants receiving a referral to address a supportive care need.

Table 1.32: Comparison of supportive care actions as reported by participants and identified by medical record audit

Action taken	**From medical record audit (*n* = 538)** **[*n* (%)]**	**From participant response (*n* = 545)** **[*n* (%)]**	**Odds ratio** **(95% CI)**	***p*-value**
Any/all actions	352 (65.4%)	529 (97.1%)	0.64 (0.5–0.8)	**< 0.001**
Issue addressed with a discussion	203 (37.7%)	182 (33.4%)	1.3 (1.1–1.7)	**0.008**
Information provided	106 (19.7%)	270 (49.5%)	0.4 (0.3–0.5)	**< 0.001**
Staff arranged a referral to another professional	252 (46.8%)	164 (30.1%)	2.0 (1.6–2.5)	**< 0.001**
Follow-up with professional already providing care	73 (13.6%)	–	–	–
No actions	22 (4.1%)	11 (2%)	2.3 (1.1–5.3)	**0.02**

Study participants were asked to identify if the supportive care activity that they received was helpful. Of the participants who responded to this question, Table 1.33 shows that 97 per cent or more felt that the actions they received were helpful.

Table 1.33: Proportion of participants reporting that the supportive care action received was helpful

Supportive care action	Number of responses	Proportion reporting helpful (%)
Issue addressed with a discussion	118	97
Written information provided	106	98
Information provided about an organisation	199	97
Information provided about a professional person	166	99
Staff arranged a referral to another professional	157	98

Participants reporting attendance at a supportive care referral

Overall, 68 per cent (189/278) of study participants reported attending an appointment following a supportive care referral. This is compared with evidence of uptake of 84 per cent of total referrals identified by the medical record audit. A direct comparison cannot be made because a proportion of participants received more than one referral.

Seventy-three per cent of study participants (132/181) reported attendance at a supportive care referral resulting from an SCST. This is compared with 66 per cent (43/65) of study participants who reported attendance at a referral resulting from an SCD and 52 per cent of study participants (14/27) who reported attendance at a referral but no identified SCD or SCST. There is a trend towards increased odds of participants reporting attendance at a referral resulting from an SCST compared with an SCD (OR 1.4, 95% CI 0.9–2.3, $p = 0.122$).

Participants who did not attend their referral were asked to provide reasons why they did not attend. The greatest proportion of participants indicated that they no longer required the referral ($n = 18$) or that they planned to arrange an appointment later ($n = 16$). Other reasons provided for non-attendance were waiting for appointment ($n = 8$), too unwell ($n = 6$), arranged an appointment with another provider ($n = 3$), too far to travel ($n = 3$) and too busy ($n = 2$).

Participants seeking information to address supportive care needs

A total of 250 study participants reported accessing information or support independently from a variety of sources to address their supportive care needs. The majority of participants accessed information from more than one source:

- 32 per cent ($n = 70$) contacted or accessed information from Cancer Council Victoria
- 30 per cent ($n = 64$) reported a general internet search
- 19 per cent ($n = 41$) sought information from their general practitioner
- 19 per cent ($n = 41$) used other support organisations (including Bowel Cancer Australia, Breast Cancer Network Australia, Leukaemia Foundation, Look Good Feel Good)

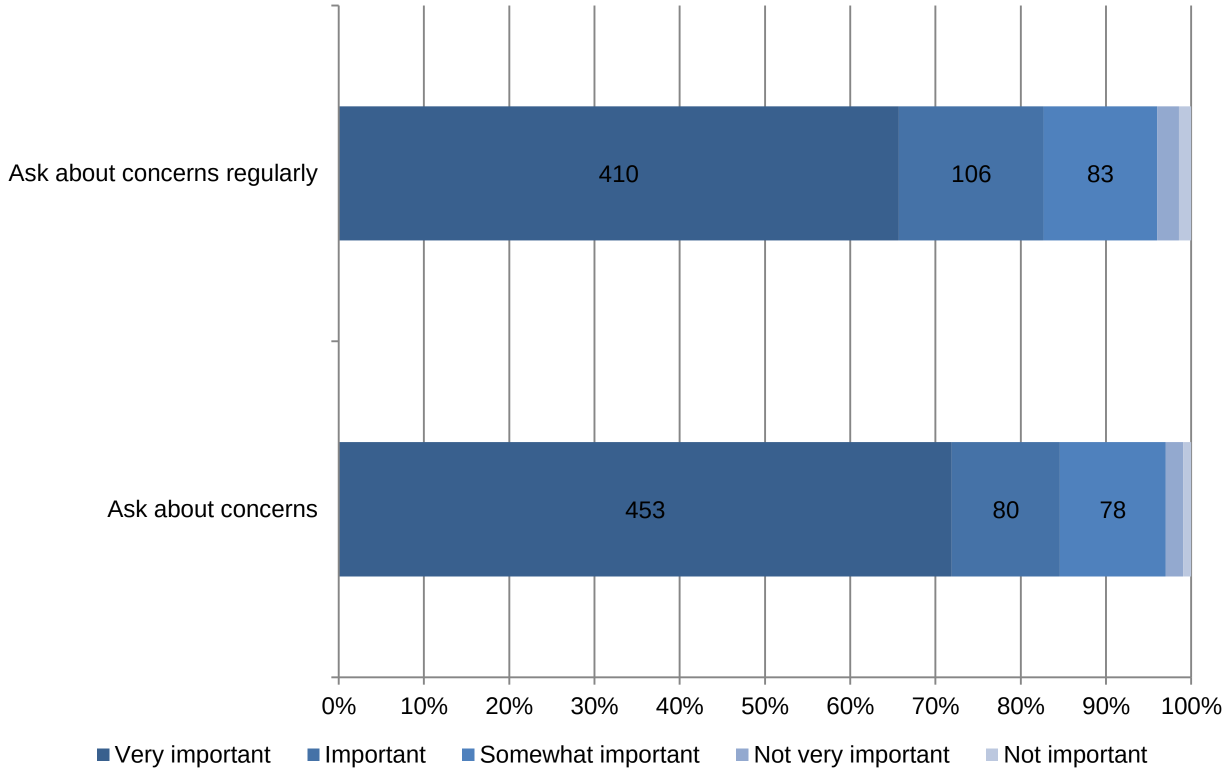
- 13 per cent (*n* = 27) identified family or friends as the provider of information, including about previous cancer experiences or gathering and sharing information
- 7 per cent (*n* = 16) reported that they sought referrals to other health professionals
- 6 per cent (*n* = 13) found written information within hospitals (not specifically provided by health professionals) such as the Wellness Centre library
- 4 per cent (*n* = 8) reported using online support forums.

38 per cent of all participants reported accessing information or support independently to address their supportive care needs.

Participant opinions on supportive care screening

Study participants were asked how important it is to them that clinicians ask about their supportive care concerns, and ask about them regularly (Figure 1.27).

Figure 1.27: Participant rating of importance of clinician-initiated discussions of supportive care concerns



More than 80 per cent of study participants felt that it was important that clinicians initiate discussions about their supportive care concerns.

When asked further about this, comments received from study participants included:

> ‘Makes you feel people are interested and care.’
>
> ‘Cancer was not something that I expected to go through, so it was important to be asked; it’s a shock.’
>
> ‘On a bad day it’s important, but on a good day it’s not.’
>
> ‘Regularly is better. At times patients can be quite stoic; more prompts can reveal more required support.’

> ‘It will prompt you to tell them; people don’t like to feel they’re a burden. It’s nice to be asked.’
>
> ‘Things can change. I have ordinary weeks.’
>
> ‘My needs change on a day-to-day basis. Needs ongoing assessment.’

Participant comments about their supportive care experience

Study participants were provided with an opportunity to provide any other comments regarding their supportive care experiences. Of 634 participants, 310 (49 per cent) provided an overall comment about their experience of having their supportive care needs identified and addressed. The majority of comments (*n* = 208, 67 per cent) were positive comments about the staff, both professionally and personally, as a source of support and care. Comments in relation to this included:

> ‘I think the wonderful caring during treatment by 90 per cent of staff is so supportive on its own.’
>
> ‘Appreciate staff touching base about how things are going … Feel that progress has been made in consolidating patient care and how people are coping.’
>
> ‘It’s important psychologically, I am proactive but it’s nice that they ask because they care.’
>
> ‘Have a good team of nursing staff that I can easily ask questions of.’

Thirty participants commented that improvements could be made in addressing supportive care needs. Comments in relation to this included:

> ‘Don’t know what services to ask for, as not made aware of what is available. Difficult to ask staff as often different people so no relationship with them. Don’t want to ask.’
>
> ‘I was surprised that I had to seek out support.’
>
> ‘Someone on the team should have responsibility to engage, capture impact and address issues.’
>
> ‘From first being diagnosed, no information, contacts, groups etc. were offered. Felt abandoned. Wasn’t given any information until starting treatment.’
>
> ‘Would be good to have a hospital follow-up – a support person to call with queries.’
>
> ‘It would be useful to deal with a single person to coordinate supportive care, rather than dealing with a different person each time on each admission.’

While participants were not specifically asked about the timing of supportive care screening, 12 participants provided comment on this including:

> ‘Can’t really recall, sometimes so much information all at once [at diagnosis] can be overwhelming.’
>
> ‘The form was given to me on my first day of treatment. I think this is too early.’
>
> ‘You don’t know what you need as soon as diagnosis occurs.’
>
> ‘Things surface at different times and if you say you’re OK one day, you might not be the next.’
>
> ‘Concerns change over the treatment period – need to know where to go for help when needed.’
>
> ‘Was offered but didn’t need it at the time. Sometimes too much information at the start, too much to take in.’

Part 2: Organisational audit

Each of the 21 participating health services was asked to provide information on current policy, guidelines and governance practices relating to supportive care screening before the study period began.

Supportive care screening policy

Site auditors provided responses to the question, *Does a formal supportive care screening in cancer policy (procedure or guideline) exist for the health service?* Table 2.1 shows that 10 of the 21 health services indicated that there was a formal supportive care screening policy in place. In most cases it was confirmed that the policy is accessible on the local intranet or other e-filing system. In all cases where a policy exists, the policies have been reviewed and updated within the past three years.

There was no significant difference in the prevalence of an SCST based on the availability of a supportive care policy.

Table 2.1 Presence of supportive care screening policy by health service variable

Variable	Detailed variable	Number of participating health services, *n* = 21 [*n* (%)]	Number of health services with formal policy [*n* (%)]
Hospital cancer volume (cancer separations/year)	≥ 10,000	6 (29%)	3 (50%)
	10,000–5,000	6 (29%)	2 (33%)
	< 5,000	9 (43%)	5 (55%)
Hospital location	Metropolitan	9 (43%)	3 (33%)
	Regional/rural	12 (57%)	7 (58%)
Public/private	Public	18 (86%)	9 (50%)
	Private	3 (14%)	1 (33%)

Supportive care screening tools

Site auditors were asked to identify the supportive care screening tools currently used in cancer care at their health service. Nineteen of the 21 health services (90 per cent) use the NCCN Distress Thermometer or a modified version of the tool for supportive care screening. One health service uses an internally developed, validated tool to identify needs across supportive care domains. One of the participating health services indicated that they do not have an SCST currently in use. Screening tools that are used by the participating health services in addition to the NCCN tool include FACT B, the Kessler Psychological Distress Scale, Prostate Cancer Distress Screen and the Malnutrition Screening Tool.

Performance indicators and targets for supportive care screening

The Victorian Cancer Service Performance Indicator (CSPI) program is in place to monitor the progress of government cancer reform policy implementation. One of the indicators of the CSPI measures the level of documented supportive care screening using a validated screening tool. The annual audits are completed by the ICS on a selected sample of patients from participating health services.

Four of the 21 health services conduct regular (monthly, quarterly or semi-annual) internal auditing in addition to the CSPI. To date, the target screening rate for Victoria through the CSPI has been 50 per cent, with some health services setting internal targets of up to 100 per cent.

Supportive care referral practices

Site auditors were asked to identify any situations in which blanket referrals are made for patients in their health service. Eight of the participating health services reported that blanket referrals were made for patients in certain circumstances. The list in Table 2.2 may not be exhaustive because it was dependent on the awareness and access of each site auditor to internal policies. The reported list of blanket referrals was collected for the purpose of cross-referencing with the documented referrals for each study participant and at each health service and to explain patterns of care.

Table 2.2 Blanket referrals in place to address supportive care needs within each health service

Site	Blanket referrals to address supportive care needs
M5	Dietitian referral for all patients with bone marrow transplant, oesophagogastric cancer, head & neck cancer and upper gastrointestinal cancer Social work referral for all patients under 50 years of age, diagnosis of acute myeloid leukaemia and acute lymphoblastic leukaemia, and stem cell transplant
M6	Psychology referral for all patients attending the breast clinic
R1	Leukaemia Foundation nurse referral for all haematology patients
R5	Physiotherapy referral for breast cancer patients undergoing surgery
R6	Cancer liaison nurse referral for all new diagnoses
R7	Dietitian referral for all head & neck, upper gastrointestinal and lung cancer patients
R10	Dietitian referral for all head & neck, upper gastrointestinal and colorectal cancer patients
R12	Physiotherapy referral for all inpatients

Part 3: Clinician survey

Description of respondents

Clinicians from a range of disciplines involved in cancer care at each of the participating health services voluntarily completed a census survey on their opinions, knowledge and practice of supportive care screening. Anonymous responses were received from 167 clinicians. The total number of clinicians involved in cancer care at each hospital during the survey period is unknown.

Table 3.1 shows that regional and rural clinicians made up the greatest proportion of respondents (53 per cent), while the remainder of respondents were based at metropolitan health services (47 per cent).

Table 3.1 Number of respondents to clinician survey by health service

Site	Number of respondents (proportion of total)
M1	18 (11%)
M2	1 (0.6%)
M3	11 (6.6%)
M4	15 (9%)
M5	3 (1.8%)
M6	1 (0.6%)

Site	Number of respondents (proportion of total)
M7	2 (1.2%)
M8	15 (9%)
M9	13 (7.8%)
R1	12 (7.2%)
R2	8 (4.8%)
R3	10 (6%)
R4	15 (9%)
R5	3 (1.8%)
R6	6 (3.6%)
R7	10 (6%)
R8	10 (6%)
R9	0 (0%)
R10	1 (0.6%)
R11	1 (0.6%)
R12	12 (7.2%)

The greatest proportion of respondents were nurses (*n* = 87, 52 per cent) (including registered nurses, care coordinators and specialist nurses), followed by allied health practitioners (*n* = 60, 36 per cent) (including dietitians, occupational therapists, speech therapists and social workers) and medical practitioners (*n* = 20, 12 per cent) (including medical oncologists, surgeons, physicians and general practitioners).

Thirty-four per cent of respondents indicated that they had less than five years of experience in cancer care, 24 per cent indicated that they had between five and 10 years of experience, and 42 per cent indicated that they had more than 10 years of experience.

Supportive care screening knowledge

Multidisciplinary clinicians were asked to rate their awareness of local policies and procedures in place for supportive care screening in their health service (Table 3.2). Eighty per cent of respondents provided a response to this question.

Table 3.2 Health professional awareness of supportive care policies and guidelines (*n* = 133)

Very poor	Lacking	Adequate	Very good
11 (8%)	40 (30%)	54 (42%)	27 (20%)

Seventy-two per cent of respondents stated that they were aware of the NCCN Distress Thermometer and Problem List in particular, while only 47 per cent of respondents indicated that they use it in practice.

Overall, 74 per cent of respondents indicated that they had ‘adequate’ or ‘very good’ knowledge of supportive care screening (Table 3.3). Fifty-three per cent of nursing staff indicated that their knowledge was ‘very good’ compared with 23 per cent of allied health respondents and 15 per cent of medical respondents.

Table 3.3 Knowledge of supportive care screening by clinical profession

Profession	Very poor	Lacking	Adequate	Very good
Nursing (*n* = 87)	1 (1%)	13 (15%)	27 (31%)	46 (53%)
Allied health (*n* = 60)	6 (10%)	17 (28%)	23 (38%)	14 (23%)
Medical practitioner (*n* = 20)	1 (5%)	5 (25%)	11 (55%)	3 (15%)
Overall (*n* = 167)	8 (5%)	35 (21%)	61 (36%)	63 (38%)

Supportive care screening opinions and practices

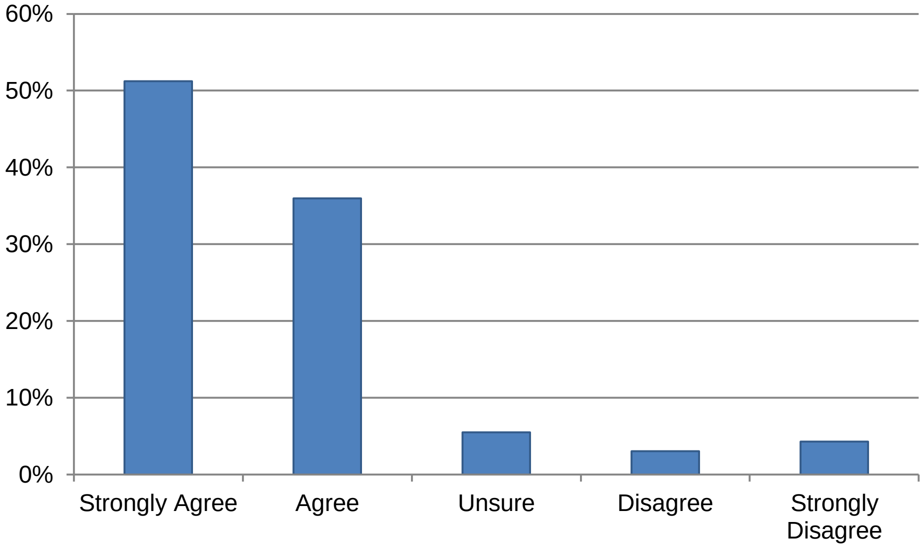
Respondents who do not routinely provide supportive care screening (*n* = 69) were further asked to identify the reasons for not undertaking screening. The reasons were listed as ‘Do not have the appropriate skills’ (*n* = 12, 17 per cent), ‘Do not have the time to undertake assessment’ (*n* = 10, 14 per cent), ‘It is not part of my job’ (*n* = 40, 58 per cent) and ‘Unaware of screening tool’ (*n* = 7, 10 per cent). The responses are further broken down by health professional in the Table 3.4.

Table 3.4 Reasons provided for not conducting supportive care screening by clinical profession

Profession	Proportion of respondents that DO NOT undertake screening	Reason for not screening: Do not have appropriate skills	Reason for not screening: Do not have time to assess	Reason for not screening: Not part of my job/refer to other clinician to complete	Reason for not screening: Unaware of screening tool
Nursing (*n* = 87)	18%	12.5%	12.5%	68.75%	0%
Allied health (*n* = 60)	67%	17.5%	12.5%	52.5%	17.5%
Medical practitioner (*n* = 20)	65%	15%	23%	61.5%	0%

There was strong agreement among clinicians (*n* = 143, 87 per cent) with the statement ‘All patients should have repeated supportive care screening at regular intervals during their cancer journey’.

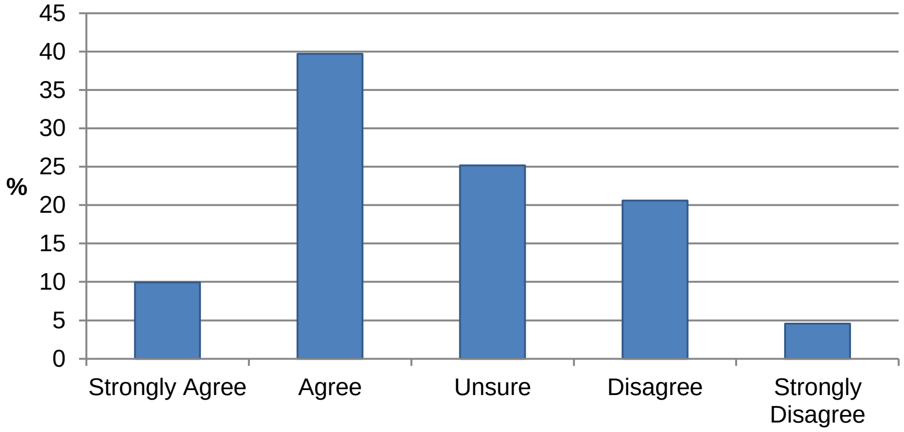
Figure 3.1: Agreement with the statement 'All patients should have repeated supportive care screening at regular intervals during their cancer journey' (*n* = 164)



Ninety-one per cent of respondents (*n* = 150) 'agreed' or 'strongly agreed' with the statement 'All patients should be screened for supportive care needs at diagnosis and 82 per cent of respondents' (*n* = 136) 'agreed' or 'strongly agreed' with the statement 'All patients should be screened for supportive care needs at admission'. Seventy-seven per cent of respondents (*n* = 126) agreed that 'All patients should have supportive care screening at discharge'.

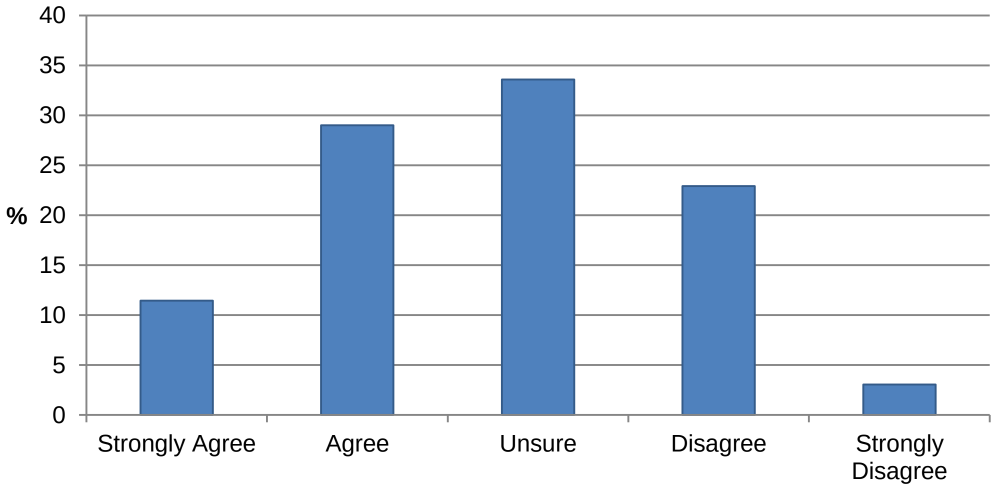
Nearly 50 per cent of respondents (*n* = 65) agreed or strongly agreed that supportive care needs are routinely discussed in ward rounds and team meetings at their health service (Figure 3.2).

Figure 3.2: Agreement with the statement 'In my health service, supportive care needs are routinely discussed for all patients in ward rounds and team meetings'



Forty-two per cent (*n* = 53) of respondents agreed or strongly agreed that patients with supportive care needs in their health service are referred to an appropriate service in a timely manner (Figure 3.3). Notably, 34 per cent of respondents (*n* = 44) were unsure about how the statement applies to their health service. Health services with a high rate of referral (more than 80 per cent of participants receiving a referral) to address supportive care needs (M3, M9, R7 and R11, see Figure 1.13) had a slightly lower percentage agreement with the statement.

Figure 3.3: Agreement with statement 'Patients with supportive care needs at my health service are referred to an appropriate service in a timely manner'



Barriers and enablers for supportive care screening

Respondents were asked to describe barriers to providing a supportive care screen to patients and to identify possible ways to address the barriers. A total of 115 respondents identified one or more barrier(s). The most common barriers were (i) time to administer and review a supportive care screen, (ii) knowledge and experience of supportive care screening, (iii) organisational support for implementing supportive care screening and addressing supportive care needs, and (iv) availability of supportive care services. These barriers are consistent with those identified in other studies that identified barriers to clinical implementation of supportive care screening (Ristevski et al. 2011). Suggestions made by respondents on how to address the barriers are detailed in Table 3.5.

Table 3.5: Barriers to supportive care screening and suggestions on how to address the barriers as identified by clinician respondents

Barriers to supportive care screening of respondents	Suggestions made by clinician respondents on how to address barriers
Time (76%)	Process improvement Dedicated personnel to provide screen and follow-up
Knowledge (46%)	Education on importance of screen Training in supportive care communication methods
Organisational support (20%)	Policies and procedures to integrate into routine care Availability of interpreters/tool in other languages/electronic tool Promotion of screening tool Private space to complete screening and assessment
Availability of supportive care services (11%)	Information on referral pathway for identified problems Information on community services available

The most commonly identified barriers to administering a supportive care screen include time to administer and review the screen, and lack of knowledge and experience in supportive care screening.

Discussion

This comprehensive study reports on the prevalence and outcomes of supportive care screening in an adult cancer population across multiple treatment settings, tumour types and stages of disease. Supportive care screening is an important mechanism to open up channels of communication between patients and clinicians and to focus discussion and interventions on current and relevant issues (McDowell et al. 2010; Richardson et al. 2007). Through the process of screening, health professionals are able to identify and prioritise the supportive care needs of their patients and initiate appropriate interventions to address these needs (Department of Health 2009). Supportive care interventions are aimed at helping the patient cope with what is happening and maintaining that person's quality of life (Fitch 1994).

Supportive care screening prevalence

The overall prevalence of documented supportive care screening using a validated screening tool in the study population was 63 per cent. The screening rate varied across the participating health services and settings; the prevalence was higher at regional health services (78.1 per cent) compared with metropolitan health services (48 per cent) and higher at private health services (84.1 per cent) than public health services (61 per cent). Supportive care screening with a validated tool was half as likely to occur in inpatients (32.7 per cent) compared with ambulatory chemotherapy (69.8 per cent) and radiotherapy patients (67.9 per cent). When analysed by tumour type, the prevalence of documented supportive care screening was highest for participants with breast cancer (76 per cent), colorectal cancer (73 per cent) and genitourinary malignancies (73 per cent). The prevalence of supportive care screening was lowest for participants with head & neck tumours (40 per cent) and haematological malignancies (39 per cent).

A further 21 per cent of study participants had documented evidence of a supportive care needs discussion with a health practitioner in the absence of a screen. For the purposes of this study, a Supportive Care Discussion was defined as a documented discussion with a health professional regarding the patient's supportive care needs relating to physical, practical, family, emotional or spiritual/religious concerns but not necessarily a comprehensive assessment of individual needs. It was observed that a large proportion of discussions documented in the medical record were in relation to an intervention to address a concern. This suggests that discussions in the absence of a screening tool were likely to be part of routine nursing care rather than a discrete supportive care assessment.

In this study, a supportive care screening tool was more likely to identify emotional and physical problems compared with a discussion. Previous studies have reported that patients who participate in a formal screening, discussion and referral process experience improved communication with their clinician, whereas formal screening encourages issues to be addressed that may otherwise be overlooked (Jones et al. 2011). Other studies have shown that in the absence of a supportive care screen, clinicians are inadequately aware of their patient's physical and psychosocial problems and that, in many cases, emotional distress is not recognised by the healthcare team until the patient reaches an observable crisis event (Fallowfield et al. 2001; Newell et al. 1998).

In this study, 41 per cent of study participants with a documented supportive care screening tool were reported to be distressed with a Distress Thermometer score of four or more. The majority of support issues causing distress for screened participants related to emotional and physical needs, whereas a discussion in the absence of a tool was more likely to identify family and practical issues. In a recent study of the supportive care needs of advanced cancer patients, the most prominent unmet need was emotional support (Wang et al. 2018). This is consistent with other studies that report a reluctance of both patients and clinicians to initiate discussions about supportive care needs and that patients are less likely to raise emotional and practical issues with their clinician unless specifically asked about it (Detmar et al. 2000). In addition to this, clinicians have reported a fear that they will upset their patient or lack the confidence to deal with non-physical supportive care needs (Güner et al. 2018; Maguire et al. 1996; Snyder et al. 2007).

Supportive care interventions

The tiered approach to supportive care defined by Fitch (2008) describes that, for some patients, the opportunity to raise and discuss a supportive care issue during a consultation may adequately address an issue; others may require verbal advice, written information or contact details for a service or support group, and some may require a referral to a supportive care practitioner. Appropriate action and referral must be matched to the identified supportive care needs of the patient.

In this study, 58 per cent of all participants with evidence of a completed supportive care screen also had evidence of a supportive care intervention to address an identified issue. In the absence of a supportive care screen, 90 per cent of participants with evidence of an SCD had evidence of a supportive care intervention. It is possible that evidence of a supportive care intervention in a participant's medical record may have signalled to the site auditor that a discussion occurred, while discussions that did not have an associated intervention may not have been recorded in the medical record, potentially inflating the rate of intervention in the absence of a screen. Through interview and survey, participants reported receiving more interventions than what was identified through the medical record audit.

A referral to another health professional for supportive care services was the most documented intervention, followed by discussion and provision of information. Through interviews and a survey, participants identified that they were provided with more information than was documented, while the medical records audit identified a higher proportion of participants who were provided with a referral to address a supportive care need. Sixty-two per cent of screened study participants had at least one referral recorded, while 64 per cent of study participants with evidence of an SCD had at least one referral recorded. The highest rate of referral was for inpatients; this group also had the lowest documented screening rate.

Referrals to social work (24 per cent) and dietetic services (22 per cent) were the most common referrals made to address supportive care needs, followed by referrals to a physiotherapist/exercise physiologist and specialist cancer nurses (11 per cent each). Referrals to social workers were proportionately greater for participants with genitourinary malignancies, breast and lung cancers. Referrals for dietetic services were proportionately greater for participants with skin cancer or melanoma, upper gastrointestinal cancers, head & neck cancers and colorectal cancers. Participants with breast cancer received the highest proportion of referrals to a specialist cancer nurse.

There was evidence of uptake of referral for 84 per cent of participants; a lower rate of uptake was documented for referrals that originated from a supportive care screen (81 per cent) compared with a discussion (91 per cent). Inpatients had a higher documented rate of uptake (95 per cent) compared with ambulatory patients (80 per cent). Documented uptake was highest for referrals at the current hospital (87 per cent) compared with external services (60 per cent); however, documented evidence may not be as readily available for external services.

Ninety per cent of documented referrals in the study were made to services within the patient's current treating hospital. Previous studies suggest that clear referral pathways and an organisational emphasis on supportive care may facilitate service use (Skaczkowski et al. 2018). Referrals to community-based services rather than services within the treatment centre may be preferred by some patients (Department of Health 2009).

Administration of supportive care screening

Best practice clinical care recommends that individuals receive ongoing supportive care screening and assessment (Fitch 2008). It is recommended that this occurs at various stages of the cancer journey including following diagnosis (such as at the initial visit), prior to each new phase of treatment (such as surgery, chemotherapy, radiotherapy), at appropriate intervals during treatment (such as significant changes in symptoms, personal circumstances, treatment plan, prognosis), at the conclusion of active treatment, during follow-up, at recurrence and during palliative care as the needs of patients change over time and with changes in circumstances (National Comprehensive Cancer Network 2017).

Nearly 60 per cent of study participants with documented supportive care screening completed the screen before their first treatment appointment. Only 21 per cent of participants were formally screened for their supportive care needs on more than one occasion. Notably, at one health service, 76 per cent of participants had evidence of a follow-up screen.

The overall rate of distress was significantly lower for participants in a follow-up screen; however, nearly 50 per cent of participants who were identified as distressed in a follow-up screen had not been identified as being distressed previously, highlighting the importance of administering a repeat screen. In repeated screening, emotional and physical problems remained most likely to be identified.

Supportive care screening using a validated tool is only the first step in the comprehensive process of providing supportive care to patients. The screen should be accompanied by a discussion with the patient to clarify identified problems and to make an initial assessment regarding any supportive care actions to address the patient’s needs (Department of Health 2009). Seventeen per cent of study participants with documented evidence of a supportive care screen did not have documented evidence of a discussion or assessment of their needs as identified by the screen. In these cases, it is possible that, in some cases, a discussion did occur but was not documented or that follow-up was not required because the patient did not identify any problems; however, one-third of this group had been identified as distressed, with a score of 4 or more on the Distress Thermometer. Notably, two regional health services (R3 and R6) reported screening follow-up rates that were significantly lower than all other sites. Overall, the results of follow-up discussions are consistent with a previous study of six health services in regional Victoria that reported a rate of 84 per cent of supportive care needs discussed across all domains, with discussion occurring less for patient needs in the family and emotional domain (Regan et al. 2012).

Supportive care screens were most commonly administered by nursing staff (78 per cent). Nursing staff were also responsible for recording the greatest proportion of SCDs in the absence of a screening tool (45 per cent). Nursing staff are uniquely placed to provide supportive care screening; however, all members of the multidisciplinary team have a role in providing supportive care (Fitch 2008).

Patient experience of supportive care

Good communication between a patient and heath professional regarding supportive care needs improves the patient experience and contributes to improved emotional and physical outcomes (Boyes et al. 2006). Furthermore, screening has been found to enhance patient satisfaction with care and to encourage greater involvement in the care process (Ristevski et al. 2013). More than 80 per cent of participants in this study commented that they felt it was very important or important that clinicians initiate discussions about their supportive care concerns. Other studies have shown that patients value communication with clinicians that comprehensively addresses wider supportive care issues rather than concentrating only on the physical (Jones et al. 2011). In this study, 97 per cent of participants felt the supportive care interventions they received were helpful, increasing their satisfaction with their care.

Patients who perceive that their clinician has provided them with support for emotional and informational issues report better adjustment and health-related quality of life (McDowell et al. 2010). In this study, many participants provided a positive comment about a relationship with a specific clinician or group of clinicians that was supportive. Other participants commented that the availability of a contact or support person at the health service would have improved their experience of having their supportive care needs addressed.

The timing of supportive care screening was another issue raised by participants who commented that their experience and needs change over time and that a supportive care screen that was administered close to diagnosis would not be relevant at a later time. Unmet supportive care needs persist and develop after a cancer diagnosis (McDowell et al. 2010), further highlighting the importance of regular screening and communication.

Thirty-nine per cent of study participants reported accessing information or support independently to address their supportive care needs, highlighting the importance of enabling consumers to ask for and seek out supportive care through advancing their knowledge and awareness of supportive care information and resources. The supportive care process has been shown to encourage patients to seek support when needed and to be active participants in their care (Jones et al. 2011).

Capacity building for optimal supportive care

Ten of the 21 participating health services have a current supportive care screening policy in place; however, very few sites have a local program of monitoring for key performance indicators relating to supportive care. Clinicians across all participating health services reported a low awareness of supportive care policies and guidelines; however, they also reported a high awareness of supportive care screening, with 74 per cent of those surveyed indicating that they had an adequate or very good knowledge of screening and that they routinely undertake supportive care screening of oncology patients.

There was strong agreement among surveyed clinicians that patients should have repeated supportive care screening at regular intervals during their cancer pathway. Less than 50 per cent of clinicians surveyed agreed or strongly agreed that patients with supportive care needs in their health service were referred to an appropriate service in a timely manner.

Clinicians acknowledge that the most significant barriers to administering a supportive care screen include time to administer and review the screen, and lack of knowledge and experience in supportive care screening. Other barriers include inadequate organisational support and a perceived lack of supportive care services to which to refer patients in need.

The organisational audit and clinician survey identified key opportunities to build capacity for optimal supportive care by refreshing workforce skills and competency in supportive care approaches:

- improve awareness among health professionals of the value and importance of supportive care screening and assessment
- improve awareness of supportive care services available to patients at the health service and in the community
- build supportive care screening skills and communication competencies among clinicians
- integrate policies and procedures to reinforce supportive care as a key component of care.

Glossary

Adult cancer patient

For the purpose of this study, a person diagnosed with cancer, aged 18 or older.

Allied health professionals

Autonomous practitioners who work collaboratively as part of effective teams alongside doctors, nurses and midwives and other professionals to provide holistic person-centred care. Allied health professionals are qualified to support and enable diagnosis of health conditions and to provide interventions to maintain and optimise the physical, social and mental wellbeing of the community.

Ambulatory patients

For the purpose of this study, ambulatory patients are those who attend hospital for a single day at a time without requiring an overnight stay. This may include patients who are admitted as ‘day only’ for specific treatments or procedures or those attending for outpatient appointments or treatments. Alternatively referred to as ‘outpatients’.

Cancer staging

Staging describes the extent or severity of an individual’s cancer based on the extent of the primary (original) tumour and the extent of spread in the body.

Clinician

Refers to a healthcare professional who works as a primary caregiver of a patient (for example, doctor, nurse, physiotherapist, clinical pharmacist, dietitian).

Health services

Refers to the public and private hospital organisations that formed the membership of this statewide study.

Inpatient

For the purpose of this study, inpatients are those requiring an admission to hospital for more than one day, which includes at least one overnight stay.

Palliative care

Care that improves the quality of life of patients and their families facing the problems associated with life-threatening or life-limiting illness through preventing and relieving suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.

Participating sites

Refers to the relevant campus/site of each participating health service.

Prevalence

A measure of the proportion of people in the population who have a specific characteristic at any point during a given time period of interest.

Site auditor

Nursing staff, allied health clinicians or quality consultants employed by the participating health service to conduct site-specific ethics assessment, medical record audit and patient surveys and interviews.

Supportive care

Services that may be required by those affected by cancer. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care. Within this definition, supportive care in cancer covers the following five inter-related domains of care: physical needs, psychological needs, social needs, information needs and spiritual needs.

Supportive care discussion

Documented evidence of a discussion with a health professional to identify the patient's supportive care needs relating to physical, practical, family, emotional or spiritual/religious concerns.

Supportive care screen

The administration of a validated test or process to identify current supportive care needs in those affected by cancer. The use of a validated screening tool must be integrated within the context of a clinical discussion.

Specialist cancer nurses

Cancer nurses who specialise in the care of particular populations of people with cancer. The role of specialist cancer nurses is to coordinate care, to provide information and psychological support and to refer to services. Examples include prostate cancer specialist nurses, breast care nurses and cancer care liaison support nurses.

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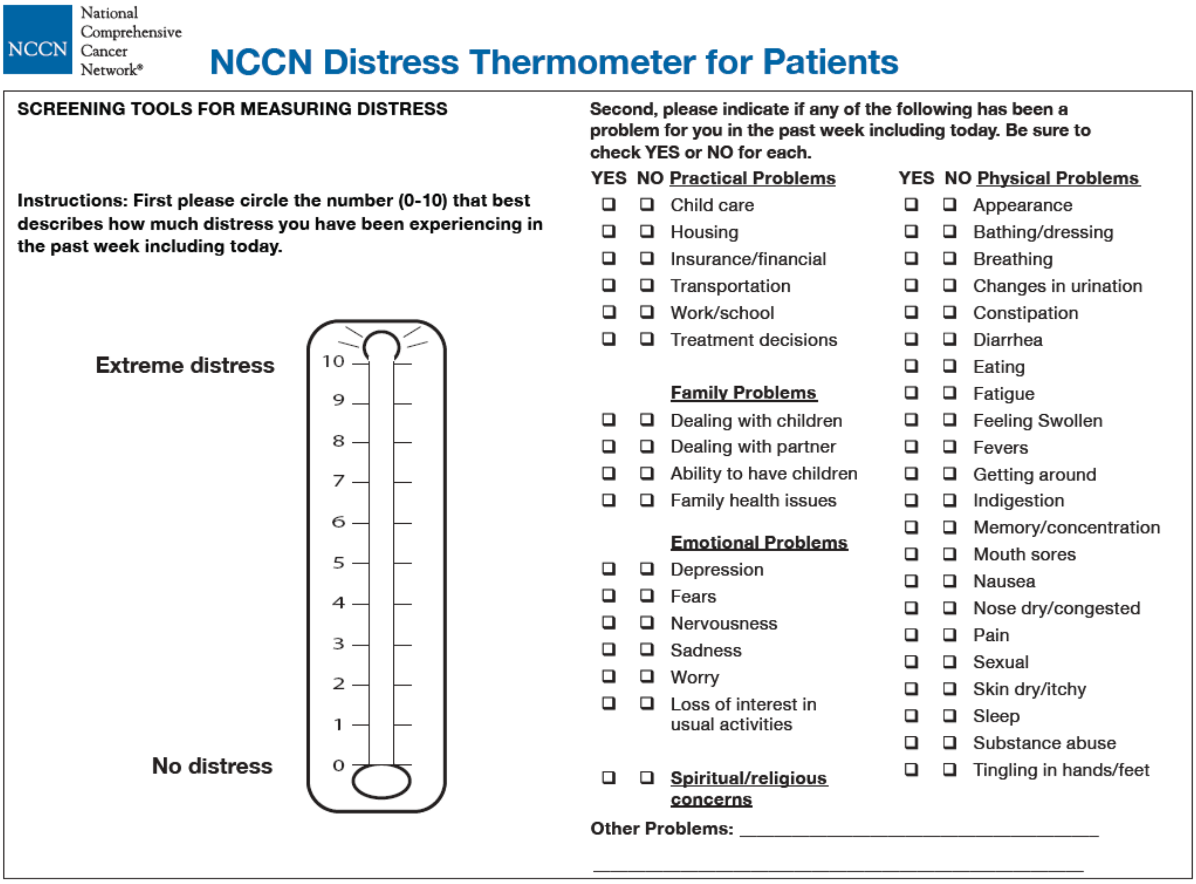
Appendix 1 – NCCN Distress thermometer for patients



National Comprehensive Cancer Network®

NCCN Distress Thermometer for Patients

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
☐	☐	Child care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school
☐	☐	Treatment decisions
		Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Ability to have children
☐	☐	Family health issues
		Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities
☐	☐	**Spiritual/religious concerns**

YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling Swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry/itchy
☐	☐	Sleep
☐	☐	Substance abuse
☐	☐	Tingling in hands/feet

Other Problems: ____

____

Appendix 2 – Organisational audit

1. Name of health service

2. Does a formal Supportive Care Screening in Cancer Policy (procedure or guideline) exist for the health service? Please attach a copy of the document(s) to return email

☐**Yes**

i) Where is the policy located/accessed from? *Eg Intranet, local filing system*

ii) When was the policy last updated/reviewed?

iii)Who is responsible for updating/reviewing the policy? *Eg position, unit (not name)*

☐**No**

3. List the supportive care screening tool(s) that are used in cancer care at the health service and the units/departments that they are used in? Please attach a copy of the template(s)
Eg NCCN Distress Thermometer in Haematology and Day Oncology, Prostate Cancer Distress Screen in Radiotherapy

4. Are there any internal auditing processes in place for the use of the screening tools? Please describe. If yes, how frequently are the audits conducted? *Eg monthly, 6 monthly, annual*

5. Does the health service have any performance indicators for supportive care screening in cancer? Please describe - what is the performance target and what is the most recently documented performance, if available?

6. Are there situations where 'blanket referrals' are in place to address supportive care needs within the health service? If yes, please provide further details.
Eg All patients treated for head and neck cancer receive a referral to a dietitian

7. Other comments

Appendix 3 – clinician survey

1. Which of the following BEST represents your clinical role?
Please select the most appropriate response

- ☐ Haematologist
- ☐ Medical Oncologist
- ☐ Oncologist
- ☐ Palliative Care Physician
- ☐ Psychiatrist
- ☐ Radiation Oncologist
- ☐ Surgeon
- ☐ Registered Nurse
- ☐ Dietitian
- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Radiation Therapist
- ☐ Speech Therapist
- ☐ Social Worker
- ☐ Other (please specify) ____

2. How many years of experience in oncology have you had?

- ☐ Less than 5 years
- ☐ 5 – 10 years
- ☐ Greater than 10 years

3. Which of the following best describes your most frequent work place? *Please select only one response*

- ☐ Albury Wodonga Regional Cancer Centre
- ☐ Alfred Health
- ☐ Austin Hospital
- ☐ Ballarat Regional Integrated Cancer Centre
- ☐ Barwon Health Cancer Services
- ☐ Cabrini - Malvern
- ☐ Eastern Health
- ☐ Gippsland Cancer Centre - Traralgon
- ☐ Goulburn Valley Health
- ☐ Melbourne Health
- ☐ Mildura Base Hospital
- ☐ Monash Health
- ☐ Northeast Health - Wangaratta
- ☐ Peninsula Health - Frankston
- ☐ Peter MacCallum Cancer Centre - Parkville

- ☐ Peter MacCallum Cancer Centre – Bendigo (radiotherapy)
- ☐ Southwest Healthcare – Warrnambool
- ☐ St John of God - Ballarat
- ☐ St John of God - Bendigo
- ☐ St Vincent's - East Melbourne
- ☐ Wimmera Base Hospital – Horsham

4. How would you rate your knowledge of supportive care screening and oncology patients?

- ☐ Very Good
- ☐ Adequate
- ☐ Lacking
- ☐ Very Poor

Please comment on your response

____

5. How would you rate your awareness of policies and guidelines relating to supportive care screening in your health service

- ☐ Very Good
- ☐ Adequate
- ☐ Lacking
- ☐ Very Poor

Please comment on your response

____

6. Have you heard of any of the following supportive care screening tools?

	Unsure/Unknown	Have heard of it/Use it	Have heard of it/ Don't use it	Have heard of it/Choose not to use it	Routinely used in my unit
NCCN Distress Thermometer	☐	☐	☐	☐	☐
Supportive Care Screening Tool	☐	☐	☐	☐	☐
Prostate Cancer Distress Screen	☐	☐	☐	☐	☐

Please specify any other tool that you are aware of that is used in your unit

____

7. Please rate your agreement with these statements in relation to oncology patients

	Strongly disagree	**Disagree**	**Unsure**	**Agree**	**Strongly agree**
All patients should be screened for supportive care needs at diagnosis	☐	☐	☐	☐	☐
All patients should be screened for supportive care needs on admission to hospital	☐	☐	☐	☐	☐
All patients should have repeated supportive care screening during their stay	☐	☐	☐	☐	☐
All patients should have supportive care screening prior to discharge	☐	☐	☐	☐	☐
All patients should have repeated supportive care screening at regular intervals during their cancer journey	☐	☐	☐	☐	☐

Please comment on your responses

____

____

____

8. What processes and policies are you aware of in your service for screening patients with cancer for supportive care needs?

____

____

____

9. In your role, do you undertake supportive care screening of your oncology patients?

☐ Yes
☐ No

10. If you are NOT involved in supportive care screening of oncology patients, what are the reasons?
You may select more than one response.

☐ Do not have the appropriate skills
☐ Do not have the time to undertake assessment
☐ Do not believe it is necessary
☐ It is not part of my job
☐ Refer to other clinician to complete supportive care screen
☐ Other (please specify)
____

11. What do you believe are the barriers for your patients to complete a supportive care screen?

____

____

____

12. How could these barriers be addressed?

____

____

____

13. What do you believe are the barriers for clinicians to provide a supportive care screen to their patients?

____

____

14. How could these barriers be addressed?

____

____

15. Rate your agreement with this statement "In my service, supportive care needs are routinely discussed for all patients in ward rounds and team meetings".

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Unsure
- ☐ Agree
- ☐ Strongly Agree

Please comment on your response

____

____

____

16. Rate your agreement with this statement “I am confident that all oncology patients with supportive care needs at my hospital are referred to an appropriate service in a timely manner”

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Unsure
- ☐ Agree
- ☐ Strongly Agree

Please comment on your response

____

____

____

17. What training or education needs related to supportive care needs in oncology patients would be of benefit to you?

____

____

____

18. Do you have any other comments about the supportive care screening and referral process for patients with cancer?

____

____

____

Appendix 4 – Medical record audit data collection tool

Patient Study Number______________________________ **Date of Survey:** DD/MM/YYYY

○ Inpatient ○ Chemotherapy day ○ Radiotherapy outpatient

Part 1: Patient Profile

1. Sex: ○ Male ○ Female ○ Intersex or Indeterminate ○ Not Recorded

2. Date of birth: DD/MM/YYYY

3. Aboriginal or Torres Strait Islander heritage
○ No or Not recorded
○ Yes, identifies as Aboriginal and/or Torres Strait Islander

4. Country of birth
○ Australia
○ Other. Please state______________________

5. Main language spoken at home
○ English
○ Other. Please state______________________

6. Interpreter required
○ Yes
○ No
○ Not Recorded

7. Postcode of usual residence
____

8. Usual living arrangement (select all that apply)
○ Lives alone
○ Lives with a partner
○ Lives with other family or friends
○ Lives in residential care
○ Not Recorded
○ Other. Please state______________________

9. Primary caregiver for another person?
○ Yes
○ No
○ Not Recorded

Part 2: Cancer Diagnosis and Treatment

10. Date of first appointment at this health service for treatment of current malignancy:
DD/MM/YYYY ○ Unknown

11. Type of primary malignancy *(choose only one)*
○ Bone & Soft Tissue
○ Breast
○ Central Nervous System
○ Colorectal
○ Endocrine & Thyroid
○ Genitourinary
○ Gynaecological
○ Haematological
○ Head & Neck
○ Lung
○ Upper gastrointestinal
○ Secondary: unknown primary
○ Skin & Melanoma
○ Other. Please state_________________

12. Date of diagnosis: DD /MM/YYYY ○ Unknown

13. Cancer stage _________________________________ ○ Unknown

14. What treatment is the patient currently receiving? (select all that apply)
○ Surgery
○ Chemotherapy
○ Radiotherapy
○ Chemoradiotherapy
○ Other. Please state____________________________________
○ None

15. What is the intent of the current treatment?
○ Active/Curative
○ Palliative (evidence that patient is or will be receiving palliative care)
○ Unknown

Part 3: Supportive Care Screen

16. Evidence of completed Supportive Care Screening Tool (SCST)

○ YES
Evidence of physical/scanned copy of completed SCST in medical record
Date(s) completed:
DD/MM/YYYY
DD/MM/YYYY
DD/MM/YYYY
DD/MM/YYYY

SCST used
○ NCCN/Distress Thermometer ○ Other. Please state ____________________

Where was the SCST completed?
○ Oncology ○ Radiotherapy ○ Ward ○ Outpatients
○ Not Documented ○ Other. Please state _________________

What was the timing of the SCST?
○ Prior to treatment
○ During treatment
○ At the conclusion of active treatment
○ During palliative care
○ Not Documented
○ Other. Please state ___________________

Continue to PART 4, Question 17

○ NO
A physical/scanned copy of a completed SCST is NOT present in medical record

and ○ Documented evidence of patient declining supportive care screen
or ○ No documented evidence that the patient declined a supportive care screen

Continue to PART 5, Question 22

Part 4: Outcomes of Completed Supportive Care Screen

17. Was the patient identified as DISTRESSED?

YES ○ Patient identified as distressed with a score of **4 or above** on NCCN distress thermometer
○ Other screening tool indicates distress. Please specify result ______________________

NO ○ Scored **less than 4** on NCCN distress thermometer
○ Other screening tool does not indicate distress. Please specify result _______________

18. Which problems did the patient identify? *Select all that apply*

○ Practical (eg. Child care, financial, transportation, work, housing)
○ Family (eg. Dealing with children, dealing with partner, fertility)
○ Emotional (eg. Depression, fears, nervousness, sadness, worry)
○ Spiritual/religious concerns
○ Physical (eg. Appearance, breathing, fatigue, nausea, pain, sleep, sexual)
○ None
○ Other

19. Follow up after supportive care screening

A. Is there documented evidence of a discussion with a health professional in regards to SC screening?
○ YES, interaction about an identified issue documented by a health professional
○ NO, there is no documentation of a discussion
○ NO, there is documentation that discussion was offered, but has not occurred/declined by patient

B. Which health professional followed up the screen with the patient?
○ Chemotherapy Nurse ○ Cancer Care Coordinator ○ Ward Nurse ○ Social Worker
○ Radiation Therapist ○ Radiotherapy Nurse ○ Other. Please state____________
○ Not identified

C. Which actions have been taken to address supportive care issues or concerns?– *tick any of these for which there is documented evidence*
○ The issue was addressed with a discussion alone
○ Written information (booklet, pamphlet etc.) was provided to patient
○ Patient provided with contact details of organisation or professional person who could help
○ Staff arranged a referral to another professional
○ Follow-up with professional(s) who is/are already providing supportive care for the identified issue(s)
○ Other. Please specify ___________________________________

20. Follow-up with General Practitioner (GP)

Is there any documented evidence of communication with the patient's GP about concerns/problems identified from the SCST?

○ YES ○ NO

21. Referrals to address supportive care needs

Please complete one for all relevant referrals

Referral 1 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?__________________________
○ NO

Referral 2 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_________________________
○ NO

Referral 3 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_____________________
○ NO

Referral 4 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?____________________
○ NO

Referral 5 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?______________________________
○ NO

Referral 6 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not

Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ Not documented

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?___________________________
○ NO

END OF AUDIT. DO NOT COMPLETE PART 5 UNLESS **NO** EVIDENCE OF COMPLETED SCST

Part 5: Supportive Care Actions in Absence of Completed SCST

22. Follow up after supportive care discussion

A. Is there documented evidence of a discussion with a health professional in regards to the patient's supportive care needs? ○ YES, interaction about an identified issue documented by a health professional ○ NO, there is no documentation recording a discussion ○ NO, there is documentation that discussion was offered, but has not occurred/declined by patient
B. Which health professional discussed supportive care needs with the patient? ○ Chemotherapy Nurse ○ Cancer Care Coordinator ○ Ward Nurse ○ Social Worker ○ Radiation Therapist ○ Radiotherapy Nurse ○ Other. Please specify_______ ○ Not identified
C. Which problems did the patient identify? *Select all that apply* ○ Practical (eg. Child care, financial, transportation, work, housing) ○ Family (eg. Dealing with children, dealing with partner, fertility) ○ Emotional (eg. Depression, fears, nervousness, sadness, worry) ○ Spiritual/religious concerns ○ Physical (eg. Appearance, breathing, fatigue, nausea, pain, sleep, sexual) ○ None ○ Other. Please specify_______
D. Which actions have been taken to address supportive care issues or concern? – *tick any of these for which there is documented evidence* ○ The issue was addressed with a discussion alone ○ Written information (booklet, pamphlet etc.) was provided to patient ○ Patient provided with contact details of organisation or professional person who could help ○ Staff arranged a referral to another professional ○ Follow-up with professional(s) who is/are already providing supportive care for the identified issue(s) ○ Other. Please specify __________________________

23. Follow-up with General Practitioner (GP)

Is there any documented evidence of communication with the patient’s GP about supportive care concerns/problems identified?

○ YES
○ NO

24. Referrals to address supportive care needs

Please complete one for all relevant referrals

Referral 1 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/religious concerns
○ Not Documented

C. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_______________________________________
○ NO

Referral 2 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/religious concerns
○ Not Documented

C. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?___________________________________
○ NO

Referral 3 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?
○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?_____________________________________
○ NO

Referral 4 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?
○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?__________________________________
○ NO

Referral 5 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?__________________________________
○ NO

Referral 6 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

D. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_________________________________
○ NO

Instructions for the completion of Data Collection Sheet

PATIENT SELECTION CRITERIA

INCLUDED	EXCLUDED
All patients must have had their cancer diagnosis for 6 months or less All patients managed by oncology specific units in acute hospital Patients with known diagnosis of malignancy at admission under other medical/surgical units in acute wards receiving treatment or management related to cancer or cancer-treatment. Examples include patient with known Ca bowel admitted for hemi-colectomy, patient with known ca lung admitted for lobectomy, patient admitted with DVT-related PICC. All adult patients admitted for administration of chemotherapy agent All adult patients attending radiotherapy	Patients with a cancer diagnosis for > 6 months Patients age 17 years and younger Cognitive Impairment unable to consent Non-English speaking – without family or translator present to assist with completion of verbal consent Terminal/End-of Life Care – where death is expected in 1 month Where participation is deemed too burdensome ** these patients may consent to information previously collected as a part of routine care to be included from the medical history* Patients with diagnosis of malignancy at admission under other medical/surgical units in acute wards but where treatment or management is unrelated to cancer or cancer-treatment. Patient is unaware of diagnosis of malignancy at admission – ie: patient with bowel tumour (un-confirmed histology at admission) admitted for hemi-colectomy Ambulatory patients attending for blood transfusions, CADD pump disconnection (or similar), IV hydration, blood tests or medical reviews only Patients admitted to sub-acute, rehabilitation or hospice care

SUPPORTIVE CARE SCREENING PREVALENCE STUDY: DATA COLLECTION TOOL

The following information will be collected from the medical record

Part 1: Patient Profile

1. Gender – male/female/intersex or indeterminate/not recorded
2. Date of Birth – DD/MM/YYYY
3. Aboriginal/Torres Strait Islander: Does the patient identify themselves as Aboriginal/Torres Strait Islander? Check for this in the patient registration details.
4. Country of Birth: Check for this in the patient registration details
5. Main language spoken at home: Check for this in the patient registration details
6. Interpreter required: Check for this in the patient registration details
7. Postcode of usual residence: Check for this in the patient registration details
8. Usual living arrangement: refers to the patients current living situation or that prior to current admission to hospital (select all that apply)
    - Lives alone: choose this if the patient lives alone
    - Lives with partner/Lives with other family or friends: choose if the patient has someone with whom they share a home
    - Lives in residential care: choose this if the patient resides in hostel or nursing home
    - Not recorded: choose this if information is not readily available
    - Other: choose this if other living arrangement (for example lives with paid carer)
9. Primary caregiver for another person: Check for this in the patient registration details.

Part 2: Cancer Diagnosis & Treatment

10. Date of first appointment at this health service for treatment of current malignancy:

    Refers to date of first appointment at this health service for treatment of current malignancy

11. Type of primary malignancy – refers to the current malignancy which is being treated. If the patient is receiving treatment to metastatic disease, choose the primary site if known
    - Bone & Soft Tissue: osteosarcoma, Ewing's Sarcoma & soft tissue sarcoma
    - Breast
    - Central Nervous System: brain & spinal cord tumours
    - Colorectal: cancers of the colon, rectum & anus
    - Endocrine & Thyroid: pituitary, thyroid & adrenal glands
    - Genitourinary: prostate, kidney, bladder, testicular
    - Gynaecological: including ovarian, cervical & vaginal cancers
    - Haematological: Leukaemia, lymphoma, multiple myeloma
    - Head & Neck: tumours of the mouth, throat & nose
    - Lung: non-small cell lung cancer (NSCLC), small cell lung cancer (SCLC), mesothelioma
    - Secondary - unknown primary: where treatment is for metastatic disease, where primary is unknown.
    - Skin & Melanoma: SCC, BCC and melanoma

- Upper Gastro-intestinal: includes oesophagus, stomach, biliary duct, liver, pancreas
- Other

12. Date of Diagnosis (Day/Month/Year) – refers to date of confirmed diagnosis of the current malignancy, if known.

13. Cancer stage? *It is acknowledged this information may be difficult to access, but should be included if it is readily available in the patient's medical record*

    - Record stage TNM (for solid tumours) or Stage/Grade for haematological malignancy or Stage/Grade for Central Nervous System tumour
    - Unknown - Not readily available in the patient's medical record and therefore not recorded

14. What treatment is the patient currently receiving?

    - Surgery – surgery to remove malignancy or metastasis
    - Chemotherapy
    - Radiotherapy
    - Chemoradiotherapy
    - Other – for example stem cell transplant
    - None – No active treatment

15. Intent of current treatment

    - Active/Curative – mark this if the intent of current treatment is to cure or obtain a period of remission
    - Palliative – mark this if the patient is receiving treatment to relieve symptoms of progressive disease including palliative radiotherapy. Evidence that patient is or will be receiving specialist palliative care
    - Unknown – Information not readily available in the patient's medical record

Part 3: Supportive Care Screen

16. Evidence of Completed Supportive Care Screening Tool

    - Choose **YES** if there is a copy of a completed SCST in medical record & record the date of completion if known. If more than one copy present, include all relevant dates.
    - Indicate which type of SCST used: NCCN/Distress Thermometer or other type of SCST. If other, indicate name of tool used.
    - Indicate which ward/treatment location the patient was attending when they completed the SCST?
    - Indicate the timing of the SCST:
        - Prior to treatment - prior to commencement of treatment (e.g. surgery, chemotherapy, radiotherapy)
        - During treatment - during period of active cancer treatment
        - At the conclusion of active treatment - at the conclusion or after treatment is completed
        - During palliative care
        - Other – at another time. Please specify.
        - Not documented - not readily available in the patient's medical record

Continue to PART 4, Question 17

- Choose **NO** if A physical/scanned copy of completed SC ST is NOT present in medical record
    - and Documented evidence of patient declining supportive care screen
    - or No documented evidence that the patient declined a supportive care screen

Continue to PART 5, Question 22
Part 4: Outcomes of Completed Supportive Care Screen

17. Was the patient identified as DISTRESSED?

Choose **YES** if patient scored 4 or above on copy of completed NCCN distress thermometer in medical record or was determined to be distressed using other screening tool.

Choose **NO** if patient scored less than 4 on copy of completed NCCN distress thermometer in medical record or was determined to not be distressed using other screening tool.

18. Which problems did the patient identify? *Select all that apply*

- *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
- *Family Problems – eg Dealing with children, partner, ability to have children*
- *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
- *Spiritual/Religious Concerns*
- *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

19. Follow up after supportive care screening

A) Is there documented evidence of a discussion with a health professional in regards to SC screening?

- Choose YES if there is documented evidence of a follow up discussion with a health professional following supportive care screen
- Choose NO if there is no documentation of a discussion or if patient has declined discussion (Continue to Question 20)

B) Which health professional followed up the screen with the patient? Choose all that apply.

C) Which actions have been taken to address supportive care issues or concerns? Choose all that apply for which there is documented evidence.

20. Follow-up with General Practitioner

Documented evidence of communication with patient's GP regarding any supportive care issues identified eg. letter to GP, record of telephone conversation, or copy GP on request form

21. Referrals to address supportive care needs

Fill in one box for each documented referral that was made to address the patients supportive care needs

A) What type of professional was the patient referred to? Select all that apply
B) Which issue was the referral intended to address? Select all issues that apply for which there is documented evidence
   - *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
   - *Family Problems – eg Dealing with children, partner, ability to have children*
   - *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
   - *Spiritual/Religious Concerns*
   - *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

C) Was this referral a result of the SCST?
   Choose YES if documented evidence present that the referral was made to address an issue that was identified by the SCST.
   Choose NO if documented evidence present that the referral was not made in response to an issue that was identified by the SCST.
   Choose Not Documented if no evidence present for the reason that the referral was made.

D) Location of referral
   Choose location of referred professional, if known.

E) Is there evidence of uptake of referral?
   Choose YES if there is evidence of uptake of appointment in medical record eg. Assessment, outcome from appointment, note.
   Choose NO if no evidence present.

DO NOT COMPLETE PART 5 UNLESS **NO** EVIDENCE OF COMPLETED SCST

Part 5: Supportive Care Actions in Absence of Completed SCST

22. Follow up after supportive care discussion:

A) Is there documented evidence of a discussion with a health professional in regards to SC needs?

- Choose YES if there is documented evidence of a follow up discussion with a health professional following supportive care screen
- Choose NO if there is no documentation of a discussion or if patient has declined discussion (continue to question 23)

B) Which health professional discussed supportive care needs with the patient? Choose all that apply.

C) Which problems did the patient identify? *Select all that apply*

- *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
- *Family Problems – eg Dealing with children, partner, ability to have children*
- *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
- *Spiritual/Religious Concerns*
- *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

D) Which actions have been taken to address supportive care issues or concerns? Choose all that apply for which there is documented evidence.

23. Follow-up with General Practitioner

Documented evidence of communication with patient's GP regarding any supportive care issues identified eg. letter to GP, record of telephone conversation, or copy GP on request form

24. Referrals to address supportive care needs

Fill in one box for each documented referral that was made to address the patients supportive care needs

A) What type of professional was the patient referred to? *Select all that apply*
B) Which issue was the referral intended to address? Select all issues that apply for which there is documented evidence
    - *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
    - *Family Problems – eg Dealing with children, partner, ability to have children*
    - *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
    - *Spiritual/Religious Concerns*
    - *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*
C) Location of referral - Choose location of referred professional, if known.
D) Is there evidence of uptake of referral?
    Choose YES if there is evidence of uptake of appointment in medical record eg. Assessment, outcome from appointment, note.
    Choose NO if no evidence present.

Appendix 5 – Guidance for approaching participants for consumer survey and consumer interview

When approaching the patient to participate in either the survey or the interview :

The study auditor will approach the patient (with pens), introduce themselves and why they would like to take a brief time to talk with them. If patient requests an interpreter all efforts will be made to obtain the assistance of a suitable interpreter.

Dialogue (in blue box) suggested to include for both survey and interview:

We know a cancer diagnosis and treatment can affect many parts of your life and indeed those who care for you. We also here at (health service) know that feedback from people receiving care is very valuable in helping us to improve this experience.

To best understand your own experience we would like to ask you how we are meeting your supportive care needs (not treatment needs).

An explanation of what we are meaning by supportive care to be provided i.e. help with emotional support, symptom control, social support (including financial) and spiritual care.

If seeking consent for <u>the survey:</u>

If you are interested in provided feedback - and please there is no pressure for you to do so - would you be interested in completing a brief survey as part of a state wide study? The study is called Investigating Practices Relating to Supportive Care Screening in Victorian Cancer Services.

If patient is interested

As indicated in patient information pamphlet : This study has been planned by the Victorian Government, Department of Health and Human Services working together with Victorian health services to better understand if we are helping you with all aspects of wellbeing for people with cancer.

Results from this study will show where changes need to be made to improve the care given to people affected by cancer. Your participation is entirely voluntary and you are free to change your mind about participating at any time.

Patient Information sheet provided . Before proceeding to obtain written consent auditor ensures the participant does not does not have questions. :

You have received information about a supportive care prevalence study we are conducting today. Have you read and understood the information provided? Are you happy to take part in this? Thank you.

Before leaving it is imperative you check in with the patient:

Should the survey raise questions or cause concern or distress – your nurse is aware you were being approached to complete the survey and should you need someone to talk to about it NAME (the nurse) would be available

When leaving patient- with pen and survey which includes a sample of the Distress Thermometer- the study auditor will say depending on the time of the day or their availability

I will be back to collect the completed survey(later in the day) or you can give it to the nurse.

If collecting from patient: ask if they had any questions, or more that they wish to say – assist and thank them for the time they have given to the survey. Again remind them that all information is confidential, will not be identified and they can withdraw from the survey at any time (refer them to the contact details of lead researchers)

If seeking consent to undertake a face to face interview:
(A patient with a UR ending in an even number per the Study Methodology)

If you are interested in provided direct feedback - and please there is no pressure for you to do so - would you be interested in answering some brief questions about a state wide study ? The study is called Investigating Practices Relating to Supportive Care Screening in Victorian Cancer Services.

If patient is interested and says yes

I have a patient information pamphlet that explains the study. This study has been planned by the Victorian Government, Department of Health and Human Services working together with Victorian health services to better understand if we are helping you with all aspects of wellbeing for people with cancer.

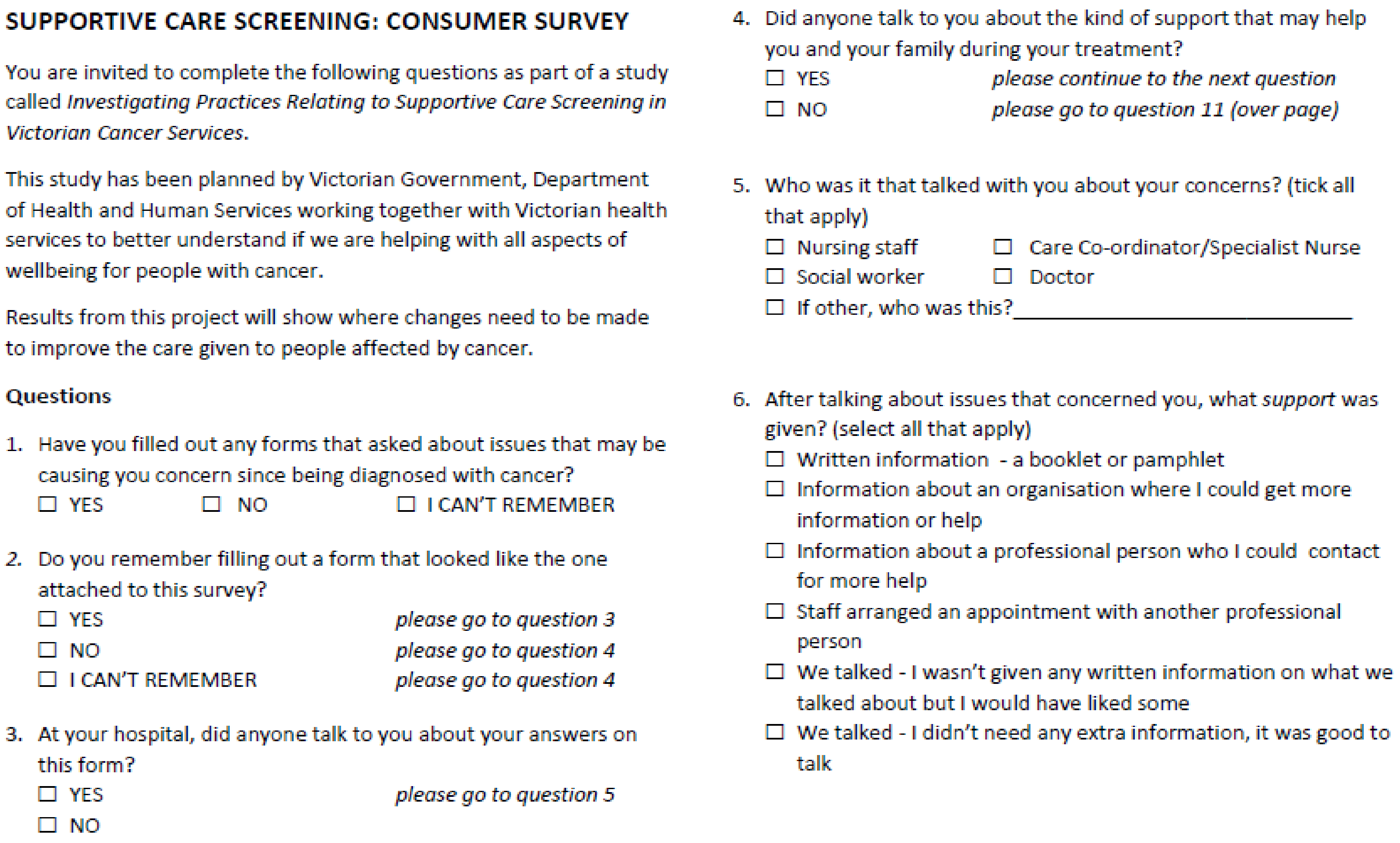
Results from this project will show where changes need to be made to improve the care given to people affected by cancer. Your participation is entirely voluntary and you are free to change your mind about participating at any time.

Patient Information sheet provided and auditor waits for any questions before proceeding to obtain written consent to participate then continuing with:

You have received information about a supportive care prevalence study we are conducting today. Have you read and understood the information provided? Are you happy to take part in this? Thank you.

Note: If patient declines an interview this will be considered as a decline to participate in the study, however if the participant offers to complete the written survey, then consent will be sought

Appendix 6 – Supportive care screening consumer survey



SUPPORTIVE CARE SCREENING: CONSUMER SURVEY

You are invited to complete the following questions as part of a study called *Investigating Practices Relating to Supportive Care Screening in Victorian Cancer Services*.

This study has been planned by Victorian Government, Department of Health and Human Services working together with Victorian health services to better understand if we are helping with all aspects of wellbeing for people with cancer.

Results from this project will show where changes need to be made to improve the care given to people affected by cancer.

Questions

1. Have you filled out any forms that asked about issues that may be causing you concern since being diagnosed with cancer?
   ☐ YES ☐ NO ☐ I CAN'T REMEMBER

2. Do you remember filling out a form that looked like the one attached to this survey?
   ☐ YES *please go to question 3*
   ☐ NO *please go to question 4*
   ☐ I CAN'T REMEMBER *please go to question 4*

3. At your hospital, did anyone talk to you about your answers on this form?
   ☐ YES *please go to question 5*
   ☐ NO

4. Did anyone talk to you about the kind of support that may help you and your family during your treatment?
   ☐ YES *please continue to the next question*
   ☐ NO *please go to question 11 (over page)*

5. Who was it that talked with you about your concerns? (tick all that apply)
   ☐ Nursing staff ☐ Care Co-ordinator/Specialist Nurse
   ☐ Social worker ☐ Doctor
   ☐ If other, who was this?______________________________

6. After talking about issues that concerned you, what *support* was given? (select all that apply)
   ☐ Written information - a booklet or pamphlet
   ☐ Information about an organisation where I could get more information or help
   ☐ Information about a professional person who I could contact for more help
   ☐ Staff arranged an appointment with another professional person
   ☐ We talked - I wasn't given any written information on what we talked about but I would have liked some
   ☐ We talked - I didn't need any extra information, it was good to talk

7. If you were given support, was it helpful?
☐ YES ☐ NO

8. If staff arranged an appointment with another professional person, did you attend this appointment?
☐ YES *please go to the next question*
☐ NO *please go to question 10*

9. Was the appointment helpful?
☐ YES ☐ NO

10. If you were not able to attend, what was/were the reason/s? (Select all that apply)
☐ Didn't need it anymore
☐ Busy with work or family
☐ Too far from home
☐ I got an appointment at a different hospital
☐ Too unwell from my treatment
☐ I plan to take up the appointment at a later time
☐ Other reason. Please state________________________

11. Did you access support or information on your own?
☐ YES ☐ NO
If so who or where? Examples may be Cancer Council Victoria, your local doctor, support groups etc.

____

____

12. How important is it that staff at your hospital ask you about your concerns?

1	2	3	4	5
Very Important		Somewhat Important		Not Important

13. How important is it that staff at your hospital ask you about your concerns **regularly** (i.e. not just at the beginning) during your cancer experience?

1	2	3	4	5
Very Important		Somewhat Important		Not Important

14. Do you have any further comments?

____

____

____

____

Thank you for taking the time to complete this.

If you have any questions in regards to your answers please let your nurse know

Study Number: HREC/17/PMCC/127
Version 2
19th July 2017

VICTORIA
State Government

Appendix 7 – Supportive care screening consumer interview

- Additional instructions, suggested dialog and prompts in blue boxes
- Document the patients comments in space provided

Ask the Patient and /or interpreter the following questions.

1. Have you filled out any forms that asked about issues that may be causing you concern since being diagnosis with cancer?

   ☐ YES ☐ NO ☐ I CAN'T REMEMBER

2. Do you remember filling out a form that looked like the one attached to this survey?

   SHOW the patient a copy of the Distress Thermometer

   ☐ YES *please go to question 3*
   ☐ NO *please go to question 4*
   ☐ I CAN'T REMEMBER *please go to question 4*

   ASK the appropriate next question depending on the answer given

3. At your hospital, did anyone talk to you about your answers on this form?

   ☐ YES *please go to question 5*
   ☐ NO

   ____
   ____

4. Did anyone talk to you about the kind of support that may help you and your family during your treatment?

   ☐ YES *please continue to the next question*
   ☐ NO *please go to question 11 (over page)*

   ____
   ____

5. Who was it that talked with you about your concerns? (tick all that apply)

   ☐ Nursing staff ☐ Care Co-ordinator/Specialist Nurse
   ☐ Social worker ☐ Doctor

   If other, who was this?

   ____
   ____

6. After talking about issues that concerned you, what *support* was given? (select all that apply)

   EXPAND by asking for specific examples when choosing answers from the options provided

   ☐ Written information - a booklet or pamphlet
   ☐ Information about an organisation where I could get more information or help

☐ Information about a professional person who I could contact for more help
☐ Staff arranged an appointment with another professional person
☐ We talked - I wasn't given any written information on what we talked about but I would have liked some
☐ We talked - I didn't need any extra information, it was good to talk

____
____

EXTRA CARE for patients emotional state when asking Question 7, 8 , 9 and 10. As per the patient information sheet you may need to reinforce that their answers will not affect their current treatment or their relationship with the hospital

7. If you were given support, was it helpful?

☐ YES
☐ NO

____
____
____
____
____

8. If staff arranged an appointment with another professional person, did you attend this appointment?

☐ YES *please go to the next question*
☐ NO *please go to question 10*

____
____

9. Was the appointment/s helpful?

If the patient attended more than one appointment note their response to each

☐ YES
☐ NO

____
____

10. If you were not able to attend, were the reasons as a result of?
(Select all that apply)

☐ Didn't need it anymore
☐ Busy with work or family
☐ Too far from home
☐ I got an appointment at a different hospital
☐ Too unwell from my treatment
☐ I plan to take up the appointment at a later time
☐ Other reason. Please state_________________________________

11. Did you access support or information on your own?

EXPLORE the types of and extent to which patient accessed information. This information may have been accessed with the assistance of members of their extended support network

☐ YES ☐ NO

If so who or where? Examples may be Cancer Council Victoria, your local doctor, support groups etc.

____

____

Be MINDFUL that depending on the answer to Question 12, the patient may be looking for the study auditor to respond to their position (positively and/or negatively), assist or even intervene with their needs.

The study auditor may need to be explicit in their role. For example *Sorry while today I am not able to assist you with your request, I will ask your nurse to follow up with you directly after this interview.*

12. How important is it that staff at your hospital ask you about your concerns?

1	2	3	4	5
Very Important		Somewhat Important		Not Important

____

____

13. How important is it that staff at your hospital ask you about your concerns **regularly** (i.e. not just at the beginning) during your cancer experience?

1	2	3	4	5
Very Important		Somewhat Important		Not Important

____

____

PROVIDE an opportunity to listen and seek any further comments

14. Do you have any further comments?

____

____

____

Thank the patient for sharing their experience and acknowledge the value of their contribution and confirm that all (de-identified) feedback will be collated and used to help improve care.
Remind the patient to seek support from their nurse, if they feel that the interview has raised any concerns

Appendix 8 – Follow-up medical record audit and guidelines

Patient Study Number_________________ Date of Audit: DD/MM/YYYY

Part 1: Supportive Care Screen

1. Evidence of Supportive Care Screening Tool (SCST) completed in last 60 days

○ YES Evidence of physical/scanned copy of SCST in medical record completed **in last 60 days**

Date(s) completed DD/MM/YYYY
DD/MM/YYYY DD/MM/YYYY
DD/MM/YYYY DD/MM/YYYY

SCST used

○ NCCN/Distress Thermometer ○ Other. Please state _______________

Where was the SCST completed?

○ Oncology ○ Radiotherapy ○ Ward ○ Outpatients
○ Not Documented ○ Other. Please state _______________

What was the timing of the SCST?

○ Prior to treatment ○ During treatment ○ At the conclusion of active treatment
○ During palliative care ○ Not documented ○ Other. Please state ______

Continue to PART 2, Question 2

○ NO A physical/scanned copy of a SCST completed **in last 60 days** is NOT present in medical record

and ○ Documented evidence of patient declining supportive care screen in last 60 days
or ○ No documented evidence that the patient declined a supportive care screen in last 60 days

Continue to PART 3, Question 7

Part 2: Outcomes of Supportive Care Screen Completed in Last 60 Days

2. Was the patient identified as DISTRESSED?

YES ○ Patient identified as distressed with a score of **4 or above** on NCCN distress thermometer
○ Other screening tool indicates distress. Please specify result ______________

NO ○ Scored **less than 4** on NCCN distress thermometer
○ Other screening tool does not indicate distress. Please specify result ____________

3. Which problems did the patient identify? *Select all that apply*

○ Practical (eg. Child care, financial, transportation, work, housing)
○ Family (eg. Dealing with children, dealing with partner, fertility)
○ Emotional (eg. Depression, fears, nervousness, sadness, worry)
○ Spiritual/religious concerns
○ Physical (eg. Appearance, breathing, fatigue, nausea, pain, sleep, sexual)
○ None
○ Other

4. Follow up after supportive care screening

A. Is there documented evidence of a discussion with a health professional **in last 60 days** in regards to a completed SCST?

○ YES, interaction about an identified issue documented by a health professional
○ NO, there is no documentation of a discussion
○ NO, there is documentation that discussion was offered, but has not occurred/declined by patient

B. Which health professional followed up the SCST with the patient?

○ Chemotherapy Nurse ○ Cancer Care Coordinator ○ Ward Nurse ○ Social Worker
○ Radiation Therapist ○ Radiotherapy Nurse ○ Other. Please state __________
○ Not identified

C. Which actions have been taken **in last 60 days** to address supportive care issues or concerns?– *tick any of these for which there is documented evidence*

○ The issue was addressed with a discussion alone
○ Written information (booklet, pamphlet etc.) was provided to patient
○ Patient provided with contact details of organisation or professional person who could help
○ Staff arranged a referral to another professional
○ Follow-up with professional(s) who is/are already providing supportive care for the identified issue(s)
○ Other. Please specify ______________________

5. Follow-up with General Practitioner (GP)

Is there any documented evidence of communication **in last 60 days** with the patient's GP about concerns/problems identified from a completed SCST?

○ YES
○ NO

6. Referrals to address supportive care needs

Please complete one for all relevant referrals made in last 60 days

Referral 1 Date of referral DD/MM/YYYY

F. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

G. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns

○ Not Documented

H. Was this referral a result of the SCST?

○ YES ○ NO ○ UNKNOWN

I. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP

○ Unknown

J. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_________________

○ NO

Referral 2 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist

○ Pastoral Care ○ General Practitioner ○ Support Group

○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns

○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP

○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?______________________

○ NO

Referral 3 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist

○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?
○ YES ○ NO ○ UNKNOWN

D. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?___________________________
○ NO

Referral 4 Date of referral DD/MM/YYYY
A. What type(s) of professional(s)/service(s) was the patient referred to?
○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?
○ YES ○ NO ○ UNKNOWN

D. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?_____________________
○ NO

Referral 5 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_________________________________
○ NO

Referral 6 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issue(s)/concern(s) was the referral intended to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of the SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?____________________
○ NO

END OF AUDIT. DO NOT COMPLETE PART 3 UNLESS **NO** EVIDENCE OF COMPLETED SCST IN LAST 60 DAYS

Part 3: Supportive Care Actions in Absence SCST Completed in Last 60 Days

7. Follow up after supportive care discussion

A. Is there documented evidence of a discussion with a health professional **in last 60 days** in regards to the patient's supportive care needs?

○ YES, interaction about an identified issue documented by a health professional
○ NO, there is no documentation recording a discussion
○ NO, there is documentation that discussion was offered, but has not occurred/declined by patient

B. Which health professional discussed supportive care with the patient?

○ Chemotherapy Nurse ○ Cancer Care Coordinator ○ Ward Nurse ○ Social Worker
○ Radiation Therapist ○ Radiotherapy Nurse ○ Other. Please specify ________
○ Not identified

C. Which problems did the patient identify? *Select all that apply*

○ Practical (eg. Child care, financial, transportation, work, housing)
○ Family (eg. Dealing with children, dealing with partner, fertility)
○ Emotional (eg. Depression, fears, nervousness, sadness, worry)
○ Spiritual/religious concerns
○ Physical (eg. Appearance, breathing, fatigue, nausea, pain, sleep, sexual)
○ None
○ Other

D. Which actions have been taken to address supportive care issues or concern? – *tick any of these for which there is documented evidence*

○ The issue was addressed with a discussion alone
○ Written information (booklet, pamphlet etc.) was provided to patient
○ Patient provided with contact details of organisation or professional person who could help
○ Staff arranged a referral to another professional
○ Follow-up with professional(s) who is/are already providing supportive care for the identified issue(s)
○ Other. Please specify ________________________________

8. Follow-up with General Practitioner (GP)

Is there any documented evidence of communication **in last 60 days** with the patient's GP about supportive care concerns/problems identified?

○ YES
○ NO

9. Referrals to address supportive care needs

Please complete one box for all relevant referrals ***made within last 60 days***

Referral 1 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?__________________________○ NO

Referral 2 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?_____________________○ NO

Referral 3 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?
○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?
○ YES ○ NO ○ UNKNOWN

D. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?_________________ ○ NO

Referral 4 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?
○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*
○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?
○ YES ○ NO ○ UNKNOWN

D. Location of referral
○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment
○ YES. What evidence is available?_______________________ ○ NO

Referral 5 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?______________________○ NO

Referral 6 Date of referral DD/MM/YYYY

A. What type(s) of professional(s)/service(s) was the patient referred to?

○ Social Worker ○ Occupational Therapist ○ Physiotherapist ○ Clinical Psychologist
○ Pastoral Care ○ General Practitioner ○ Support Group
○ Other. Please state ____

B. Which issues/concerns was the referral to address? *Select all that apply*

○ Physical ○ Practical ○ Family ○ Emotional ○ Spiritual/ religious concerns
○ Not Documented

C. Was this referral a result of a completed SCST?

○ YES ○ NO ○ UNKNOWN

D. Location of referral

○ Within current hospital ○ Other hospital ○ Community-based service ○ GP
○ Unknown

E. Is there evidence of uptake of referral? e.g. assessment, outcome from appointment

○ YES. What evidence is available?____○ NO

The following information will be collected from the medical record

Part 1: Supportive Care Screen

1. Evidence of Supportive Care Screening Tool Completed ***in last 60 days***

- Choose **YES** if there is a copy of a SCST in medical record completed in last 60 days. Record the date of completion if known. If more than one copy present, include all relevant dates.
- Indicate which type of SCST used: NCCN/Distress Thermometer or other type of SCST. If other, indicate name of tool used.
- Indicate which ward/treatment location the patient was attending when they completed the SCST?
- Indicate the timing of the SCST:
  - Prior to treatment - prior to commencement of treatment (e.g. surgery, chemotherapy, radiotherapy)
  - During treatment - during period of active cancer treatment
  - At the conclusion of active treatment - at the conclusion or after treatment is completed
  - During palliative care
  - Other – at another time. Please specify.
  - Not documented - not readily available in the patient's medical record

Continue to PART 2, Question 2

- Choose **NO** if A physical/scanned copy of a SCST completed in last 60 days is NOT present in medical record
  - and Documented evidence of patient declining supportive care screen
  - or No documented evidence that the patient declined a supportive care screen

Continue to PART 3, Question 7

Part 2: Outcomes of Completed Supportive Care Screen

2. Was the patient identified as DISTRESSED?

Choose **YES** if patient scored 4 or above on copy of completed NCCN distress thermometer in medical record or was determined to be distressed using other screening tool.

Choose **NO** if patient scored less than 4 on copy of completed NCCN distress thermometer in medical record or was determined to not be distressed using other screening tool.

3. Which problems did the patient identify? *Select all that apply*

- *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
- *Family Problems – eg Dealing with children, partner, ability to have children*
- *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
- *Spiritual/Religious Concerns*

- *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

4. Follow up after supportive care screening

A) Is there documented evidence of a discussion with a health professional in regards to SC screening?

- Choose YES if there is documented evidence of a follow up discussion with a health professional following supportive care screen (Continue to 4B)
- Choose NO if there is no documentation of a discussion or if patient has declined discussion (Continue to Question 5)

B) Which health professional followed up the screen with the patient? Choose all that apply.

C) Which actions have been taken to address supportive care issues or concerns? Choose all that apply for which there is documented evidence.

5. Follow-up with General Practitioner

Documented evidence of communication with patient's GP in last 60 days regarding any supportive care issues eg. letter to GP, record of telephone conversation, or copy GP on request form

6. Referrals to address supportive care needs

Fill in one box for each documented referral that was made to address the patients supportive care needs in last 60 days

F) What type of professional was the patient referred to? Select all that apply

G) Which issue was the referral intended to address? Select all issues that apply for which there is documented evidence
  - *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
  - *Family Problems – eg Dealing with children, partner, ability to have children*
  - *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
  - *Spiritual/Religious Concerns*
  - *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

H) Was this referral a result of the SCST?
Choose YES if documented evidence present that the referral was made to address an issue that was identified by the SCST.
Choose NO if documented evidence present that the referral was not made in response to an issue that was identified by the SCST.
Choose Unknown if no evidence present for the reason that the referral was made.

I) Location of referral
Choose location of referred professional, if known.

J) Is there evidence of uptake of referral?
Choose YES if there is evidence of uptake of appointment in medical record eg. Assessment, outcome from appointment, note.
Choose NO if no evidence present.

DO NOT COMPLETE PART 3 UNLESS **NO** EVIDENCE OF COMPLETED SCST

Part 3: Supportive Care Actions in Absence of Completed SCST

7. Follow up after supportive care discussion:

A) Is there documented evidence of a discussion with a health professional in regards to SC needs?

- Choose YES if there is documented evidence of a follow up discussion with a health professional following supportive care screen (continue to question 7B)
- Choose NO if there is no documentation of a discussion or if patient has declined discussion (continue to question 8)

B) Which health professional discussed supportive care needs with the patient? Choose all that apply.

C) Which problems did the patient identify? *Select all that apply*

- *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
- *Family Problems – eg Dealing with children, partner, ability to have children*
- *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
- *Spiritual/Religious Concerns*
- *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

D) Which actions have been taken to address supportive care issues or concerns? Choose all that apply for which there is documented evidence.

8. Follow-up with General Practitioner

Documented evidence of communication with patient's GP in last 60 days regarding any supportive care issues eg. letter to GP, record of telephone conversation, or copy GP on request form

9. Referrals to address supportive care needs

Fill in one box for each documented referral that was made in last 60 days to address the patients supportive care needs

E) What type of professional was the patient referred to? *Select all that apply*

F) Which issue was the referral intended to address? Select all issues that apply for which there is documented evidence

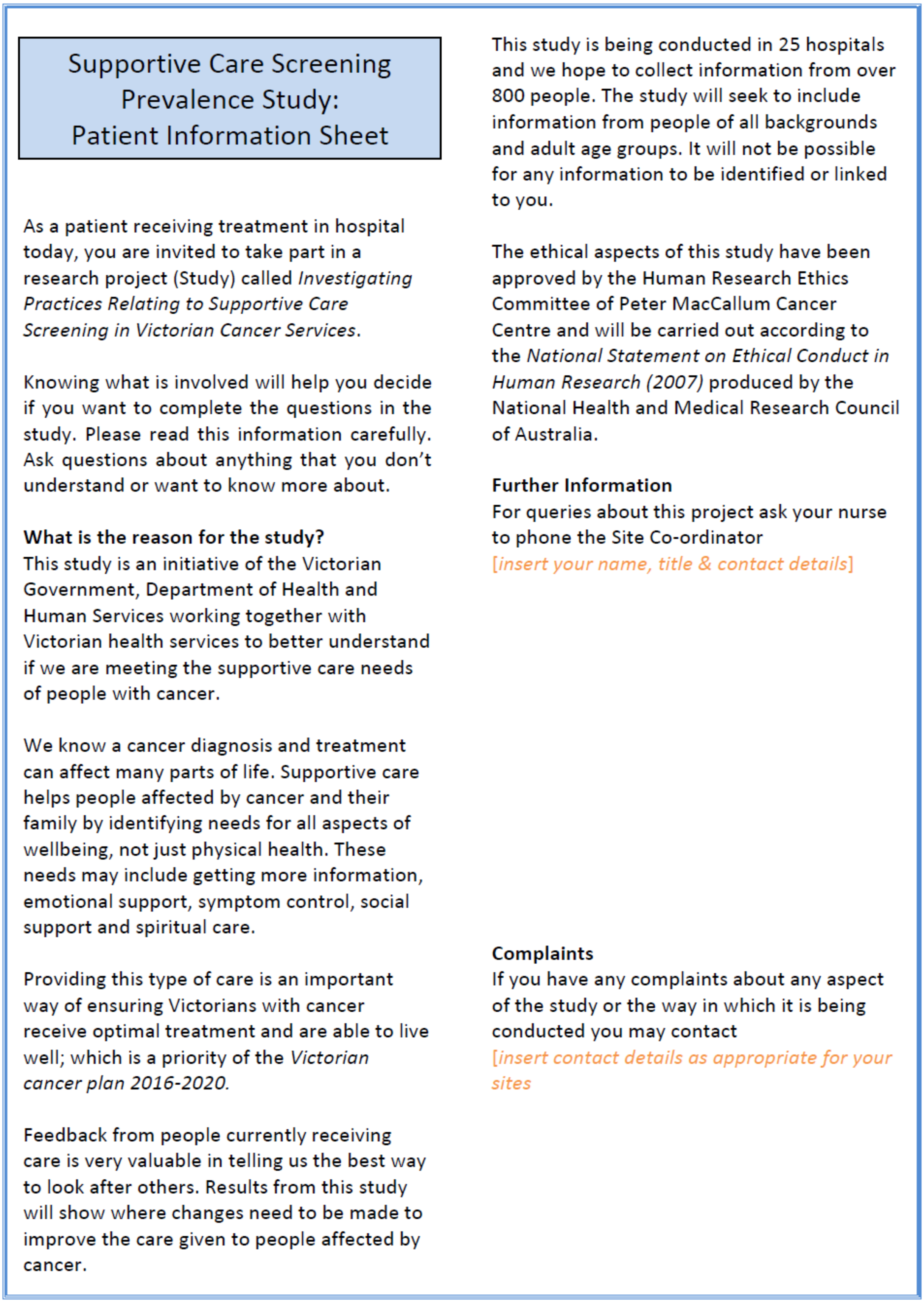
- *Practical Problems – eg. Childcare. Housing, insurance/financial, transportation, work/school*
- *Family Problems – eg Dealing with children, partner, ability to have children*
- *Emotional problems – eg Depression, fears, nervousness, sadness, worry, loss of interest in usual activities*
- *Spiritual/Religious Concerns*
- *Physical Problems – eg Appearance, bathing/dressing, breathing, changes in urination, constipation, eating, fatigue, pain, sexual, sleep, tingling in hands/feet*

G) Was this referral a result of a completed SCST?
Choose YES if documented evidence present that the referral was made to address an issue that was identified by an SCST completed anytime since diagnosis.
Choose NO if documented evidence present that the referral was not made in response to an issue that was identified by an SCST completed anytime since diagnosis.
Choose UNKNOWN if no evidence present for the reason that the referral was made.

H) Location of referral - Choose location of referred professional, if known.

I) Is there evidence of uptake of referral?
Choose YES if there is evidence of uptake of appointment in medical record eg. Assessment, outcome from appointment, note.
Choose NO if no evidence present.

Appendix 9 – Patient information sheet



Supportive Care Screening Prevalence Study: Patient Information Sheet

As a patient receiving treatment in hospital today, you are invited to take part in a research project (Study) called *Investigating Practices Relating to Supportive Care Screening in Victorian Cancer Services*.

Knowing what is involved will help you decide if you want to complete the questions in the study. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

What is the reason for the study?
This study is an initiative of the Victorian Government, Department of Health and Human Services working together with Victorian health services to better understand if we are meeting the supportive care needs of people with cancer.

We know a cancer diagnosis and treatment can affect many parts of life. Supportive care helps people affected by cancer and their family by identifying needs for all aspects of wellbeing, not just physical health. These needs may include getting more information, emotional support, symptom control, social support and spiritual care.

Providing this type of care is an important way of ensuring Victorians with cancer receive optimal treatment and are able to live well; which is a priority of the *Victorian cancer plan 2016-2020.*

Feedback from people currently receiving care is very valuable in telling us the best way to look after others. Results from this study will show where changes need to be made to improve the care given to people affected by cancer.

This study is being conducted in 25 hospitals and we hope to collect information from over 800 people. The study will seek to include information from people of all backgrounds and adult age groups. It will not be possible for any information to be identified or linked to you.

The ethical aspects of this study have been approved by the Human Research Ethics Committee of Peter MacCallum Cancer Centre and will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)* produced by the National Health and Medical Research Council of Australia.

Further Information
For queries about this project ask your nurse to phone the Site Co-ordinator
[*insert your name, title & contact details*]

Complaints
If you have any complaints about any aspect of the study or the way in which it is being conducted you may contact
[*insert contact details as appropriate for your sites*