User’s guide to surveying patients about their care experiences

The Victorian Patients’ Experience of Cancer Care Survey

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Contents

Glossary of Terms

Term	**Meaning**
ACCESS database	A database management system. It is one of Microsoft office's suite of applications.
HREC	Human Research Ethics Committee
Low and Negligible Risk Research projects	Low Risk research is research where the only foreseeable risk is one of discomfort. Negligible risk research is research where inconvenience is the only foreseeable risk to participants. Staff and patients surveys that do not include questions that have the potential to cause distress and are not about sensitive topics are generally considered Low or Negligible risk project. In addition most quality assurance activities fall into this type of research
Readability	How easily text is read and understood. In this report, readability is expressed as the education level (Year level) needed to read and understand the survey text.
Response rate	The proportion of people returning completed surveys.
SPSS	Statistical package for social sciences. A software package for statistical analysis.
Survey Module	A section of the survey that contains questions assessing a specific area of care, eg surgery, radiotherapy, information provision.
Study ID	A unique number assigned to each participant mailed a survey. The number is assigned to each survey sent to the patient.
Treatment specific survey	Only those patients attending a specific unit for cancer care (e.g. Chemotherapy Day Unit) are surveyed. A reduced version of the survey is completed.
'Whole of service' survey	All patients attending the treatment centre for any cancer treatment (e.g. surgery, chemotherapy, radiotherapy as an inpatient or as an outpatient) eligible for the survey. Patients complete the full survey.
VPECCS	Victorian Patients' Experience of Cancer Care Survey
95% Confidence Intervals (CI)	Provides a range around an estimate that, if the survey was repeated 100 times, for 95 of these repeats, the estimate obtained would fall within that range.

Introduction

The Victorian Patients' Experience of Cancer Care survey (VPECCS) is a questionnaire designed to collect information about the care experiences of patients treated for cancer in Victorian hospitals. The survey aims to understand patients' experiences regarding their interactions with health care providers and the provision of information and supportive-care services *throughout* the care pathway: from diagnosis and treatment through to follow-up. The information collected through the survey can be utilised by hospitals and health services in their quality improvement initiatives and provides a platform for comparing care experiences at a state and/or at a treatment centre level.

Background

The *2008-2011 Victoria's Cancer Action Plan* (VCAP) prioritised the need to create better experiences for cancer patients and their carers. To this end, the Patient Management Frameworks orientated the health system to ensure that quality cancer care included the delivery of both anti-cancer therapy and supportive care to patients and their families. Additionally the Victorian Department of Health's 'Clinical Excellence in Cancer Care' blueprint defined quality health care as that which meets the needs of the consumer.

Broadening the concept of quality health care to include the consumer's needs necessitates that quality assessments focuses on the interpersonal domains of care (eg supportive care, interactions with medical staff) along with the technical and environmental (e.g. facilities) domain in quality assessments. Patients' perceptions of the interpersonal, supportive and service delivery aspects of care have become an important component of quality care.

One approach to assessing patients' perspectives of the quality of care has been to ask patients whether specific events or care components occurred during their care, for example, whether they were told about possible side-effects of treatment. While several survey instruments assessing patient experiences of care have now been developed these have tended to focus on the experiences of a specific cancer (e.g. prostate (Tarrent et al, 2009) or breast cancer (de Kok et al 2010)), a specific treatment (e.g. chemotherapy (van Weert et al 2009), or a specific component of care (e.g. inpatient care) (Arraras et al 2009).

Few survey tools have assessed cancer patients' experiences of care across the care trajectory (from diagnosis through to cancer follow-up). The National Health Service (NHS) in the United Kingdom (UK) has developed a survey tool that assesses the diagnosis process, surgical care, care from hospital doctors and nurses, care delivered by general practitioners and the NHS overall. Questions assessing chemotherapy and radiotherapy experiences in this survey are limited with only two questions assessing chemotherapy and radiotherapy care in the 2014 and 2015 surveys with these questions differing in focus between the two surveys. In Canada, a different survey instrument was used to assess the care of cancer patients. This survey focused on the diagnosis and primary treatment phase of care with questions assessing diagnosis, treatment planning, surgical, chemotherapy and radiotherapy care, symptom management, interactions with health care providers and overall care. However as questions assessing symptom management and interactions with health care providers were not embedded into the different treatment modality sections (i.e., surgery), responses from this survey could not be used to assess patient-health care professional interactions within specific treatment units. The limited number of questions assessing chemotherapy and radiotherapy care in the NHS and the lack of specificity of questions assessing symptom management in the Canadian survey, neither adequately addressed the Victorian cancer reform priority areas across the entire care pathway.

Both the UK and the Canadian surveys take a similar approach to the phrasing of questions and response options, with both asking patients to report whether events happened during their care interactions. Similar response scales are used in both surveys with many questions responded to on either a frequency type scale (eg, “never” to “always; “yes definitely”, “yes to some extent”, “no not at all”) or scales indicating whether an event happened (eg, “yes”/”no”).

The Victorian Department of Health contracted the Centre for Behavioural Research in Cancer (CBRC) to engage in a program of work to develop and test a survey tool to assess adult cancer patients’ experiences of care across the care trajectory. As part of this work, 21 tools that assessed patients’ experiences of care were reviewed (See https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project for copy of report) . The tools were assessed according to whether they i) could be used with all cancer patients and ii) assessed experiences across the cancer care trajectory. Two survey tools were identified as meeting both criteria.

Consumers and health professionals were consulted to identify areas of care that were important in determining quality perceptions and to seek feedback on the suitability of the two identified survey tools (See https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project for copy of report). Forty-four consumers and 96 health professionals participated in this consultation process. The consultations suggested that neither survey tool was adequate, with both health professionals and consumers wanting items from the existing tools combined into a new survey. In response a new survey tool was developed that, following consumers’ feedback, was structured around the care trajectory, with the survey divided into sections relating to specific components of care. Cognitive testing of the new survey with 22 patients resulted in some revisions to a number of questions to clarify the meaning of the items.

Two pilot studies have assessed the use of the survey tool in assessing patients’ care experiences. A number of revisions were made to the survey tool after the first pilot study including: deleting a section assessing hormonal treatment, removing several questions including those assessing why patients did not have some treatments, revising questions assessing out of pocket costs and including questions assessing some supportive care events (e.g. assessing side-effects, providing information) in each treatment section.

The pilot studies also developed and tested a method for identifying and approaching patients to complete the survey, including developing a reminder schedule. The main method for identifying patients was through the Victorian Admitted Episodes Database (VAED) held by the Victorian Department of Health and Human Services. This database records dates and reasons for admission into all Victorian hospitals enabling identification of patients attending a specific hospital for a cancer-related episode of care. Using the VAED, a sample of eligible patients was identified. This list was then provided to participating hospitals, where it was merged with patient contact information. Hospital staff then mailed the survey to patients. Three hospitals (one metropolitan and two regional) participated in the first pilot study. The second pilot study involved two regional hospitals, three metropolitan hospitals and two treatment units (one regional and one metropolitan). This pilot study tested the revised survey as well as examining the impact of sending the survey invitation from the treatment centre or the Victorian Department of Health and Human Services, on response rates and responses. This pilot demonstrated that the organisation sending the invitation letter did not influence response rates or survey responses.

Purpose of this manual

In this manual we outline procedures for surveying patients attending Victorian health services for cancer care using the Victorian Patients’ Experience of Cancer Care Survey (VPECCS). We provide information about the survey tool including using the tool in its entirety or using survey modules, as well as information for administering the VPECCS at a Victorian based treatment centre. The information provided includes: methods for identifying eligible patients, conducting the survey, data entry, data analysis and reporting. A consistent approach to both administering and reporting the VPECCS will allow data from different sites to be compared across Victoria.

Detailed procedures for using the database developed for entering data from the survey can be found in a Data entry Manual located at [https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project]. Procedures for extracting data from the database into a file that can be analysed using the statistical package SPSS are described in the current manual. The current manual provides some information on using SPSS to analyse the survey data in Appendix 11.

Profile of the Victorian Patients’ Experience of Cancer Care Survey

The questionnaire consists of a total of nine modules relating to cancer care and one module assessing patient demographics. Of the nine modules relating to cancer care, seven focus on specific stages of care (e.g. diagnosis, surgery, chemotherapy, follow-up) and two assess overall experiences of care and information provision. In each module, survey items are structured to assess whether specific events happened during the patient’s care. Each treatment related module contains questions assessing: provision of information relating to treatment (e.g. what happens during treatment, possible side effects), interactions with health professionals including monitoring for side-effects, managing side-effects, scheduling appointments and waiting times at appointments.

Response scales

Similar to the NHS survey from the UK, the response scales used throughout the survey generally ask patients to report the frequency of an event occurring, the extent to which they are certain an event occurred, or whether the event happened or not.

For items assessing whether information was provided or whether patients had access to different services, the response scales used are generally:

a	(1) Yes definitely;	(2) Yes, I think so,	
	(3) No, I don’t think so,	(4) No, definitely not	
b)	(1) Yes definitely;	(2) Yes to some extent;	(3) No

Questions assessing how often events happened are generally responded to using the following response scales:

a	(1) All of the time;	(2) Most of the time;	
	(3) Some of the time;	(4) Rarely,	(5) Never
b)	(1) Yes always;	(2) Yes sometimes;	(3) No

In the section asking about information received, responses indicate whether the information was received, whether more information was wanted, whether the information was not received or whether the information was not needed. Response scales generally used are:

a)	(1) Yes;	(2) Yes, but I would have liked more;	
	3) No, I wasn’t given this information;	(4) I did not need this information	
b)	(1) Yes;	(2) No but I would have liked them to	(3) No but I didn’t need them to

Readability

Reading level for the survey was calculated using the computerised Flesh-Kincaid Grade level score. The reading levels of different modules in the survey are shown in Table1.

Table 1: Overall reading levels for each survey module

Module	Reading level Grade	Module	Reading level Grade
Survey Information	8	Deciding on treatment	11
Finding out what was wrong	11	Your Radiotherapy^	8-9
Your Surgery^	9	Emergency Department	10
Your Chemotherapy^	9	Information Received	9
Your Follow-up^	9-10	About you	7
Your overall care	9		

^After excluding medical words like chemotherapy, radiotherapy, lymphoedema

The survey information section refers to the first two pages of the survey where information about completing the survey is provided.

Currently the survey tool is only available in English.

Procedures

Questionnaire Format

A pencil and paper version of the survey was trialled in the two pilot studies and it is recommended to use this format of the survey.

Modules to be completed

The complete survey consists of nine care-related modules with a tenth module assessing patient demographics. It is possible to use the entire survey or to use specific treatment modules (e.g. surgery, radiotherapy, chemotherapy). The complete survey is shown in Appendix 1A. If a treatment module is to be used, it is recommended that all questions from the “Background” module, and several questions from the ‘Finding out’, ‘Deciding on Treatment’ and the ‘Overall care’ modules are also included. Including questions from these other modules will allow an assessment of the type of cancer the patient has, when they were first diagnosed, treatments undergone and provision of information regarding treatment. The questions from the three modules recommended for use when conducting a treatment specific survey are shown in Table 2 below.

Table 2. Questions from other modules suggested for inclusion with a treatment module survey.

Module	**Questions to be included**
Module 1: Finding out:	Q3, Q4, Q7
Module 2: Deciding on Treatment:	Q3 (revised to include treatment centre and other response—see below) Q4, Q5
Module 9: Overall Care	Q1, Q4, Q5, Q13
Module 10: Your Background:	All questions

When used in a treatment specific survey, the wording and format of Q3 in Module 2, ‘Deciding on Treatment’, has been changed to the format shown below. The revised format allows treatment centre information to be collected.

3 From the list below, please indicate the treatments you have had, or are having, for your cancer and the hospital or clinic where your received this treatment

☐$_1$ *Surgery* → *Hospital/Clinic Name__________________*

☐$_2$ *Radiotherapy* → *Hospital/Clinic Name__________________*

☐$_3$ *Chemotherapy* → *Hospital/Clinic Name__________________*

☐$_4$ *Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®)*

Other (please specify) ______________________________

Space for comments about care experiences should be allowed for in all surveys as this provides useful qualitative information about the patients' care experiences.

The questions recommended for use with a treatment module survey are shown in Appendix 1B.

If the treatment specific survey focuses on chemotherapy, also consider including the 'Emergency Department' module in the survey. Including the Emergency Department module will provide information regarding patients' experiences of having to attend an Emergency Department for the management of side-effects from their chemotherapy treatment.

Appendix 1C provides an example of the suggested chemotherapy specific survey.

Conducting the survey

This section provides information about conducting the survey at an individual hospital or unit.

Information on the need for ethical clearance, eligibility criteria, how to identify eligible patients, the timing of contacting patients about completing the survey including follow-up reminders and setting up a database to record contact with patients is provided. Information on the sample size and possible response rates to the survey is also provided.

This section assumes that a paper version of the survey will be mailed to patients.

Figure 1 outlines the main steps in conducting the study.

Ethical Clearance

The survey may need to be approved by the health service's Human Research Ethics Committee (HREC) or equivalent before it can be conducted. Contact the research office at your treatment centre to discuss the project and seek advice about the approvals needed for this study.

Most HRECs will have different application procedures for research projects that pose a "low or negligible risk" to research participants and those that pose a moderate to high risk. "Low risk research" is research where the only foreseeable risk for study participants is discomfort, while "negligible risk research" is research where the only foreseeable risk to participants is inconvenience. In the two pilot studies conducted with this survey, the survey was approved as a low or negligible risk research project at participating health services. Discuss conducting the project as a low/negligible risk research project with the Research Office.

Application forms for low or negligible risk projects will be available through your treatment centre's Research Office. The Research Office will advise you regarding the application forms that need to be completed for a low or negligible risk project and how you can access them. A research protocol may be needed for this application. A draft research protocol for a 'whole of service' patient survey is provided in Appendix 2A and a protocol for a treatment specific survey is shown in Appendix 2B. These documents can be used as a starting point for your survey's protocol.

Preparing the ethics application forms may take some time as information regarding budget and signatures from Heads of Departments may be needed. Once submitted, the application needs to be reviewed and approved. Discuss likely approval times with your Research Office.

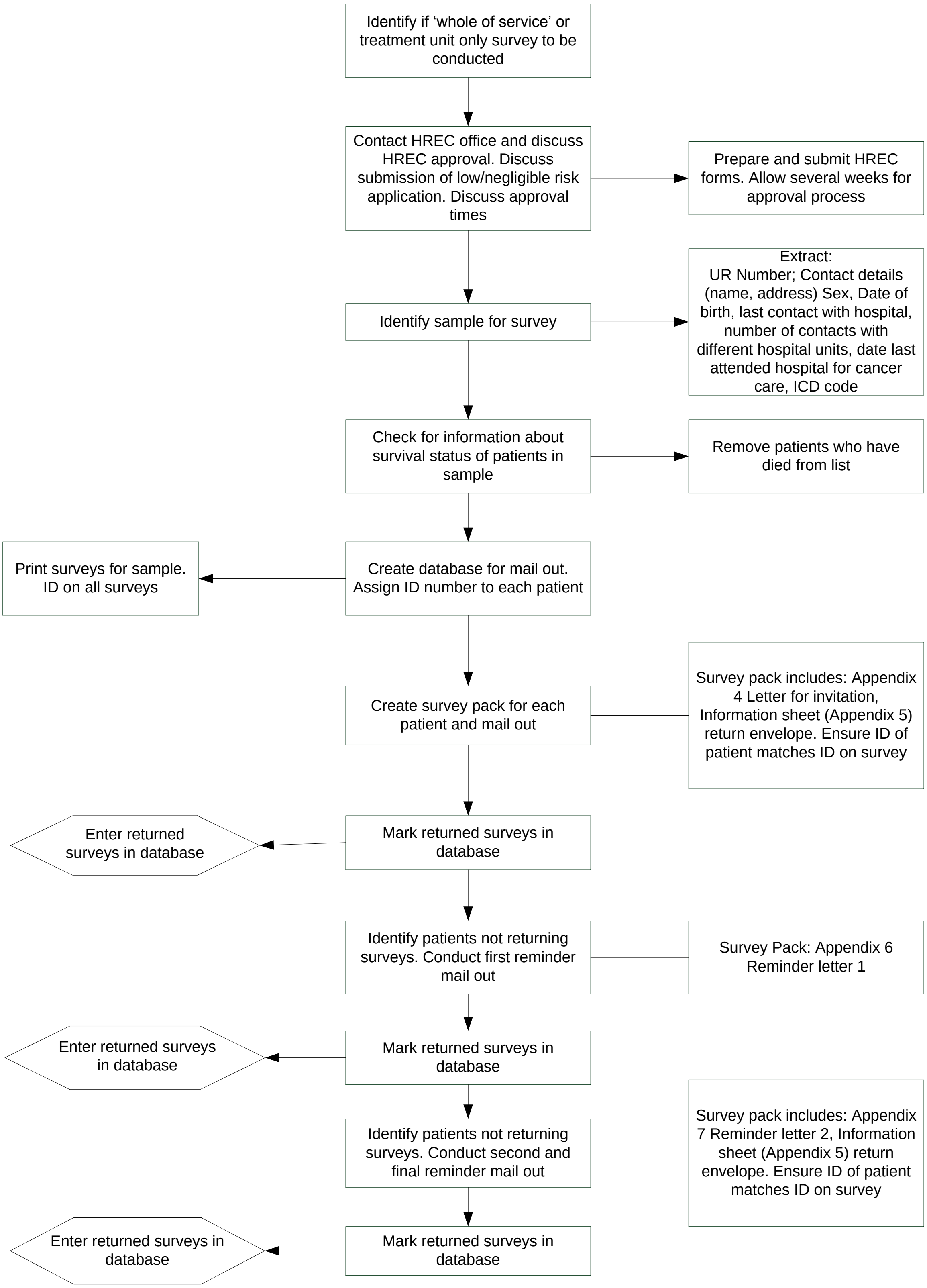


Figure 1: Overview of survey procedures

Eligibility Criteria

The inclusion and exclusion criteria for the survey sample are:

Inclusion

- diagnosis of invasive cancer with an ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or in situ breast cancer (ICD code D05);
- aged18 and over;
- a cancer episode of care as either an inpatient or a day patient during the study period;
- English speaking.
- Alive at time of approach.

Exclusion

- Exclude patients if previous cancer diagnosed 2 to 5 years ago. (Note this exclusion criteria may not be needed if only patients from a specific treatment unit are being surveyed.)
- Exclude patients that have not had treatment within 6 months of a biopsy. (Note this exclusion criteria may not be needed if only patients from a specific treatment unit are being surveyed.)
- Exclude in situ patients (excluding breast), non-melanoma or early melanoma (levels 0-III) cases (C44). (Note this exclusion criteria may not be needed if only patients from a specific treatment unit are being surveyed.)
- Exclude patients discharged to somewhere other than a private residence/ accommodation (e.g. exclude if discharged to a nursing home).
- Exclude patients who need an interpreter.
- Exclude if patient has been selected for another internal survey within previous 12 months.

Sampling frame and sampling method

Sampling for a 'whole of service' survey

In a 'whole of service' survey all patients attending the health service for any cancer treatment are eligible to be surveyed, and the full survey is used. This section provides information on selecting a sample of patients attending the health service for any cancer treatment.

Before starting on the process of selecting the study sample, ascertain if the treatment centre's central database includes information for all cancer patients attending the health service for treatment. That is, ensure that patients attending the health service for outpatient care are recorded in the central database. If the central database does not include all cancer patients strategies for combining data from multiple databases and removing multiple records for the same patient will need to be established.

Using the treatment centre's central database, or the combined list of all cancer patients, identify all patients meeting the eligibility criteria specified above.

Extract from the database:

- Hospital Unit Record number
- Contact details: name (First and surname and preferred title), address, phone number
- Sex and date of birth
- Last contact with hospital
- Date last attended for cancer related care
- Units attended and last unit attended
- ICD code

Defining the sample

Compile a list of eligible patients who have attended the service for a cancer related episode of care within the previous 12 months.

The list should only include patients once. If a patient is listed multiple times, their information should be consolidated into a unique case.

Order patients by date of last contact with hospital for cancer related care. Determine the number of unique patients on the list.

If there are more patients than the number required: Starting from the most recent date, count backwards until the required number of patients is obtained. This group will form the patient list.

If there are fewer patients than the number required: Increase the sample size by including eligible patients who attended the service up to 18 months previously. Identify duplicate patients on the complete list and consolidate these into a unique case. Order patients by the date of last contact and again determine the number of patients on the list.

Sampling for a 'treatment specific' survey

Sampling patients for a treatment specific survey follows the same procedures as sampling for a 'whole of service' survey except that rather than selecting patients who have had any cancer related treatment, only those patients having a specific treatment are selected. If the treatment unit's database can be used to identify all patients attending the centre for that treatment over a specific period of time, that database should be used. If the treatment unit's database cannot do this, then the health service's central database should be used.

Extract from database:

- Hospital Unit Record number.
- Contact details: name (First and surname and preferred title), address, phone number.
- Sex and date of birth.
- Last contact with hospital.
- Number of contacts with treatment unit.
- Last contact with treatment unit.
- Date last attended health service for cancer related care.
- ICD code.

Follow procedures described under 'Defining the sample' above to compile the sample list for surveying.

Facilities that deliver only one treatment modality

It would be preferable not to go back further than 18 months to identify patients. If the required number of patients is not achieved by selecting patients attending the service over an 18-month period, determine whether the smaller sample size can be used. If not, plan to collect data over two periods of time: first from patients attending the service in the previous 18 months, and then from the unique group of patients attending the service in the next 6 months. Data from the two surveys can be combined.

Removing patients who have died from the sample list

Before conducting the mail-out it is important that the list is checked to determine whether any patients have died. It is understood that the hospital may not know of all deaths, especially if a death did not occur at the hospital. However, if someone did die at the hospital, it is important that that information is accessed and used to check the status of patients on the sample list. While most relatives will understand that hospitals may not be aware of someone's death if that death occurred elsewhere, they may be less sympathetic if the death occurred at the hospital and the hospital appears to be unaware of this death. Therefore it is essential that the patient list be checked against information regarding deaths at the hospital.

Repeat the death check process before every mail-out to patients.

Sample size

If you have access to a statistician, they could be consulted to assist with determining an appropriate sample size for your centre's survey. Information the statistician may want to know includes:

- Number of unique patients treated at the service over a 6- or 12 month period.
- The number of patients with different cancers;
- If you are doing a whole of service survey, the proportion of patients likely to have chemotherapy and/or radiotherapy at the treatment centre;
- The type of analysis you want to do—ie, reporting results for the entire sample only or for subgroups (different types of cancers, men and women, age groups); change in results between surveys;
- Likely response rates to the survey.

Some information regarding response rates and the proportion of patients likely to have the different treatments at the health service they were recruited through, obtained from the pilot studies is provided below.

The health service's patient profile should be used to determine the mix of cancers attending the service for treatment

Considerations when determining sample size

Proportion of patients likely to have different treatments at a health service

Using data from the second pilot study, Table 3 shows the proportion of patients participating in the second pilot study, having surgery, chemotherapy and radiotherapy and the proportion having these treatments at the treatment centre they were recruited through (Note: two treatment centres did not have a co-located radiotherapy unit).

Table 3 shows that a sizeable proportion of patients treated for cancer at one hospital will have some of their care at another hospital. This movement of patients between treatment services needs to be considered in sample size calculations if a central database is used to identify patients for the survey and the survey aims to determine experiences across multiple treatment modalities.

Table 3: From Pilot study 2: the proportion of patients having different cancer treatments and the proportion treated at their recruiting hospital

	Surgery (%)	Chemotherapy (%)	Radiotherapy	
			Unit not co-located (%)	Unit co-located (%)
Had treatment	71	71	31	49
Of those having treatment, % treated at recruiting hospital	70	84	62	81
% of all patients having the treatment, treated at the recruiting hospital	50	60	19	40

Response rates

Not all patients who are sent a survey will return a completed survey. In the second pilot study, two reminder letters were sent to non-respondents and an overall response rate of 56% was achieved.
If two reminders cannot be used, the response rate will be lower. For example, the first pilot study used only 1 reminder letter and achieved a response rate of 45%.

Recommended sample sizes

For treatment centres delivering more than one treatment modality, a sample size of between 150 and 200 completed questionnaires per treatment modality assessed is recommended.
For treatment centres that deliver only one type of treatment modality, aim to collect around 100-120 completed surveys.

Examples: Working out the number of surveys to send out

1) A health service wants to survey patients about their cancer care experiences when having surgery at that service. They use a central admissions database to identify all patients having surgery for cancer at the health service. They aim to have 150 completed surveys from patients having surgery. If a response rate of 55% is achieved, the centre will need to send out 273 surveys to achieve 150 surveys from patients having surgery at the treatment centre.

e.g.: 273 * 0.55=200

2) A health service wants to survey patients about their cancer care experiences when having any cancer related treatment at that service. The service delivers chemotherapy care and surgical care to cancer patients. They use a central admissions database to identify all patients having any cancer treatment at their health service. They aim to have 150 completed surveys from patients having chemotherapy. Table 1 suggests that if they identify patients with a cancer diagnosis from their central database (with no consideration of treatment), 71% will have had chemotherapy with 84% having chemotherapy at that centre. With a response rate of 55%, the centre will need to send out 610 surveys to achieve 150 surveys from patients having chemotherapy at the treatment centre.

e.g.: 457 *0.55 * 0.71 * 0.84=150

Confidence errors around estimates

The survey aims to produce estimates of the percentage of patients indicating that a specific care event happened (e.g. 80% definitely received information about possible side-effects from chemotherapy). As a sample of patients treated at a clinic will be selected for surveying, it is important to consider the sampling error around any estimates produced. For percentages and proportions, the sampling error is commonly indicated by the 95% Confidence Interval (95% CI). The 95% CIs is based on both the size of the sample and the size of prevalence estimates and they are largest when the sample size is small and estimates are around 50%. For instance, with a sample size of 100, an estimate of 50% has a 95% CI of ±9.8%. A larger sample size will produce smaller 95% CIs around estimates. Appendix 2 provides an estimate of the 95% CIs for different sample sizes for different percentage estimates. The formula for calculating the 95% CI around a proportion is also shown in Appendix 3.

If the aim of the survey is to find out if there have been changes in patients' experiences over time, sample size also needs to be considered. A small sample size means that only very large changes will be statistically different. To determine the significance of a difference between two percentages, 95% CI around the difference can be calculated. If the 95% CI includes 0, the difference is not statistically significant. Table 2 in Appendix 2 provides estimates of the 95% CI for different percentage changes and for different sample sizes. The formula for calculating the 95% CI around a difference in percentages is provided in Appendix 3.

Conducting the mail out of questionnaires

For mailed questionnaires, a cover letter needs to accompany the survey. The cover letter should be on the treatment centre's letterhead. If the full survey is used, the Head of Cancer Services at the treatment centre should sign the letter. If a treatment module is used, the Unit's Head should sign the letter. An example letter is shown in Appendix 4. A survey information sheet and reply paid envelope for the return of the survey should be included in the mail out. A survey information sheet template is shown in Appendix 5.

Reminder letters will be needed. In the second pilot study two reminders were sent to non-responders. The first reminder consisted only of a reminder letter and was sent approximately 2 weeks after the first mail out. The second reminder consisted of a cover letter, the survey and a reply paid envelope. This reminder was sent approximately 4 weeks after the initial mail out. Examples of the first and second reminder letter are shown in Appendix 6 and 7 respectively. To achieve a response rate greater than 50% we recommend including the two reminders in the survey process.

The coloured text in the documents provided in Appendix 4 through 7 should be changed to suit your survey needs.

The initial approach letter should (see Appendix 4 for example):

- Be addressed to a specific patient. Use the patient's name in the salutation. Do not use a generic greeting.
- State why the patient is being contacted. This can include that they have attended the service for treatment.
- State what is being requested and include a return date for the survey.
- State that completing the survey is voluntary.
- Provide contact details of someone the patient can contact if they want more information about the survey or they have questions.
- Include a statement specifying what patients can do if they believe they have been sent the survey in error.
- Include a statement thanking the patient for considering the request.
- State that if you do not hear from them they will be contacted again in 2 weeks' time.
- Include signature of Head of Cancer Services or Head of Treatment Unit.

The first reminder letter should (see Appendix 6 for example)

- State that the patient was contacted previously and sent a survey.
- State why they are being contacted again.
- Include a statement thanking patients if they have already returned the survey.
- Provide contact details of someone the patient can contact if they want more information about the survey or they have questions.
- Provide details of how patients can receive another copy of the survey.
- State that if you do not hear from them they will be contacted again in 2 weeks’ time.
- State that completing the survey is voluntary.
- Thanks the patient for considering the request.
- Include signature of Head of Cancer Services or Head of Treatment Unit.

The second and last reminder letter should (see Appendix 7 for example)

- State that the patient was contacted previously and sent a survey.
- State why they are being contacted again.
- State that the survey has been included.
- Include a statement thanking patients if they have already returned the survey.
- Provide contact details of someone the patient can contact if they want more information about the survey or they have questions.
- Provide details of how patients can receive another copy of the survey.
- State that if you do not hear from them this time, they will not be contacted again.
- State that completing the survey is voluntary.
- Thank the patient for considering the request.
- Include signature of Head of Cancer Services or Head of Treatment Unit.

Patient confidentiality

Patients’ responses to the survey are anonymous and confidential. The survey should not contain any identifying information. An ID number needs to be assigned to the survey that will be linked to the patient on the sample database. The ID is used to monitor returned surveys and to identify patients that need reminder letters. To help ensure confidentiality of responses, the patient’s UR number should not be used as the survey ID. An identifier specific to this project should be used as the ID.

The survey information sheet that is sent to patients with their survey assures them that their responses are confidential. If comments are used in any reports, they must be presented in a way that does not identify the person making the comment.

Assigning a study ID to all patients in the study sample

Each patient should be assigned a study ID. This should be a 5 digit number in the form 10001, 10002 etc.

Each patient’s study ID, should be included in the participant database for the study and should be included in any correspondence to the patient and on all surveys sent to the patient. The patient’s ID should be placed on the top right hand corner of the survey.

Response to relatives of patients who have died

Despite efforts to remove people who have died from the sample list, it is likely that some surveys will be sent to people who have died. Relatives of deceased patients may be in contact to let you know this is the case. When this happened in the pilot studies, relatives generally wanted to inform the study team that the patient had passed away so that records could be updated. Any contact from bereaved relatives needs to be handled with sensitivity with the relatives knowing they are being listened too. If the relative wants further information or support, they can be referred to the Cancer Information and Support Service at Cancer Council Victoria on 13 11 20.

If a relative informs you that the patient has passed away please ensure that this is marked in the patient database and no further surveys are sent to this patient.

Logistics of conducting survey mail-out

The mail out will involve using the mail merge facility in word. For instructions regarding use of Mail Merge see Appendix 8.

Initial mail out

What is needed:

- Survey pack: consisting of: the information sheet, a questionnaire with ID, and a reply paid envelope.
- A4 Envelope for mail out.
- A cover letter for mail merge signed by Head of Department/Head of Unit,
- Address labels for envelope.
- Database containing patient contact details (name, postal address), Study ID.

Cover letter (see Appendix 4 for example) should be set-up for mail merge extracting patient name, address and ID from the patient database. Mail merge should place patient's study ID above the patient's name and address on the cover letter. Mail merge should ensure the patient's name is used in the salutation.

Labels for the envelope used to send the questionnaire to patients should be printed using mail merge facility available in Microsoft Office.

The printed cover letter, the survey pack with the matching ID should be inserted into the A4 envelope. The matching label should be adhered to the front of the envelope.

The ID on the cover letter needs to match the ID on the survey. The name on the cover letter needs to match the name on the envelope's label. Please double-check that the Survey ID, the ID on the cover letter and name on the cover letter and envelope match.

Reminder mail outs

Using the study database, identify patients who have not returned their survey and who have not withdrawn from the study. This set of patients will be used for the mail merge. If using Excel for the contact database, use the filter option to identify patients who have not returned the survey (see below).

<u>First reminder:</u> send only the reminder letter (Appendix 6).

Identify patients who have not returned their survey and who have not withdrawn from the study in the database. This set of patients will be used for the mail merge.

What is needed:

- Window DL envelope
- The first reminder letter signed by Head of Department/Head of Unit,
- Database containing patient contact details (name, postal address), Study ID.

Mail merge the reminder letter with contact details and Study ID from database. The person who signed the first letter should sign the reminder letter. The salutation should be individualised to the patient. The letter can be sent in a window DL envelope.

<u>Second reminder:</u> send the entire survey pack with the second and final reminder letter.

Identify patients who have not returned their survey and who have not withdrawn from the study in the database. This set of patients will be used for the mail merge.

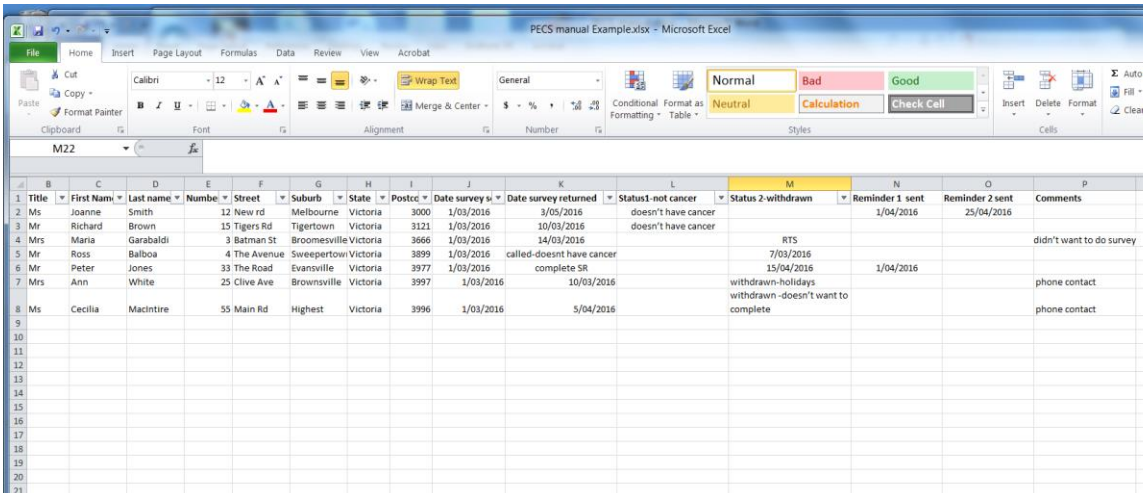
Follow the same procedure as for the first mail out for creating the mail out package. Please double-check that the ID on the survey and the cover letter match and that the name on the cover letter and the envelope label match.

Study database

Develop a study database to manage the mail-out, reminders and return of surveys. Excel can be used for this purpose as it can be used in the mail merge facility in Word. A simple database in Excel will consist of a worksheet with the following column headings:

- Study ID.
- Title.
- First name.
- Last Name.
- Street number.
- Street.
- Suburb.
- State.
- Postcode.
- Date survey sent.
- Date survey returned.
- Status1-no cancer.
- Status2-withdrawn.
- Reminder 1 sent.
- Reminder 2 sent.
- Comments.

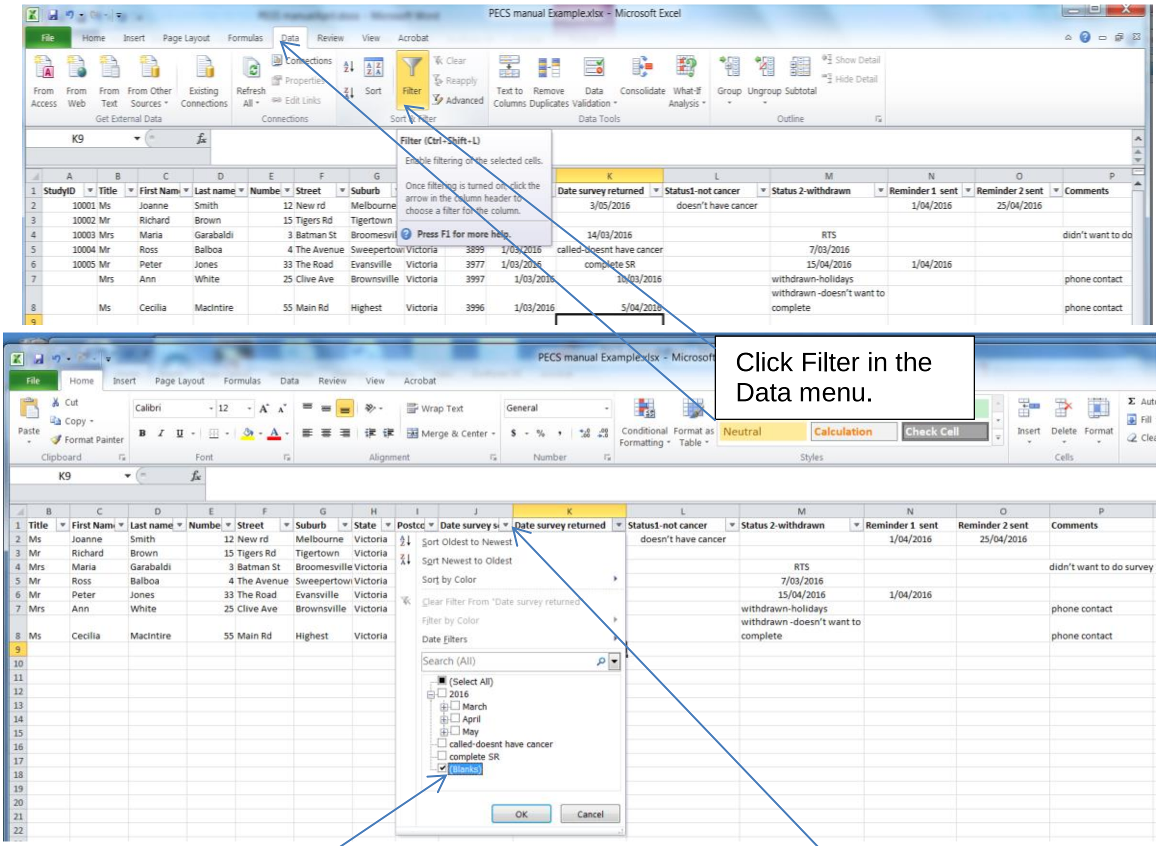
An example of an excel database is shown below and in Appendix 9.



	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
1	Title	First Nam	Last name	Numbe	Street	Suburb	State	Postcc	Date survey s	Date survey returned	Status1-not cancer	Status 2-withdrawn	Reminder 1 sent	Reminder 2 sent	Comments
2	Ms	Joanne	Smith	12	New rd	Melbourne	Victoria	3000	1/03/2016	3/05/2016	doesn't have cancer		1/04/2016	25/04/2016	
3	Mr	Richard	Brown	15	Tigers Rd	Tigertown	Victoria	3121	1/03/2016	10/03/2016	doesn't have cancer				
4	Mrs	Maria	Garabaldi	3	Batman St	Broomesville	Victoria	3666	1/03/2016	14/03/2016		RTS			didn't want to do survey
5	Mr	Ross	Balboa	4	The Avenue	Sweepertowı	Victoria	3899	1/03/2016	called-doesnt have cancer		7/03/2016			
6	Mr	Peter	Jones	33	The Road	Evansville	Victoria	3977	1/03/2016	complete SR		15/04/2016	1/04/2016		
7	Mrs	Ann	White	25	Clive Ave	Brownsville	Victoria	3997	1/03/2016	10/03/2016		withdrawn-holidays			phone contact
8	Ms	Cecilia	MacIntire	55	Main Rd	Highest	Victoria	3996	1/03/2016	5/04/2016		withdrawn -doesn't want to complete			phone contact

In the database enter the dates when surveys are sent, the dates when surveys are returned, dates when patients contact the study co-ordinator to withdraw from the study.

Use Excel's Filter options to identify patients who have returned or not returned their survey. The Filter option can be turned on by highlighting the column you want to filter, then in the Data menu, click on the filter option (see image below). To identify patients who have not returned a survey and need a reminder letter, click on the filter icon in the column header, and tick the box marked 'blank', and untick all other boxes shown (see image below). Only those patients who have not returned their survey will be shown in the work sheet. Use this filtered worksheet to conduct the next mail merge for the reminder letters.



Filter (Ctrl+Shift+L)

Enable filtering of the selected cells.

Once filtering is turned on, click the arrow in the column header to choose a filter for the column.

Press F1 for more help.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
1	StudyID	Title	First Nam	Last name	Numbe	Street	Suburb	State	Postcc	Date survey s	Date survey returned	Status1-not cancer	Status 2-withdrawn	Reminder 1 sent	Reminder 2 sent	Comments
2	10001	Ms	Joanne	Smith	12	New rd	Melbourne	Victoria			3/05/2016	doesn't have cancer		1/04/2016	25/04/2016	
3	10002	Mr	Richard	Brown	15	Tigers Rd	Tigertown	Victoria								
4	10003	Mrs	Maria	Garabaldi	3	Batman St	Broomesville	Victoria			14/03/2016		RTS			didn't want to do survey
5	10004	Mr	Ross	Balboa	4	The Avenue	Sweepertowi	Victoria	3899	1/03/2016	called-doesnt have cancer		7/03/2016			
6	10005	Mr	Peter	Jones	33	The Road	Evansville	Victoria	3977	1/03/2016	complete SR		15/04/2016	1/04/2016		
7		Mrs	Ann	White	25	Clive Ave	Brownsville	Victoria	3997	1/03/2016	10/03/2016		withdrawn-holidays			phone contact
8		Ms	Cecilia	MacIntire	55	Main Rd	Highest	Victoria	3996	1/03/2016	5/04/2016		withdrawn -doesn't want to complete			phone contact

■ (Select All)
☐ 2016
☐ March
☐ April
☐ May
☐ called-doesnt have cancer
☐ complete SR
☑ (Blanks)

OK   Cancel

Click Filter in the Data menu.

Tick the Blanks option to display only those cases with no return date in this column.

Click arrow to display filter options.

Returned Surveys

When a survey is returned, check responses for completeness and/or comments from patitents. Move any blank surveys to a separate pile. Read any messages from patients and identify any indicating they were sent the survey incorrectly or that they do not want to do the survey.

Mark off returned surveys in the contact database.

Recording returned surveys

- In a column headed ‘Date survey returned’ enter the date the survey was received for each returned survey regardless of whether the survey was completed or not. If the survey was returned blank and the patient indicated that they did not have cancer or survey was sent to them in error, please indicate this reason in the column headed “Status 1-no cancer’. If the survey was returned blank or return to sender (RTS) record this in the column headed “Status 2-withdrawn’. Add new reasons for withdrawal as needed. Record any reason for declining to do the survey in the comments column.
- If the patient phones to withdraw from the survey, record the date of the phone contact in the ‘Date survey returned’ column of the database. Indicate that the patient has withdrawn in the ‘Status2-withdrawn’ column. Record method of contact and any reasons patients gave in the comment column.

Data entry of returned surveys

Before surveys are entered, each one should be checked to examine responses given.

For some questions, patients may tick a response and also write a response in the comment section. Examine responses and determine whether the comment and response match. If the responses do not match determine whether information can be retained or whether it should be coded ‘88’ multiple response or 77 invalid response.

Please examine the name of hospitals or treatment centres written in the different modules of the survey. Ensure that there is consistency in the name patients provide for the different treatment centres.

If responses are changed in this review process, please make it clear which response is to be entered in the database and initial any changes on the survey.

ACCESS database for data entry

An ACCESS database has been developed for data entry. ACCESS software is available in Microsoft Office packages.

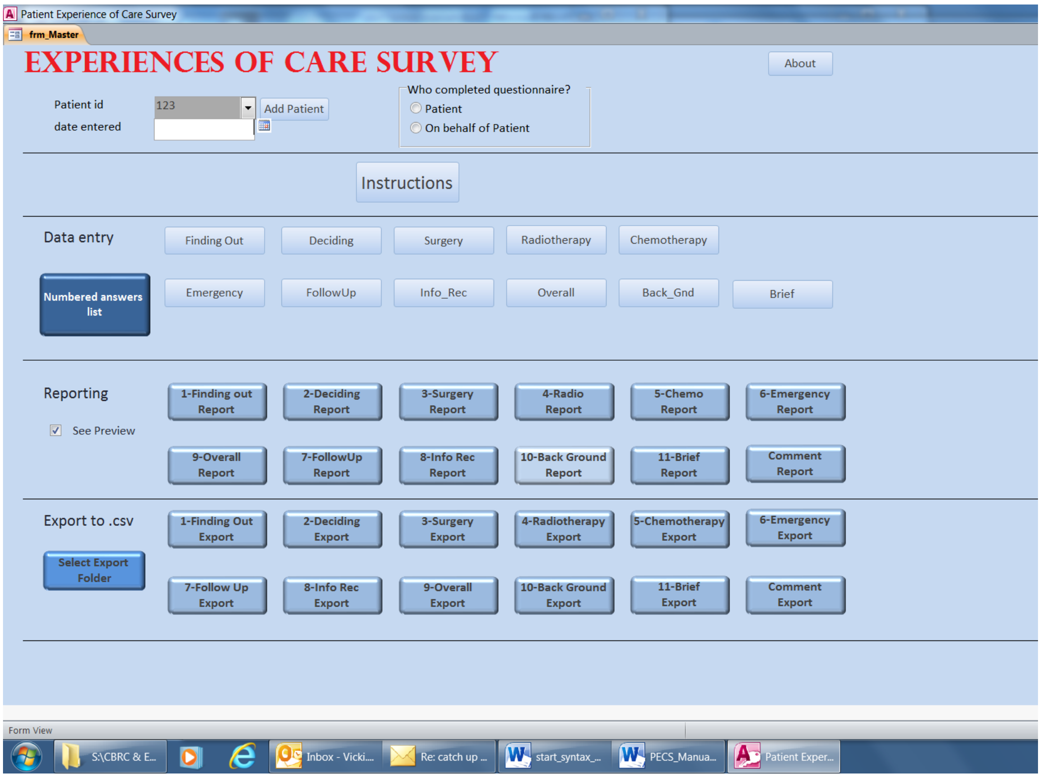
To be able to use the database, you will need to have the Microsoft ACCESS database program installed on your computer.

The ACCESS database and procedures for using it for data entry are provided separately in the database manual which can be downloaded from https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project.

General information about entry of the surveys is provided here. See the database manual for specific information on using the database for entry.

Access Database Landing Page

The landing page for the database is shown below.


Patient id 123
date entered
Who completed questionnaire?
○ Patient
○ On behalf of Patient
☑ See Preview

The landing page is divided into four sections. The first section defines the patient through their ID and indicates when the survey was entered and whether the patient completed the survey or not.

The second section relates to data entry. There is a data entry module for each module in the survey and for the introduction questions for the treatment specific survey (Brief). Clicking on these buttons opens up the data entry window for the specific survey module.

The third section relates to generating frequency reports for each module. Clicking on these buttons will show a report that displays a frequency count of responses for each question in the module. A button also displays a report for all comments in the survey. This report collates the comments across the different survey modules. If you have a large number of surveys with lots of comments this could be a large report.

Section four relates to exporting the data for each module into a format that can be imported into a statistical analysis package for example SPSS. Clicking on each button exports the data for that module into a specific .csv data file. A *.csv file is a file that uses a comma to separate variables. The .csv data file can be opened in Excel. You can set the location for the data export using the ‘Select Export Folder’ button. This will let you browse your computer or your network to locate a folder for exporting the data into. Once a folder is selected all data will be exported to this folder. This choice will stay in place until another location is specified.

General data entry procedures

Responses to each question are indicated by a numbered code. The subscript numbers beside response boxes indicate the number code assign to each response (typically 1-10). E.g. ☐$_1$ ☐$_2$ ☐$_3$. The number next to the boxed ticked by the patient should be entered.
Throughout the survey, specific codes should be used when a question is

- not answered and it should be—a missing response,
- more than one option is ticked—a multiple response,
- the answer does not make sense—an invalid response,
- question is validly left blank-- question is not applicable and skipped.

The codes to be used for these responses are shown in Table 4.

Table 4: Codes to be used when answers are: missing, multiple responses or invalid responses are given

Type of response	Code	To be used when:
Skipped/Not applicable	55	No response is given because (a) skip question or (b) not required to answer for valid reasons
Invalid response	77	Response is not a possible value or is not one of the allowed responses (for ticks marked between boxes this should be entered as invalid rather than missing)
Multiple response	88	More than one response has been given for a single response question
Missing response	99	No response is given (response left blank)

Most questions ask for only one response to be entered and the data entry system will only allow one response for these questions. Some questions allow patients to select more than one response. For these questions each response option is shown on the data base and the button next to the item needs to be ticked if that option was ticked on the survey. You only need to tick the items that are ticked on the survey. The survey modules and questions that allow multiple options to be ticked are:

Deciding on treatment:	Q3. What treatment/s have you had, or are you currently having, for your cancer (tick all that apply)?
Follow-up care:	Q1 Which doctor is mainly in charge of your follow-up care (if there is more than one doctor please tick all that apply)?
Overall Care:	Q2: Which doctor/s were in charge of your care (tick all that apply)?

For these questions you can enter each response option ticked by the patient. For example, if the patient indicated their follow-up care was overseen by their haematologist and their GP, enter as follows:

Surgeon:	☐
Haematologist:	✓
Medical oncologist	☐
Radiation Oncologist:	☐
GP:	✓
Other doctor:	☐
Other	☐
I am not sure:	☐

Recoding of hospitals attended for each treatment modality, emergency department care and follow-up

Respondents are asked to write the name of the treatment centre where they had surgery, chemotherapy, radiotherapy, follow-up care and if they attended an Emergency Department (ED) the name of the ED's hospital.
Enter the name of the treatment centre as text in the database. Please make sure that all text responses are entered in the same format, that is, enter all the text as lower case only or lower case with the first letter capitalised. Please ensure that the spelling of the hospital name is consistent across respondents.

Comments

At the end of each section of the survey, respondents are asked for any comments they might have on the care they received. Comments provided should be recorded and examined for themes. The database allows for the comments to be recorded. Please enter any comments patients may have made on their survey in the appropriate section of the database.

Skip questions and issues for each module in the survey

Questions and responses that require respondents to skip questions or provide a written response are specified below.

Module 1: Finding out

Q1a: Those choosing response 2 or 3 should answer Q1b. Everyone else skips Q1b .
Q3: For those choosing response 20 (Other), key in text as provided.
Q4: Key in as much of date as provided.

Module 2: Deciding on Treatment

Q2: Those choosing No (not having treatment) are skipped to the BACKGROUND module. Please confirm that the patient has not had any treatment for cancer. If the patient has responded to other sections of the survey capture all responses provided, even if participant should have skipped these questions.
Q3: Multiple response options allowed. There are 4 variables for this question representing each treatment modality. Please enter [1] for treatments ticked and [0] for treatments left blank.

Comments: Patients may provide a text response in several questions in this module. Please enter any text provided by the patient in the appropriate area.

Module 3: Surgery

Q1: Those choosing No are skipped to the next Module.
Q3: Hospital for surgery: Key in name of hospital provided; AND

Postcode/suburb town: Key in postcode only.
If suburb is provided, look up postcode for that suburb.

Q5a Those choosing response (1) should skip Q5b.
Q7a: Those choosing response (2) or (3) should answer Q7b.
Q7a: Those answering Other (5), enter text as provided.
Q7b: Those answering Other (4), enter text as provided.

Comments: Patients may provide a text response in several questions in this module. Please enter any text provided by the patient in the appropriate area.

Module 4: Radiotherapy

Q1: Those indicating they did not have Radiotherapy are skipped to the next module.
Q3: Hospital for radiotherapy: Key in name of hospital provided; AND
Postcode/suburb town: Key in postcode only.
If suburb is provided, look up postcode for suburb.
Q5a Those choosing response (1) will skip to Q7.
Q7a: Those answering Yes (1) should answer Q7b.
Q7b: Those answering Other (5), enter [1] if there are comments in the comments variable.
Q8a: Those choosing response (2) or (3) should answer Q8b.

Q8a: Those answering Other (5) enter text as provided.

Q8b: Those answering Other (4) enter text as provided.

Comments: Patients may provide a text response in several questions in this module. Please enter any text provided by the patient in the appropriate area.

Module 5: Chemotherapy

Q1: Those indicating they did not have chemotherapy are skipped the next module.
Q3: Hospital for chemotherapy: Key in name of hospital provided; AND
Postcode/suburb town: Key in postcode only
If suburb is provided, look up postcode for suburb.
Q4: Those answering Other (6), enter text as provided.
Q5a: Those answering No (1) skip to Q7.

Q7a: Those answering Yes (1) should answer Q7b.
Q7b: Those answering Other (5), enter text as provided.

Q8a: Those choosing response (2) or (3) should answer Q8b.

Q8a: Those answering Other (5) enter text as provided.

Q8b: Those answering Other (4) enter text as provided.

Comments: Patients may provide a text response in several questions in this section. Please enter any text provided by the patient in the appropriate area.

Module 6: Emergency Department care

Q1: Those indicating they have not gone to the Emergency Department (ED) (response 4) should go to the next module.
Q2: ED hospital: Key in name of hospital provided; AND
Postcode/suburb town: Key in postcode only
If suburb is provided, look up postcode for suburb.

Comments: Patients may provide a text response in some questions. Please enter any text provided by the patient in the appropriate area.

Module 7: Follow-up care

Q1: Multiple response options allowed. Please enter response [1] for each doctor indicated.
Q1: Those answering ‘Other’ enter text as provided.
Q1: Those answering ‘other medical doctor’: enter text as provided.
Q2: Hospital for follow-up: Key in name of hospital provided; AND
Postcode/suburb town: Key in postcode only.
If suburb is provided, look up postcode for suburb.

Comments: Patients may provide a text response in several questions in this module. Please enter any text provided by the patient in the appropriate area.

Module 8: Information received

Comments: Patients may provide a text response in some questions. Please enter any text provided by the patient in the appropriate area.

Module 9: Overall care

Q2: Multiple response options allowed. Please enter response [1] for each doctor indicated or for response ‘I am not sure who is in charge’.

Q1: Those answering ‘other medical doctor’: enter text in the space provided.

Q1: Those answering ‘Other’ enter text in the space provided.

Q4: Those choose response 2 or 3 will skip to Q8.

Comments: Patients may provide a text response in several questions in this module. Please enter any text provided by the patient in the appropriate area.

Module 10: Background

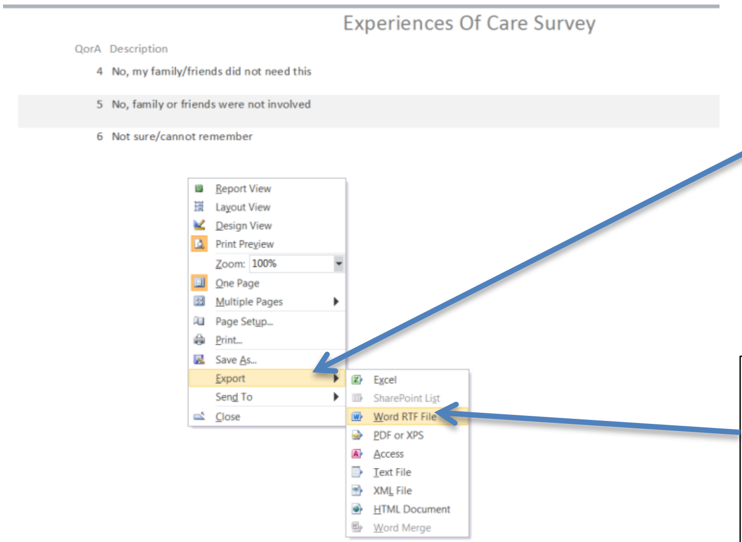
Q2: Key in age of respondent in years.

Q3: Key in name of suburb/town provided; AND
Postcode: key in postcode only.

Q4: For those who lived in different town when being treated for cancer, enter 2 for variable *txtlive*, then enter postcode of location in variable *txtlivepc*.

Saving the reports generated through the DataBase.

As indicated, the reports generated through the database will provide a frequency count of responses for each question in a survey module. Clicking on the report button for a module will generate and display the report. You can save the report by right clicking on the report page which will display a pop up box with different option regarding actions to take. Click on the Export option and a second pop-up box appears. This pop-up box specifies the format for exporting the report, click on the Word RTF option. After clicking on this option, a new window will pop up. This window allows you to specify where you want the file to be exported to. Use the browse option on this window to locate the folder you want to save the word document to. After providing a name to the file, click on OK to export and save the report. Screen shots describing this process are shown below.

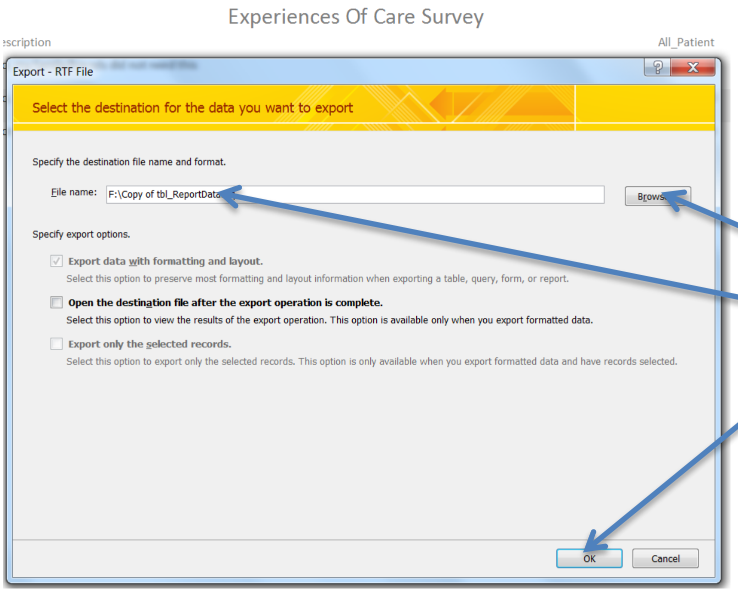


Experiences Of Care Survey

QorA	Description
4	No, my family/friends did not need this
5	No, family or friends were not involved
6	Not sure/cannot remember

Right clicking on the report page brings up the first pop up box. In this pop up box click on Export. This brings up a new pop up box.

Select the Word RTF file and click on this option. This will bring up the window below,



Experiences Of Care Survey

Export - RTF File

Select the destination for the data you want to export

Specify the destination file name and format.

File name: F:\Copy of tbl_ReportData

Specify export options.

☑ Export data with formatting and layout.
Select this option to preserve most formatting and layout information when exporting a table, query, form, or report.

☐ Open the destination file after the export operation is complete.
Select this option to view the results of the export operation. This option is available only when you export formatted data.

☐ Export only the selected records.
Select this option to export only the selected records. This option is only available when you export formatted data and have records selected.

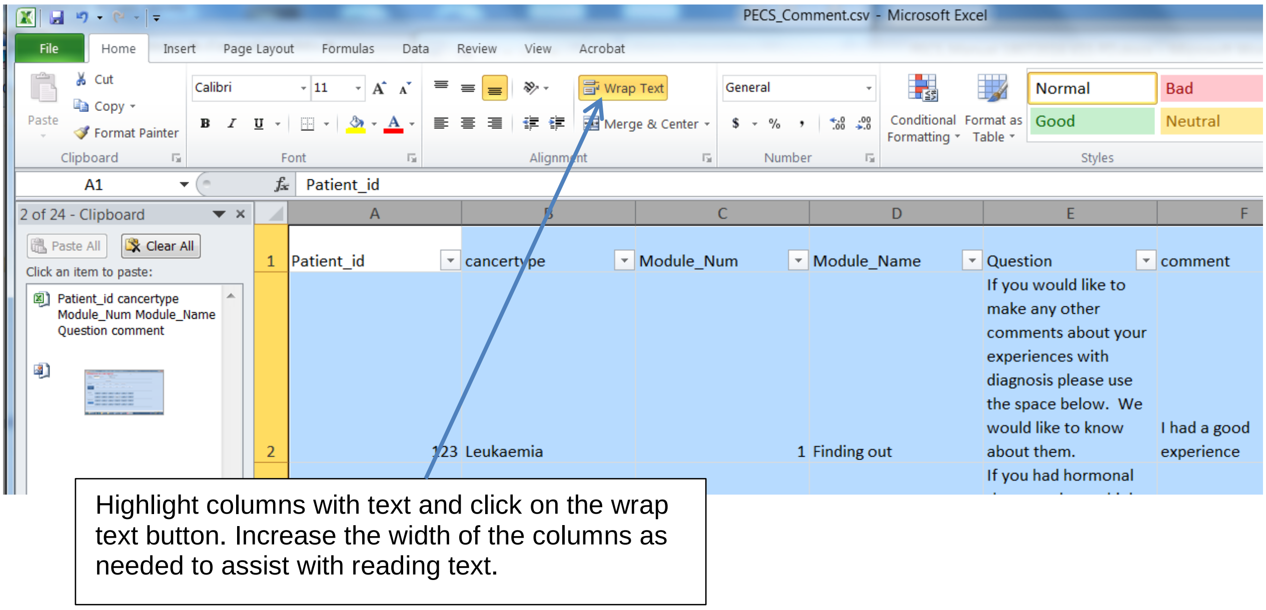
Use the browse function to locate the folder you want the report to be saved into. Change name if needed. Click on OK

Examining respondents' comments

Comments at the end of each module and at other sections of the survey are entered in the database. Respondents' comments can also be exported into a .csv file using the export button. The comments are exported to a file called **PECS_Comments.csv.**
The information exported into this file is:

Patient_id	Study Id of patient
cancertype	Type of cancer the patient has
Module_Num	The number of the survey module (eg, 5 for chemotherapy)
Module_Name	The name of the survey Module (e.g. Chemotherapy)
Question	Question number associated with the comment
Comment	Text of the comment.

Comments will be grouped by patients ID. To assist with reading, it is suggested that the columns in the Excel sheet are formatted with the text wrapping. A screenshot to do this is shown below

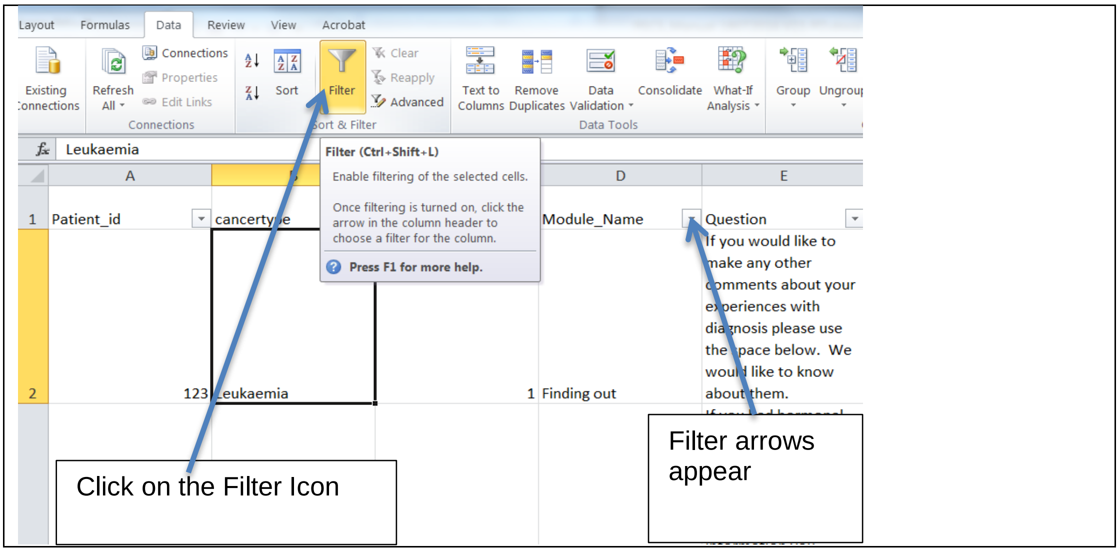


Patient_id

	A	B	C	D	E	F
1	Patient_id	cancertype	Module_Num	Module_Name	Question	comment
2	123	Leukaemia	1	Finding out	If you would like to make any other comments about your experiences with diagnosis please use the space below. We would like to know about them.	I had a good experience
					If you had hormonal	

Highlight columns with text and click on the wrap text button. Increase the width of the columns as needed to assist with reading text.

To identify all comments made for a specific survey module (e.g. surgery), turn the filter function on in Excel and then filter the data that you want to view. To turn the Filter function on, click on the Data tab and click on the Filter icon. Arrow boxes on row 1’s column labels will appear after clicking the Filter Icon. Click on the arrow and a box showing the type of entries in the column will be displayed. If all boxes are ticked, this means there is no filter on. Tick the “Select All” box to deselect all entries. Then tick the box next to the entry you want to filter the output by and click OK. Once this box is ticked only those responses with this response will be displayed.



Leukaemia

Filter (Ctrl+Shift+L)

Enable filtering of the selected cells.

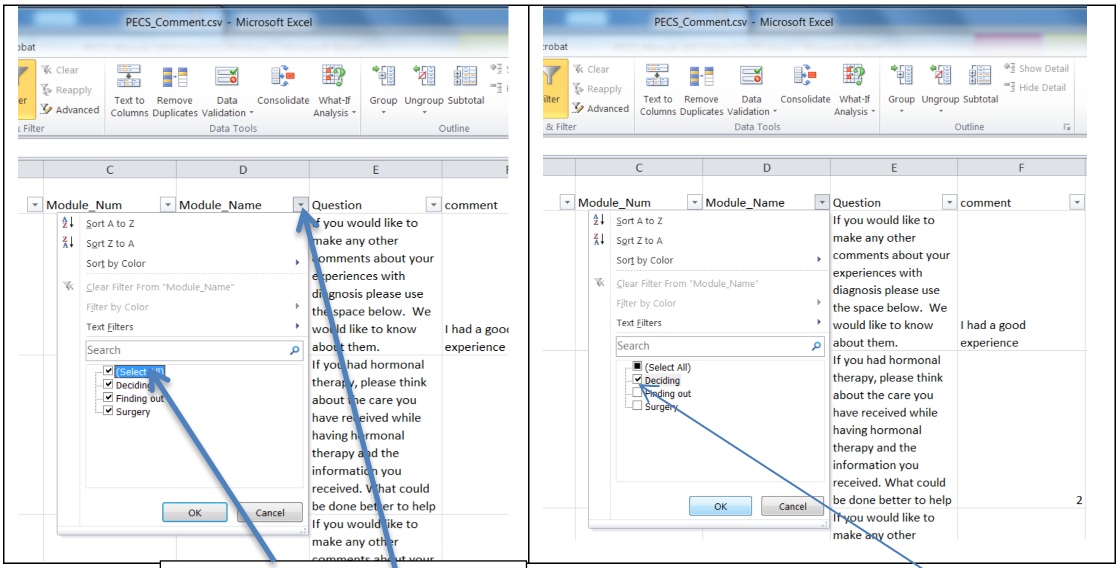
Once filtering is turned on, click the arrow in the column header to choose a filter for the column.

Press F1 for more help.

	A	B	D	E
1	Patient_id	cancertype	Module_Name	Question
2	123	Leukaemia	1 Finding out	If you would like to make any other comments about your experiences with diagnosis please use the space below. We would like to know about them.

Click on the Filter Icon

Filter arrows appear



If you would like to make any other comments about your experiences with diagnosis please use the space below. We would like to know about them.

I had a good experience

If you had hormonal therapy, please think about the care you have received while having hormonal therapy and the information you received. What could be done better to help

2

If you would like to make any other

Click on the arrow and the filter box appears. This will list all the types of entries in the column. All entries will be selected. Clicking on the box ‘Select All’ removes all ticks.

Tick the box next to the entry you want to filter responses by. Click OK to turn the filter on.

Display comments provided at the end of each module using the Filter function. Read through the comments with the aim of providing a summary of the comments provided by respondents in your reports. Comments will generally be able to be grouped into positive or negative comments and within these groups a number of common themes will emerge. Themes might relate to the professionalism of health professionals, the communication style of health professionals, the availability of car parking, information provision, etc. Note the number of people making a comment and the number making comments for the different themes. Report this information in your reports. Quoting some of the comments from patients in your report can help to demonstrate the different themes emerging from the comments.

Reporting results from the survey

When a ‘whole of service’ survey has been undertaken, reporting results from the survey will involve identifying patients having different treatments at the health service and those having all their treatment at the health service and reporting the percentage and number of respondents providing different responses to survey questions about their care. If a treatment module has been administered, all respondents will have attended the health service for that treatment. Therefore results will be based on responses for all patients returning the survey.

For survey questions asking about events experienced during care, responses indicating that the event definitely happened or happened at least most of the time suggest that optimal care was provided. Responses indicating that an event may have happened or happened but not all the time, suggest that optimal care was not delivered consistently to the patient.

Responses indicating that care events didn’t happen suggest that optimal care did not happen for the patient.

A ‘traffic light’ system has been developed for reporting results. This system provides a graphic demonstration of the percentage of respondents indicating that care was optimal (green), inconsistently optimal (amber) or not optimal (red).

Figure 2 below provides an example of a ‘traffic light’ graph showing the percentage of optimal, inconsistent optimal and not optimal responses from Hospital 1 for the question “health care professionals involved in my care regularly checked if I was experiencing any side effects”. The distribution of responses for the hospital can be compared to the distribution of responses obtained from public hospital patients in the two pilot studies.

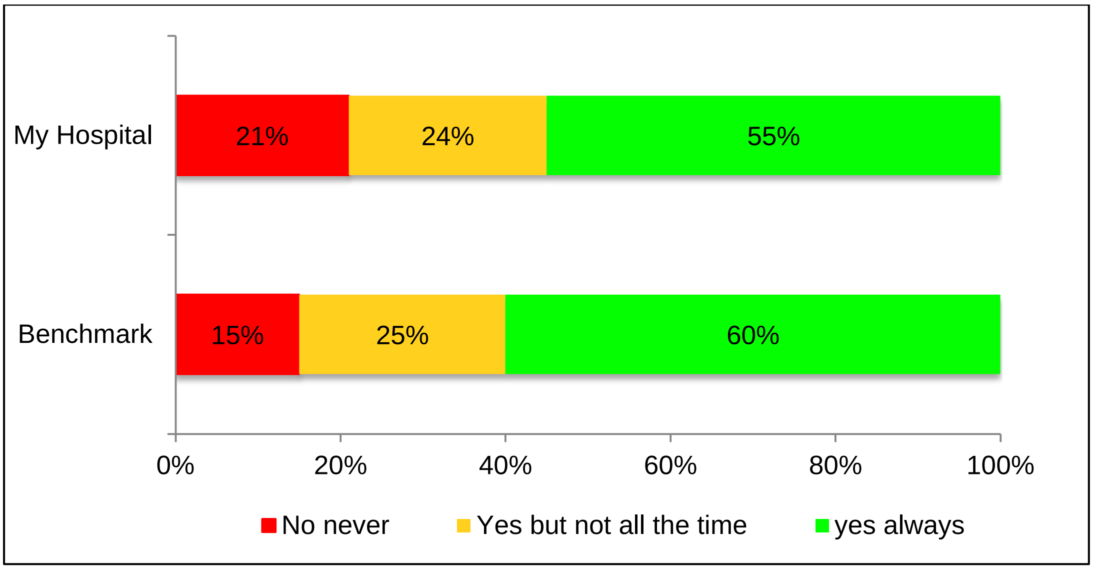


Figure 2: Example of a “traffic light” graph

An alternate way of presenting data from the survey in graphic form is to show the percentage of patients reporting a specific response for several different items in the one graph. An example of this presentation is shown in Figure 3 below. These graphs have been termed either optimal response graphs (when graph shows items that more than 85% of respondents indicated happened) or negative events (graph shows per cent of respondents indicating a negative event happened at least once during care (shown in Figure 3 below)).

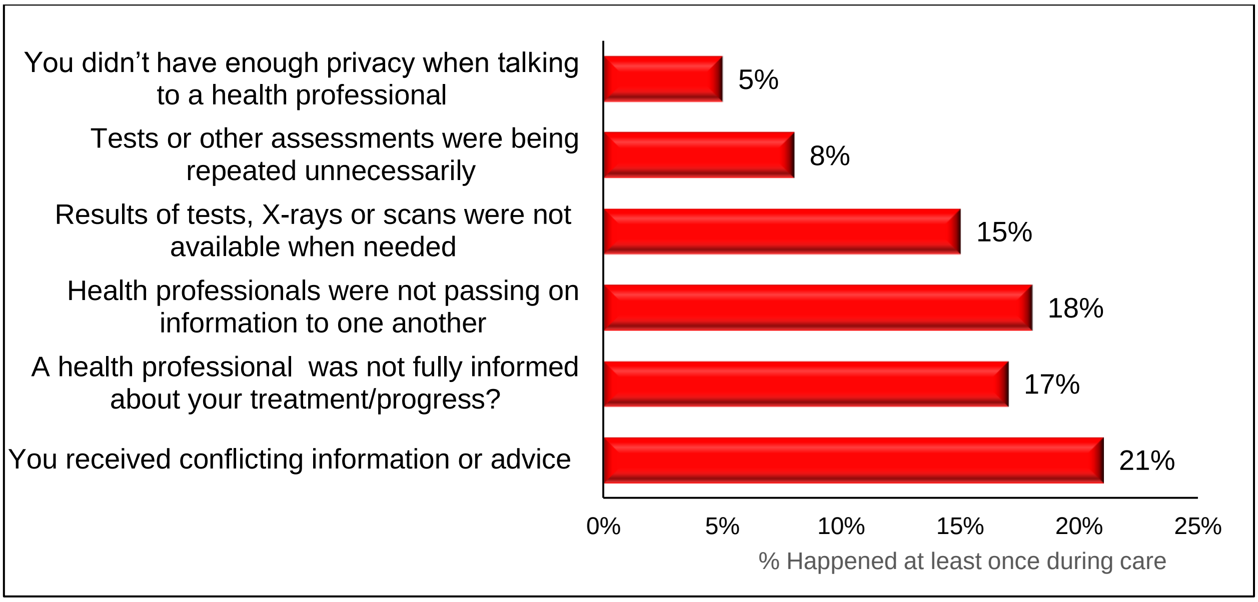


Figure 3: Example of negative event graph showing the percent of respondents indicating the event happened one or more times

Excel can be used to generate both sets of graphs. A series of Excel spreadsheets providing templates for different graphs and the tables needed to generate these graphs can be downloaded from https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project

There are two sets of templates. One set provides templates with comparison data from four metropolitan public hospitals. The second set provides templates with comparison data from four regional public hospitals. Use the set of templates appropriate to the location of your service. Please note that for items assessing diagnosis and deciding on treatment, the location of the treatment centre the patient was recruited through determines location for these responses. For items assessing overall care, information provision, identify patients having all their treatment at the recruiting health service. The location of this health service is used to determine treatment location for these items.

Table 5 shows the items in the different modules for which a template graph is provided.

Table 5: Survey items with template graphs shown in each Excel book

Excel book name	Questions
Surgery	Q7a, Q9a, Q10a, Q10b, Q11, Q14, Q17, Q18, Q20, Q21, Q22, Q23
Radiotherapy	Q8a, Q9a-9e, Q10, Q11, Q12, Q13, Q14, Q16, Q17,Q18, Q19, Q21
Chemotherapy	Q8,Q9a-9f, Q10, Q11, Q12, Q13, Q14, Q16, Q17, Q18, Q19, Q20, Q21
Treatment Satisfaction	Satisfaction: Surgery: Q24; Radiotherapy: Q22; Chemotherapy Q23, Overall Care: Q11 Respect and dignity: Surgery: Q19; Radiotherapy Q15, Chemotherapy: Q15
Optimal response and negative events	Optimal response Radiotherapy: Q9a, Q9c, Q9d, Q10, Q14, Q19 Chemotherapy: Q9a, Q9d, Q9e, Q9f, Q10, Q13, Q14, Q19, Q20 Negative event (happened at least once) Overall Care: Q3a-3f^

^ note metropolitan and regional data for comparison is based on location of respondent's recruitment hospital

The sample size for the comparison data is provided for each question in the template graphs. Due to differences in some questions used in the first and second pilot study, sample size may differ between items. You can use the sample size provided to determine the confidence intervals around estimates. You can also use the sample size to recalculate percentages shown if you want to exclude a response option from the analysis. This might be used if, for example, you wanted to examine a response about managing side-effects only for those people who experienced side effects (eg, Chemotherapy Module Question 14). By multiplying the sample size by the percent of respondents providing a response (expressed as a decimal) the number of respondents giving each answer can be determined. By subtracting the number of respondents giving the response you want to exclude from the total sample size, you will get a new sample size to base your results on. To determine the new percentages, divide the number of respondents giving each relevant answer by the new total respondents and multiply by 100 to get a percentage. Examples of these calculations are shown below in Table 6.

Table 6: How to calculate the number of respondents giving each response

Were you given information about how you would feel at the end of the chemotherapy treatment? (Total N=200)		% of all respondents giving each response	Number of respondents giving each response	% of valid responses (excludes not sure/cannot remember, invalid responses, multiple response, missing responses) (eg, N-d-e-f-g 200-8-6- 2-4=180)
a	Yes I was given this information	50%	200*0.50=100	(100/180)*100=55.5%
b	Yes, but I would have liked more	15%	200*0.15=30	(30/180)*100=16.7%
c	I was not given this information	25%	200*0.25=50	(50/180)*100=27.8%
d	Not Sure/cannot remember	4%	200*0.04=8	-
e	Invalid response	3%	200*0.04=6	-
f	Multiple response	1%	200*0.01=2	-
g	Missing	2%	200*0.02=4	-
Total		100%	200	180

Identifying patients who have had treatment at the treatment centre

NB: If a treatment specific survey has been conducted all patients will have had treatment at the health service. Information contained in this section is not relevant when a treatment specific survey has been conducted.

If a ‘whole of service’ survey has been conducted, some patients may have had some of their treatment for cancer at another health service. Patients are asked for the name and suburb/postcode of the treatment centre where they had their surgery, chemotherapy, radiotherapy for cancer as well as the name and suburb/postcode of the hospital providing their follow-up care. Patients attending an Emergency Department as a consequence of their cancer care are also asked to provide the name and suburb/postcode of the Emergency Department.

When a ‘whole of service’ survey has been conducted it will be important to identify patients who have had treatment at your treatment centre and report results only for these patients.

If the complete survey has been used, you can identify patients who have had all their care at your centre. Analyses of patients’ responses to questions assessing overall care, information provision and follow-up care can be conducted for patients having all their treatment at your centre. Focusing on this group of patients will provide information about how well the health service provides information and care overall.

Procedures for identifying patients at different treatment centres when analysing the data in the statistical software package SPSS are provided in the next section.

Frequencies

The report buttons in the ACCESS database can be used to generate frequency reports for each question in each survey module. The frequency reports provide a count of the number of respondents answering each question and the per cent of respondents giving each response option. In these reports missing responses, invalid responses and multiple responses (response categories e, f, g in Table 2 above) are not included in the frequencies and are not shown. Frequencies can also be generated using the statistical package SPSS.

Generating results from SPSS

Data from the ACCESS database can be exported into a ".csv" data file that can then be imported into SPSS or another statistical package (e.g. Stata) for further data analysis.
This section provides a brief general overview of procedures for importing the ".csv" files, and using SPSS to conduct some frequency analyses. More details on using SPSS for analyses of the survey data is provided in Appendix 12.

Importing data into SPSS.

The ACCESS database will export a file containing questions in all modules in the survey or it can export questions in each survey module separately. Exporting the data for each module is done through the export button for that module in Section 5 of the home page. A screen shot of the database's home page is shown above. More information about the database can be found in the database manual available at https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project

The name of the exported data file for each module and its corresponding SPSS data specification file (or shell file) is shown below. Corresponding names for saved SPSS data files are also shown.

Survey module	**Datafile name**	**SPSS shell file Name**	**SPSS data file names**
Module 1	PECS_Section01_find_out.csv	diagnosis_specification.sps	Diagnosis.sav
Module 2	PECS_Section02_deciding.csv	deciding_specification.sps	Deciding.sav
Module 3	PECS_Section03_Surgery.csv	surgery_specification.sps	Surgery.sav
Module 4	PECS_Section04_Radio.csv	radio_specification.sps	radio.sav
Module 5	PECS_Section05_chemo.csv	chemo_specification.sps	Chemo.sav
Module 6	PECS_Section06_Emerg.csv	ED_specification.sps	ED.sav
Module 7	PECS_Section07_FollowUp.csv	followUp_specification.sps	followUp.sav
Module 8	PECS_Section08_Info_Rec.csv	Info_recvd_specification.sps	Info_recvd.sav
Module 9	PECS_Section09_Overall.csv	Overallcare_specification.sps	Overallcare.sav
Module 10.	PECS_Section10_Back_Gnd.csv	Back_Gnd_specification.sps	Back_Gnd.sav
Brief Survey	PECS_Section11_Brief.csv	Briefsurvey_specification.sps	Briefsurvey.sav

The SPSS specification or shell file for each of the .csv files can be downloaded from https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects/victorian-cancer-patient-experience-survey-tool-project

SPSS shell files provide information about the data that the file will contain. It specifies the variable name for each data item (eg, a survey question), a label for each variable, a value label for each response (eg, 1 for "yes" 2 "no"), declares values to be excluded from analyses or frequencies (eg, missing values, multiple response values, invalid values). It also defines the data as being numeric or text (eg, name of hospital).
The data specifications for each survey module are shown in Appendix 11.
Procedures for importing the ".csv" data into the appropriate SPSS shell file are provided in Appendix 12.
Once you have imported the ".csv" file into SPSS, save the data file for future use.

Joining SPSS data files together

You may want to join the data sets from the different survey modules together. Data in the different SPSS data files can be joined using the patient id variable (s00_id). Before files can be joined, the data files will need to be sorted so that all the patient ids are in the same sequential order. The procedures for sorting the data files by the ID variable are shown in Appendix 12.

Identifying patients having different treatments at your service

For 'whole of service' surveys, some patients may have had some of their treatment at another health service. For reporting, you may want to identify those patients having the different treatments at your health service and report the experiences of only these patients.
The SPSS procedures for doing this are shown in Appendix 12. In brief, for each treatment the patient had, information provided about the treatment location is used to identify patients having that treatment at your health service. A new variable is created indicting that the treatment was at your health service (coded 1) or not (coded 0). Separate variables for surgery, chemotherapy and radiotherapy are created.

Identifying patients treated only at your treatment centre

For 'whole of service' surveys, you may want to identify those patients having all their treatment at your health service. Reporting the information or overall care experiences of this group of patients can provide information about how patients experience these aspects of care at your health service. The variables used to identify patients having surgery or chemotherapy or radiotherapy at your health service can be used for this. The SPSS code for identifying this group of patients and creating a variable that indicates that the patient had all their treatment at your treatment centre is shown in Appendix 12.

Running frequencies to obtain response distributions

In general the report you produce from the survey, will show the frequency of different responses to the survey questions. SPSS can produce frequency tables for the entire sample or for patients attending your health service for their treatment. Once you have the sample that you want to report on you need to run frequencies on the variables that you are interested in.
The data dictionary shown in Appendix 10 provides the list of variable names assigned to each question in the survey. Using this information will enable you to identify the variables you want to analyse.
The procedures for running frequencies in SPSS are shown in Appendix 12.

Frequencies Output

The Frequency output from SPSS is shown in below.

Typical output from a frequencies analysis in SPSS.

Use % from the "Valid Percent' column for reporting.

cleanwc ‘how clean were the toilets and bathrooms used in hospital?'

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 ‘Very clean’	770	43.9	72.7	72.7
	2 ‘Fairly clean’	233	13.3	22.0	94.7
	3 ‘Not very clean’	30	1.7	2.8	97.5
	4 ‘Not at all clean’	10	.6	.9	98.5
	5 ‘Not sure cannot remember’	16	.9	1.5	100.0
	Total	1059	60.4	100.0	
Missing	88 Multiple	2	.1		
	99	3	.2		
	System	699	39.4		
	Total	694	39.6		
	1753	100.0			

The frequency tables will provide the number of cases that choose each response option (column headed “Frequency”). The number of cases with missing data is also shown in the section with the side heading “Missing’. Patients who have not had surgery and so did not complete this section are shown in the row titled “System”.

The “Percent” column uses all cases (including cases with missing data) as the denominator. The percent in this column is the frequency count divided by the total number of cases. For example, the percent of cases responding ‘very clean’ out of all cases in the survey is: 777/1753 = 43.9%.

The “Valid Percent” column reports the percent of cases giving the different response options out of those cases that have a valid answer for this question (that is, cases with missing data excluded). In the table above, the percent of valid cases responding ‘very clean’ is: 777/1059 = 72.7%.

The “Cumulative Percent” column shows the running total for each subsequent response. For example the table above shows that the first two options account for 94.7% of valid responses. The cumulative percent is based on valid responses only.

When reporting data from the survey, the percentage from the “Valid Percent” column should be used.

Excluding options indicating the event was not relevant to the participant.

While most questions in the survey are intended to be answered by everyone, there are some questions that may not be relevant to people. An example of questions that may not be relevant to everyone is the question asking about satisfaction with car parking at their chemotherapy or radiotherapy treatment centres. These questions include a ‘not applicable’ response option that may be used by people who didn’t drive to the treatment centres, or who didn’t have to access car parking.

You can choose to include or exclude responses from those people responding ‘not applicable’ from the frequency counts.

The simplest way to exclude the response is to declare the value associated with the response ‘missing’ using the procedures described above.

If you exclude these responses from your frequency analysis, please ensure that you indicate this when describing the percentages in the text and in descriptions of the graphs. Examples of how this might be phrased are shown below.

For example if you exclude people who ticked ‘not applicable’ to the question on satisfaction with car parking at their radiotherapy clinic, you can say :

***Example:** excluding ‘not applicable’ responses from car parking satisfaction question.*

“Of those needing car parking …’ OR
“Of those indicating this question was relevant to them,…” OR
“Excluding those indicating they didn’t need car parking …”

Questions where there is a “not applicable” response or its equivalent are:

Module	Questions
Finding out	Q8
Deciding on Treatment	Q9
Surgery	Q8, Q14, Q17,Q18,Q22,
Radiotherapy	Q11, Q14,Q20,Q21
Chemotherapy	Q11,Q12, Q14,Q21, Q22
Follow-up Care	Q3, Q7,Q8
Information Received	Q1a-1c, Q2.Q4a-4h,Q5a-5e
Overall Care	Q5, Q7,Q9,Q10,

You can also choose to define the ‘cannot say’ responses as missing. We have left them as valid to show the complete range of options used by patients.

References

Arraras JI, Vera R, Martinez M, Hernandez B, Lainez N, Rico M, Vila M, Chicata V, Asin G. The EORTC cancer in-patient satisfaction with care questionnaire: EORTC IN-PATSAT32 Validation study for Spanish patients. *Clinical & Translational Oncology* 2009; 11 (4)**:** 237-242.

de Kok M, Sixma HJ, van der Weijden T, Kessels AG, Dirksen CD, Spijkers KF, van de Velde CJ, Roukema JA, van der Ent FW, Finaly-Marais C, von Meyenfeldt MF. A patient-centred instrument for assessment of quality of breast cancer care: results of a pilot questionnaire. *Quality & Safety in Health Care* 2010; 19 (6)**:** e40.

Tarrant C, Baker R, Colman AM, Sinfield P, Agarwal S, Mellon JK, Steward W, Kockelbergh R. The prostate care questionnaire for patients (PCQ-P): reliability, validity and acceptability. *BMC Health Services Research* 2009; 9**:** 199.

van Weert JC, Jansen J, de Bruijn GJ, Noordman J, van Dulmen S, Bensing JM. QUOTEchemo: a patient-centred instrument to measure quality of communication preceding chemotherapy treatment through the patient's eyes. *European Journal of Cancer* 2009; 45 (17)**:** 2967-2976.

Appendix 1A: Survey

ID _ _ _ _ _

Experiences of Care Survey

Are you completing this questionnaire as the patient or on behalf of the patient?

Patient ☐$_1$ **On behalf of patient** ☐$_2$

This survey is about the care you received during your cancer treatment.

Taking part in this survey is voluntary. Your responses are confidential. They will be combined with the responses of others in reports.

Completing this survey:

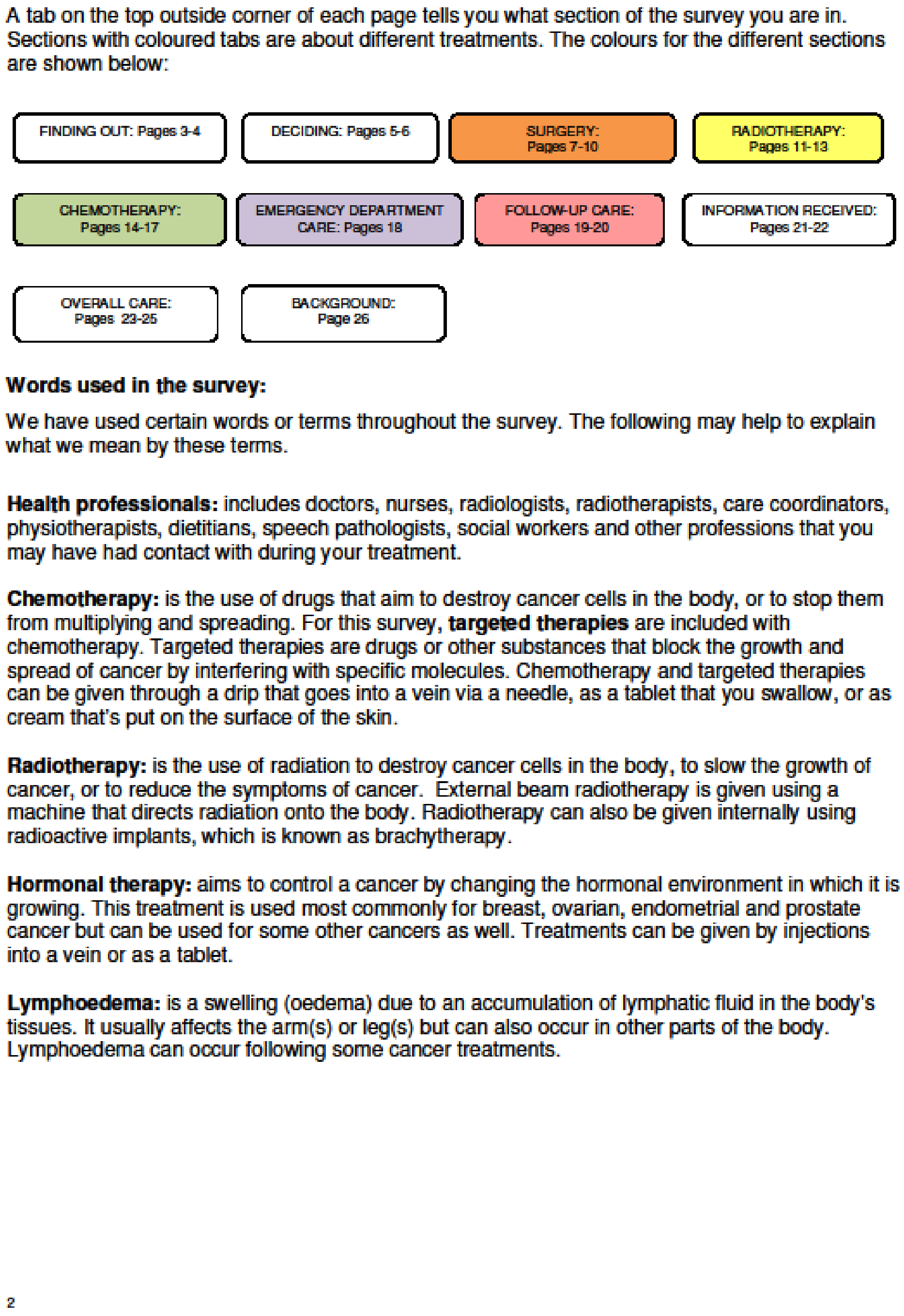
For most questions there is a choice of answers. Pick the response that is true for you and tick the box next to it. Sometimes, more than one box may be ticked. If you make a mistake, scribble out the mistake and put a tick in the correct box.

There is space throughout the survey for you to make any comments about your care. There is also space at the end of the survey for any comments you want to make.

The instructions before the questions will tell you who should answer the questions. You may be able to skip questions if you haven't had particular treatments (e.g. radiotherapy, chemotherapy).

You may not have had treatment in the order presented in the survey.

The survey may take 30 minutes to complete, depending on what treatment you have had.



A tab on the top outside corner of each page tells you what section of the survey you are in. Sections with coloured tabs are about different treatments. The colours for the different sections are shown below:

FINDING OUT: Pages 3-4

DECIDING: Pages 5-6

SURGERY: Pages 7-10

RADIOTHERAPY: Pages 11-13

CHEMOTHERAPY: Pages 14-17

EMERGENCY DEPARTMENT CARE: Pages 18

FOLLOW-UP CARE: Pages 19-20

INFORMATION RECEIVED: Pages 21-22

OVERALL CARE: Pages 23-25

BACKGROUND: Page 26

Words used in the survey:

We have used certain words or terms throughout the survey. The following may help to explain what we mean by these terms.

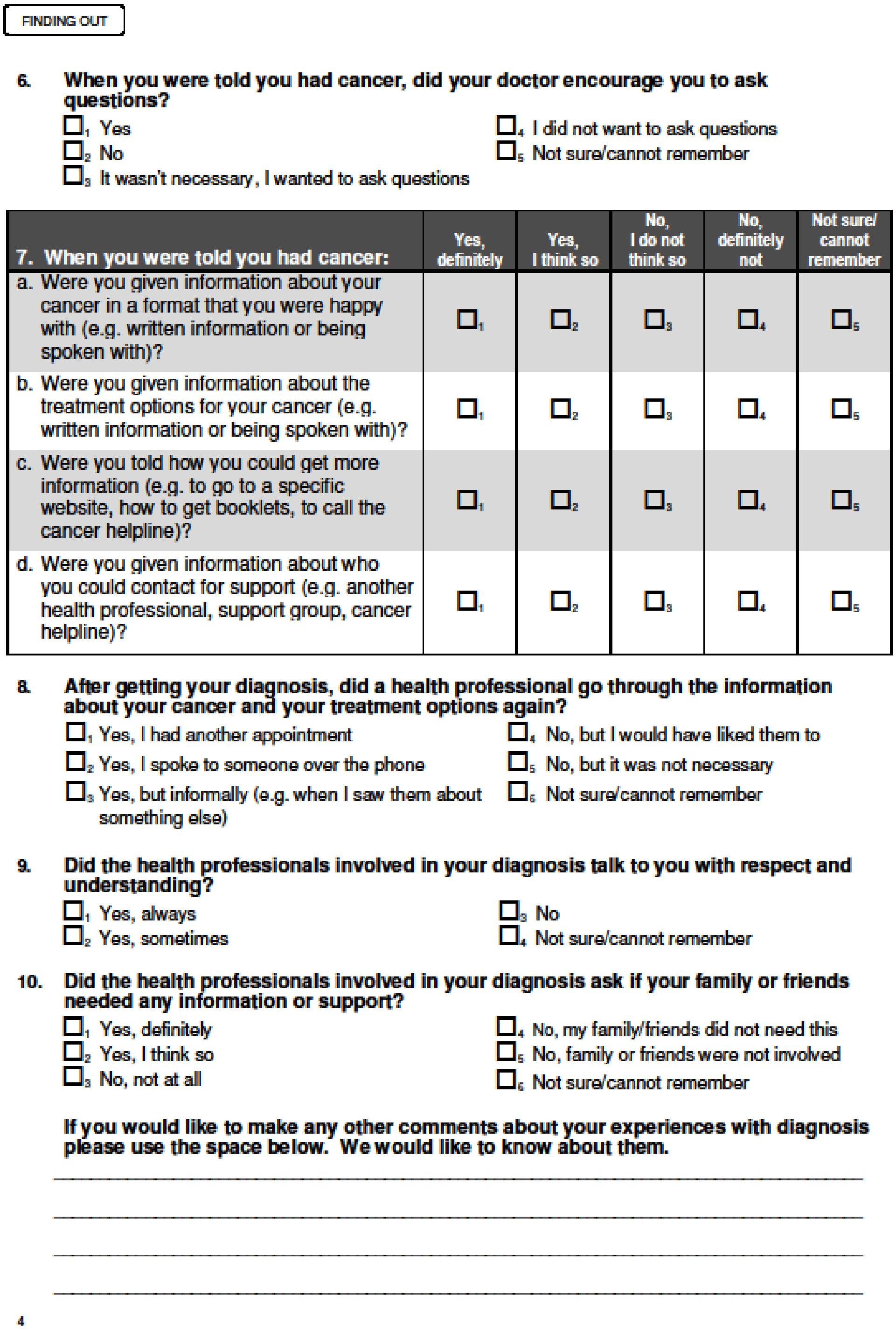
Health professionals: includes doctors, nurses, radiologists, radiotherapists, care coordinators, physiotherapists, dietitians, speech pathologists, social workers and other professions that you may have had contact with during your treatment.

Chemotherapy: is the use of drugs that aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. For this survey, **targeted therapies** are included with chemotherapy. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy and targeted therapies can be given through a drip that goes into a vein via a needle, as a tablet that you swallow, or as cream that's put on the surface of the skin.

Radiotherapy: is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External beam radiotherapy is given using a machine that directs radiation onto the body. Radiotherapy can also be given internally using radioactive implants, which is known as brachytherapy.

Hormonal therapy: aims to control a cancer by changing the hormonal environment in which it is growing. This treatment is used most commonly for breast, ovarian, endometrial and prostate cancer but can be used for some other cancers as well. Treatments can be given by injections into a vein or as a tablet.

Lymphoedema: is a swelling (oedema) due to an accumulation of lymphatic fluid in the body's tissues. It usually affects the arm(s) or leg(s) but can also occur in other parts of the body. Lymphoedema can occur following some cancer treatments.



FINDING OUT

6. When you were told you had cancer, did your doctor encourage you to ask questions?

☐1 Yes
☐2 No
☐3 It wasn't necessary, I wanted to ask questions
☐4 I did not want to ask questions
☐5 Not sure/cannot remember

7. When you were told you had cancer:	Yes, definitely	Yes, I think so	No, I do not think so	No, definitely not	Not sure/ cannot remember
a. Were you given information about your cancer in a format that you were happy with (e.g. written information or being spoken with)?	☐1	☐2	☐3	☐4	☐5
b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)?	☐1	☐2	☐3	☐4	☐5
c. Were you told how you could get more information (e.g. to go to a specific website, how to get booklets, to call the cancer helpline)?	☐1	☐2	☐3	☐4	☐5
d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)?	☐1	☐2	☐3	☐4	☐5

8. After getting your diagnosis, did a health professional go through the information about your cancer and your treatment options again?

☐1 Yes, I had another appointment
☐2 Yes, I spoke to someone over the phone
☐3 Yes, but informally (e.g. when I saw them about something else)
☐4 No, but I would have liked them to
☐5 No, but it was not necessary
☐6 Not sure/cannot remember

9. Did the health professionals involved in your diagnosis talk to you with respect and understanding?

☐1 Yes, always
☐2 Yes, sometimes
☐3 No
☐4 Not sure/cannot remember

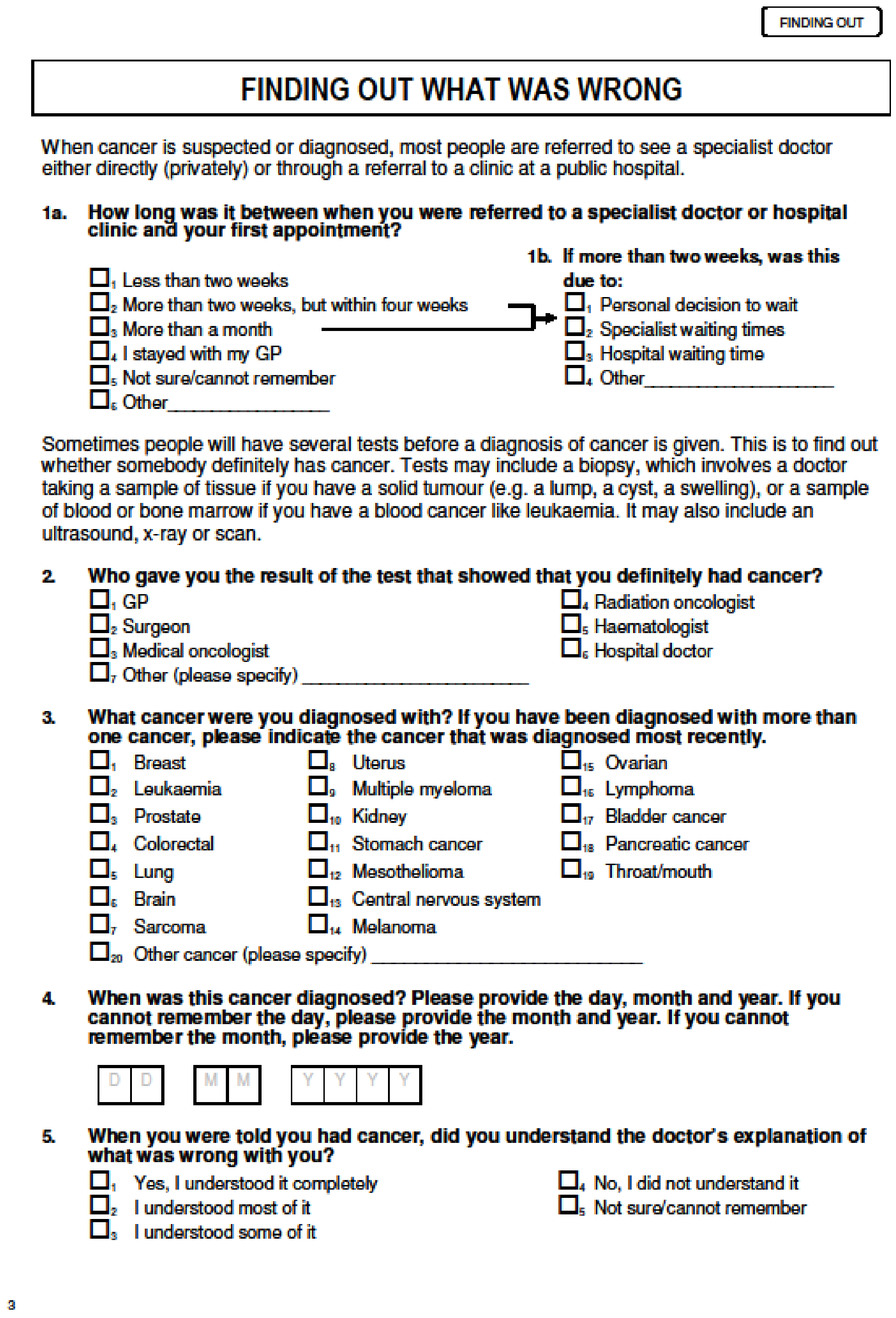
10. Did the health professionals involved in your diagnosis ask if your family or friends needed any information or support?

☐1 Yes, definitely
☐2 Yes, I think so
☐3 No, not at all
☐4 No, my family/friends did not need this
☐5 No, family or friends were not involved
☐6 Not sure/cannot remember

If you would like to make any other comments about your experiences with diagnosis please use the space below. We would like to know about them.

____
____
____
____

4



FINDING OUT

FINDING OUT WHAT WAS WRONG

When cancer is suspected or diagnosed, most people are referred to see a specialist doctor either directly (privately) or through a referral to a clinic at a public hospital.

1a. How long was it between when you were referred to a specialist doctor or hospital clinic and your first appointment?

☐1 Less than two weeks
☐2 More than two weeks, but within four weeks
☐3 More than a month
☐4 I stayed with my GP
☐5 Not sure/cannot remember
☐6 Other_______________

1b. If more than two weeks, was this due to:

☐1 Personal decision to wait
☐2 Specialist waiting times
☐3 Hospital waiting time
☐4 Other_________________

Sometimes people will have several tests before a diagnosis of cancer is given. This is to find out whether somebody definitely has cancer. Tests may include a biopsy, which involves a doctor taking a sample of tissue if you have a solid tumour (e.g. a lump, a cyst, a swelling), or a sample of blood or bone marrow if you have a blood cancer like leukaemia. It may also include an ultrasound, x-ray or scan.

2. Who gave you the result of the test that showed that you definitely had cancer?

☐1 GP
☐2 Surgeon
☐3 Medical oncologist
☐4 Radiation oncologist
☐5 Haematologist
☐6 Hospital doctor
☐7 Other (please specify) _____________________

3. What cancer were you diagnosed with? If you have been diagnosed with more than one cancer, please indicate the cancer that was diagnosed most recently.

☐1 Breast
☐2 Leukaemia
☐3 Prostate
☐4 Colorectal
☐5 Lung
☐6 Brain
☐7 Sarcoma
☐8 Uterus
☐9 Multiple myeloma
☐10 Kidney
☐11 Stomach cancer
☐12 Mesothelioma
☐13 Central nervous system
☐14 Melanoma
☐15 Ovarian
☐16 Lymphoma
☐17 Bladder cancer
☐18 Pancreatic cancer
☐19 Throat/mouth
☐20 Other cancer (please specify) _________________________

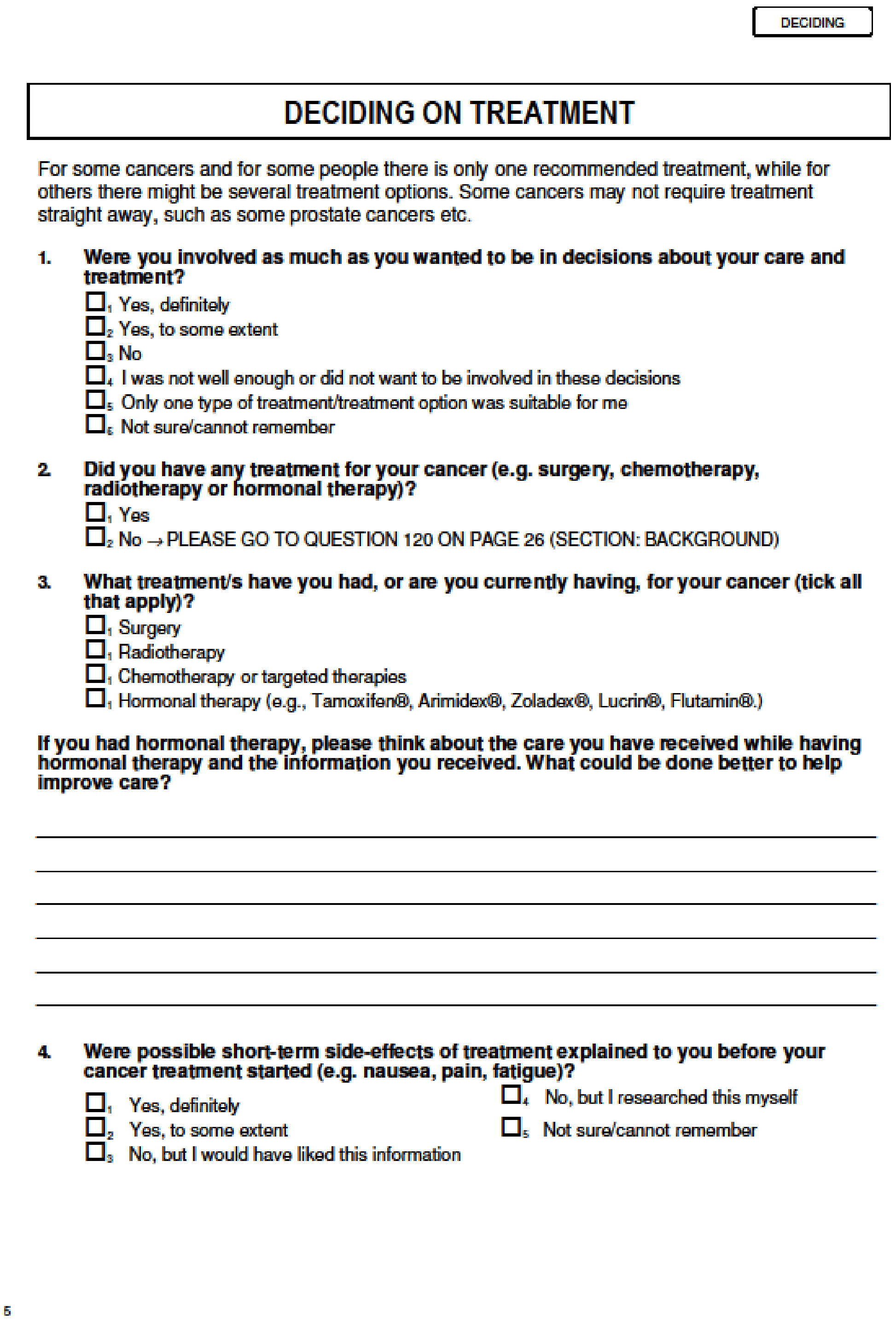
4. When was this cancer diagnosed? Please provide the day, month and year. If you cannot remember the day, please provide the month and year. If you cannot remember the month, please provide the year.

D D / M M / Y Y Y Y

5. When you were told you had cancer, did you understand the doctor's explanation of what was wrong with you?

☐1 Yes, I understood it completely
☐2 I understood most of it
☐3 I understood some of it
☐4 No, I did not understand it
☐5 Not sure/cannot remember

3



DECIDING ON TREATMENT

For some cancers and for some people there is only one recommended treatment, while for others there might be several treatment options. Some cancers may not require treatment straight away, such as some prostate cancers etc.

1. Were you involved as much as you wanted to be in decisions about your care and treatment?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No
☐4 I was not well enough or did not want to be involved in these decisions
☐5 Only one type of treatment/treatment option was suitable for me
☐6 Not sure/cannot remember

2. Did you have any treatment for your cancer (e.g. surgery, chemotherapy, radiotherapy or hormonal therapy)?

☐1 Yes
☐2 No → PLEASE GO TO QUESTION 120 ON PAGE 26 (SECTION: BACKGROUND)

3. What treatment/s have you had, or are you currently having, for your cancer (tick all that apply)?

☐1 Surgery
☐1 Radiotherapy
☐1 Chemotherapy or targeted therapies
☐1 Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®.)

If you had hormonal therapy, please think about the care you have received while having hormonal therapy and the information you received. What could be done better to help improve care?

____

____

____

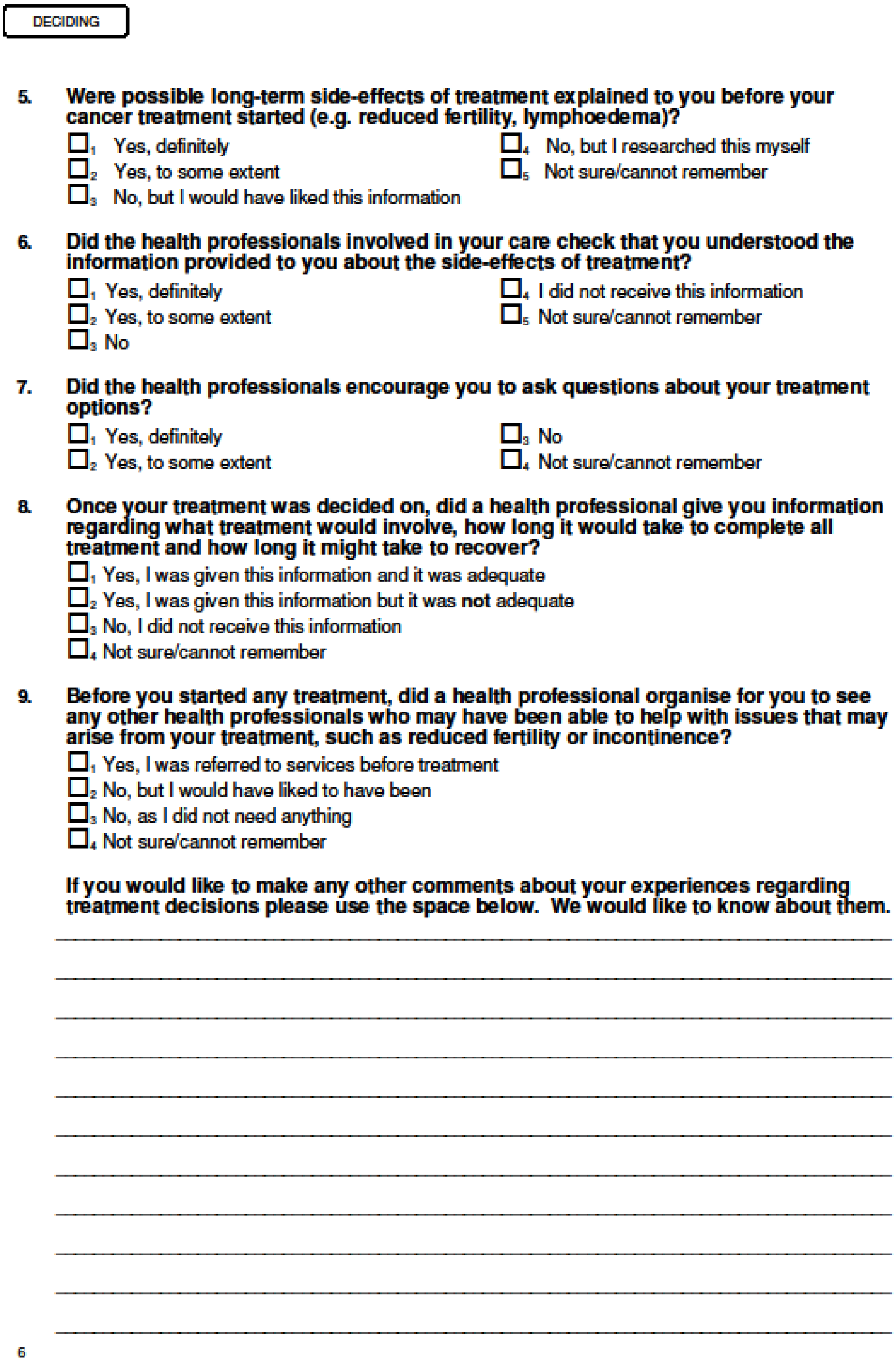
____

____

____

4. Were possible short-term side-effects of treatment explained to you before your cancer treatment started (e.g. nausea, pain, fatigue)?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No, but I would have liked this information
☐4 No, but I researched this myself
☐5 Not sure/cannot remember



DECIDING

5. Were possible long-term side-effects of treatment explained to you before your cancer treatment started (e.g. reduced fertility, lymphoedema)?

☐$_1$ Yes, definitely
☐$_2$ Yes, to some extent
☐$_3$ No, but I would have liked this information
☐$_4$ No, but I researched this myself
☐$_5$ Not sure/cannot remember

6. Did the health professionals involved in your care check that you understood the information provided to you about the side-effects of treatment?

☐$_1$ Yes, definitely
☐$_2$ Yes, to some extent
☐$_3$ No
☐$_4$ I did not receive this information
☐$_5$ Not sure/cannot remember

7. Did the health professionals encourage you to ask questions about your treatment options?

☐$_1$ Yes, definitely
☐$_2$ Yes, to some extent
☐$_3$ No
☐$_4$ Not sure/cannot remember

8. Once your treatment was decided on, did a health professional give you information regarding what treatment would involve, how long it would take to complete all treatment and how long it might take to recover?

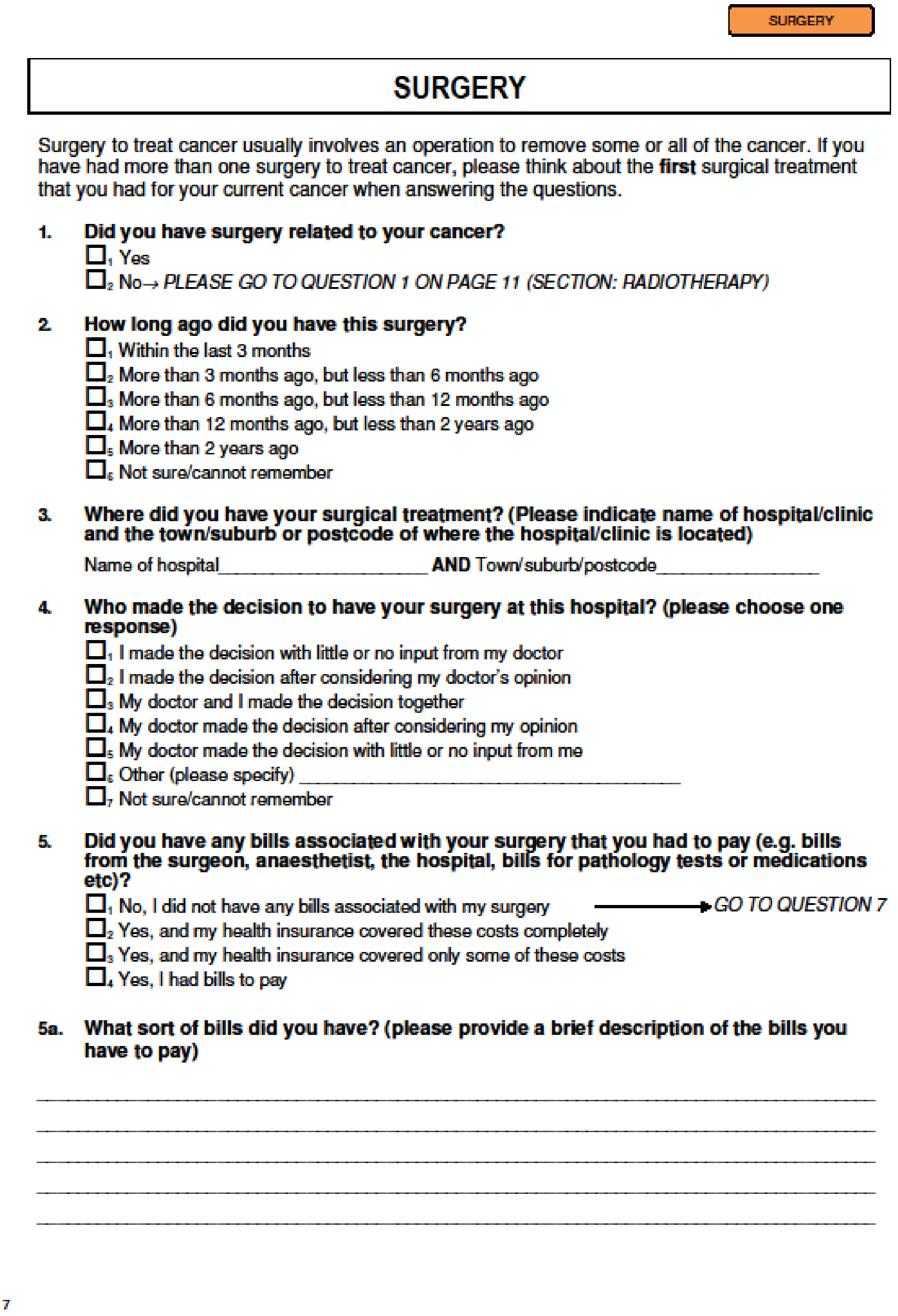
☐$_1$ Yes, I was given this information and it was adequate
☐$_2$ Yes, I was given this information but it was **not** adequate
☐$_3$ No, I did not receive this information
☐$_4$ Not sure/cannot remember

9. Before you started any treatment, did a health professional organise for you to see any other health professionals who may have been able to help with issues that may arise from your treatment, such as reduced fertility or incontinence?

☐$_1$ Yes, I was referred to services before treatment
☐$_2$ No, but I would have liked to have been
☐$_3$ No, as I did not need anything
☐$_4$ Not sure/cannot remember

If you would like to make any other comments about your experiences regarding treatment decisions please use the space below. We would like to know about them.

6



SURGERY

SURGERY

Surgery to treat cancer usually involves an operation to remove some or all of the cancer. If you have had more than one surgery to treat cancer, please think about the **first** surgical treatment that you had for your current cancer when answering the questions.

1. Did you have surgery related to your cancer?

☐$_1$ Yes
☐$_2$ No→ *PLEASE GO TO QUESTION 1 ON PAGE 11 (SECTION: RADIOTHERAPY)*

2. How long ago did you have this surgery?

☐$_1$ Within the last 3 months
☐$_2$ More than 3 months ago, but less than 6 months ago
☐$_3$ More than 6 months ago, but less than 12 months ago
☐$_4$ More than 12 months ago, but less than 2 years ago
☐$_5$ More than 2 years ago
☐$_6$ Not sure/cannot remember

3. Where did you have your surgical treatment? (Please indicate name of hospital/clinic and the town/suburb or postcode of where the hospital/clinic is located)

Name of hospital____________________ **AND** Town/suburb/postcode________________

4. Who made the decision to have your surgery at this hospital? (please choose one response)

☐$_1$ I made the decision with little or no input from my doctor
☐$_2$ I made the decision after considering my doctor's opinion
☐$_3$ My doctor and I made the decision together
☐$_4$ My doctor made the decision after considering my opinion
☐$_5$ My doctor made the decision with little or no input from me
☐$_6$ Other (please specify) _____________________________________
☐$_7$ Not sure/cannot remember

5. Did you have any bills associated with your surgery that you had to pay (e.g. bills from the surgeon, anaesthetist, the hospital, bills for pathology tests or medications etc)?

☐$_1$ No, I did not have any bills associated with my surgery ———→ *GO TO QUESTION 7*
☐$_2$ Yes, and my health insurance covered these costs completely
☐$_3$ Yes, and my health insurance covered only some of these costs
☐$_4$ Yes, I had bills to pay

5a. What sort of bills did you have? (please provide a brief description of the bills you have to pay)

____
____
____
____
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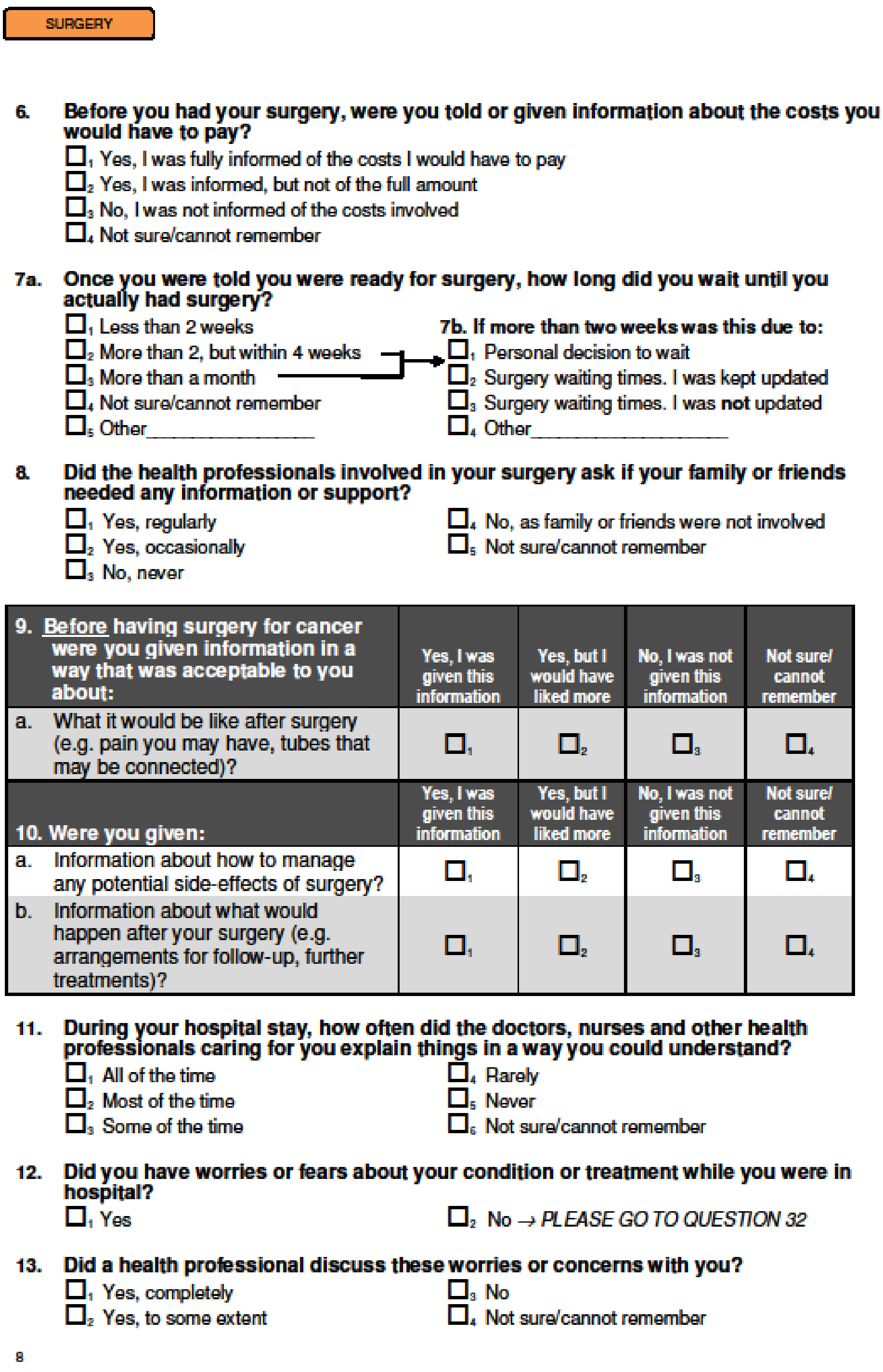


SURGERY

6. Before you had your surgery, were you told or given information about the costs you would have to pay?

☐$_1$ Yes, I was fully informed of the costs I would have to pay
☐$_2$ Yes, I was informed, but not of the full amount
☐$_3$ No, I was not informed of the costs involved
☐$_4$ Not sure/cannot remember

7a. Once you were told you were ready for surgery, how long did you wait until you actually had surgery?

☐$_1$ Less than 2 weeks
☐$_2$ More than 2, but within 4 weeks → 7b
☐$_3$ More than a month → 7b
☐$_4$ Not sure/cannot remember
☐$_5$ Other_______________

7b. If more than two weeks was this due to:

☐$_1$ Personal decision to wait
☐$_2$ Surgery waiting times. I was kept updated
☐$_3$ Surgery waiting times. I was **not** updated
☐$_4$ Other__________________

8. Did the health professionals involved in your surgery ask if your family or friends needed any information or support?

☐$_1$ Yes, regularly
☐$_2$ Yes, occasionally
☐$_3$ No, never
☐$_4$ No, as family or friends were not involved
☐$_5$ Not sure/cannot remember

9. Before having surgery for cancer were you given information in a way that was acceptable to you about:	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure/ cannot remember
a. What it would be like after surgery (e.g. pain you may have, tubes that may be connected)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
10. Were you given:	**Yes, I was given this information**	**Yes, but I would have liked more**	**No, I was not given this information**	**Not sure/ cannot remember**
a. Information about how to manage any potential side-effects of surgery?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
b. Information about what would happen after your surgery (e.g. arrangements for follow-up, further treatments)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$

11. During your hospital stay, how often did the doctors, nurses and other health professionals caring for you explain things in a way you could understand?

☐$_1$ All of the time
☐$_2$ Most of the time
☐$_3$ Some of the time
☐$_4$ Rarely
☐$_5$ Never
☐$_6$ Not sure/cannot remember

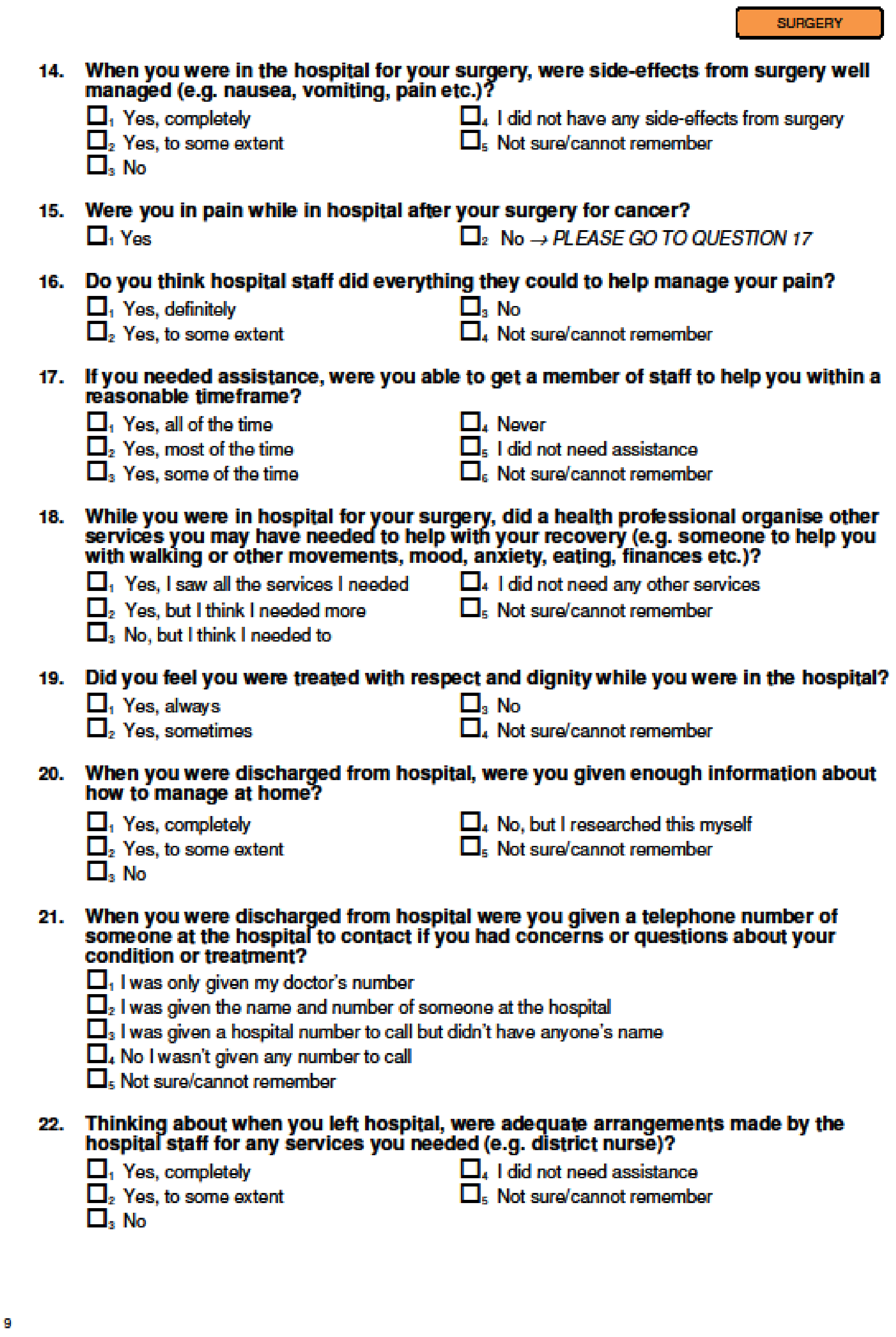
12. Did you have worries or fears about your condition or treatment while you were in hospital?

☐$_1$ Yes
☐$_2$ No → *PLEASE GO TO QUESTION 32*

13. Did a health professional discuss these worries or concerns with you?

☐$_1$ Yes, completely
☐$_2$ Yes, to some extent
☐$_3$ No
☐$_4$ Not sure/cannot remember

8



SURGERY

14. When you were in the hospital for your surgery, were side-effects from surgery well managed (e.g. nausea, vomiting, pain etc.)?

☐1 Yes, completely
☐2 Yes, to some extent
☐3 No
☐4 I did not have any side-effects from surgery
☐5 Not sure/cannot remember

15. Were you in pain while in hospital after your surgery for cancer?

☐1 Yes
☐2 No → *PLEASE GO TO QUESTION 17*

16. Do you think hospital staff did everything they could to help manage your pain?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No
☐4 Not sure/cannot remember

17. If you needed assistance, were you able to get a member of staff to help you within a reasonable timeframe?

☐1 Yes, all of the time
☐2 Yes, most of the time
☐3 Yes, some of the time
☐4 Never
☐5 I did not need assistance
☐6 Not sure/cannot remember

18. While you were in hospital for your surgery, did a health professional organise other services you may have needed to help with your recovery (e.g. someone to help you with walking or other movements, mood, anxiety, eating, finances etc.)?

☐1 Yes, I saw all the services I needed
☐2 Yes, but I think I needed more
☐3 No, but I think I needed to
☐4 I did not need any other services
☐5 Not sure/cannot remember

19. Did you feel you were treated with respect and dignity while you were in the hospital?

☐1 Yes, always
☐2 Yes, sometimes
☐3 No
☐4 Not sure/cannot remember

20. When you were discharged from hospital, were you given enough information about how to manage at home?

☐1 Yes, completely
☐2 Yes, to some extent
☐3 No
☐4 No, but I researched this myself
☐5 Not sure/cannot remember

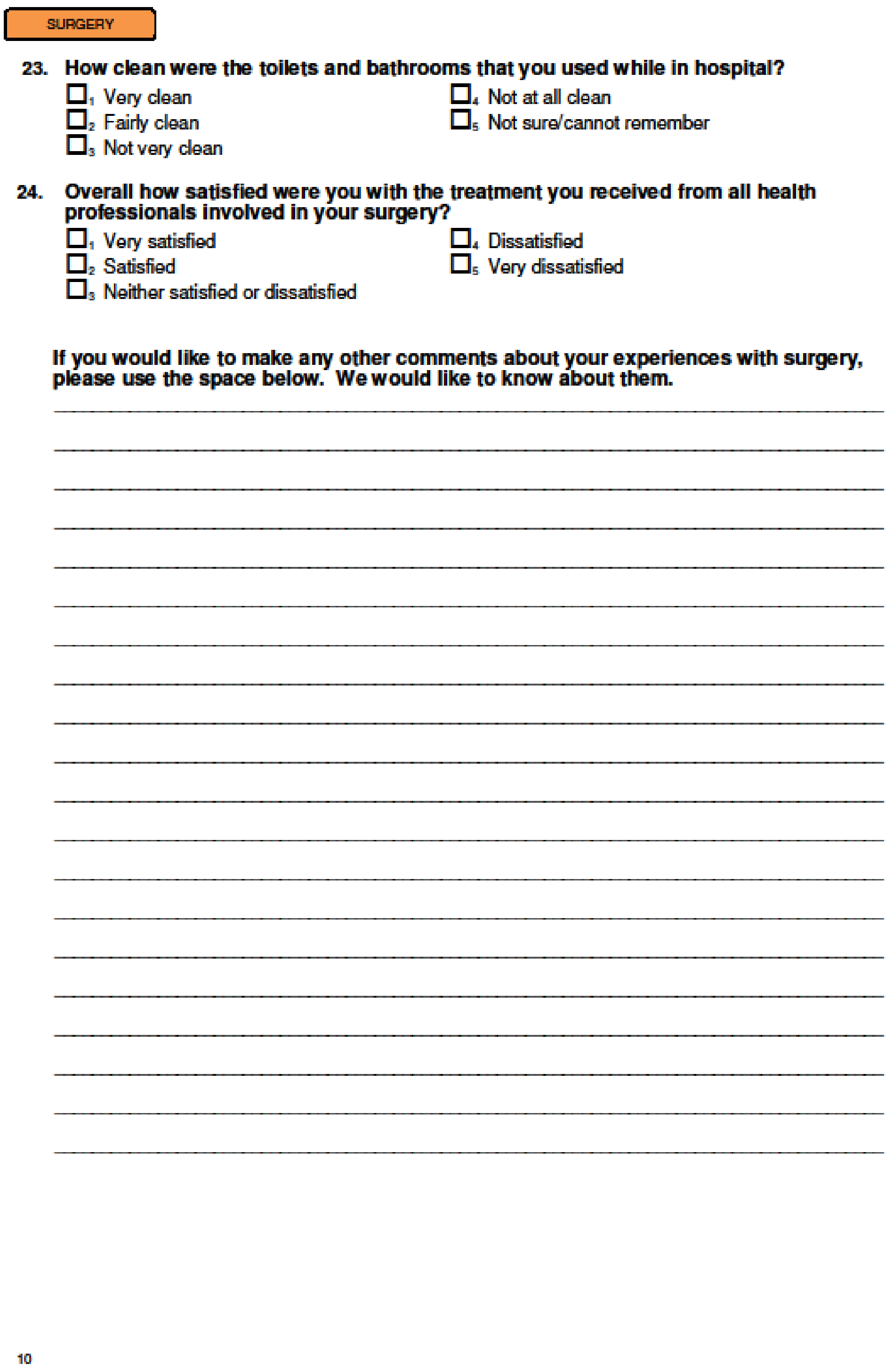
21. When you were discharged from hospital were you given a telephone number of someone at the hospital to contact if you had concerns or questions about your condition or treatment?

☐1 I was only given my doctor's number
☐2 I was given the name and number of someone at the hospital
☐3 I was given a hospital number to call but didn't have anyone's name
☐4 No I wasn't given any number to call
☐5 Not sure/cannot remember

22. Thinking about when you left hospital, were adequate arrangements made by the hospital staff for any services you needed (e.g. district nurse)?

☐1 Yes, completely
☐2 Yes, to some extent
☐3 No
☐4 I did not need assistance
☐5 Not sure/cannot remember

9



SURGERY

23. How clean were the toilets and bathrooms that you used while in hospital?

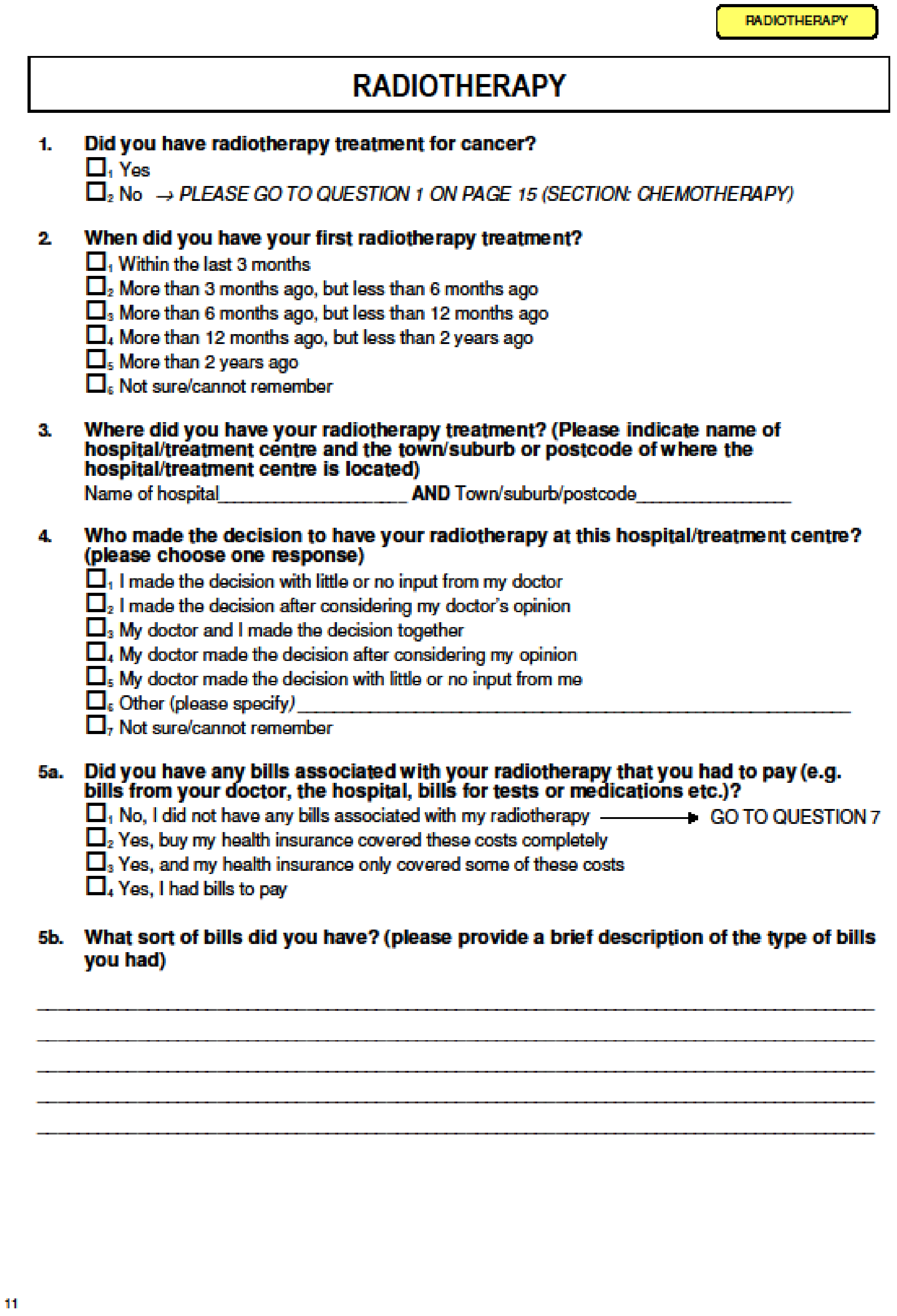
☐1 Very clean
☐2 Fairly clean
☐3 Not very clean
☐4 Not at all clean
☐5 Not sure/cannot remember

24. Overall how satisfied were you with the treatment you received from all health professionals involved in your surgery?

☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied

If you would like to make any other comments about your experiences with surgery, please use the space below. We would like to know about them.

10



RADIOTHERAPY

RADIOTHERAPY

1. **Did you have radiotherapy treatment for cancer?**
   ☐$_1$ Yes
   ☐$_2$ No → *PLEASE GO TO QUESTION 1 ON PAGE 15 (SECTION: CHEMOTHERAPY)*

2. **When did you have your first radiotherapy treatment?**
   ☐$_1$ Within the last 3 months
   ☐$_2$ More than 3 months ago, but less than 6 months ago
   ☐$_3$ More than 6 months ago, but less than 12 months ago
   ☐$_4$ More than 12 months ago, but less than 2 years ago
   ☐$_5$ More than 2 years ago
   ☐$_6$ Not sure/cannot remember

3. **Where did you have your radiotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)**
   Name of hospital__________________ **AND** Town/suburb/postcode_______________

4. **Who made the decision to have your radiotherapy at this hospital/treatment centre? (please choose one response)**
   ☐$_1$ I made the decision with little or no input from my doctor
   ☐$_2$ I made the decision after considering my doctor's opinion
   ☐$_3$ My doctor and I made the decision together
   ☐$_4$ My doctor made the decision after considering my opinion
   ☐$_5$ My doctor made the decision with little or no input from me
   ☐$_6$ Other (please specify*)*____
   ☐$_7$ Not sure/cannot remember

5a. **Did you have any bills associated with your radiotherapy that you had to pay (e.g. bills from your doctor, the hospital, bills for tests or medications etc.)?**
☐$_1$ No, I did not have any bills associated with my radiotherapy ——→ GO TO QUESTION 7
☐$_2$ Yes, buy my health insurance covered these costs completely
☐$_3$ Yes, and my health insurance only covered some of these costs
☐$_4$ Yes, I had bills to pay

5b. **What sort of bills did you have? (please provide a brief description of the type of bills you had)**

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11

RADIOTHERAPY

6. Before your radiotherapy treatment started, were you told or given information about the costs you would have to pay?

☐$_1$ Yes, I was fully informed of the costs I would have to pay
☐$_2$ Yes, I was informed, but not of the full amount
☐$_3$ No, I was not informed of the costs involved
☐$_4$ Not sure/cannot remember

7 Did you have to stay away from home while receiving radiotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

☐$_1$ Yes →
☐$_2$ No

7b. Who arranged this accommodation?

☐$_1$ I did/my family or friends did
☐$_2$ Staff at the hospital
☐$_3$ Staff associated with my doctor
☐$_4$ Not sure/cannot remember
☐$_5$ Other_________________

8a. Once you had your radiotherapy planning or mapping appointment (to scan or measure your body and mark the area to treat), how long did you wait before your first radiotherapy treatment?

☐$_1$ Less than 2 weeks
☐$_2$ More than 2, but within 4 weeks →
☐$_3$ More than a month →
☐$_4$ Not sure/cannot remember
☐$_5$ Other_________________

8b. If more than two weeks was this due to:

☐$_1$ Personal decision to wait
☐$_2$ Radiotherapy waiting times. I was kept updated.
☐$_3$ Radiotherapy waiting times. I was **not** updated.
☐$_4$ Other_________________

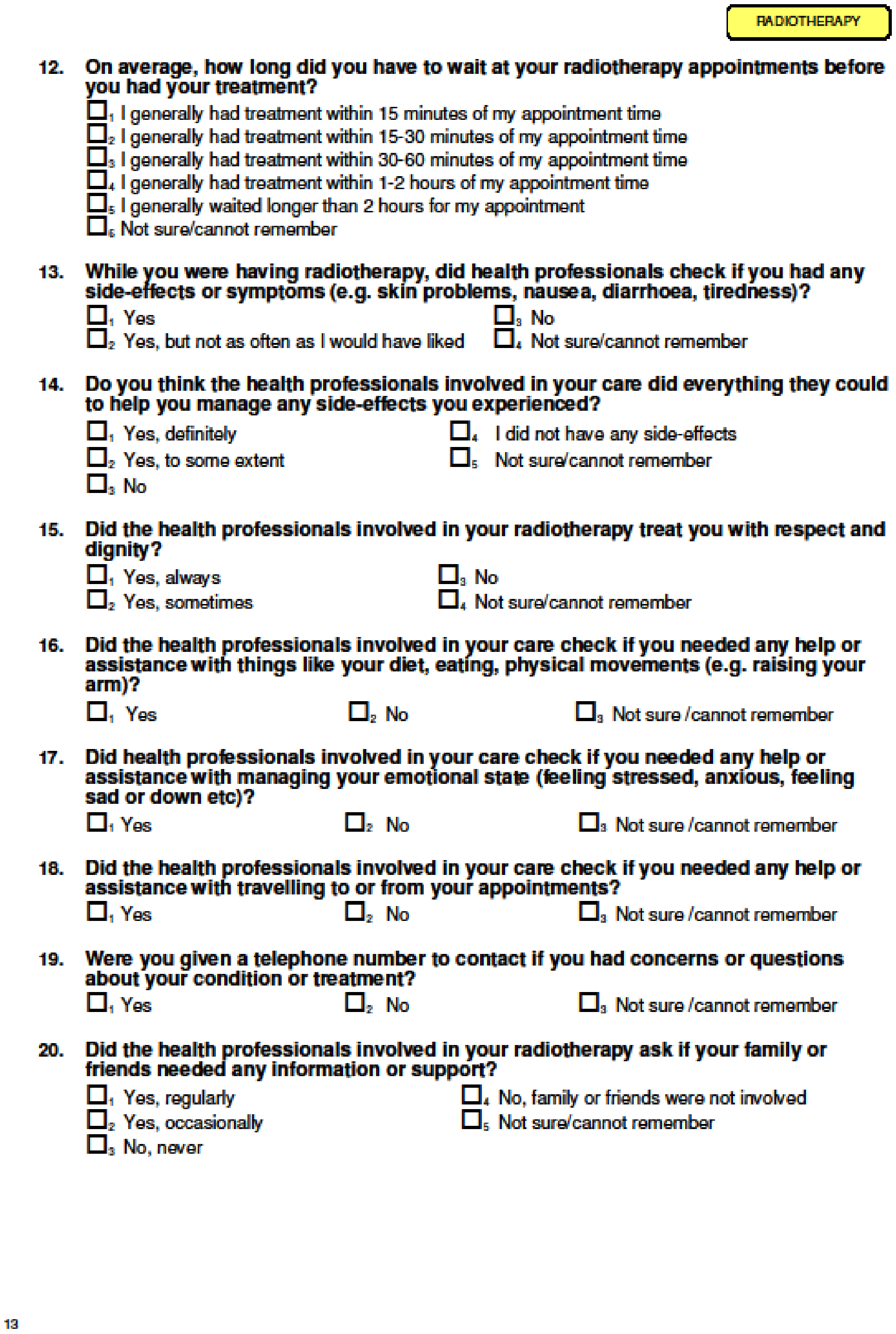
9. Before starting radiotherapy for the first time were you given information about:	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure/ cannot remember
a. How to prepare for radiotherapy (e.g. any changes to other medications, not to use moisturisers etc.)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
b. How to manage any anxiety or stress you might experience before your radiotherapy treatments?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
c. How you might manage side-effects from radiotherapy (e.g. apply ointments, change bandages, exercise etc.)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
d. How you might feel at the end of treatment (e.g., fatigued or tired)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
e. How long it might take to recover from having radiotherapy?	☐$_1$	☐$_2$	☐$_3$	☐$_4$

10. Did a health professional check that you understood the information provided to you?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure/cannot remember

11. Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

☐$_1$ Yes, definitely
☐$_2$ Yes, as much as they could
☐$_3$ No, not at all
☐$_4$ Travel/other commitments were not a problem
☐$_5$ Not sure/cannot remember



RADIOTHERAPY

12. On average, how long did you have to wait at your radiotherapy appointments before you had your treatment?

☐1 I generally had treatment within 15 minutes of my appointment time
☐2 I generally had treatment within 15-30 minutes of my appointment time
☐3 I generally had treatment within 30-60 minutes of my appointment time
☐4 I generally had treatment within 1-2 hours of my appointment time
☐5 I generally waited longer than 2 hours for my appointment
☐6 Not sure/cannot remember

13. While you were having radiotherapy, did health professionals check if you had any side-effects or symptoms (e.g. skin problems, nausea, diarrhoea, tiredness)?

☐1 Yes
☐2 Yes, but not as often as I would have liked
☐3 No
☐4 Not sure/cannot remember

14. Do you think the health professionals involved in your care did everything they could to help you manage any side-effects you experienced?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No
☐4 I did not have any side-effects
☐5 Not sure/cannot remember

15. Did the health professionals involved in your radiotherapy treat you with respect and dignity?

☐1 Yes, always
☐2 Yes, sometimes
☐3 No
☐4 Not sure/cannot remember

16. Did the health professionals involved in your care check if you needed any help or assistance with things like your diet, eating, physical movements (e.g. raising your arm)?

☐1 Yes
☐2 No
☐3 Not sure /cannot remember

17. Did health professionals involved in your care check if you needed any help or assistance with managing your emotional state (feeling stressed, anxious, feeling sad or down etc)?

☐1 Yes
☐2 No
☐3 Not sure /cannot remember

18. Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?

☐1 Yes
☐2 No
☐3 Not sure /cannot remember

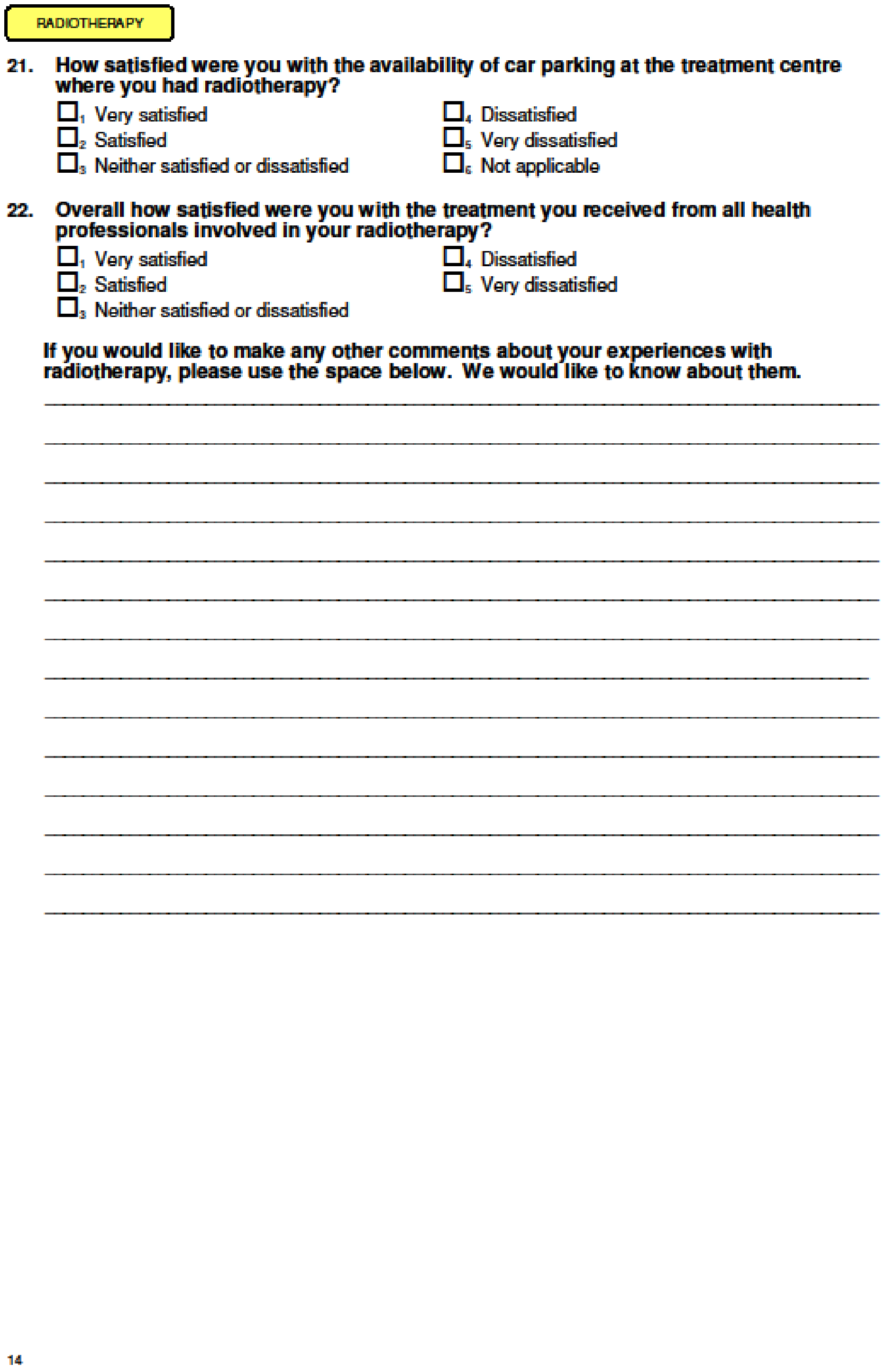
19. Were you given a telephone number to contact if you had concerns or questions about your condition or treatment?

☐1 Yes
☐2 No
☐3 Not sure /cannot remember

20. Did the health professionals involved in your radiotherapy ask if your family or friends needed any information or support?

☐1 Yes, regularly
☐2 Yes, occasionally
☐3 No, never
☐4 No, family or friends were not involved
☐5 Not sure/cannot remember

13



RADIOTHERAPY

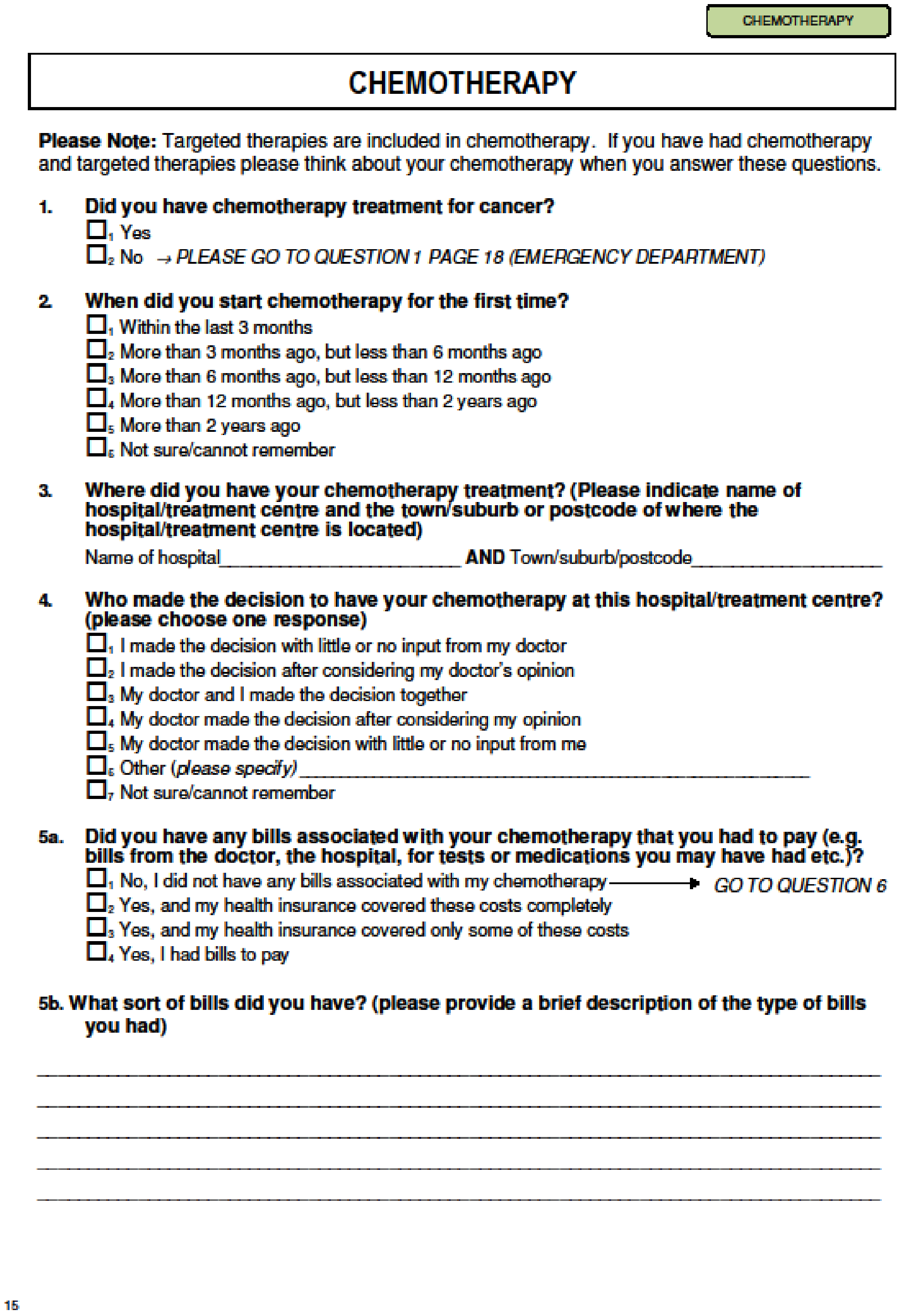
21. How satisfied were you with the availability of car parking at the treatment centre where you had radiotherapy?

☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied
☐6 Not applicable

22. Overall how satisfied were you with the treatment you received from all health professionals involved in your radiotherapy?

☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied

If you would like to make any other comments about your experiences with radiotherapy, please use the space below. We would like to know about them.



CHEMOTHERAPY

Please Note: Targeted therapies are included in chemotherapy. If you have had chemotherapy and targeted therapies please think about your chemotherapy when you answer these questions.

1. Did you have chemotherapy treatment for cancer?

☐$_1$ Yes
☐$_2$ No → *PLEASE GO TO QUESTION 1 PAGE 18 (EMERGENCY DEPARTMENT)*

2. When did you start chemotherapy for the first time?

☐$_1$ Within the last 3 months
☐$_2$ More than 3 months ago, but less than 6 months ago
☐$_3$ More than 6 months ago, but less than 12 months ago
☐$_4$ More than 12 months ago, but less than 2 years ago
☐$_5$ More than 2 years ago
☐$_6$ Not sure/cannot remember

3. Where did you have your chemotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)

Name of hospital______________________ **AND** Town/suburb/postcode__________________

4. Who made the decision to have your chemotherapy at this hospital/treatment centre? (please choose one response)

☐$_1$ I made the decision with little or no input from my doctor
☐$_2$ I made the decision after considering my doctor's opinion
☐$_3$ My doctor and I made the decision together
☐$_4$ My doctor made the decision after considering my opinion
☐$_5$ My doctor made the decision with little or no input from me
☐$_6$ Other (*please specify)*____
☐$_7$ Not sure/cannot remember

5a. Did you have any bills associated with your chemotherapy that you had to pay (e.g. bills from the doctor, the hospital, for tests or medications you may have had etc.)?

☐$_1$ No, I did not have any bills associated with my chemotherapy → *GO TO QUESTION 6*
☐$_2$ Yes, and my health insurance covered these costs completely
☐$_3$ Yes, and my health insurance covered only some of these costs
☐$_4$ Yes, I had bills to pay

5b. What sort of bills did you have? (please provide a brief description of the type of bills you had)

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____
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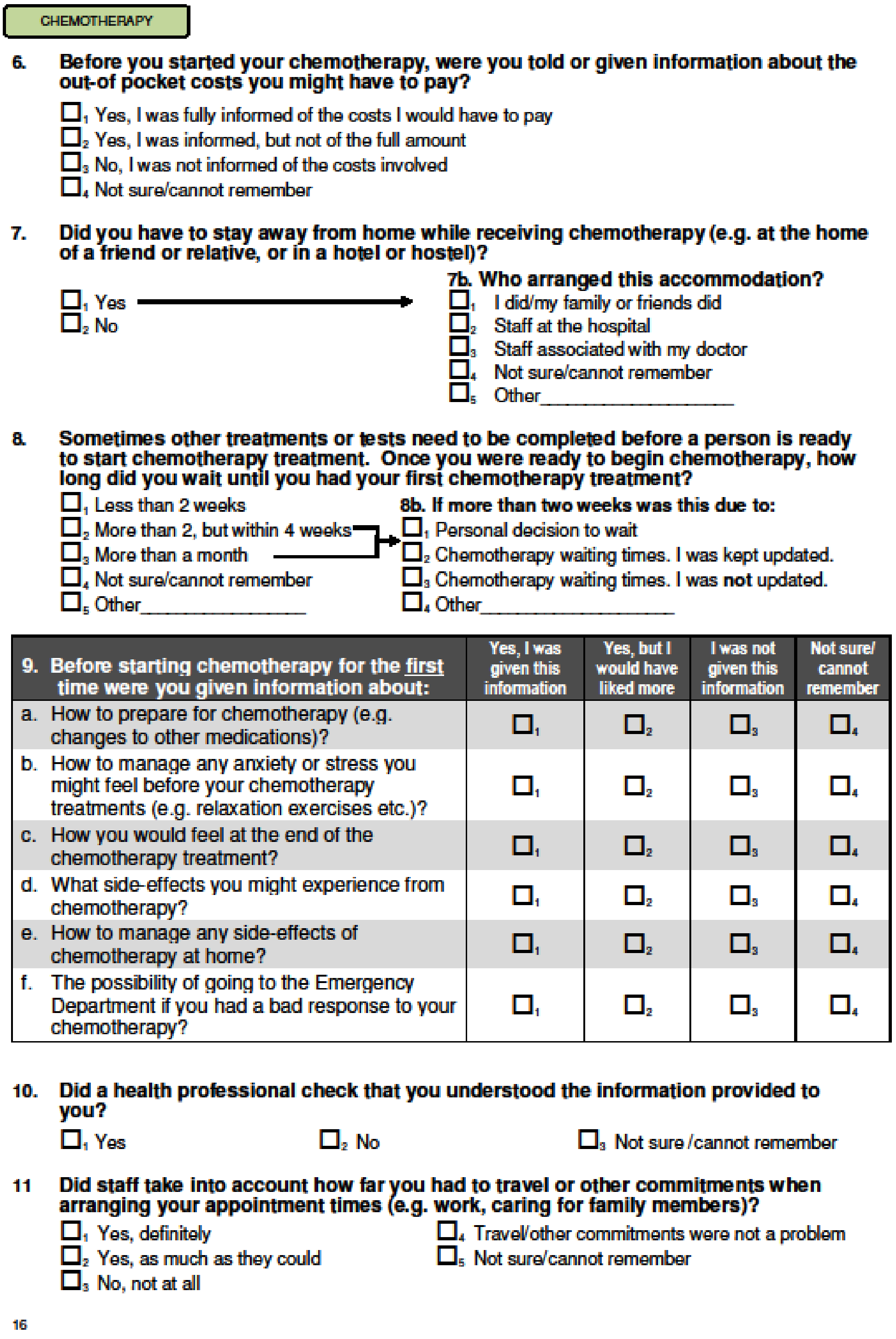


CHEMOTHERAPY

6. Before you started your chemotherapy, were you told or given information about the out-of pocket costs you might have to pay?

☐1 Yes, I was fully informed of the costs I would have to pay
☐2 Yes, I was informed, but not of the full amount
☐3 No, I was not informed of the costs involved
☐4 Not sure/cannot remember

7. Did you have to stay away from home while receiving chemotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

☐1 Yes →
☐2 No

7b. Who arranged this accommodation?

☐1 I did/my family or friends did
☐2 Staff at the hospital
☐3 Staff associated with my doctor
☐4 Not sure/cannot remember
☐5 Other___________________

8. Sometimes other treatments or tests need to be completed before a person is ready to start chemotherapy treatment. Once you were ready to begin chemotherapy, how long did you wait until you had your first chemotherapy treatment?

☐1 Less than 2 weeks
☐2 More than 2, but within 4 weeks
☐3 More than a month
☐4 Not sure/cannot remember
☐5 Other________________

8b. If more than two weeks was this due to:

☐1 Personal decision to wait
☐2 Chemotherapy waiting times. I was kept updated.
☐3 Chemotherapy waiting times. I was **not** updated.
☐4 Other___________________

9. Before starting chemotherapy for the first time were you given information about:	**Yes, I was given this information**	**Yes, but I would have liked more**	**I was not given this information**	**Not sure/ cannot remember**
a. How to prepare for chemotherapy (e.g. changes to other medications)?	☐1	☐2	☐3	☐4
b. How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?	☐1	☐2	☐3	☐4
c. How you would feel at the end of the chemotherapy treatment?	☐1	☐2	☐3	☐4
d. What side-effects you might experience from chemotherapy?	☐1	☐2	☐3	☐4
e. How to manage any side-effects of chemotherapy at home?	☐1	☐2	☐3	☐4
f. The possibility of going to the Emergency Department if you had a bad response to your chemotherapy?	☐1	☐2	☐3	☐4

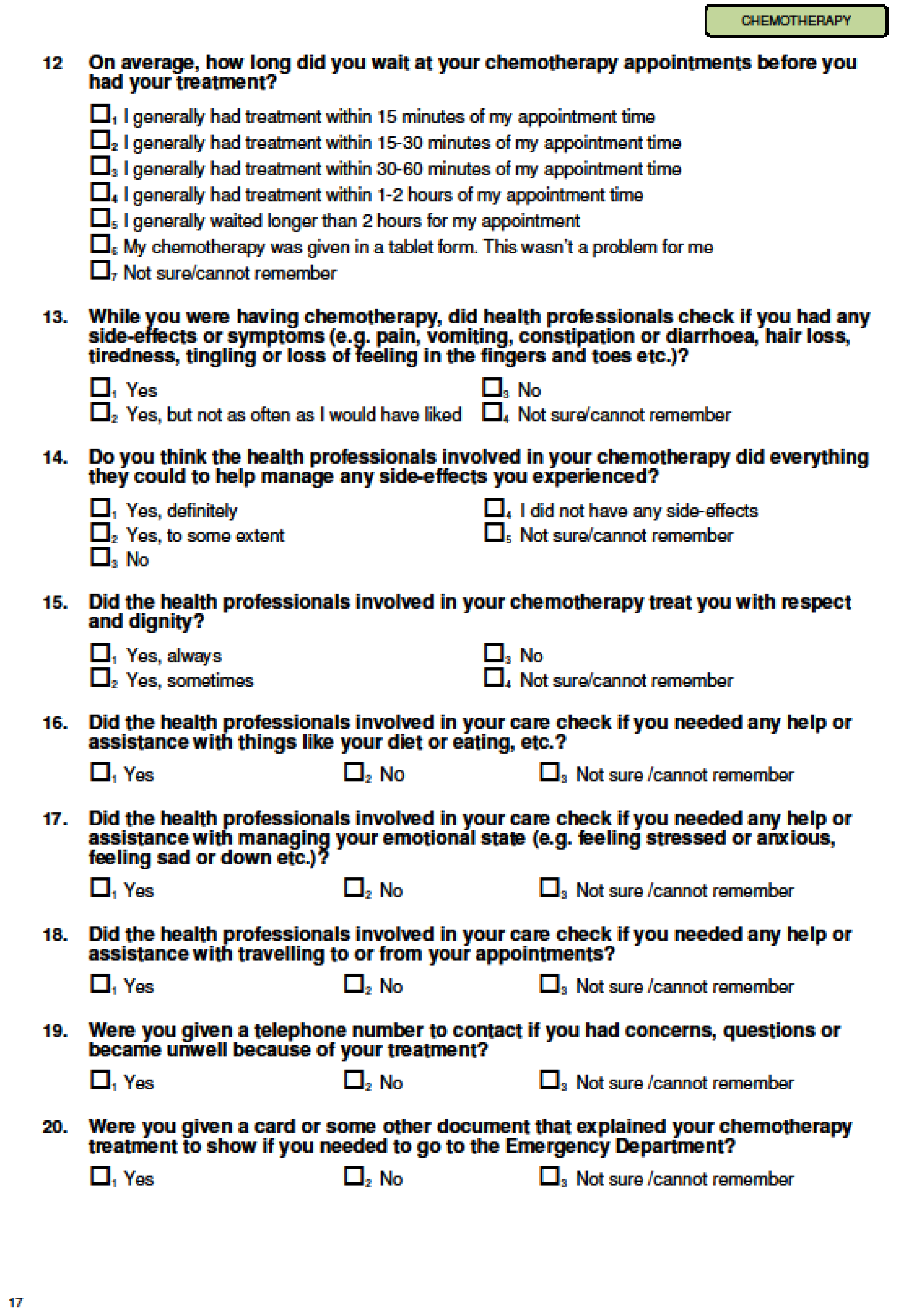
10. Did a health professional check that you understood the information provided to you?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

11 Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

☐1 Yes, definitely
☐2 Yes, as much as they could
☐3 No, not at all
☐4 Travel/other commitments were not a problem
☐5 Not sure/cannot remember

16



CHEMOTHERAPY

12 On average, how long did you wait at your chemotherapy appointments before you had your treatment?

☐1 I generally had treatment within 15 minutes of my appointment time
☐2 I generally had treatment within 15-30 minutes of my appointment time
☐3 I generally had treatment within 30-60 minutes of my appointment time
☐4 I generally had treatment within 1-2 hours of my appointment time
☐5 I generally waited longer than 2 hours for my appointment
☐6 My chemotherapy was given in a tablet form. This wasn't a problem for me
☐7 Not sure/cannot remember

13. While you were having chemotherapy, did health professionals check if you had any side-effects or symptoms (e.g. pain, vomiting, constipation or diarrhoea, hair loss, tiredness, tingling or loss of feeling in the fingers and toes etc.)?

☐1 Yes
☐2 Yes, but not as often as I would have liked
☐3 No
☐4 Not sure/cannot remember

14. Do you think the health professionals involved in your chemotherapy did everything they could to help manage any side-effects you experienced?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No
☐4 I did not have any side-effects
☐5 Not sure/cannot remember

15. Did the health professionals involved in your chemotherapy treat you with respect and dignity?

☐1 Yes, always
☐2 Yes, sometimes
☐3 No
☐4 Not sure/cannot remember

16. Did the health professionals involved in your care check if you needed any help or assistance with things like your diet or eating, etc.?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

17. Did the health professionals involved in your care check if you needed any help or assistance with managing your emotional state (e.g. feeling stressed or anxious, feeling sad or down etc.)?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

18. Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

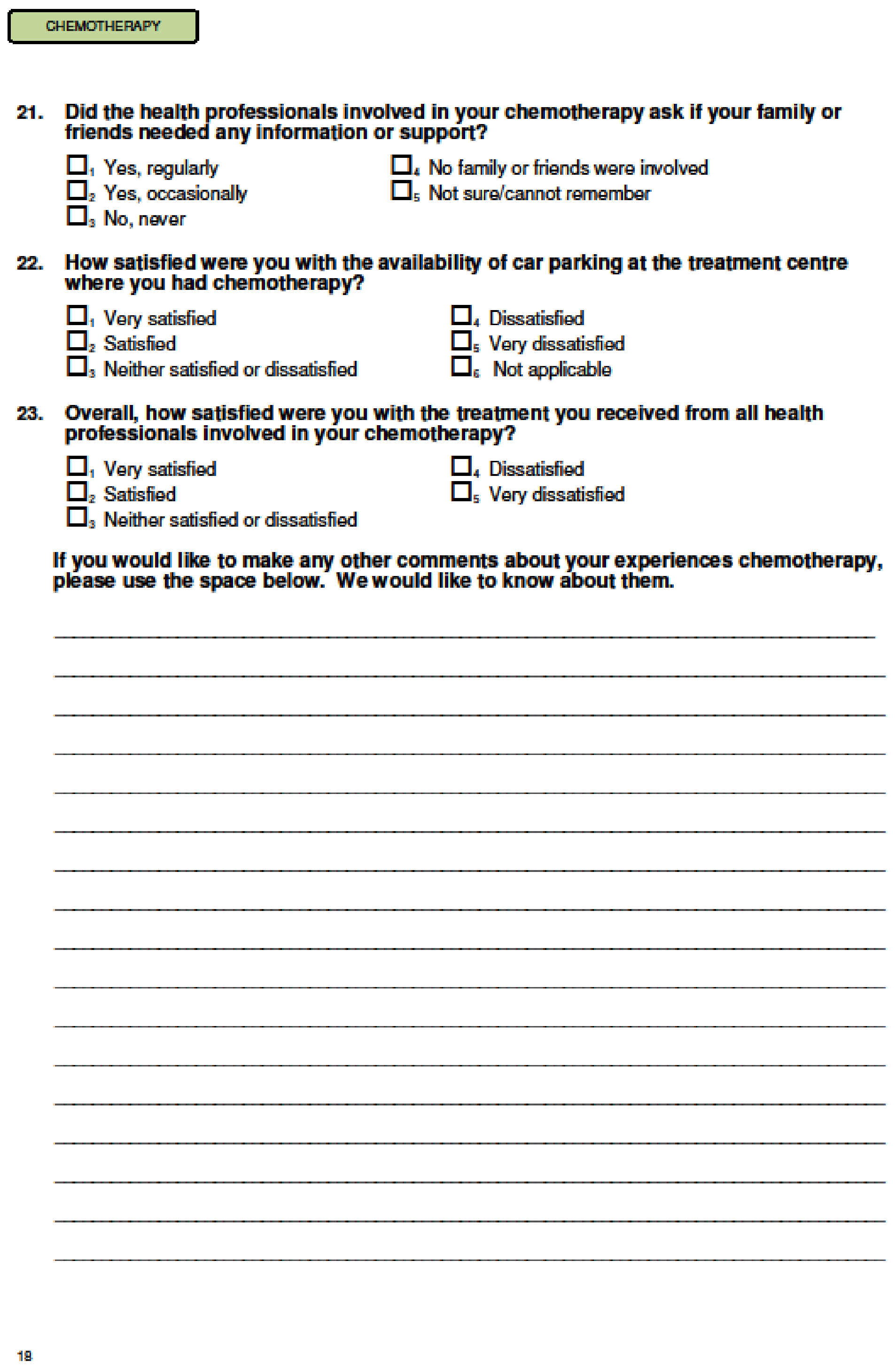
19. Were you given a telephone number to contact if you had concerns, questions or became unwell because of your treatment?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

20. Were you given a card or some other document that explained your chemotherapy treatment to show if you needed to go to the Emergency Department?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

17



CHEMOTHERAPY

21. Did the health professionals involved in your chemotherapy ask if your family or friends needed any information or support?

☐1 Yes, regularly
☐2 Yes, occasionally
☐3 No, never
☐4 No family or friends were involved
☐5 Not sure/cannot remember

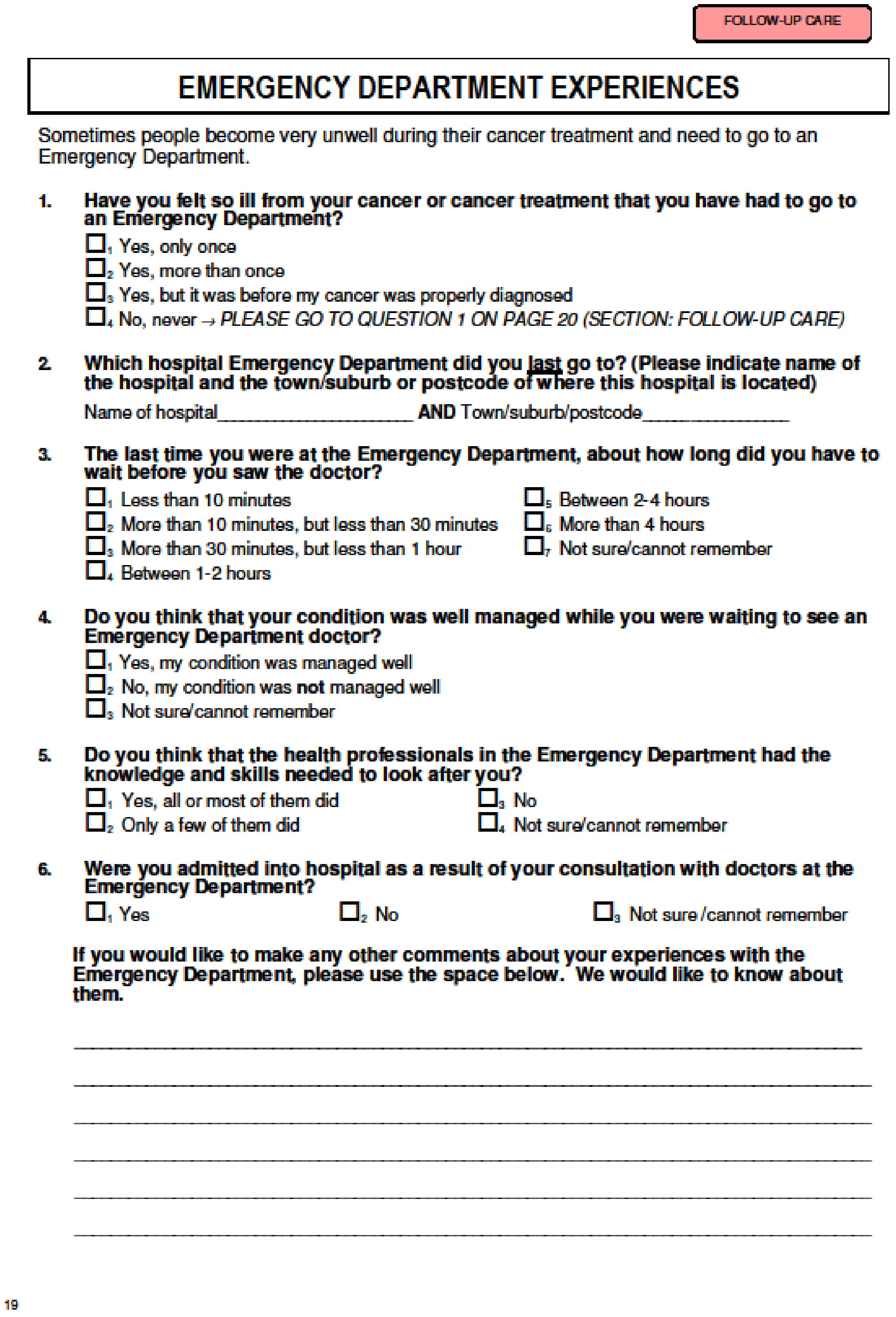
22. How satisfied were you with the availability of car parking at the treatment centre where you had chemotherapy?

☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied
☐6 Not applicable

23. Overall, how satisfied were you with the treatment you received from all health professionals involved in your chemotherapy?

☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied

If you would like to make any other comments about your experiences chemotherapy, please use the space below. We would like to know about them.



EMERGENCY DEPARTMENT EXPERIENCES

Sometimes people become very unwell during their cancer treatment and need to go to an Emergency Department.

1. **Have you felt so ill from your cancer or cancer treatment that you have had to go to an Emergency Department?**
   - ☐$_1$ Yes, only once
   - ☐$_2$ Yes, more than once
   - ☐$_3$ Yes, but it was before my cancer was properly diagnosed
   - ☐$_4$ No, never → *PLEASE GO TO QUESTION 1 ON PAGE 20 (SECTION: FOLLOW-UP CARE)*

2. **Which hospital Emergency Department did you last go to? (Please indicate name of the hospital and the town/suburb or postcode of where this hospital is located)**

   Name of hospital_____________________ **AND** Town/suburb/postcode_______________

3. **The last time you were at the Emergency Department, about how long did you have to wait before you saw the doctor?**
   - ☐$_1$ Less than 10 minutes
   - ☐$_2$ More than 10 minutes, but less than 30 minutes
   - ☐$_3$ More than 30 minutes, but less than 1 hour
   - ☐$_4$ Between 1-2 hours
   - ☐$_5$ Between 2-4 hours
   - ☐$_6$ More than 4 hours
   - ☐$_7$ Not sure/cannot remember

4. **Do you think that your condition was well managed while you were waiting to see an Emergency Department doctor?**
   - ☐$_1$ Yes, my condition was managed well
   - ☐$_2$ No, my condition was **not** managed well
   - ☐$_3$ Not sure/cannot remember

5. **Do you think that the health professionals in the Emergency Department had the knowledge and skills needed to look after you?**
   - ☐$_1$ Yes, all or most of them did
   - ☐$_2$ Only a few of them did
   - ☐$_3$ No
   - ☐$_4$ Not sure/cannot remember

6. **Were you admitted into hospital as a result of your consultation with doctors at the Emergency Department?**

   ☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

If you would like to make any other comments about your experiences with the Emergency Department, please use the space below. We would like to know about them.

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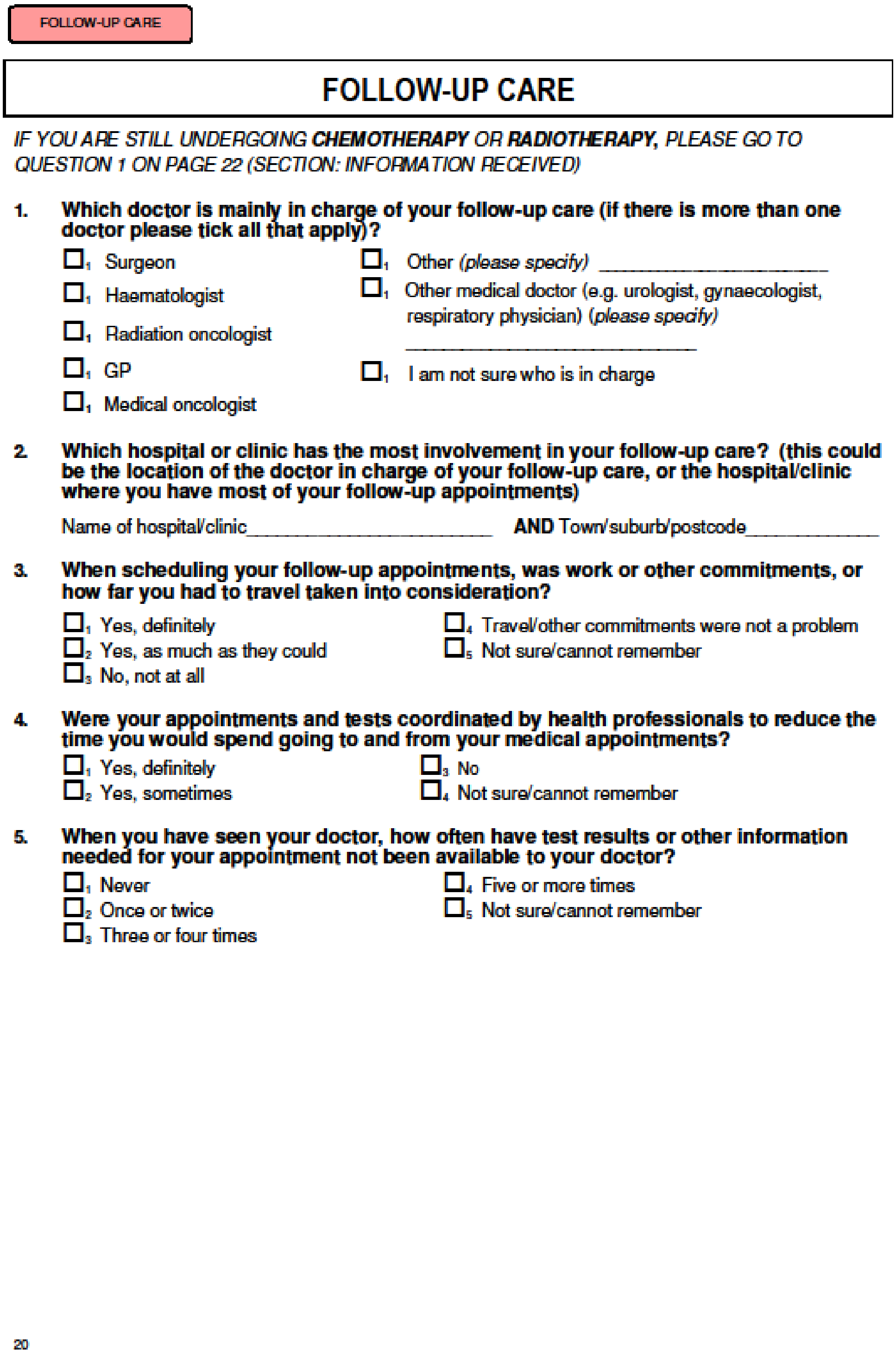


FOLLOW-UP CARE

FOLLOW-UP CARE

*IF YOU ARE STILL UNDERGOING **CHEMOTHERAPY** OR **RADIOTHERAPY**, PLEASE GO TO QUESTION 1 ON PAGE 22 (SECTION: INFORMATION RECEIVED)*

1. Which doctor is mainly in charge of your follow-up care (if there is more than one doctor please tick all that apply)?

☐1 Surgeon
☐1 Haematologist
☐1 Radiation oncologist
☐1 GP
☐1 Medical oncologist
☐1 Other *(please specify)* ______________________
☐1 Other medical doctor (e.g. urologist, gynaecologist, respiratory physician) (*please specify)* ____________________________
☐1 I am not sure who is in charge

2. Which hospital or clinic has the most involvement in your follow-up care? (this could be the location of the doctor in charge of your follow-up care, or the hospital/clinic where you have most of your follow-up appointments)

Name of hospital/clinic________________________ **AND** Town/suburb/postcode____________

3. When scheduling your follow-up appointments, was work or other commitments, or how far you had to travel taken into consideration?

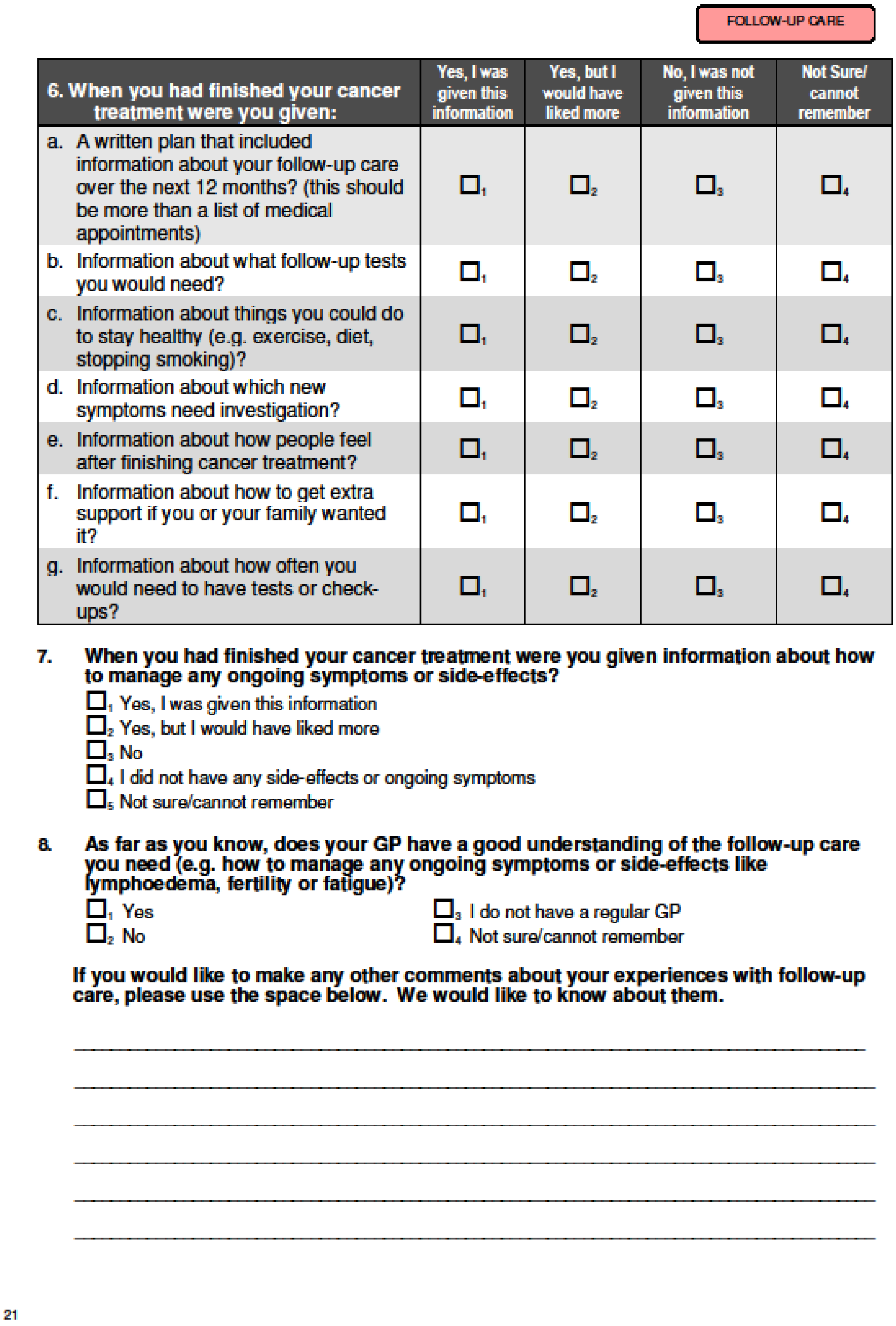
☐1 Yes, definitely
☐2 Yes, as much as they could
☐3 No, not at all
☐4 Travel/other commitments were not a problem
☐5 Not sure/cannot remember

4. Were your appointments and tests coordinated by health professionals to reduce the time you would spend going to and from your medical appointments?

☐1 Yes, definitely
☐2 Yes, sometimes
☐3 No
☐4 Not sure/cannot remember

5. When you have seen your doctor, how often have test results or other information needed for your appointment not been available to your doctor?

☐1 Never
☐2 Once or twice
☐3 Three or four times
☐4 Five or more times
☐5 Not sure/cannot remember



6. When you had finished your cancer treatment were you given:	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not Sure/ cannot remember
a. A written plan that included information about your follow-up care over the next 12 months? (this should be more than a list of medical appointments)	☐$_1$	☐$_2$	☐$_3$	☐$_4$
b. Information about what follow-up tests you would need?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
c. Information about things you could do to stay healthy (e.g. exercise, diet, stopping smoking)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
d. Information about which new symptoms need investigation?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
e. Information about how people feel after finishing cancer treatment?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
f. Information about how to get extra support if you or your family wanted it?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
g. Information about how often you would need to have tests or check-ups?	☐$_1$	☐$_2$	☐$_3$	☐$_4$

7. When you had finished your cancer treatment were you given information about how to manage any ongoing symptoms or side-effects?

☐$_1$ Yes, I was given this information
☐$_2$ Yes, but I would have liked more
☐$_3$ No
☐$_4$ I did not have any side-effects or ongoing symptoms
☐$_5$ Not sure/cannot remember

8. As far as you know, does your GP have a good understanding of the follow-up care you need (e.g. how to manage any ongoing symptoms or side-effects like lymphoedema, fertility or fatigue)?

☐$_1$ Yes
☐$_2$ No
☐$_3$ I do not have a regular GP
☐$_4$ Not sure/cannot remember

If you would like to make any other comments about your experiences with follow-up care, please use the space below. We would like to know about them.

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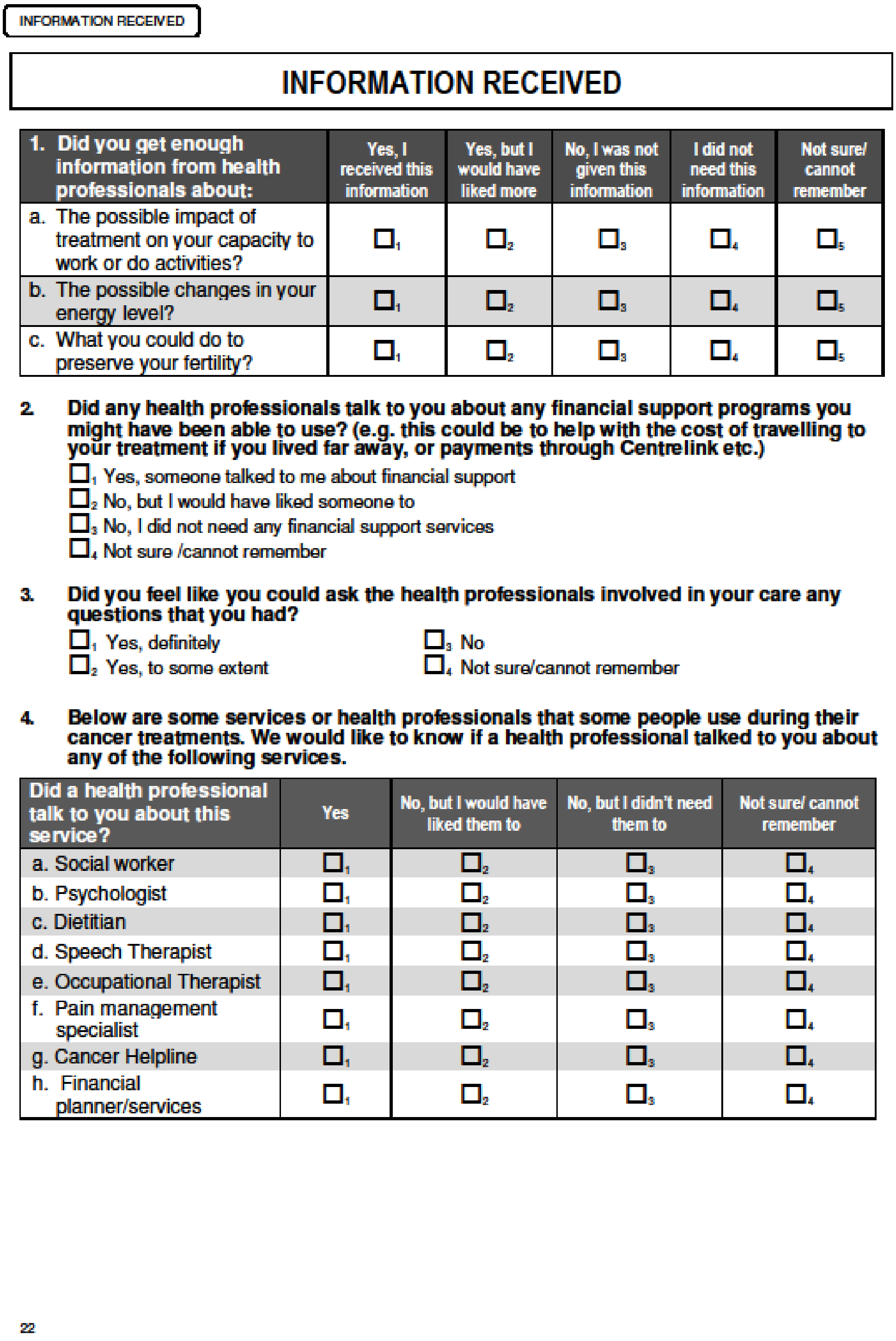


INFORMATION RECEIVED

INFORMATION RECEIVED

1. Did you get enough information from health professionals about:	Yes, I received this information	Yes, but I would have liked more	No, I was not given this information	I did not need this information	Not sure/ cannot remember
a. The possible impact of treatment on your capacity to work or do activities?	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
b. The possible changes in your energy level?	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$
c. What you could do to preserve your fertility?	☐$_1$	☐$_2$	☐$_3$	☐$_4$	☐$_5$

2. Did any health professionals talk to you about any financial support programs you might have been able to use? (e.g. this could be to help with the cost of travelling to your treatment if you lived far away, or payments through Centrelink etc.)

☐$_1$ Yes, someone talked to me about financial support
☐$_2$ No, but I would have liked someone to
☐$_3$ No, I did not need any financial support services
☐$_4$ Not sure /cannot remember

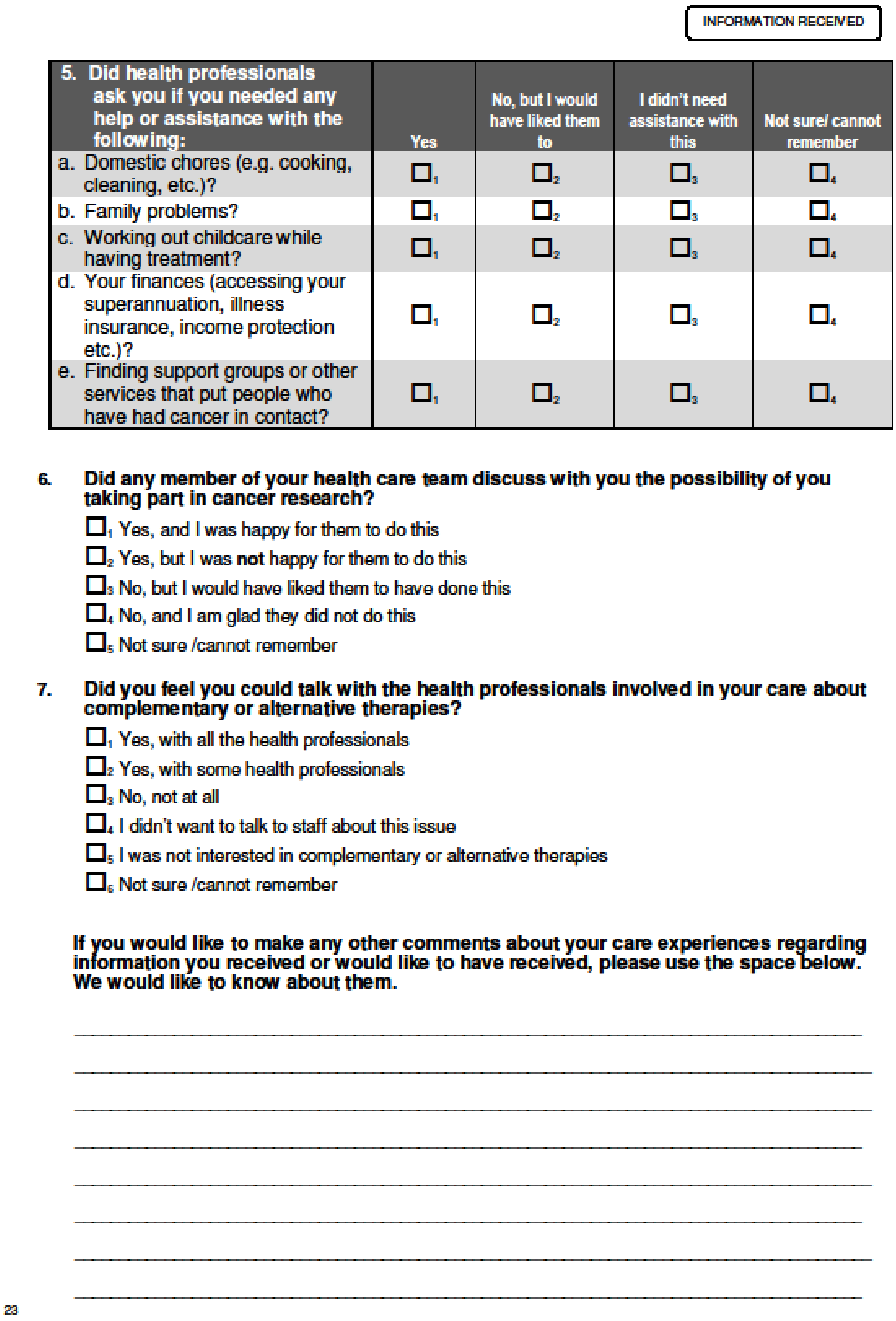
3. Did you feel like you could ask the health professionals involved in your care any questions that you had?

☐$_1$ Yes, definitely
☐$_2$ Yes, to some extent
☐$_3$ No
☐$_4$ Not sure/cannot remember

4. Below are some services or health professionals that some people use during their cancer treatments. We would like to know if a health professional talked to you about any of the following services.

Did a health professional talk to you about this service?	Yes	No, but I would have liked them to	No, but I didn't need them to	Not sure/ cannot remember
a. Social worker	☐$_1$	☐$_2$	☐$_3$	☐$_4$
b. Psychologist	☐$_1$	☐$_2$	☐$_3$	☐$_4$
c. Dietitian	☐$_1$	☐$_2$	☐$_3$	☐$_4$
d. Speech Therapist	☐$_1$	☐$_2$	☐$_3$	☐$_4$
e. Occupational Therapist	☐$_1$	☐$_2$	☐$_3$	☐$_4$
f. Pain management specialist	☐$_1$	☐$_2$	☐$_3$	☐$_4$
g. Cancer Helpline	☐$_1$	☐$_2$	☐$_3$	☐$_4$
h. Financial planner/services	☐$_1$	☐$_2$	☐$_3$	☐$_4$

22



5. Did health professionals ask you if you needed any help or assistance with the following:	Yes	No, but I would have liked them to	I didn't need assistance with this	Not sure/ cannot remember
a. Domestic chores (e.g. cooking, cleaning, etc.)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
b. Family problems?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
c. Working out childcare while having treatment?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
d. Your finances (accessing your superannuation, illness insurance, income protection etc.)?	☐$_1$	☐$_2$	☐$_3$	☐$_4$
e. Finding support groups or other services that put people who have had cancer in contact?	☐$_1$	☐$_2$	☐$_3$	☐$_4$

6. Did any member of your health care team discuss with you the possibility of you taking part in cancer research?

☐$_1$ Yes, and I was happy for them to do this
☐$_2$ Yes, but I was **not** happy for them to do this
☐$_3$ No, but I would have liked them to have done this
☐$_4$ No, and I am glad they did not do this
☐$_5$ Not sure /cannot remember

7. Did you feel you could talk with the health professionals involved in your care about complementary or alternative therapies?

☐$_1$ Yes, with all the health professionals
☐$_2$ Yes, with some health professionals
☐$_3$ No, not at all
☐$_4$ I didn't want to talk to staff about this issue
☐$_5$ I was not interested in complementary or alternative therapies
☐$_6$ Not sure /cannot remember

If you would like to make any other comments about your care experiences regarding information you received or would like to have received, please use the space below. We would like to know about them.

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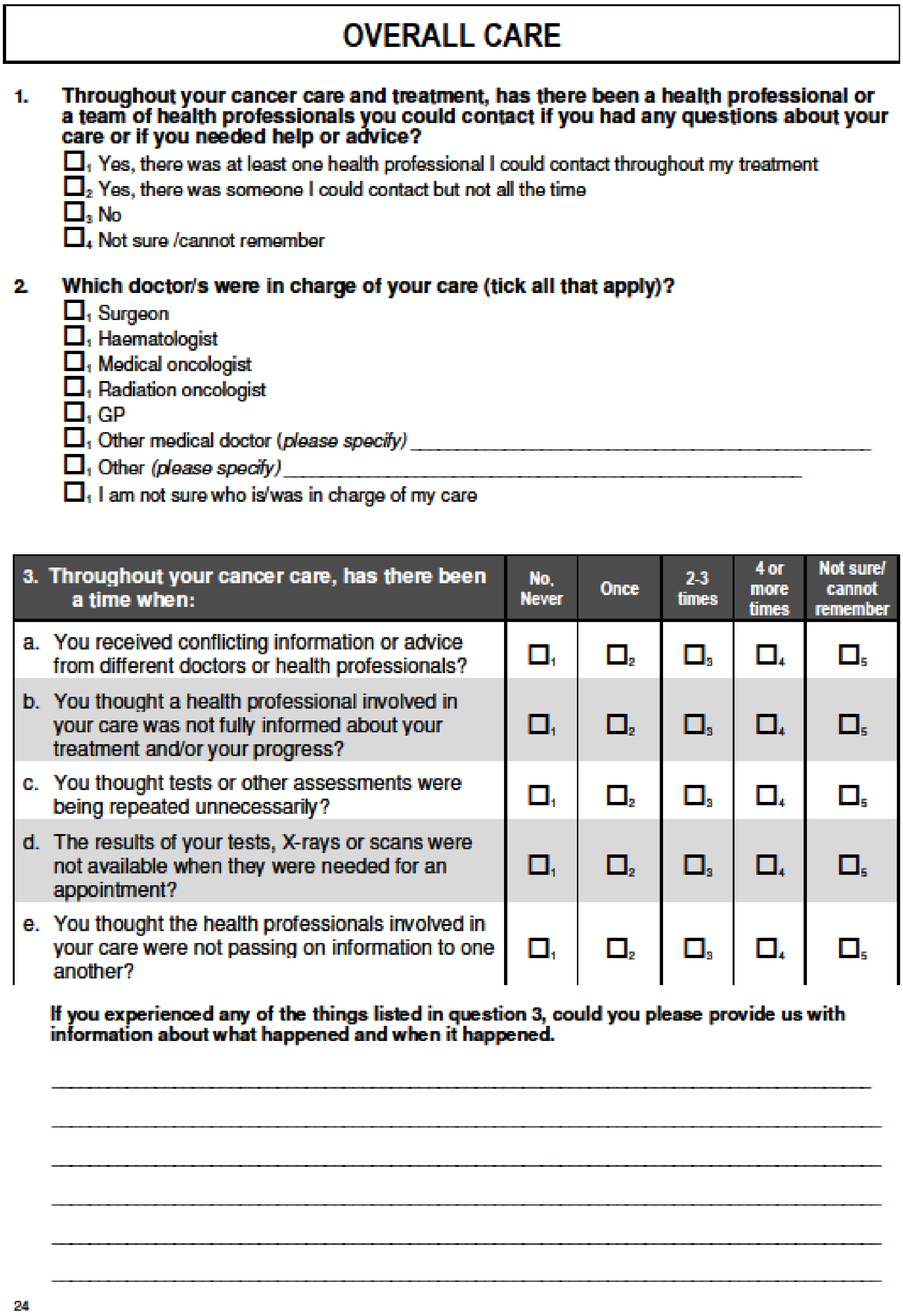

OVERALL CARE

1. Throughout your cancer care and treatment, has there been a health professional or a team of health professionals you could contact if you had any questions about your care or if you needed help or advice?

☐1 Yes, there was at least one health professional I could contact throughout my treatment
☐2 Yes, there was someone I could contact but not all the time
☐3 No
☐4 Not sure /cannot remember

2. Which doctor/s were in charge of your care (tick all that apply)?

☐1 Surgeon
☐1 Haematologist
☐1 Medical oncologist
☐1 Radiation oncologist
☐1 GP
☐1 Other medical doctor (*please specify*) ____
☐1 Other (*please specify*) ____
☐1 I am not sure who is/was in charge of my care

3. Throughout your cancer care, has there been a time when:	**No, Never**	**Once**	**2-3 times**	**4 or more times**	**Not sure/ cannot remember**
a. You received conflicting information or advice from different doctors or health professionals?	☐1	☐2	☐3	☐4	☐5
b. You thought a health professional involved in your care was not fully informed about your treatment and/or your progress?	☐1	☐2	☐3	☐4	☐5
c. You thought tests or other assessments were being repeated unnecessarily?	☐1	☐2	☐3	☐4	☐5
d. The results of your tests, X-rays or scans were not available when they were needed for an appointment?	☐1	☐2	☐3	☐4	☐5
e. You thought the health professionals involved in your care were not passing on information to one another?	☐1	☐2	☐3	☐4	☐5

If you experienced any of the things listed in question 3, could you please provide us with information about what happened and when it happened.

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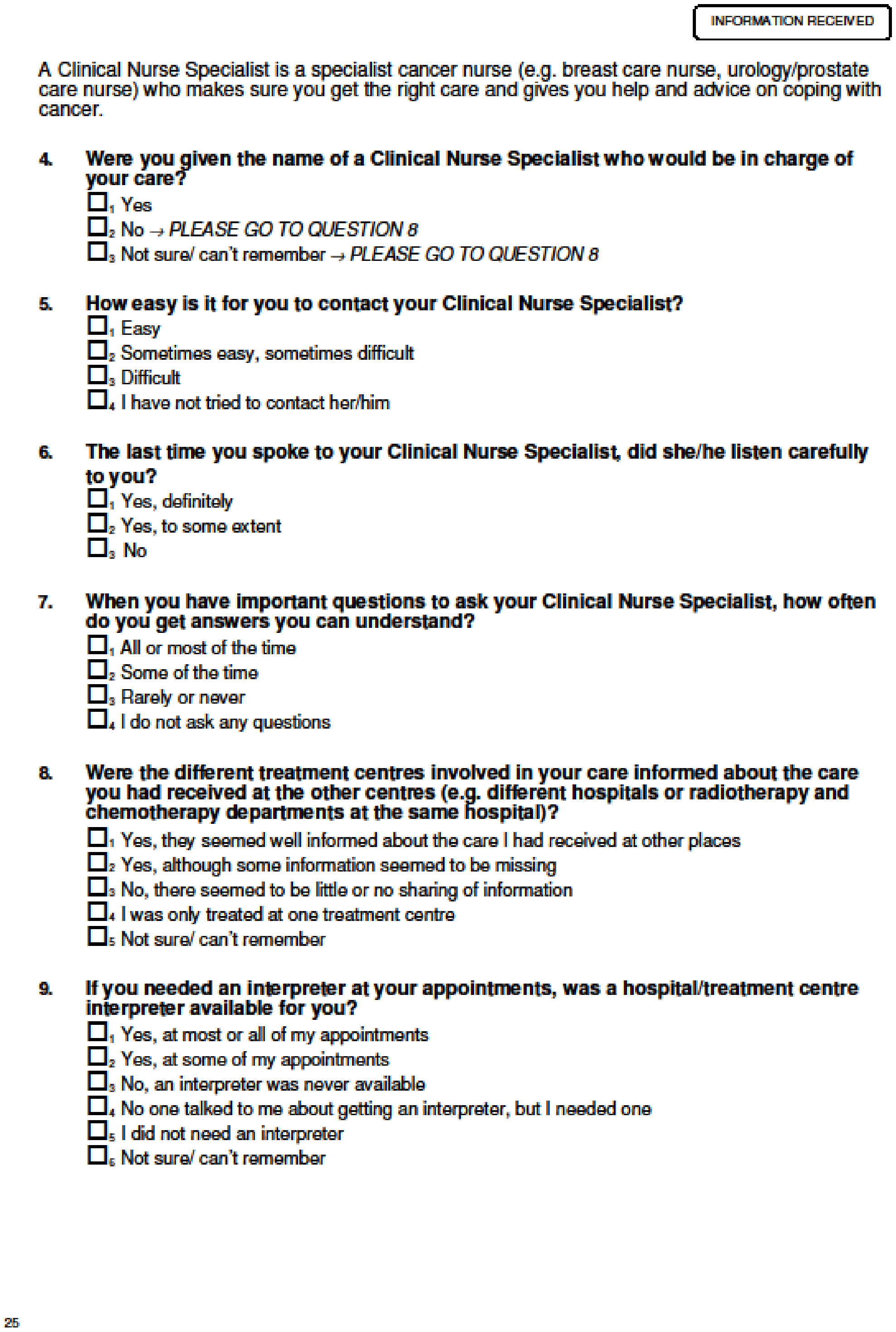

INFORMATION RECEIVED

A Clinical Nurse Specialist is a specialist cancer nurse (e.g. breast care nurse, urology/prostate care nurse) who makes sure you get the right care and gives you help and advice on coping with cancer.

4. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

☐1 Yes
☐2 No → *PLEASE GO TO QUESTION 8*
☐3 Not sure/ can't remember → *PLEASE GO TO QUESTION 8*

5. How easy is it for you to contact your Clinical Nurse Specialist?

☐1 Easy
☐2 Sometimes easy, sometimes difficult
☐3 Difficult
☐4 I have not tried to contact her/him

6. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No

7. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

☐1 All or most of the time
☐2 Some of the time
☐3 Rarely or never
☐4 I do not ask any questions

8. Were the different treatment centres involved in your care informed about the care you had received at the other centres (e.g. different hospitals or radiotherapy and chemotherapy departments at the same hospital)?

☐1 Yes, they seemed well informed about the care I had received at other places
☐2 Yes, although some information seemed to be missing
☐3 No, there seemed to be little or no sharing of information
☐4 I was only treated at one treatment centre
☐5 Not sure/ can't remember

9. If you needed an interpreter at your appointments, was a hospital/treatment centre interpreter available for you?

☐1 Yes, at most or all of my appointments
☐2 Yes, at some of my appointments
☐3 No, an interpreter was never available
☐4 No one talked to me about getting an interpreter, but I needed one
☐5 I did not need an interpreter
☐6 Not sure/ can't remember

10. As far as you know, was your GP kept informed about your condition and your treatment?

☐$_1$ Yes, my GP seemed very well informed
☐$_2$ Yes, to some extent
☐$_3$ No, my GP did not know much about my cancer or the treatment I had
☐$_4$ I do not have a regular GP
☐$_5$ Not sure/ can't remember

11. How would you rate how well the doctors and nurses involved in your cancer care worked together?

☐$_1$ Excellent
☐$_2$ Very good
☐$_3$ Good
☐$_4$ Fair
☐$_5$ Poor

12 How satisfied were you with the overall care you received from all health professionals involved in your treatment?

☐$_1$ Very satisfied
☐$_2$ Satisfied
☐$_3$ Neither satisfied or dissatisfied
☐$_4$ Dissatisfied
☐$_5$ Very dissatisfied

13. Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it (this includes medical treatment, the way you were treated personally and the way that healthcare professionals communicated with you)?

☐$_1$ Yes, there was at least one time → **Go to Q13b**
☐$_2$ No, my care was generally fine
☐$_3$ No, my care was excellent
☐$_4$ Not sure/cannot remember

13b If yes, what was the issue you wanted to complain about?

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If you would like to make any other comments about your overall care experiences please use the space below. We would like to know about them.

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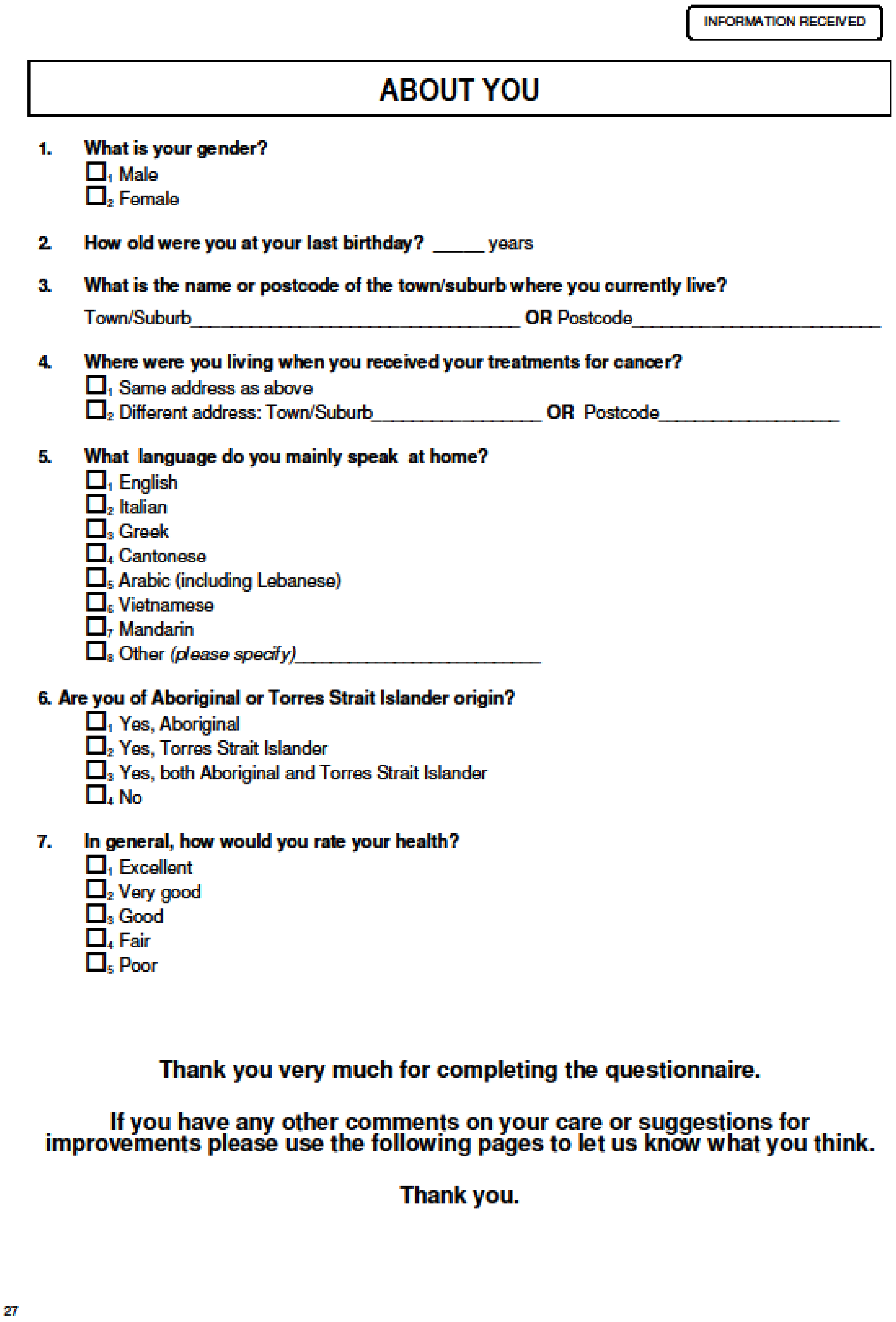


INFORMATION RECEIVED

ABOUT YOU

1. **What is your gender?**
   ☐$_1$ Male
   ☐$_2$ Female

2. **How old were you at your last birthday?** _____ years

3. **What is the name or postcode of the town/suburb where you currently live?**
   Town/Suburb________________________________ **OR** Postcode________________________

4. **Where were you living when you received your treatments for cancer?**
   ☐$_1$ Same address as above
   ☐$_2$ Different address: Town/Suburb________________ **OR** Postcode_________________

5. **What language do you mainly speak at home?**
   ☐$_1$ English
   ☐$_2$ Italian
   ☐$_3$ Greek
   ☐$_4$ Cantonese
   ☐$_5$ Arabic (including Lebanese)
   ☐$_6$ Vietnamese
   ☐$_7$ Mandarin
   ☐$_8$ Other *(please specify)*________________________

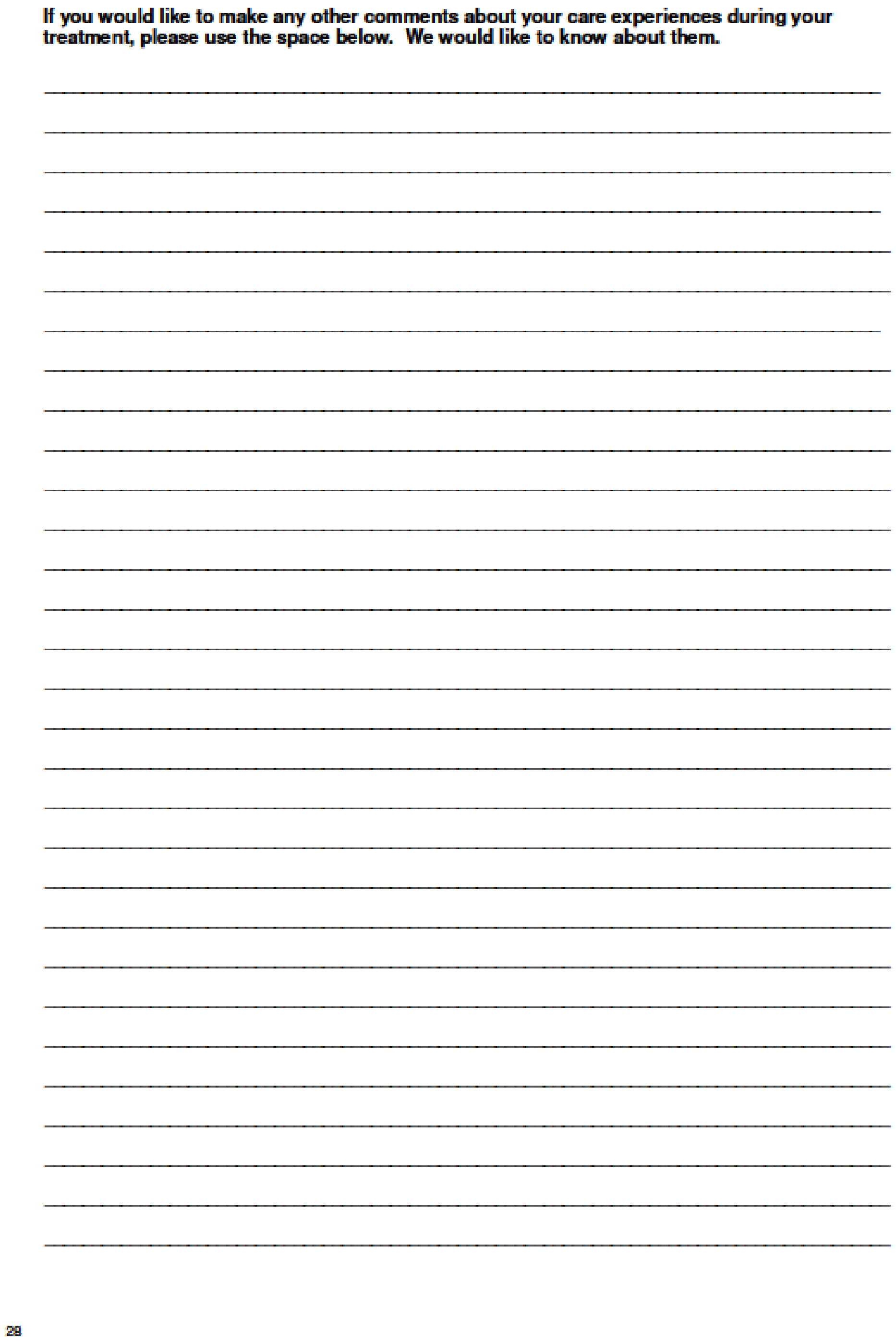
6. **Are you of Aboriginal or Torres Strait Islander origin?**
   ☐$_1$ Yes, Aboriginal
   ☐$_2$ Yes, Torres Strait Islander
   ☐$_3$ Yes, both Aboriginal and Torres Strait Islander
   ☐$_4$ No

7. **In general, how would you rate your health?**
   ☐$_1$ Excellent
   ☐$_2$ Very good
   ☐$_3$ Good
   ☐$_4$ Fair
   ☐$_5$ Poor

Thank you very much for completing the questionnaire.

If you have any other comments on your care or suggestions for improvements please use the following pages to let us know what you think.

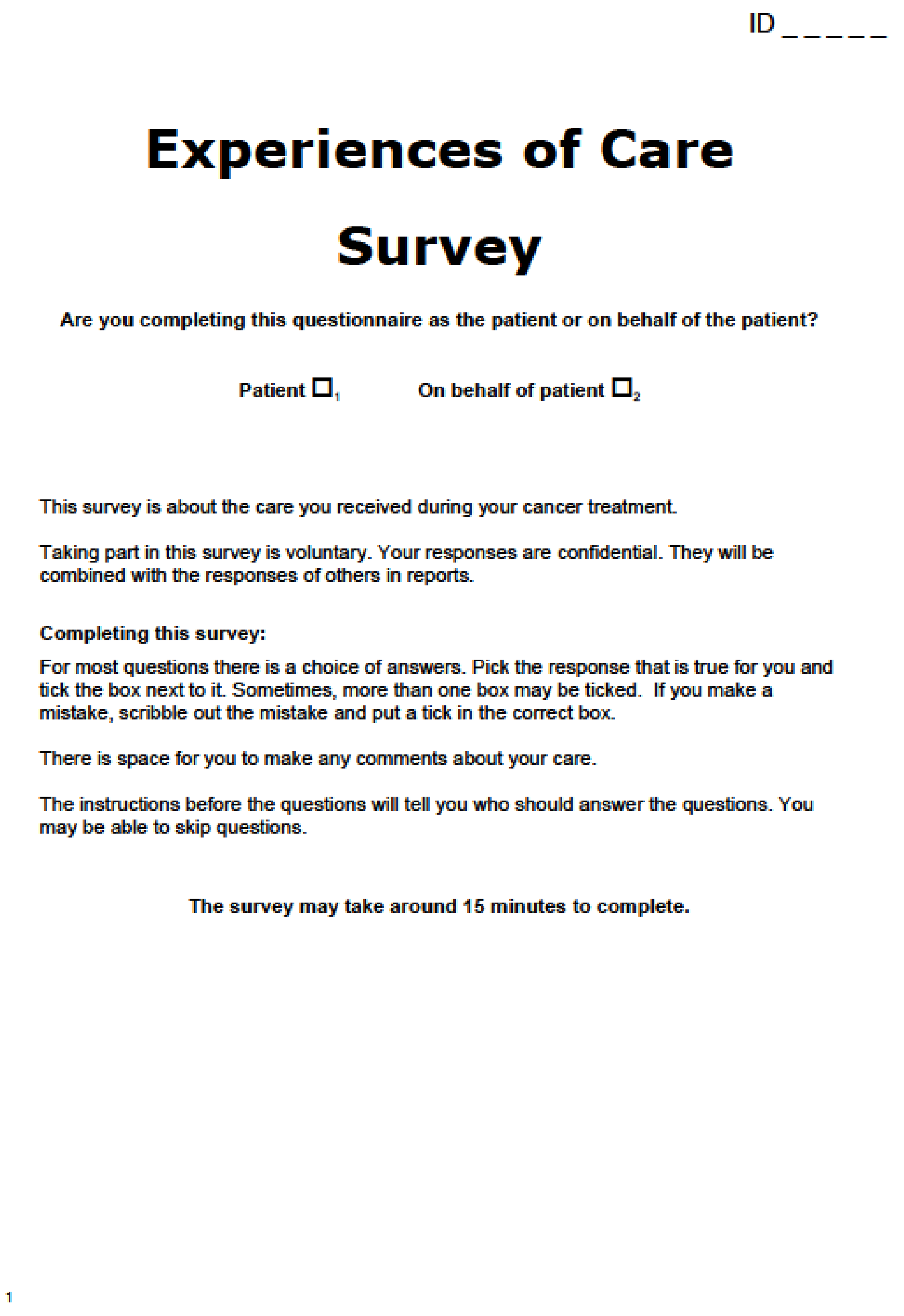
Thank you.



If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them.

28

Appendix 1B Short Survey



ID _ _ _ _ _

Experiences of Care Survey

Are you completing this questionnaire as the patient or on behalf of the patient?

Patient ☐1 **On behalf of patient** ☐2

This survey is about the care you received during your cancer treatment.

Taking part in this survey is voluntary. Your responses are confidential. They will be combined with the responses of others in reports.

Completing this survey:

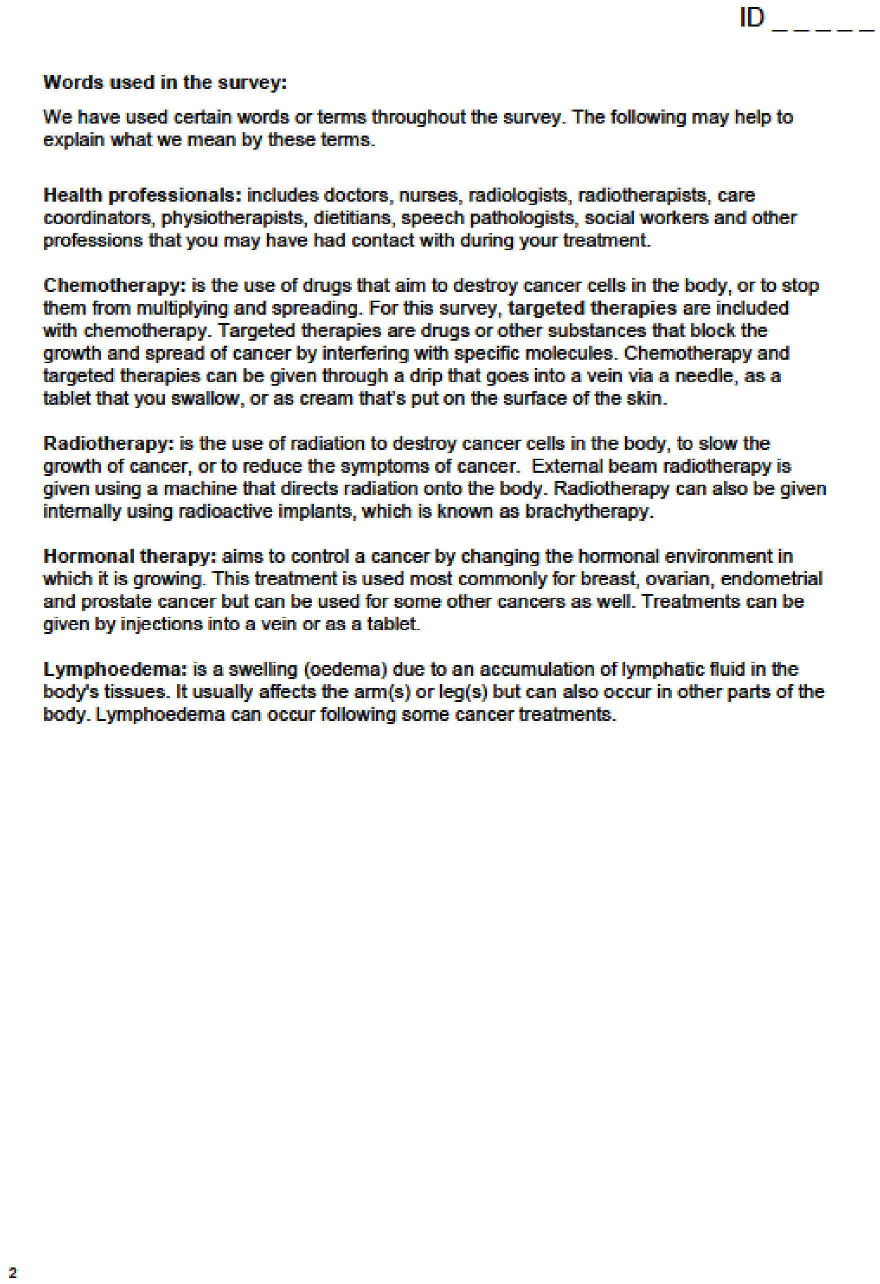
For most questions there is a choice of answers. Pick the response that is true for you and tick the box next to it. Sometimes, more than one box may be ticked. If you make a mistake, scribble out the mistake and put a tick in the correct box.

There is space for you to make any comments about your care.

The instructions before the questions will tell you who should answer the questions. You may be able to skip questions.

The survey may take around 15 minutes to complete.

1



ID _ _ _ _ _

Words used in the survey:

We have used certain words or terms throughout the survey. The following may help to explain what we mean by these terms.

Health professionals: includes doctors, nurses, radiologists, radiotherapists, care coordinators, physiotherapists, dietitians, speech pathologists, social workers and other professions that you may have had contact with during your treatment.

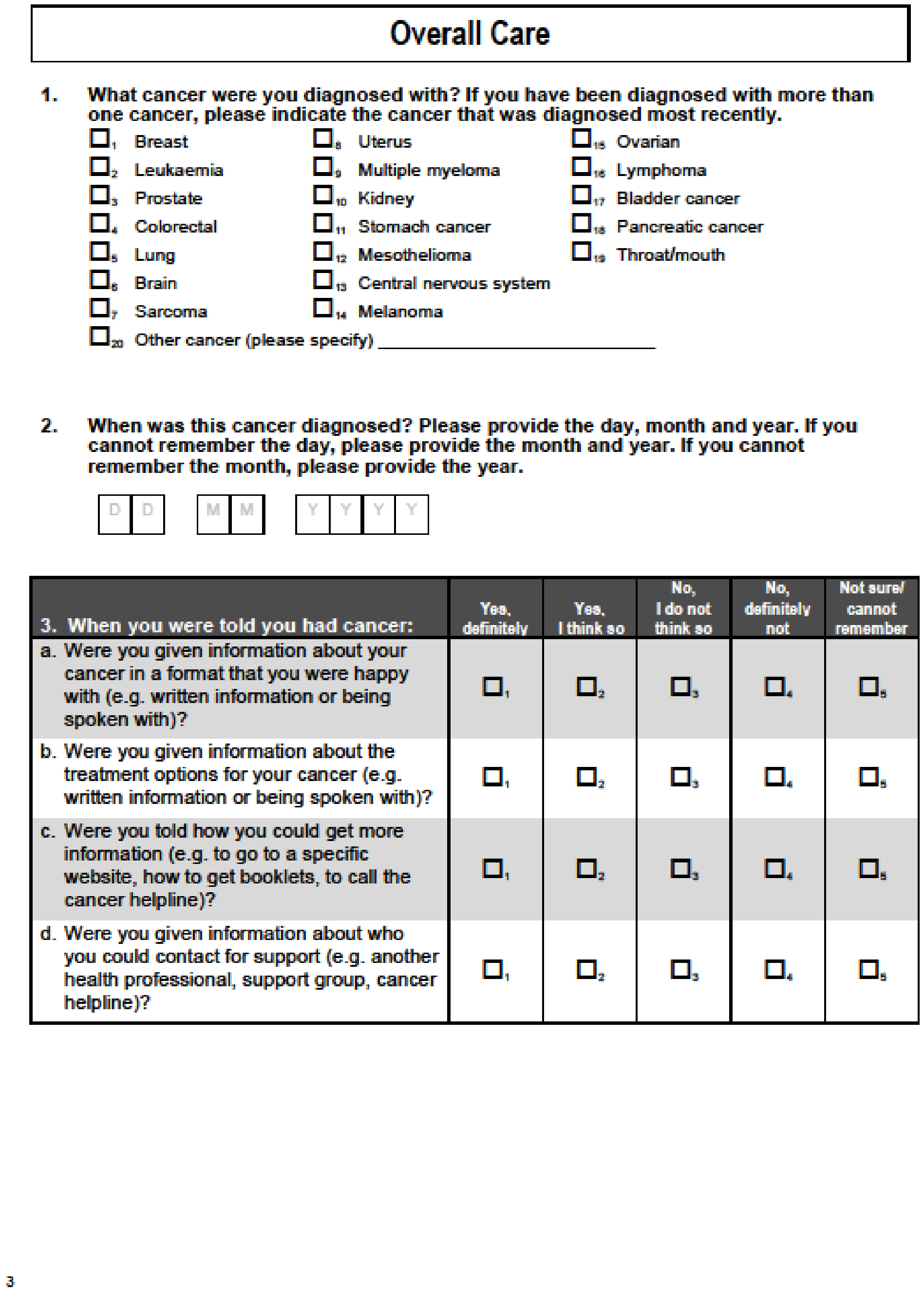
Chemotherapy: is the use of drugs that aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. For this survey, **targeted therapies** are included with chemotherapy. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy and targeted therapies can be given through a drip that goes into a vein via a needle, as a tablet that you swallow, or as cream that's put on the surface of the skin.

Radiotherapy: is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External beam radiotherapy is given using a machine that directs radiation onto the body. Radiotherapy can also be given internally using radioactive implants, which is known as brachytherapy.

Hormonal therapy: aims to control a cancer by changing the hormonal environment in which it is growing. This treatment is used most commonly for breast, ovarian, endometrial and prostate cancer but can be used for some other cancers as well. Treatments can be given by injections into a vein or as a tablet.

Lymphoedema: is a swelling (oedema) due to an accumulation of lymphatic fluid in the body's tissues. It usually affects the arm(s) or leg(s) but can also occur in other parts of the body. Lymphoedema can occur following some cancer treatments.

2



Overall Care

1. What cancer were you diagnosed with? If you have been diagnosed with more than one cancer, please indicate the cancer that was diagnosed most recently.

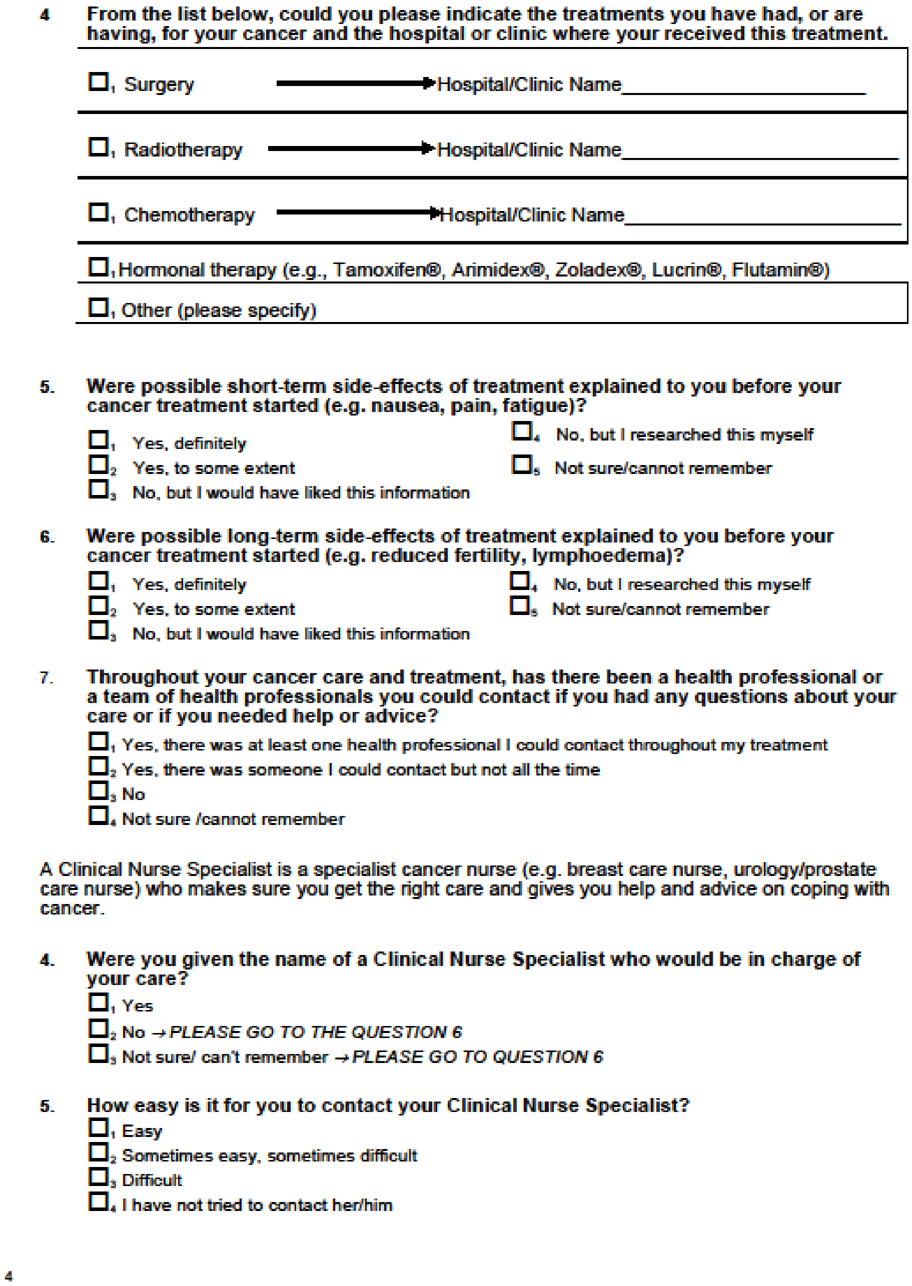
☐$_{1}$ Breast
☐$_{2}$ Leukaemia
☐$_{3}$ Prostate
☐$_{4}$ Colorectal
☐$_{5}$ Lung
☐$_{6}$ Brain
☐$_{7}$ Sarcoma
☐$_{8}$ Uterus
☐$_{9}$ Multiple myeloma
☐$_{10}$ Kidney
☐$_{11}$ Stomach cancer
☐$_{12}$ Mesothelioma
☐$_{13}$ Central nervous system
☐$_{14}$ Melanoma
☐$_{15}$ Ovarian
☐$_{16}$ Lymphoma
☐$_{17}$ Bladder cancer
☐$_{18}$ Pancreatic cancer
☐$_{19}$ Throat/mouth
☐$_{20}$ Other cancer (please specify) ____________________________

2. When was this cancer diagnosed? Please provide the day, month and year. If you cannot remember the day, please provide the month and year. If you cannot remember the month, please provide the year.

D D M M Y Y Y Y

3. When you were told you had cancer:	Yes, definitely	Yes, I think so	No, I do not think so	No, definitely not	Not sure/ cannot remember
a. Were you given information about your cancer in a format that you were happy with (e.g. written information or being spoken with)?	☐$_{1}$	☐$_{2}$	☐$_{3}$	☐$_{4}$	☐$_{5}$
b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)?	☐$_{1}$	☐$_{2}$	☐$_{3}$	☐$_{4}$	☐$_{5}$
c. Were you told how you could get more information (e.g. to go to a specific website, how to get booklets, to call the cancer helpline)?	☐$_{1}$	☐$_{2}$	☐$_{3}$	☐$_{4}$	☐$_{5}$
d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)?	☐$_{1}$	☐$_{2}$	☐$_{3}$	☐$_{4}$	☐$_{5}$

3



4 From the list below, could you please indicate the treatments you have had, or are having, for your cancer and the hospital or clinic where your received this treatment.

☐1 Surgery → Hospital/Clinic Name____________________

☐1 Radiotherapy → Hospital/Clinic Name____________________

☐1 Chemotherapy → Hospital/Clinic Name____________________

☐1 Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®)

☐1 Other (please specify)

5. Were possible short-term side-effects of treatment explained to you before your cancer treatment started (e.g. nausea, pain, fatigue)?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No, but I would have liked this information
☐4 No, but I researched this myself
☐5 Not sure/cannot remember

6. Were possible long-term side-effects of treatment explained to you before your cancer treatment started (e.g. reduced fertility, lymphoedema)?

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No, but I would have liked this information
☐4 No, but I researched this myself
☐5 Not sure/cannot remember

7. Throughout your cancer care and treatment, has there been a health professional or a team of health professionals you could contact if you had any questions about your care or if you needed help or advice?

☐1 Yes, there was at least one health professional I could contact throughout my treatment
☐2 Yes, there was someone I could contact but not all the time
☐3 No
☐4 Not sure /cannot remember

A Clinical Nurse Specialist is a specialist cancer nurse (e.g. breast care nurse, urology/prostate care nurse) who makes sure you get the right care and gives you help and advice on coping with cancer.

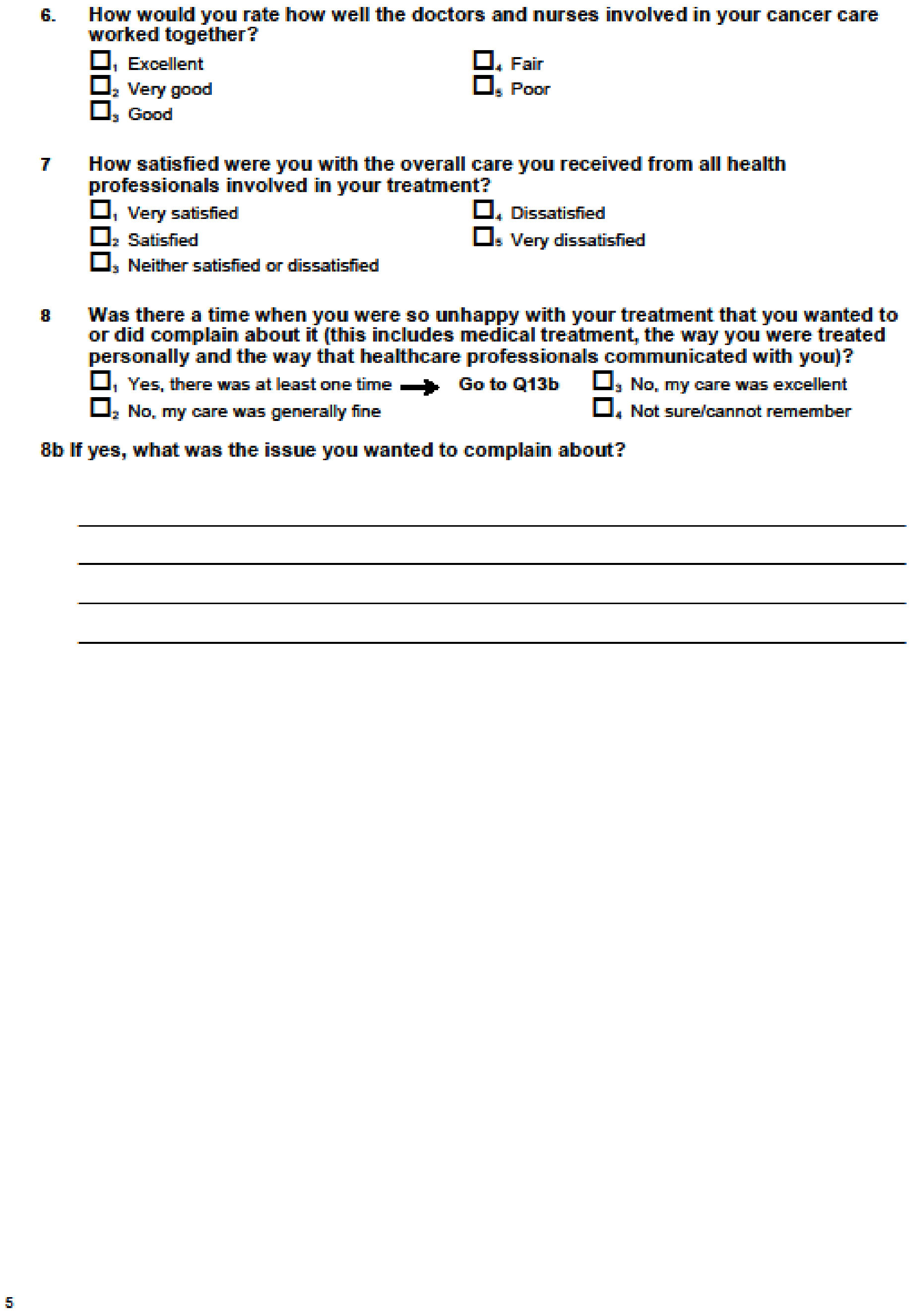
4. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

☐1 Yes
☐2 No → *PLEASE GO TO THE QUESTION 6*
☐3 Not sure/ can't remember → *PLEASE GO TO QUESTION 6*

5. How easy is it for you to contact your Clinical Nurse Specialist?

☐1 Easy
☐2 Sometimes easy, sometimes difficult
☐3 Difficult
☐4 I have not tried to contact her/him

4



6. **How would you rate how well the doctors and nurses involved in your cancer care worked together?**

☐1 Excellent
☐2 Very good
☐3 Good
☐4 Fair
☐5 Poor

7 **How satisfied were you with the overall care you received from all health professionals involved in your treatment?**

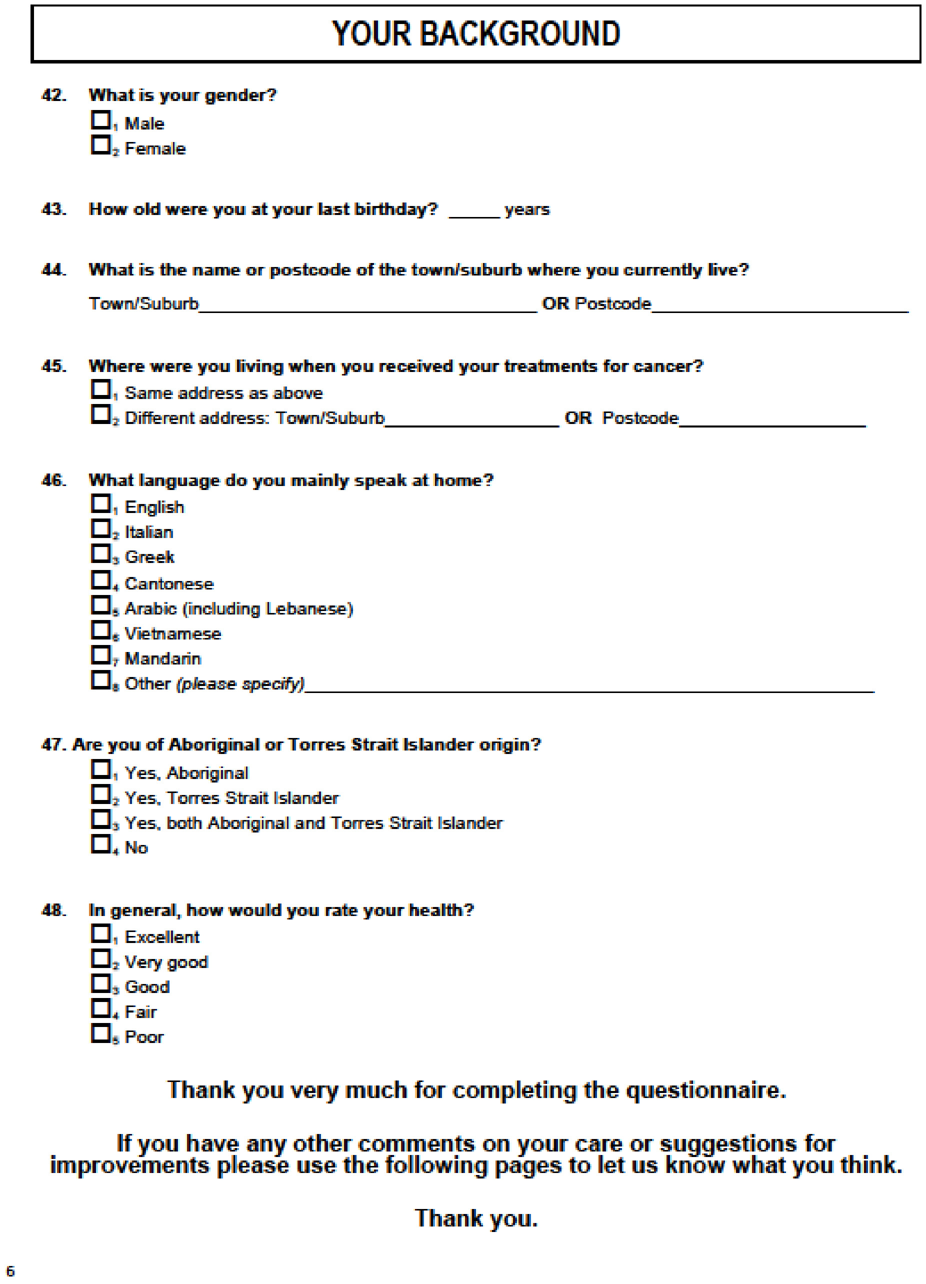
☐1 Very satisfied
☐2 Satisfied
☐3 Neither satisfied or dissatisfied
☐4 Dissatisfied
☐5 Very dissatisfied

8 **Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it (this includes medical treatment, the way you were treated personally and the way that healthcare professionals communicated with you)?**

☐1 Yes, there was at least one time → **Go to Q13b**
☐2 No, my care was generally fine
☐3 No, my care was excellent
☐4 Not sure/cannot remember

8b If yes, what was the issue you wanted to complain about?

5



YOUR BACKGROUND

42. What is your gender?

☐$_1$ Male
☐$_2$ Female

43. How old were you at your last birthday? _____ years

44. What is the name or postcode of the town/suburb where you currently live?

Town/Suburb________________________________ **OR** Postcode________________________

45. Where were you living when you received your treatments for cancer?

☐$_1$ Same address as above
☐$_2$ Different address: Town/Suburb________________ **OR** Postcode_________________

46. What language do you mainly speak at home?

☐$_1$ English
☐$_2$ Italian
☐$_3$ Greek
☐$_4$ Cantonese
☐$_5$ Arabic (including Lebanese)
☐$_6$ Vietnamese
☐$_7$ Mandarin
☐$_8$ Other *(please specify)*____

47. Are you of Aboriginal or Torres Strait Islander origin?

☐$_1$ Yes, Aboriginal
☐$_2$ Yes, Torres Strait Islander
☐$_3$ Yes, both Aboriginal and Torres Strait Islander
☐$_4$ No

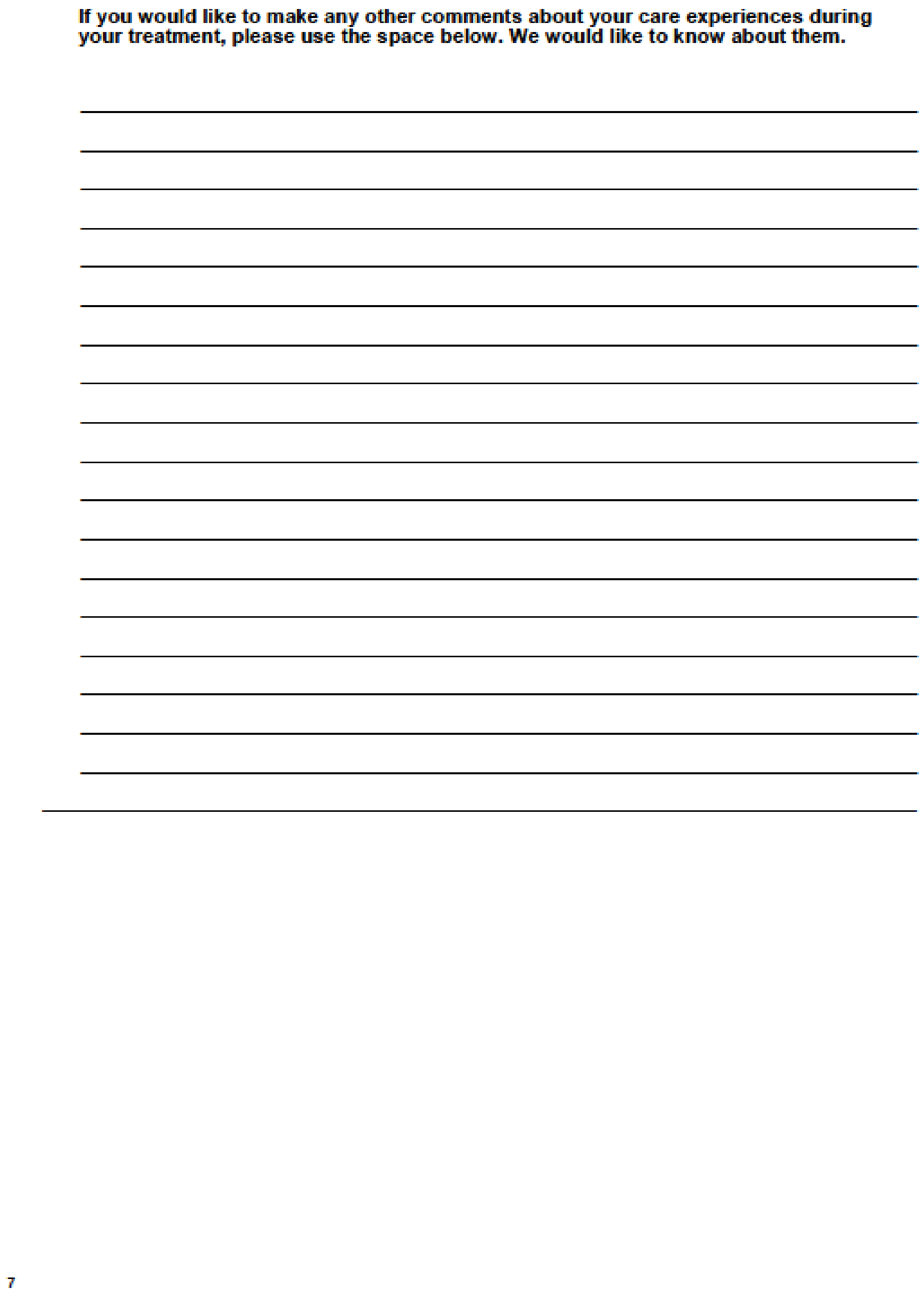
48. In general, how would you rate your health?

☐$_1$ Excellent
☐$_2$ Very good
☐$_3$ Good
☐$_4$ Fair
☐$_5$ Poor

Thank you very much for completing the questionnaire.

If you have any other comments on your care or suggestions for improvements please use the following pages to let us know what you think.

Thank you.



If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them.

7

Appendix 1C: Chemotherapy specific survey

ID _ _ _ _ _

Experiences of Care Survey

Are you completing this questionnaire as the patient or on behalf of the patient?

Patient ☐1 **On behalf of patient** ☐2

This survey is about the care you received during your cancer treatment.

Taking part in this survey is voluntary. Your responses are confidential. They will be combined with the responses of others in reports.

Completing this survey:

For most questions there is a choice of answers. Pick the response that is true for you and tick the box next to it. Sometimes, more than one box may be ticked. If you make a mistake, scribble out the mistake and put a tick in the correct box.

There is space for you to make any comments about your care.

The instructions before the questions will tell you who should answer the questions. You may be able to skip questions.

The survey may take around 15 minutes to complete.

ID _ _ _ _ _

Words used in the survey:

We have used certain words or terms throughout the survey. The following may help to explain what we mean by these terms.

Health professionals: includes doctors, nurses, radiologists, radiotherapists, care coordinators, physiotherapists, dietitians, speech pathologists, social workers and other professions that you may have had contact with during your treatment.

Chemotherapy: is the use of drugs that aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. For this survey, **targeted therapies** are included with chemotherapy. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy and targeted therapies can be given through a drip that goes into a vein via a needle, as a tablet that you swallow, or as cream that's put on the surface of the skin.

Radiotherapy: is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External beam radiotherapy is given using a machine that directs radiation onto the body. Radiotherapy can also be given internally using radioactive implants, which is known as brachytherapy.

Hormonal therapy: aims to control a cancer by changing the hormonal environment in which it is growing. This treatment is used most commonly for breast, ovarian, endometrial and prostate cancer but can be used for some other cancers as well. Treatments can be given by injections into a vein or as a tablet.

Lymphoedema: is a swelling (oedema) due to an accumulation of lymphatic fluid in the body's tissues. It usually affects the arm(s) or leg(s) but can also occur in other parts of the body. Lymphoedema can occur following some cancer treatments.

Overall Care

1. What cancer were you diagnosed with? If you have been diagnosed with more than one cancer, please indicate the cancer that was diagnosed most recently.

- ☐ 1 Breast
- ☐ 2 Leukaemia
- ☐ 3 Prostate
- ☐ 4 Colorectal
- ☐ 5 Lung
- ☐ 6 Brain
- ☐ 7 Sarcoma
- ☐ 8 Uterus
- ☐ 9 Multiple myeloma
- ☐ 10 Kidney
- ☐ 11 Stomach cancer
- ☐ 12 Mesothelioma
- ☐ 13 Central nervous system
- ☐ 14 Melanoma
- ☐ 15 Ovarian
- ☐ 16 Lymphoma
- ☐ 17 Bladder cancer
- ☐ 18 Pancreatic cancer
- ☐ 19 Throat/mouth
- ☐ 20 Other cancer (please specify) ____________________

2. When was this cancer diagnosed? Please provide the day, month and year. If you cannot remember the day, please provide the month and year. If you cannot remember the month, please provide the year.

D	D		M	M		Y	Y	Y	Y

3. When you were told you had cancer:	Yes, definitely	Yes, I think so	No, I do not think so	No, definitely not	Not sure/ cannot remember
a. Were you given information about your cancer in a format that you were happy with (e.g. written information or being spoken with)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c. Were you told how you could get more information (e.g. to go to a specific website, how to get booklets, to call the cancer helpline)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4 **From the list below, could you please indicate the treatments you have had, or are having, for your cancer and the hospital or clinic where your received this treatment.**

☐1 Surgery → Hospital/Clinic Name______________________

☐1 Radiotherapy → Hospital/Clinic Name_________________________

☐1 Chemotherapy → Hospital/Clinic Name_________________________

☐1 Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®)

☐1 Other (please specify)

5. **Were possible short-term side-effects of treatment explained to you before your cancer treatment started (e.g. nausea, pain, fatigue)?**

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No, but I would have liked this information
☐4 No, but I researched this myself
☐5 Not sure/cannot remember

6. **Were possible long-term side-effects of treatment explained to you before your cancer treatment started (e.g. reduced fertility, lymphoedema)?**

☐1 Yes, definitely
☐2 Yes, to some extent
☐3 No, but I would have liked this information
☐4 No, but I researched this myself
☐5 Not sure/cannot remember

7. **Throughout your cancer care and treatment, has there been a health professional or a team of health professionals you could contact if you had any questions about your care or if you needed help or advice?**

☐1 Yes, there was at least one health professional I could contact throughout my treatment
☐2 Yes, there was someone I could contact but not all the time
☐3 No
☐4 Not sure /cannot remember

A Clinical Nurse Specialist is a specialist cancer nurse (e.g. breast care nurse, urology/prostate care nurse) who makes sure you get the right care and gives you help and advice on coping with cancer.

4. **Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?**

☐1 Yes
☐2 No → *PLEASE GO TO THE QUESTION 6*
☐3 Not sure/ can't remember → *PLEASE GO TO QUESTION 6*

5. **How easy is it for you to contact your Clinical Nurse Specialist?**

☐1 Easy
☐2 Sometimes easy, sometimes difficult
☐3 Difficult
☐4 I have not tried to contact her/him

6. How would you rate how well the doctors and nurses involved in your cancer care worked together?

☐$_1$ Excellent
☐$_2$ Very good
☐$_3$ Good
☐$_4$ Fair
☐$_5$ Poor

7 How satisfied were you with the overall care you received from all health professionals involved in your treatment?

☐$_1$ Very satisfied
☐$_2$ Satisfied
☐$_3$ Neither satisfied or dissatisfied
☐$_4$ Dissatisfied
☐$_5$ Very dissatisfied

8 Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it (this includes medical treatment, the way you were treated personally and the way that healthcare professionals communicated with you)?

☐$_1$ Yes, there was at least one time ⟶ **Go to Q13b**
☐$_2$ No, my care was generally fine
☐$_3$ No, my care was excellent
☐$_4$ Not sure/cannot remember

8b If yes, what was the issue you wanted to complain about?

If you would like to make any comments about your overall care experiences please use the space below. We would like to know about them.

CHEMOTHERAPY

Please Note: Targeted therapies are included in chemotherapy. If you have had chemotherapy and targeted therapies please think about your chemotherapy when you answer these questions.

1. Did you have chemotherapy treatment for cancer?

☐1 Yes
☐2 No → *PLEASE GO TO QUESTION 1 PAGE 18 (EMERGENCY DEPARTMENT)*

2. When did you start chemotherapy for the first time?

☐1 Within the last 3 months
☐2 More than 3 months ago, but less than 6 months ago
☐3 More than 6 months ago, but less than 12 months ago
☐4 More than 12 months ago, but less than 2 years ago
☐5 More than 2 years ago
☐6 Not sure/cannot remember

3. Where did you have your chemotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)

Name of hospital_______________________ **AND** Town/suburb/postcode__________________

4. Who made the decision to have your chemotherapy at this hospital/treatment centre? (please choose one response)

☐1 I made the decision with little or no input from my doctor
☐2 I made the decision after considering my doctor's opinion
☐3 My doctor and I made the decision together
☐4 My doctor made the decision after considering my opinion
☐5 My doctor made the decision with little or no input from me
☐6 Other (*please specify)* ____
☐7 Not sure/cannot remember

5a. Did you have any bills associated with your chemotherapy that you had to pay (e.g. bills from the doctor, the hospital, for tests or medications you may have had etc.)?

☐1 No, I did not have any bills associated with my chemotherapy ——→ *GO TO QUESTION 6*
☐2 Yes, and my health insurance covered these costs completely
☐3 Yes, and my health insurance covered only some of these costs
☐4 Yes, I had bills to pay

5b. What sort of bills did you have? (please provide a brief description of the type of bills you had)

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6. Before you started your chemotherapy, were you told or given information about the out-of pocket costs you might have to pay?

☐1 Yes, I was fully informed of the costs I would have to pay
☐2 Yes, I was informed, but not of the full amount
☐3 No, I was not informed of the costs involved
☐4 Not sure/cannot remember

7. Did you have to stay away from home while receiving chemotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

☐1 Yes → **7b. Who arranged this accommodation?**
☐2 No

7b. Who arranged this accommodation?
☐1 I did/my family or friends did
☐2 Staff at the hospital
☐3 Staff associated with my doctor
☐4 Not sure/cannot remember
☐5 Other___________________

8. Sometimes other treatments or tests need to be completed before a person is ready to start chemotherapy treatment. Once you were ready to begin chemotherapy, how long did you wait until you had your first chemotherapy treatment?

☐1 Less than 2 weeks
☐2 More than 2, but within 4 weeks → 8b
☐3 More than a month → 8b
☐4 Not sure/cannot remember
☐5 Other________________

8b. If more than two weeks was this due to:
☐1 Personal decision to wait
☐2 Chemotherapy waiting times. I was kept updated.
☐3 Chemotherapy waiting times. I was **not** updated.
☐4 Other___________________

9. Before starting chemotherapy for the <u>first</u> time were you given information about:	Yes, I was given this information	Yes, but I would have liked more	I was not given this information	Not sure/ cannot remember
a. How to prepare for chemotherapy (e.g. changes to other medications)?	☐1	☐2	☐3	☐4
b. How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?	☐1	☐2	☐3	☐4
c. How you would feel at the end of the chemotherapy treatment?	☐1	☐2	☐3	☐4
d. What side-effects you might experience from chemotherapy?	☐1	☐2	☐3	☐4
e. How to manage any side-effects of chemotherapy at home?	☐1	☐2	☐3	☐4
f. The possibility of going to the Emergency Department if you had a bad response to your chemotherapy?	☐1	☐2	☐3	☐4

10. Did a health professional check that you understood the information provided to you?

☐1 Yes ☐2 No ☐3 Not sure /cannot remember

11 Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

☐1 Yes, definitely
☐2 Yes, as much as they could
☐3 No, not at all
☐4 Travel/other commitments were not a problem
☐5 Not sure/cannot remember

12 On average, how long did you wait at your chemotherapy appointments before you had your treatment?

☐$_1$ I generally had treatment within 15 minutes of my appointment time
☐$_2$ I generally had treatment within 15-30 minutes of my appointment time
☐$_3$ I generally had treatment within 30-60 minutes of my appointment time
☐$_4$ I generally had treatment within 1-2 hours of my appointment time
☐$_5$ I generally waited longer than 2 hours for my appointment
☐$_6$ My chemotherapy was given in a tablet form. This wasn't a problem for me
☐$_7$ Not sure/cannot remember

13. While you were having chemotherapy, did health professionals check if you had any side-effects or symptoms (e.g. pain, vomiting, constipation or diarrhoea, hair loss, tiredness, tingling or loss of feeling in the fingers and toes etc.)?

☐$_1$ Yes
☐$_2$ Yes, but not as often as I would have liked
☐$_3$ No
☐$_4$ Not sure/cannot remember

14. Do you think the health professionals involved in your chemotherapy did everything they could to help manage any side-effects you experienced?

☐$_1$ Yes, definitely
☐$_2$ Yes, to some extent
☐$_3$ No
☐$_4$ I did not have any side-effects
☐$_5$ Not sure/cannot remember

15. Did the health professionals involved in your chemotherapy treat you with respect and dignity?

☐$_1$ Yes, always
☐$_2$ Yes, sometimes
☐$_3$ No
☐$_4$ Not sure/cannot remember

16. Did the health professionals involved in your care check if you needed any help or assistance with things like your diet or eating, etc.?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

17. Did the health professionals involved in your care check if you needed any help or assistance with managing your emotional state (e.g. feeling stressed or anxious, feeling sad or down etc.)?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

18. Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

19. Were you given a telephone number to contact if you had concerns, questions or became unwell because of your treatment?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

20. Were you given a card or some other document that explained your chemotherapy treatment to show if you needed to go to the Emergency Department?

☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

21. Did the health professionals involved in your chemotherapy ask if your family or friends needed any information or support?

☐$_1$ Yes, regularly
☐$_2$ Yes, occasionally
☐$_3$ No, never
☐$_4$ No family or friends were involved
☐$_5$ Not sure/cannot remember

22. How satisfied were you with the availability of car parking at the treatment centre where you had chemotherapy?

☐$_1$ Very satisfied
☐$_2$ Satisfied
☐$_3$ Neither satisfied or dissatisfied
☐$_4$ Dissatisfied
☐$_5$ Very dissatisfied
☐$_6$ Not applicable

23. Overall, how satisfied were you with the treatment you received from all health professionals involved in your chemotherapy?

☐$_1$ Very satisfied
☐$_2$ Satisfied
☐$_3$ Neither satisfied or dissatisfied
☐$_4$ Dissatisfied
☐$_5$ Very dissatisfied

If you would like to make any other comments about your experiences chemotherapy, please use the space below. We would like to know about them.

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EMERGENCY DEPARTMENT EXPERIENCES

Sometimes people become very unwell during their cancer treatment and need to go to an Emergency Department.

1. **Have you felt so ill from your cancer or cancer treatment that you have had to go to an Emergency Department?**
   - ☐$_1$ Yes, only once
   - ☐$_2$ Yes, more than once
   - ☐$_3$ Yes, but it was before my cancer was properly diagnosed
   - ☐$_4$ No, never → *PLEASE GO TO QUESTION 1 ON PAGE 20 (SECTION: FOLLOW-UP CARE)*

2. **Which hospital Emergency Department did you <u>last</u> go to? (Please indicate name of the hospital and the town/suburb or postcode of where this hospital is located)**

   Name of hospital____________________ **AND** Town/suburb/postcode_______________

3. **The last time you were at the Emergency Department, about how long did you have to wait before you saw the doctor?**
   - ☐$_1$ Less than 10 minutes
   - ☐$_2$ More than 10 minutes, but less than 30 minutes
   - ☐$_3$ More than 30 minutes, but less than 1 hour
   - ☐$_4$ Between 1-2 hours
   - ☐$_5$ Between 2-4 hours
   - ☐$_6$ More than 4 hours
   - ☐$_7$ Not sure/cannot remember

4. **Do you think that your condition was well managed while you were waiting to see an Emergency Department doctor?**
   - ☐$_1$ Yes, my condition was managed well
   - ☐$_2$ No, my condition was **not** managed well
   - ☐$_3$ Not sure/cannot remember

5. **Do you think that the health professionals in the Emergency Department had the knowledge and skills needed to look after you?**
   - ☐$_1$ Yes, all or most of them did
   - ☐$_2$ Only a few of them did
   - ☐$_3$ No
   - ☐$_4$ Not sure/cannot remember

6. **Were you admitted into hospital as a result of your consultation with doctors at the Emergency Department?**

   ☐$_1$ Yes ☐$_2$ No ☐$_3$ Not sure /cannot remember

If you would like to make any other comments about your experiences with the Emergency Department, please use the space below. We would like to know about them.

____

____

____

____

____

YOUR BACKGROUND

1. **What is your gender?**
   - ☐1 Male
   - ☐2 Female

2. **How old were you at your last birthday?** _____ years

3. **What is the name or postcode of the town/suburb where you currently live?**

   Town/Suburb________________________________ **OR** Postcode________________________

4. **Where were you living when you received your treatments for cancer?**
   - ☐1 Same address as above
   - ☐2 Different address: Town/Suburb________________ **OR** Postcode_________________

5. **What language do you mainly speak at home?**
   - ☐1 English
   - ☐2 Italian
   - ☐3 Greek
   - ☐4 Cantonese
   - ☐5 Arabic (including Lebanese)
   - ☐6 Vietnamese
   - ☐7 Mandarin
   - ☐8 Other *(please specify)*____

6. **Are you of Aboriginal or Torres Strait Islander origin?**
   - ☐1 Yes, Aboriginal
   - ☐2 Yes, Torres Strait Islander
   - ☐3 Yes, both Aboriginal and Torres Strait Islander
   - ☐4 No

7. **In general, how would you rate your health?**
   - ☐1 Excellent
   - ☐2 Very good
   - ☐3 Good
   - ☐4 Fair
   - ☐5 Poor

Thank you very much for completing the questionnaire.

If you have any other comments on your care or suggestions for improvements please use the following pages to let us know what you think.

Thank you.

If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them.

Appendix 2A: Protocol for whole of service survey

STUDY PROTOCOL

Experiences and satisfaction of being treated for cancer at [Name of Health Service], a whole of service survey

Version: 1
Date:

Author/s:
[to be complete]

Sponsor/s:
[to be complete]

.

Statement of Compliance

This document is a protocol for a research project. This study will be conducted in compliance with all stipulation of this protocol, the conditions of the ethics committee approval, the NHMRC National Statement on ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95).

TABLE OF CONTENTS

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1. GLOSSARY OF ABBREVIATIONS & TERMS

Abbreviation	Description (using lay language)
Consumer	Someone who has been diagnosed and treated for cancer
Response Rates	The proportion of people sent a survey returning a completed survey.
VPECCS	Victorian Patients' Experience of Cancer Care Survey

2. STUDY SITES

2.1 STUDY LOCATION/S

Site	Address	Contact Person	Phone	Email

3. INTRODUCTION/BACKGROUND INFORMATION

3.1 LAY SUMMARY

A cancer diagnosis places considerable stress on patients and their families. Health services throughout Victoria along with the Department of Health and Human Services have identified the need to deliver patient-centred care and to create better care experiences for cancer patients as a priority. In 2011, the then Victorian Department of Health commissioned a series of studies to develop and test a survey tool to assess consumers' experiences of cancer care. This work has involved a literature review, consultations with health professionals and consumers, and two pilot studies to test the survey tool and methodology with patients. The two pilot studies suggested that the methodology of inviting patients to complete a survey about their care was acceptable to patients with a response rate of 55% achieved in the second pilot study. The survey called the Victorian Patients' Experiences of Cancer Care Survey (VPECCS) was also deemed appropriate with the vast majority of patients completing the questions appropriately. The VPECCS is now available for general use.

This study uses the VPECCS to assess the care experiences of patients treated for cancer at [NAME OF HEALTH SERVICE]. Patients treated for cancer in the past 12-18 months at [NAME OF HEALTH SERVICE] will be identified and sent a survey through the post for completion. The survey includes questions assessing information provision, waiting times, referral to support services and communication with their health care team. Care experiences at [NAME OF HEALTH CENTRE] will be determined.

3.2 INTRODUCTION

The Victorian Cancer Action Plan (VCAP) has identified as a priority the need to create better treatment experiences for cancer patients. To this end, the Patient Management Frameworks have orientated the health system to the delivery of patient-centred care - an orientation that views the patient as active participants in their care with their values, beliefs and preferences informing the delivery of care. VCAP acknowledges that quality cancer care includes the delivery of both anti-cancer therapy and supportive care to patients and their families. To this end the Victorian Department of Health and Human Services commissioned researchers at the Cancer Council Victoria (CCV) to develop a consumer experience tool that could be used throughout Victoria. After reviewing the literature and conducting focus groups with consumers and health professionals a new survey tool was developed. This survey tool, called the Victorian Patient Experience Cancer Care Survey (VPECCS) was pilot tested in two studies and found to be acceptable to consumers. The survey consists of 10 modules which assess care experiences throughout the cancer care trajectory with modules focusing on specific treatment (eg, surgery, radiotherapy chemotherapy, follow-up, Emergency Department) as well as modules focusing on diagnosis, information provision, overall care, and the patient's background (e.g. age, gender etc).

4. STUDY OBJECTIVES

4.1 STUDY AIMS

The study aims are to:

i) determine the care experiences of patients receiving cancer-related care at [Name of Hospital]

ii) Identify areas where delivery of cancer care are not meeting patient needs to assist identification of quality improvement opportunities.

4.2 OUTCOME MEASURES

As the study aims to examine the experiences of care of cancer patients and determine the response to the survey, it is not appropriate to use a single outcome for this study. Instead the following outcomes will be examined:

- Proportion of respondents indicating that provision of information in the different care components (e.g. surgery, chemotherapy, radiotherapy etc) occurred.
- Proportion of respondents indicating good communication with health care team.
- Proportion of respondents indicating that their commitments and travel times considered when scheduling appointments.
- Proportion of respondents not referred to support services when they services were needed.
- Proportion of respondents indicating that negative care events (e.g. receiving conflicting information from health professionals, test results not available at appointments etc) occurred at least once.

5. STUDY DESIGN

5.1 STUDY TYPE & DESIGN & SCHEDULE

Cross-sectional survey of adults (18 years and over) with a cancer diagnosis who have attended [NAME of Health Service] for treatment of their cancer within the last [12-18 months].

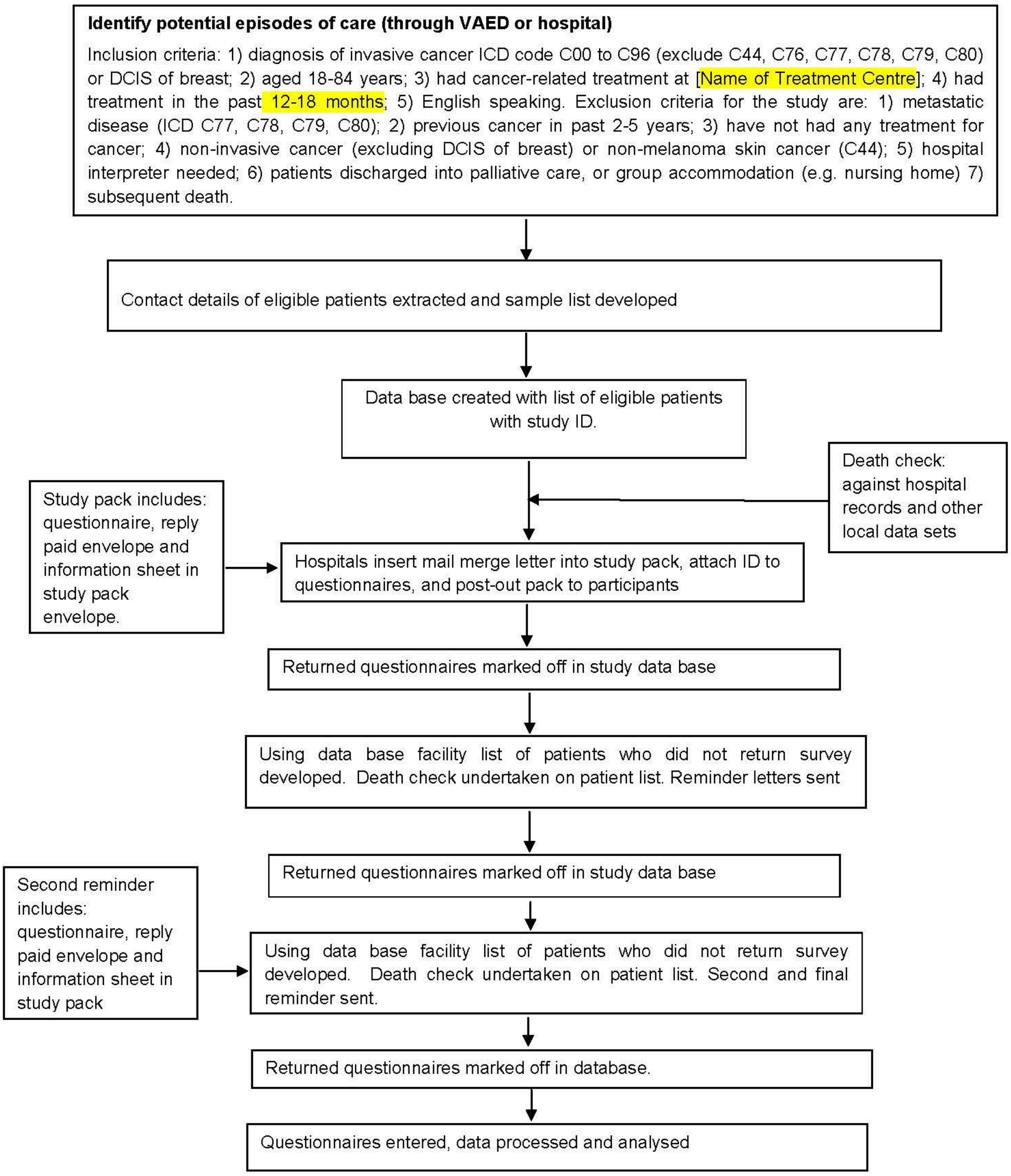
Participants will be approached by mail and asked to complete a questionnaire about their experiences of being treated for cancer. Completed questionnaires will be returned in a supplied reply paid envelope. Participants' names will not appear on the questionnaire Instead the questionnaire will only contain a study ID.

Patients who do not return the questionnaire within 2 weeks of receiving the survey will be sent a reminder letter. A second and final reminder will be sent to those patients who have not responded to the survey request after a further three weeks. These patients will be sent the invitation letter, the questionnaire and a reply paid envelope. Patients will be told that this is the last time they will be contacted about the survey.

5.2 STUDY METHODOLOGY

Figure 1 provides a basic description of the study procedures including eligibility criteria, approach to patients and return of questionnaires.

Figure 1: Flow chart showing the procedure for survey.



Identify potential episodes of care (through VAED or hospital)

Inclusion criteria: 1) diagnosis of invasive cancer ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or DCIS of breast; 2) aged 18-84 years; 3) had cancer-related treatment at [Name of Treatment Centre]; 4) had treatment in the past 12-18 months; 5) English speaking. Exclusion criteria for the study are: 1) metastatic disease (ICD C77, C78, C79, C80); 2) previous cancer in past 2-5 years; 3) have not had any treatment for cancer; 4) non-invasive cancer (excluding DCIS of breast) or non-melanoma skin cancer (C44); 5) hospital interpreter needed; 6) patients discharged into palliative care, or group accommodation (e.g. nursing home) 7) subsequent death.

Contact details of eligible patients extracted and sample list developed

Data base created with list of eligible patients with study ID.

Death check: against hospital records and other local data sets

Study pack includes: questionnaire, reply paid envelope and information sheet in study pack envelope.

Hospitals insert mail merge letter into study pack, attach ID to questionnaires, and post-out pack to participants

Returned questionnaires marked off in study data base

Using data base facility list of patients who did not return survey developed. Death check undertaken on patient list. Reminder letters sent

Returned questionnaires marked off in study data base

Second reminder includes: questionnaire, reply paid envelope and information sheet in study pack

Using data base facility list of patients who did not return survey developed. Death check undertaken on patient list. Second and final reminder sent.

Returned questionnaires marked off in database.

Questionnaires entered, data processed and analysed

Approach to patients about the survey

Hospital staff will complete the mail out. The first mail out will consist of an invitation letter (Appendix A), and a study pack as described below. Once the study pack is complete, hospital staff will post the study pack.

To ensure that correspondence is not sent to people who are deceased, the recruitment list will be cross checked against hospital information regarding status of patients. Participants will have two weeks to complete the survey. If a survey is not received after this time frame a reminder letter will be sent to non-responders. If a survey is not received after a further 3 weeks, a reminder letter and additional study pack will be sent. A telephone number and email address will be supplied to participants in the patient information sheet. This number and email address can be used to inform the researchers that they do not want to participate in the study or as a means of contacting the researchers to ask questions about the survey or approach.

Study packs

A study pack will be assembled consisting of: an information sheet, a questionnaire, and a reply paid envelope. The information sheet is shown in Appendix B.

The survey for this study has been developed after consultation with cancer patients and health professionals. The survey has been tested for comprehension and sense with approximately 20 cancer patients. The survey is shown in Appendix C.

A reply paid envelope will be supplied to participants, for the return of surveys.

Follow-up of unreturned surveys

Hospital staff will mark off the IDs of returned questionnaires as they come in. At the end of the two week mail out period, non-responders will be identified and staff will send them a reminder letter. After a further 3 weeks, patients still not responding to the survey request will be sent a second and final reminder letter that will include another copy of the information sheet, survey and reply paid envelope. The first and second reminder letter is shown in Appendix D and E.

Processing returned surveys

Completed surveys will be returned be assessed for data completeness and data entered into a database for data analyses.

At the end of the study period, staff will use the list of potential participants to determine response rates.

5.3 RECRUITMENT PROCEDURE

Identification of eligible patients

A nominated person at the hospital will interrogate the hospital database to identify eligible patients. The following information will be extracted from the hospital database for each eligible patient:

- Hospital Unit Record number

- Contact details: name (First and surname and preferred title), address, phone number
- Sex and date of birth
- Last contact with hospital
- Date last attended for cancer related care
- Units attended and last unit attended
- Cancer type/ICD code.

This information will be exported to the study database. A nominated staff member will undertake a death check on the list of eligible patients. Patients identified as having died will be removed from the sample list.

Step 3: Approach to Patients

As indicated above, patients will be approached by mail to complete the survey. The questionnaire will be included in this approach along with the approach letter, information sheet and a reply paid envelope.

5.4 INCLUSION CRITERIA

Eligibility Criteria

The inclusion and exclusion criteria for the survey sample are:

Inclusion:

1. diagnosis of invasive cancer with an ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or in situ breast cancer (ICD code D05);
2. aged18 and over;
3. a cancer episode of care as either an inpatient or a day patient during the study period;
4. English speaking.
5. Alive at time of approach.

Exclusion:

1. a previous cancer diagnosed 2 to 5 years ago.
2. not had treatment within 6 months of a biopsy.
3. diagnosed with in situ disease (excluding breast), non-melanoma or early melanoma (levels 0-III) cases (C44).
4. does not have a separation code of H (select only those episodes of care going to private residence/accommodation).
5. Interpreter needed.
6. Patient selected for another internal survey within previous 12 months.

5.5 CONSENT

Participants will provide consent for study participation by completing and returning the survey. Participants will be informed that completing and returning the survey will be taken as consent.

Participant Safety and Withdrawal

5.6 RISK MANAGEMENT AND SAFETY

Participation in this study poses no or negligible risks to the individual. In case completing the questionnaire raises questions for the patient regarding treatment for cancer or access to services the telephone number for the Cancer Information and Support Service at Cancer Council Victoria has been provided and patients are informed they can ring this service during business hours. Cancer nurses trained to respond to patient requests for information and support staff the Cancer Information and Support Service.

5.7 HANDLING OF WITHDRAWALS

As the study involves the completion of a one off survey, it is unlikely that participants will want to withdraw from the study once they have returned the survey.

6. STATISTICAL METHODS

6.1 SAMPLE SIZE ESTIMATION & JUSTIFICATION

We aim to approach [INSERT NUMBER] patients. Based on the response rate obtained in the pilot test (55%), we expect [INSERT NUMBER] of surveys to be completed

6.2 POWER CALCULATIONS

The study is interested in examining the proportion of respondents who indicate that events did or did not happen during their care. With a sample of [INSERT NUMBER] respondents, proportions will be within X% of their true value (eg 95% confidence intervals around estimates of 50%, ±4%).

Statistical Methods To Be Undertaken

The response rate to the survey will be determined. As the study is descriptive frequencies will be used to determine the distribution of responses to the different questions in the survey. The proportion of respondents indicating that an event happened or did not happen will be determined and reported.

7. DATA SECURITY & HANDLING

7.1 DETAILS OF WHERE RECORDS WILL BE KEPT & HOW LONG WILL THEY BE STORED

All personal information collected as part of this study will be kept private and confidential. It will be stored securely. Only persons involved with the study at the health centre will have access to data identifying patients involved in the study. Questionnaires are de-identified and do not contain any identifying information. No participant will be identified in any report of the results from the study. No personal information will be provided to any person, except as described above, or as required by law. At the end of the research project, de-identified data will be stored securely at the [Name of Health Service] for a period of 5 years after which it will be destroyed.

7.2 CONFIDENTIALITY AND SECURITY

Only study staff will have access to the study database that contains information linking patient contact details with the study ID. This database will be maintained until all data collection and processing is complete. Once data processing is complete the data base will be destroyed. The study database will be password protected and will be stored on a secure, electronic environment.

Only the research team (study investigators and research staff) will have access to the data collected (both hard copies and electronic files).

No identifying information will be stored with responses to the survey. All electronic data will be stored on password protected computers in a restricted access area.

No individual or staff member will be identified in any reports produced for this study.

Additionally all staff involved in the project have signed a confidentiality agreements.

Data will be managed according to [Name of Health Service] protocols, which includes protocols for the disposal of electronic and paper-based data.

8. APPENDIX

List of Attachments included:

Document Name	Date
Appendix A: Approach letter	
Appendix B: Study information sheet	
Appendix C: Survey	
Appendix D: Reminder letter 1	
Appendix E: Reminder letter 2	

Appendix 2B: Protocol for a treatment specific survey

STUDY PROTOCOL

Experiences and satisfaction with [radiotherapy/chemotherapy/surgical] services for cancer at [Name of Health Service]

Version: 1
Date:

Author/s:
[to be complete]

Sponsor/s:
[to be complete]

.

Statement of Compliance

This document is a protocol for a research project. This study will be conducted in compliance with all stipulation of this protocol, the conditions of the ethics committee approval, the NHMRC National Statement on ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95).

TABLE OF CONTENTS

CONTENTS

1. GLOSSARY OF ABBREVIATIONS & TERMS

Abbreviation	Description (using lay language)
Consumer	Someone who has been diagnosed and treated for cancer
Response Rates	The proportion of people sent a survey returning a completed survey.
VPECCS	Victorian Patients' Experience of Cancer Care Survey

2. STUDY SITES

2.1 STUDY LOCATION/S

Site	Address	Contact Person	Phone	Email

3. INTRODUCTION/BACKGROUND INFORMATION

3.1 LAY SUMMARY

A cancer diagnosis places considerable stress on patients and their families. Health services throughout Victoria along with the Department of Health and Human Services have identified the need to deliver patient-centred care and to create better care experiences for cancer patients as a priority. In 2011, the then Victorian Department of Health commissioned a series of studies to develop and test a survey tool to assess consumers' experiences of cancer care. This work has involved a literature review, consultations with health professionals and consumers, and two pilot studies to test the survey tool and methodology with patients. The two pilot studies suggested that the methodology of inviting patients to complete a survey about their care was acceptable to patients with a response rate of 55% achieved in the second pilot study. The survey called the Victorian Patients' Experiences of Cancer Care Survey (VPECCS) was also deemed appropriate with the vast majority of patients completing the questions appropriately. The VPECCS is now available for use for use in its entirety or as a module version with a focus on a specific treatment.

This study uses the VPECCS to assess the care experiences of patients receiving [chemotherapy/radiotherapy/surgical care] for cancer at [NAME OF HEALTH SERVICE]. Patients treated for cancer in the past 12-18 months at [NAME OF HEALTH SERVICE] will be identified and sent a survey through the post for completion. The survey includes questions assessing information provision, management of side-effect, waiting times, and communication with health care professionals. Care experiences at [NAME OF HEALTH CENTRE] will be determined.

3.2 INTRODUCTION

The Victorian Cancer Action Plan (VCAP) has identified as a priority the need to create better treatment experiences for cancer patients. To this end, the Patient Management Frameworks have orientated the health system to the delivery of patient-centred care - an orientation that views the patient as active participants in their care with their values, beliefs and preferences informing the delivery of care. VCAP acknowledges that quality cancer care includes the delivery of both anti-cancer therapy and supportive care to patients and their families. To this end the Victorian Department of Health and Human Services commissioned researchers at the Cancer Council Victoria (CCV) to develop a consumer experience tool that could be used throughout Victoria. After reviewing the literature and conducting focus groups with consumers and health professionals a new survey tool was developed. This survey tool, called the Victorian Patient Experience Cancer Care Survey (VPECCS) was pilot tested in two studies and found to be acceptable to consumers. The survey consists of 10 modules which assess care experiences throughout the cancer care trajectory with modules focusing on specific treatment (eg, surgery, radiotherapy chemotherapy, follow-up, Emergency Department) as well as modules focusing on diagnosis, information provision, and overall care. Treatment modules can be used separately allowing treatment centres the opportunity to assess their patients' care experiences.

4. STUDY OBJECTIVES

4.1 STUDY AIMS

The study aims are to:

i) determine the care experiences of patients receiving [radiotherapy/chemotherapy/surgery for cancer] at [Name of Hospital]

ii) Identify areas where delivery of cancer care are not meeting patient needs to assist identification of quality improvement opportunities.

4.2 OUTCOME MEASURES

As the study aims to examine the experiences of [radiotherapy/chemotherapy/surgical care] it is not appropriate to use a single outcome for this study. Instead the following outcomes will be examined:

- Proportion of respondents indicating that provision of information occurred.
- Proportion of respondents indicating good communication with health care team.
- Proportion of respondents indicating that their commitments and travel times considered when scheduling appointments.
-

5. STUDY DESIGN

5.1 STUDY TYPE & DESIGN & SCHEDULE

Cross-sectional survey of adults (18 years and over) with a cancer diagnosis who have attended [NAME of Health Service] for [chemotherapy/radiotherapy/surgery for cancer] within the last [12-18 months].

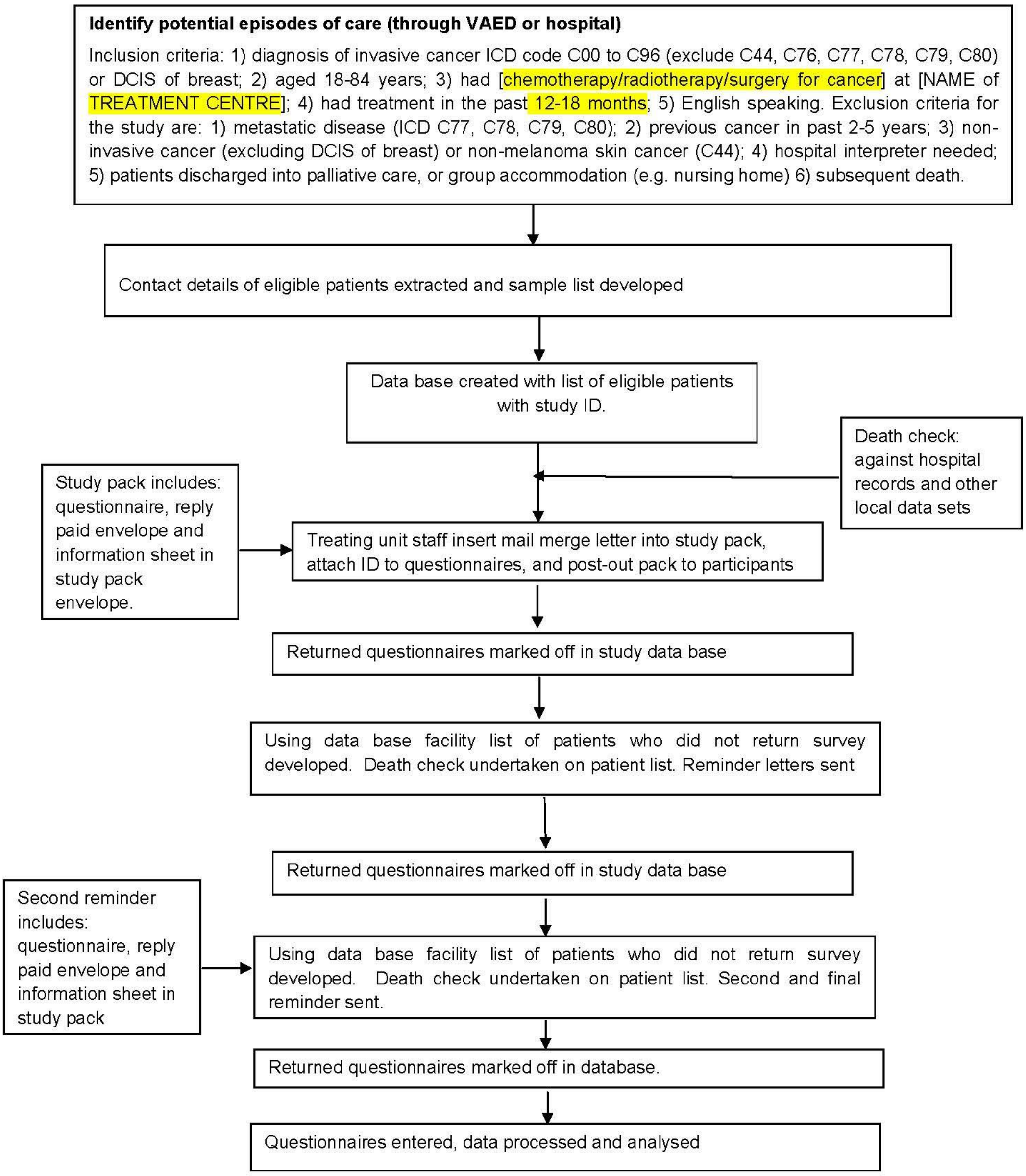
Participants will be approached by mail and asked to complete a questionnaire about their experiences of being treated for cancer. Completed questionnaires will be returned in a reply paid envelope supplied with the survey. Participants' names will not appear on the questionnaire Instead the questionnaire will only contain a study ID.

Patients who do not return the questionnaire within 2 weeks of receiving the survey will be sent a reminder letter. A second and final reminder will be sent to those patients who have not responded to the survey request after a further three weeks. These patients will be sent the invitation letter, the questionnaire and a reply paid envelope. Patients will be told that this is the last time they will be contacted about the survey.

5.2 STUDY METHODOLOGY

Figure 1 provides a basic description of the study procedures including eligibility criteria, approach to patients and return of questionnaires.

Figure 1: Flow chart showing the procedure for survey.



Identify potential episodes of care (through VAED or hospital)

Inclusion criteria: 1) diagnosis of invasive cancer ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or DCIS of breast; 2) aged 18-84 years; 3) had [chemotherapy/radiotherapy/surgery for cancer] at [NAME of TREATMENT CENTRE]; 4) had treatment in the past 12-18 months; 5) English speaking. Exclusion criteria for the study are: 1) metastatic disease (ICD C77, C78, C79, C80); 2) previous cancer in past 2-5 years; 3) non-invasive cancer (excluding DCIS of breast) or non-melanoma skin cancer (C44); 4) hospital interpreter needed; 5) patients discharged into palliative care, or group accommodation (e.g. nursing home) 6) subsequent death.

Contact details of eligible patients extracted and sample list developed

Data base created with list of eligible patients with study ID.

Death check: against hospital records and other local data sets

Study pack includes: questionnaire, reply paid envelope and information sheet in study pack envelope.

Treating unit staff insert mail merge letter into study pack, attach ID to questionnaires, and post-out pack to participants

Returned questionnaires marked off in study data base

Using data base facility list of patients who did not return survey developed. Death check undertaken on patient list. Reminder letters sent

Returned questionnaires marked off in study data base

Second reminder includes: questionnaire, reply paid envelope and information sheet in study pack

Using data base facility list of patients who did not return survey developed. Death check undertaken on patient list. Second and final reminder sent.

Returned questionnaires marked off in database.

Questionnaires entered, data processed and analysed

Approach to patients about the survey

Treating Unit staff will complete the mail out. The first mail out will consist of an invitation letter (Appendix A), and a study pack as described below. Once the study pack is complete, staff will post the study pack.

To ensure that correspondence is not sent to people who are deceased, the recruitment list will be cross checked against hospital information regarding status of patients. Participants will have two weeks to complete the survey. If a survey is not received after this time frame a reminder letter will be sent to non-responders. If a survey is not received after a further 3 weeks, a reminder letter and additional study pack will be sent. A telephone number and email address will be supplied to participants in the patient information sheet. This number and email address can be used to inform the researchers that they do not want to participate in the study or as a means of contacting the researchers to ask questions about the survey or approach.

Study packs

A study pack will be assembled consisting of: an information sheet, a questionnaire, and a reply paid envelope. The information sheet is shown in Appendix B.

The survey for this study has been developed after consultation with cancer patients and health professionals. The survey has been tested for comprehension and sense with approximately 20 cancer patients. The survey is shown in Appendix C.

A reply paid envelope will be supplied to participants.

Follow-up of unreturned surveys

Unit staff will mark off the IDs of returned questionnaires as they come in. At the end of the two week mail out period, non-responders will be identified and staff will send them a reminder letter. After a further 3 weeks, patients still not responding to the survey request will be sent a second and final reminder letter that will include another copy of the information sheet, survey and reply paid envelope. The first and second reminder letter is shown in Appendix D and E.

Processing returned surveys

Completed surveys will be returned be assessed for data completeness and data entered into a database for data analyses.

At the end of the study period, staff will use the list of potential participants to determine response rates.

5.3 RECRUITMENT PROCEDURE

Identification of eligible patients

A nominated person at the treating unit will interrogate the unit's database to identify eligible patients. The following information will be extracted from the database for each eligible patient:

- Hospital Unit Record number

- Contact details: name (First and surname and preferred title), address, phone number
- Sex and date of birth
- Last contact with unit
- Date last attended for treatment
- Cancer type/ICD code

This information will be incorporated into the study database. A nominated staff member will undertake a death check on the list of eligible patients. Patients identified as having died will be removed from the sample list.

Step 3: Approach to Patients

As indicated above, patients will be approached by mail and invited to complete the survey. The questionnaire will be included in this approach along with the approach letter, information sheet and a reply paid envelope.

5.4 INCLUSION CRITERIA

Eligibility Criteria

The inclusion and exclusion criteria for the survey sample are:

Inclusion:

1. diagnosis of invasive cancer with an ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or in situ breast cancer (ICD code D05);
2. aged18 and over;
3. received treatment during the study period;
4. English speaking.
5. Alive at time of approach.

Exclusion:

1. a previous cancer diagnosed 2 to 5 years ago.
2. diagnosed with in situ disease (excluding breast), non-melanoma or early melanoma (levels 0-III) cases (C44).
3. Does not have a separation code of H (select only those episodes of care going to private residence/accommodation).
4. Interpreter needed.
5. Patient selected for another internal survey within previous 12 months.

5.5 CONSENT

Participants will provide consent for study participation by completing and returning the survey. Participants will be informed that completing and returning the survey will be taken as consent.

Participant Safety and Withdrawal

5.6 RISK MANAGEMENT AND SAFETY

Participation in this study poses no or negligible risks to the individual. In case completing the questionnaire raises questions for the patient regarding treatment for cancer or access to services the telephone number for the Cancer Information and Support Service at Cancer Council Victoria has been provided and patients are informed they can ring this service during business hours. Cancer nurses trained to respond to patient requests for information and support staff the Cancer Information and Support Service.

5.7 HANDLING OF WITHDRAWALS

As the study involves the completion of a one off survey, it is unlikely that participants will want to withdraw from the study once they have returned the survey.

6. STATISTICAL METHODS

6.1 SAMPLE SIZE ESTIMATION & JUSTIFICATION

We aim to approach [INSERT NUMBER] patients. Based on the response rate obtained in the pilot test (55%), we expect [INSERT NUMBER] of surveys to be completed

6.2 POWER CALCULATIONS

The study is interested in examining the proportion of respondents who indicate that events did or did not happen during their care. With a sample of [INSERT NUMBER] respondents, proportions will be within X% of their true value (eg 95% confidence intervals around estimates of 50%, ±4%).

Statistical Methods To Be Undertaken

The response rate to the survey will be determined. As the study is descriptive frequencies will be used to determine the distribution of responses to the different questions in the survey. The proportion of respondents indicating that an event happened or did not happen will be determined and reported.

7. DATA SECURITY & HANDLING

7.1 DETAILS OF WHERE RECORDS WILL BE KEPT & HOW LONG WILL THEY BE STORED

All personal information collected as part of this study will be kept private and confidential. It will be stored securely. Only persons involved with the study at the health centre will have access to data identifying patients involved in the study. Questionnaires are de-identified and do not contain any identifying information. No participant will be identified in any report of the results from the study. No personal information will be provided to any person, except as described above, or as required by law. At the end of the research project, de-identified data will be stored securely at the [Name of Health Service] for a period of 5 years after which it will be destroyed.

7.2 CONFIDENTIALITY AND SECURITY

Only study staff will have access to the study database that contains information linking patient contact details with the study ID. This database will be maintained until all data collection and processing is complete. Once data processing is complete the data base will be destroyed. The study database will be password protected and will be stored on a secure, electronic environment.

Only the research team (study investigators and research staff) will have access to the data collected (both hard copies and electronic files).

No identifying information will be stored with responses to the survey. All electronic data will be stored on password protected computers in a restricted access area.

No individual or staff member will be identified in any reports produced for this study.

Additionally all staff involved in the project have signed a confidentiality agreements.

Data will be managed according to [Name of Health Service] protocols, which includes protocols for the disposal of electronic and paper-based data.

8. APPENDIX

List of Attachments included:

Document Name	**Date**
Appendix A: Approach letter	
Appendix B: Study information sheet	
Appendix C: Survey	
Appendix D: Reminder letter 1	
Appendix E: Reminder letter 2	

Appendix 3: Confidence intervals for different sample sizes and differences between proportions

Sample Size and 95% confidence intervals

95% confidence intervals around proportions and around differences in proportions
95% Confidence Intervals (CI) around a proportion
The formula for calculating the 95% CI around a proportion is:
$=\sqrt{((p_1q_1)/N)}*1.96$ where p_1=proportion 1, $q=100-p_1$ and N=sample size.

Example: Let p1 =50% and q1=100-50%=50. Let N=100.

95% CI $=\sqrt{((50*50)/100)}*1.96=5*1.96$.

95% CI around 50% when N=100: ±9.80%

Table 3A: 95% confidence intervals associated with different proportions and for various sample sizes

Sample size	40%/60%	50%/50%	75%/25%	80%/20%	90%/10%
50	±13.6%	±13.9%	±12.0%	±11.1%	±8.3%
80	±10.7%	±11.0%	±9.5%	±8.8%	±6.6%
100	±9.6%	±9.8%	±8.5%	±7.8%	±5.9%
150	±7.8%	±8.0%	±6.9%	±6.4%	±4.8%
200	±6.8%	±6.9%	±6.0%	±5.5%	±4.2%
250	±6.1%	±6.2%	±5.4%	±5.0%	±3.7%
300	±5.5%	±5.7%	±4.9%	±4.5%	±3.4%
400	±4.8%	±4.9%	±4.2%	±3.9%	±2.9%
450	±4.5%	±4.6%	±4.0%	±3.7%	±2.8%
500	±4.3%	±4.4%	±3.8%	±3.5%	±2.6%

95% confidence intervals around differences in proportions

The formula for calculating the 95% CI around a difference in proportions is:
$=\sqrt{(((p_1q_1)/N_1) + ((p_2q_2)/N_2))}*1.96$
If 0 is included in the 95% CI around a difference, difference is not statistically significant.

Example: What is the 95% CI around the difference between p_1=50% and p_2=35% when N_1=150 and N_2=150.

=(√(((50%*50%)/150) +((35%*65%)/150)))*1.96
= (√(16. 7%+15.2%)) *1.96
= (√31.9%)*1.96
=5.64%*1.96
=11%

Difference=50%-35%=15%± 11% range (4%--26%)

As 0 is not included in the range of possible values, the difference is statistically significant

Table 3B: 95% confidence intervals around 5%, difference between proportion 1 and proportion 2 for different proportions and sample sizes

	p1/p2				
	40%/35%	50%/45%	75%/70%	80%/75%	90%/85%
50	±18.95	±19.55	±17.48	±16.34	±12.93
80	±4.98	±15.46	±13.82	±12.92	±10.22
100	±13.40	±13.82	±12.36	±11.55	±9.14
150	±10.94	±11.29	±10.09	±9.43	±7.46
200	±9.48	±9.78	±8.74	±8.17	±6.46
250	±8.48	±8.74	±7.82	±7.31	±5.78
300	±7.74	±7.98	±7.13	±6.67	±5.28
400	±6.70	±6.91	±6.18	±5.78	±4.57
450	±6.32	±6.52	±5.83	±5.45	±4.31
500	±5.99	±6.18	±5.53	±5.17	±4.09

Table 3C: 95% confidence intervals around 10%, difference between proportion 1 and proportion 2 for different proportions and sample sizes (NB for simplicity proportion 2 is always less than proportion 1)

	p1/p2				
	40%/35%	**50%/45%**	**75%/70%**	**80%/75%**	**90%/85%**
50	±18.59	±19.40	±17.86	±16.86	±11.43
80	±14.70	±15.34	±14.12	±13.33	±9.04
100	±13.15	±13.72	±12.63	±11.92	±8.08
150	±10.74	±11.20	±10.31	±9.73	±6.60
200	±9.30	±9.70	±8.93	±8.43	±5.71
250	±8.32	±8.68	±7.99	±7.54	±5.11
300	±7.59	±7.92	±7.29	±6.88	±4.67
400	±6.57	±6.86	±6.31	±5.96	±4.04
450	±6.20	±6.47	±5.95	±5.62	±3.81
500	±5.88	±6.14	±5.65	±5.33	±3.61

Table 3D: 95% confidence intervals around 20%, difference between proportion 1 and proportion 2 for different proportions and sample sizes (NB for simplicity proportion 2 is always less than proportion 1)

	p1/p2				
	40%/35%	**50%/45%**	**75%/70%**	**80%/75%**	**90%/85%**
50	17.53	18.80	18.28	17.53	15.18
80	13.86	14.86	14.45	13.86	12.00
100	12.40	13.29	12.93	12.40	10.74
150	10.12	10.85	10.55	10.12	8.77
200	8.77	9.40	9.14	8.77	7.59
250	7.84	8.41	8.18	7.84	6.79
300	7.16	7.67	7.46	7.16	6.20
400	6.20	6.65	6.46	6.20	5.37
450	5.84	6.27	6.09	5.84	5.06
500	5.54	5.94	5.78	5.54	4.80

Appendix 4: First invitation letter

Date

[Study ID]
Stephen King
13 Sleepy Hollow Drive
Hollowbrooke VIC 3075

Dear Stephen

[Hospital] is working to make sure that everyone treated at our service receives the best care possible. To help achieve this, we need to find out what people think about the care they have received so we can identify what is being done well and what areas need to be improved.

We are contacting you because you have recently been a patient at [Hospital]. We are hoping that you could take the time to tell us about your experiences by completing the attached survey and returning it in the enclosed reply paid envelope by [XDate].

An information sheet explaining why the survey is being done and how the information collected will be used is also enclosed. The names and phone numbers of people you can contact if you have any questions are given in the information sheet.

If you decide to take part in the survey, please complete the questionnaire and return it in the reply paid envelope.

If you believe that you have been sent this survey in error, or you do not wish to participate, please return the blank survey to us and let us know that this is the case.
If we do not hear from you in two weeks' time, we will send a letter to remind you.

Thank you for considering this request.

Yours sincerely

Appendix 5: Information sheet Example

Information Sheet

Project Title: Cancer Treatment Experiences Survey

You are invited to complete the enclosed questionnaire that aims to collect information on people's experiences of being treated for cancer. You are being invited to complete the questionnaire because you have attended [HOSPITAL] for some cancer related treatment in the past [X] months.

Completing the survey is voluntary. You don't have to complete the survey if you don't want to. You will receive the best possible care at [HOSPITAL] whether you complete the survey or not.

If you decide to take part in survey, please complete the enclosed questionnaire and return it in the reply paid envelop provided. Returning a completed survey will be taken as consent.

Why is the survey being done?

[HOSPITAL] wants to make sure that all patients receive the best care possible. We are asking people what they thought about their medical care to help identify areas that may need to be improved.

What will happen to the information you provide?

The information received will be collated and a report for [HOSPITAL] produced. The report will only contain data that has been grouped meaning it will only show how many people (eg, percentage) give a particular answer to each question. No one will be identified in any report.

Who should complete the survey?

We would like all people who have been treated at [HOSPITAL] to complete the survey. If you have been satisfied with your care we would like to hear about your experiences. If you have not been satisfied with your care we would like to hear about your experiences.

You may not have had all your treatment at [HOSPITAL]. The survey asks you to indicate where you had different treatments so you can let us know which part of your care was at [HOSPITAL].

Will the hospital or my medical team know what I have said?

No. Your responses to the survey are completely confidential. Your treatment team will not be told what you say in the survey.

What if I have questions about the survey?

If you have questions about the survey please contact [contact person]

What if you want to complain about the project?

If you have any complaints about the project, the way it is being conducted or any questions about your rights, please contact: contact name and number]

Thank you very much for considering this invitation.

The people involved in this project and their contact numbers are:

Person 1 Name	Position and Contact details
Person 2 Name	Position and Contact details
	Add more as needed

Appendix 6: Reminder Letter 1

Date

[Study ID]
Stephen King
13 Sleepy Hollow Drive
HollowBrook Vic 3075

Dear Stephen

RE: Cancer Treatment Experiences Survey

I am writing about the treatment experiences project we are currently conducting at [Hospital]. A few weeks ago you were sent an information pack containing information about the project, a copy of the questionnaire and a reply paid envelope.

If you are still interested in completing the survey we would be very happy to receive your completed questionnaire.

If you have decided not to participate in this project, then please return the blank survey to us in the reply paid envelope previously provided.

If you have recently returned the survey to us, thank-you and please ignore this letter.
If you have any questions about the project, or require another copy of the questionnaire, please feel free to call [contact person] on phone number.

If we do not hear from you in two weeks' time, we will contact you one final time to make sure you can participate in the survey if you want to.

Yours sincerely

Appendix 7: Reminder Letter 2 (final reminder)

[Date]

[Study ID]
Stephen King
13 Sleepy Hollow Drive
HollowBrook Vic 3075

Dear Stephen

RE: Cancer Treatment Experiences Survey

I am writing about the experiences of care project we are conducting at [Hospital]. A few weeks ago you were sent a reminder letter about this project.

If you are still interested in completing the survey we would be very happy to receive your completed questionnaire. To help you, we have enclosed another copy of the questionnaire and the information sheet explaining the project.

If you have recently returned the survey to us, please ignore this letter.

If you have decided not to participate that is fine. Thank you for your time in reading this letter. We will not contact you anymore about this project.

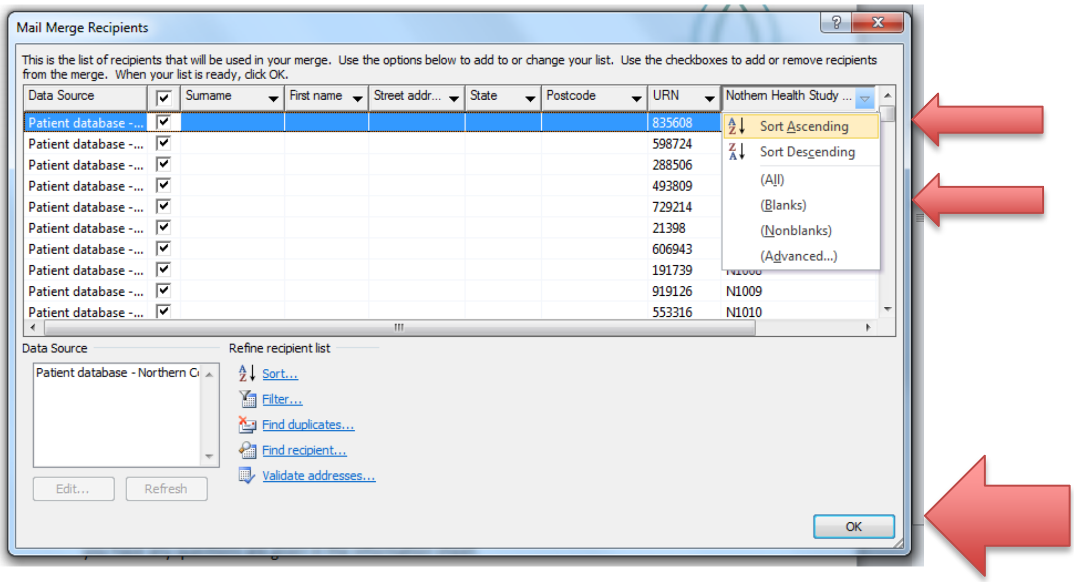
If you have any questions about the project or the questionnaire, please feel free to call [contact person].

Yours sincerely

Appendix 8: How to Mail merge

The approach letters need to be mail merged using the following files:
Patient database (Excel file)– e.g. Patient_List.xlsx
First approach Letter (Word file) – e.g. Approach letter.docx

1. Open the Excel data base, then the Word file containing the approach letter.
2. In the Word doc, select the **Mailings** tab.
3. Click **Select Recipients**, choose Use Existing List.
4. Browse to the location of the excel file and open it.
5. Return to Word, where a pop-up will ask you which Table to use. Choose the excel worksheet containing the patient list (usually the first one listed)
6. Click **Insert Merge Field** and embed them where appropriate.
7. You can click on **Highlight Merge Fields** or **Preview Results** to show where merge fields have been inserted



Mail Merge Recipients

This is the list of recipients that will be used in your merge. Use the options below to add to or change your list. Use the checkboxes to add or remove recipients from the merge. When your list is ready, click OK.

Data Source	☑	Surname	First name	Street addr...	State	Postcode	URN	Nothern Health Study ...
Patient database -...	☑						835608	
Patient database -...	☑						598724	
Patient database -...	☑						288506	
Patient database -...	☑						493809	
Patient database -...	☑						729214	
Patient database -...	☑						21398	
Patient database -...	☑						606943	
Patient database -...	☑						191739	
Patient database -...	☑						919126	N1009
Patient database -...	☑						553316	N1010

Data Source

Patient database - Northern C

1. Click **Edit Recipient List**, and sort the Study ID column by ascending order (this will be the order in which letters are printed later). If merging a Reminder letter, filter out patients who have already responded by selecting (Blanks) under the 'Date Survey Returned' column). You may also need to filter other columns, such as removing patients who have passed away. You can do this by clicking the triangle next to the column name, or use the refining options at the bottom.
2. Click **Finish & Merge**, and choose Edit Individual Documents. Choose 'All' in the pop-up, click OK.
3. Print one test page to make sure the letter will print OK and that the contact details of patients are in the correct spots. It is a good idea to skim through every page at this point, and make sure the formatting hasn't gone off (i.e. the placement of the signatures may have shifted). If you need to make adjustments, the best way would be to fix these in the merged document (which does not contain Merge Fields).
4. If you need to reprint any letters, you can go back to step 7 and use the **Find recipient** search tool at the bottom (see big arrow). Tick to select/deselect the patients as required.

Appendix 9: Example Patient contact database

Patient ID	Title	First Name	Last name	No.	Street	Suburb	State	Postcode	Date survey sent	Survey returned	Date survey returned	Reminder 1 sent	Reminder 2 sent	Comments
10001	Ms	Joanne	Smith	12	Stripe Rd	Tigertown	Victoria	3000	1/03/16	returned	3/05/16	1/04/16	25/04/16	
10002	Mr	Richard	Brown	15	Tigers Rd	Tigertown	Victoria	3121	1/03/16	returned	10/03/16			
10003	Mrs	Maria	White	3	Batman St	Catsville	Victoria	3666	1/03/16	blank	14/03/16			
10004	Mr	Ross	Green	4	Kitten Close	Catsville	Victoria	3899	1/03/16	called-	7/03/16			Doesn’t have cancer
10005	Mr	Peter	Jones	33	Dogleg Road	Dogswood	Victoria	3977	1/03/16	returned	15/04/16	1/04/16		

Appendix 10: Data Dictionary

Question numbers, variable names and labels, missing values allowed and value numbers and labels. Alpha in the column headed "Missing Values" indicates the response is written text and therefore no missing values are needed.

Module 1: Finding Out

Question No.	Variable	Label	Missing Values	Values	Value labels
	s00_id	**patient id**			
1a	S0101ahowlongref	'how long wait for specialist or doctor'	55 through 99	1	Less than two weeks
				2	More than two weeks, but within four weeks
				3	More than a month
				4	I stayed with my GP
				5	Not sure, cannot remember
				6	Other
				88	Multiple
1a	S0101howlongrefcf	comment flag	Alpha		Type in text provided
1b	S0101by2wksref	'why was wait more than two weeks'	55 through 99	1	Personal decision to wait
				2	Specialist waiting times
				3	Hospital waiting time
				4	Other
				55	NA Skipped
				88	Multiple
1b	S0101by2wksrefcf	comment flag	Alpha		Type in text provided
2	S0102whoresult	'who gave result of test showing you had cancer'	55 through 99	1	GP
				2	Surgeon
				3	Medical oncologist

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	Radiation oncologist
				5	Haematologist
				6	Hospital doctor
				7	Other
				88a	Multiple
2	S0102whoresultcf	comment flag	Alpha		Type in text provided
3	S0103cancertype	‘what cancer diagnosed with'		1	breast
				2	leukaemia
				3	Prostate
				4	Colorectal
				5	Lung
				6	Brain
				7	Sarcoma
				8	Uterus
				9	Multiple myeloma
				10	Kidney
				11	Stomach cancer
				12	Mesothelioma
				13	Central nervous system
				14	Melanoma
				15	Ovarian
				16	Lymphoma
				17	Bladder cancer
				18	Pancreatic cancer
				19	Throat/mouth

Question No.	Variable	Label	Missing Values	Values	Value labels
				20	Other
				88	Multiple
3	S0103cancertycf	comment flag	Alpha		Type in text provided
4	S0104Datedxdd	‘date of diagnosis'	99		Date in format day/month/your eg, 12/03/2016
	S0104datedxmm		99		
	S0104datedxyyy		9999		
5	S0105dxexplok	‘understand the doctor’s explanation of what was wrong with you?'	55 through 99,	1	‘Yes, I understood it completely’
				2	‘Yes, I understood most of it’’
				3	‘I understood some of it’
				4	‘No, I did not understand it’
				5	‘not sure, cannot remember’
				88a	Multiple
6	S0106drencqn	‘did your doctor encourage you to ask questions?'	55 through 99	1	‘Yes’
				2	‘No’
				3	‘It wasn’t necessary, I wanted to ask questions’
				4	‘I did not want to ask questions’
				5	‘not sure, cannot remember’
				88a	Multiple
7a	S0107acancerinfo	'information in a format you were happy with '	55 through 99 and 0	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘No I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
7b	S0107btctoptinfo	information about treatment options for your cancer '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘No I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
7c	S0107cmoreinfo	‘told how you could get more information '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘NO I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
7d	S0107dsupportinfo	‘information who you could contact for support '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘NO I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
8	S0108hpgothruinfo	‘health professional go through the information about your cancer and your treatment again'	55 through 99	1	Yes, I had another appointment’
				2	‘Yes, I spoke to someone over the phone’
				3	‘Yes, but only informally ’
				4	‘No, but I would have liked them to’
				5	‘No, but it was not necessary’
				6	‘Not sure cannot remember’
				88a	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
9	S0109dxrespect	‘health professionals involved in your diagnosis talk to you with respect and understanding?'	55 through 99	1	Yes, always’
				2	‘Yes, sometimes’
				3	‘No'
				4	‘not sure, cannot remember’
				88	Multiple
10	S0110dxfamsup	‘health professionals involved in your diagnosis ask if your family or friends needed any information or support?'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, I think so’
				3	‘No, not at all’
				4	‘My family, friends did not need any extra information or support’
					‘No, as family or friends were not involved’
				5	‘not sure, cannot remember’
				6	Multiple
				88a	‘Yes, I think so’

Module 2: Deciding on treatment

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0201txtdec	‘involved as much as you wanted to be in decisions about your care and treatment?'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘I was not well enough or did not want to be involved in these decisions‘
2	S0202havetxt	‘have any treatment for cancer'	55 through 99	1	Yes
				2	No
				88	Multiple
3	S0203txtsurg	‘had surgery as treatment for cancer '	55 through 99	0	No surgery
				1	Surgery
3	S0203txtradio	'had radiotherapy as treatment for cancer'	55 through 99	0	No radiotherapy
				1	Radiotherapy
3	S0203txtchemo	'had chemotherapy for cancer '	55 through 99	0	No chemo
				1	Chemotherapy/targetted therapies
3	S0203txthorm	'had hormonal therapy'	55 through 99	0	No hormonal therapy
				1	Hormonal therapy
4	S0204shortsideeff	‘possible short term side effects explained'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No, and I would have liked this information’
				4	‘No, but I researched this myself ‘
				5	‘Not sure cannot remember’
				88	Multiple
5	S0205longsideeff	‘possible long term side effects explained'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No, and I would have liked this information’

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	‘No, but I researched this myself ‘
				5	‘Not sure cannot remember’
				88	Multiple
6	S0206understseff	‘health professionals check you understood side effects information'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No ‘
				4	‘I did not receive this information’
				5	‘Not sure cannot remember’
				88	Multiple
7	S0207hpencqntxt	'did health professionals encourage questions on treatment options'	55 through 99	1	Yes definitely
				2	Yes to some extent
				3	No
				4	Not sure/cannot remember
				88	Multiple
8	S0208txtplaninfo	‘did you get information about what treatment would involve'	55 through 99	1	‘Yes, I was given written information and it was adequate ‘
				2	‘Yes, I was given written information but it was not adequate ‘
				3	‘No, I did not receive this information’
				4	‘Not sure cannot remember’
				88	Multiple
Question No.	Variable	Label	Missing Values	Values	Value labels
9	S0209Seeothrhp	‘see other health profs before treatment started?"	55 through 99	1	‘Yes, I was referred to services before treatment’
				2	‘No, I was not referred, but I would have liked to have been’
				3	‘No, I was not referred, as I did not need them’
				4	‘Not sure cannot remember’

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple

Module 3: Surgery

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0301surgery	‘did you have surgery for cancer?'	55 through 99	1	Yes
				2	No
				88	Multiple
2	S0302whensurg	‘how long ago did you have surgery'	55 through 99	1	‘Within the last 3 months’
				2	‘More than 3 months ago, but less than 6 months ago’
				3	‘More than 6 months ago, but less than 12 months ago’
				4	‘More than 12 months ago, but less than 2 years ago’
				5	‘More than 2 years ago’
				6	‘Not sure cannot remember’
				88	Multiple
3	S0303hospsurg	‘what hospital did you have surgery in?'	Alpha		Type in text provided
3	S0303surgpc	‘what is the postcode of the surgery hospital'	5555 through 9999		Type in postcode
4	S0304sghospdec	‘who decided what hospital to have surgery in?'	55 through 99	1	‘I made the decision with little or no input from my doctor’
				2	‘I made the decision after considering my doctor’s opinion’
				3	‘My doctor and I made the decision together’
				4	‘My doctor made the decision after considering my opinion’
				5	‘My doctor made the decision with little or no input from me’
				6	‘Other please specify’
				7	Not sure/cannot remember
				88	Multiple
4	S0304sghospdeccf	comment flag	Alpha		Type in text provided
5	S0305surgbills	'any bills associated with your surgery that you had to pay'	55 through 99	1	No I did not have any bills associated with surgery
				2	Yes, health insurance covered these costs completely
				3	Yes, health insurance covered only some of these costs

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	Yes I had bills to pay
				88	multiple
5	S0305surgbillcf	Description of the type of bills had to pay COMMENT	Alpha		Type in text provided

Question No.	Variable	Label	Missing Values	Values	Value labels
6	S0306surgcosts	‘were any out of pocket costs explained?'	55 through 99	1	‘Yes, I was fully informed of the costs I would have to pay’
				2	‘Yes, I was informed, but not of the full amount’
				3	‘No, I was not informed of the costs involved ‘
				4	‘not sure, cannot remember’
				88	Multiple
7a	S0307asurgwait	‘how long did you have to wait to have surgery'	55 through 99	1	‘Less than 2 weeks’
				2	‘More than 2, but within 4 weeks’
				3	‘More than a month ‘
				4	‘not sure, cannot remember’
				5	‘Other’
				88	Multiple
7a	S0307asurgwaitcf	comment flag	Alpha		Type in text provided
7b	S0307bysurg2wk	‘why longer than 2 week wait?'	55 through 99	1	Personal decision to wait
				2	Surgery waiting times. I was kept updated
				3	Surgery waiting times. I was NOT updated
				4	Other
				88	Multiple
7b	S0307bysurg2wkcf	comment flag	Alpha		Type in text provided
8	S0308surgfam	‘health prof involved in surgery ask if family or friends need support'	55 through 99	1	‘Yes, regularly’
				2	‘Yes, occasionally’
				3	‘No, never’
				4	‘No, as family or friends were not involved’
				5	‘not sure, cannot remember’
				88	Multiple
9a	S0309aaftersurg	‘what it would be like after surgery information'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’

Question No.	Variable	Label	Missing Values	Values	Value labels
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
10a	S0310asurgsdeff	‘side effects of surgery information'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
10b	S0310bsurgnext	‘what would happen next information'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
11	S0311hpexpunder	‘health professionals explain things in a way you could understand?'	55 through 99	1	‘All of the time’
				2	‘Most of the time’
				3	‘Some of the time’
				4	‘Rarely’
				5	‘Never’
				6	‘not sure, cannot remember’
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
12	S0312hospfears	‘have worries or fears while in hospital?'	55 through 99	1	Yes
				2	No
				88	Multiple
13	S0313hptalkfrs	‘health professionals discuss worries or fears'	55 through 99	1	‘Yes, completely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘not sure, cannot remember’
				88	Multiple
14	S0314hsmanside	‘were side effects well managed in hospital'	55 through 99	1	‘Yes, completely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘I did not have any side-effects from surgery’
				5	‘not sure, cannot remember’
				88	Multiple
15	S0315painaftrsg	'were you in pain while in hospital after surgery'	55 through 99	1	Yes
				2	No
				88	Multiple
16	S0316hsmanpain	'did hospital staff do everything they could to help manage pain'	55 through 99	1	Yes, definitely
				2	Yes, to some extent
				3	No
				4	Not sure/cannot remember
				88	Multiple
17	S0317timeok	‘were you able to get a member of staff to help you within reasonable time'	55 through 99	1	‘Yes, all of the time’
				2	‘Yes, most of the time’
				3	‘Yes, some of the time’
				4	‘Never’

Question No.	Variable	Label	Missing Values	Values	Value labels
				5	‘I did not need assistance’
				6	‘not sure, cannot remember’
				88	Multiple
18	S0318hospserv	‘health professional organise services needed to help recovery'	55 through 99	1	‘Yes, I saw all the other services I needed’
				2	‘Yes, but I think I needed more’
				3	‘No, but I think I needed to’
				4	‘I did not need any other services’
				5	‘not sure, cannot remember’
				88	Multiple
19	S0319hosprespect	‘hospital staff treat you with respect and dignity"	55 through 99	1	‘Yes, always’
				2	‘Yes, sometimes’
				3	‘No'
				4	‘not sure, cannot remember’
				88	Multiple
20	S0320hospmanhome	‘when discharged were you given enough information about managing at home?'	55 through 99	1	‘Yes, completely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘No, but I researched this myself through the internet, books, family or friends’
				5	‘Not sure cannot remember’
				88	Multiple
21	S0321hospcontact	‘when discharge were you given contact number to call?'	55 through 99	1	‘I was only given my doctor's number’
				2	‘I was given the name and number of someone at the hospital’
				3	‘I was given a hospital number to call but didn't have anyone's name’
				4	No I wasn't given any number to call

Question No.	Variable	Label	Missing Values	Values	Value labels
				5	Not sure/cannot remember
				88	Multiple
22	S0322homeservice	‘when left hospital were arrangement made by staff for service you needed?'	55 through 99	1	‘Yes, completely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘I did not need any services’
				5	‘Not sure cannot remember’
				88	Multiple
23	S0323cleanwc	‘how clean were the toilets and bathrooms used in hospital?'	55 through 99	1	‘Very clean’
				2	‘Fairly clean’
				3	‘Not very clean’
				4	‘Not at all clean’
				5	‘Not sure cannot remember’
				88	Multiple
24	S0324surgsat	‘how satisfied were you with the treatment received from all health professionals involved in your surgery?'	55 through 99	1	Very satisfied
				2	Satisfied
				3	Neither satisfied or dissatisfied
				4	Dissatisfied
				5	Very dissatisfied
				88	Multiple

Module 4: Radiotherapy

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0401haveradio	‘did you have radiotherapy'	55 through 99	1	Yes
				2	No
				88	Multiple
2	S0402whenradio	‘when did you have radiotherapy'	55 through 99	1	‘Within the last 3 months’
				2	‘More than 3 months ago, but less than 6 months ago’
				3	‘More than 6 months ago, but less than 12 months ago’
				4	‘More than 12 months ago, but less than 2 years ago’
				5	‘More than 2 years ago’
				6	‘Not sure cannot remember’
				88	Multiple
3	S0403radiohosp	‘what hospital did you have radiotherapy at''	Alpha		Type in text provided
3	S0403radiohosppc	‘radiotherapy hospital postcode'	5555 through 9999		Type in postcode
4	S0404rxthospdec	‘who decided to have radiotherapy at that hospital'	55 through 99	1	‘I made the decision with little or no input from my doctor’
				2	‘I made the decision after considering my doctor’s opinion’
				3	‘My doctor and I made the decision together’
				4	‘My doctor made the decision after considering my opinion’
				5	‘My doctor made the decision with little or no input from me’
				6	‘Other please specify’
				7	Not sure/cannot remember
				88	Multiple
4	S0404rxthospdeccf	comment flag	Alpha		Type in text provided
5	S0405radiobills	'did you have any bills associated with radiotherapy'	55 through 99	1	No, I did not have bills associated with my radiotherapy
				2	Yes, but my health insurance covered these completely

Question No.	Variable	Label	Missing Values	Values	Value labels
				3	Yes, and my health insurance only covered some of these costs
				4	Not sure/cannot remember
				88	Multiple
	S0405radiobillscf	Comment flag what bills had to pay	Alpha		Type in text provided
6	S0406radiocosts	‘were you told about any out of pocket costs'	55 through 99	1	‘Yes, I was fully informed of the costs I would have to pay’
				2	‘Yes, I was informed, but not of the full amount’
				3	‘No, I was not informed of the costs involved ‘‘not sure, cannot remember’
				4	Multiple
				88	‘Yes, I was informed, but not of the full amount’
7a	S0407rxtaway	‘did you have to stay away from home while having radiotherapy'	55 through 99	1	‘Yes’ '
				2	No
				88	Multiple
7b	S0407brxtarrange	‘who arranged the accommodation you stayed at'	55 through 99	1	I did or family friends did
				2	staff at hospital
				3	staff associated with my doctor
				4	not sure/cannot remember
				88	Multiple
7b	S0407brxtarrangecf	comment flag	Alpha		Type in text provided

Question No.	Variable	Label	Missing Values	Values	Value labels
8a	S0408waitrxt	‘how long did you have to wait to start radiotherapy'	55 through 99	1	‘Less than 2 weeks’
				2	‘More than 2, but within 4 weeks’
				3	‘More than a month ‘

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	‘not sure, cannot remember’
				5	‘Other’
				88	Multiple
8a	S0408waitrxtcf	comment flag	Alpha		Type in text provided
8b	S0408brxtwait2wks	‘why did you wait longer than 2 weeks'	55 through 99	1	‘Personal decision to wait’
				2	‘Radiotherapy waiting times I was kept updated’
				3	‘Radiotherapy waiting times I was not updated’
				4	Other
				88	Multiple
8b	S0408brxtwait2wkscf	comment flag	Alpha		Type in text provided
9a	S0409apreprxt	‘how to prepare for radiotherapy'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9b	S0409bmanrxtstrss	'how to manage anxiety or stress from radiotherapy''	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9c	S0409crxtsideff	‘how to manage any side effects from radiotherapy'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
9d	S0409dendrxt	'how you might feel at the end of treatment'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9e	S0409erecovrxt	'how long it might take to recover from having radiotherapy'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
10	S0410rxthpunderst	‘did health professional check you understood information'	55 through 99	1	‘Yes’
				2	‘No'
				3	‘not sure, cannot remember’
				88	Multiple
11	S0411rxttravelchk	‘did they take into account how far you had to travel when arranging appointments'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, as much as they could’
				3	‘No, not at all’
				4	‘Travel times or other commitments were not a problem for me’
				5	‘not sure, cannot remember’
				88	Multiple
12	S0412waitrxtapp	‘how long did you have to wait at appointment'	55 through 99	1	‘within 15 minutes of my appointment time’
				2	‘within 15-30 minutes of my appointment time’
				3	‘within 30-60 minutes of my appointment time’
				4	‘within 1-2 hours of my appointment time’

Question No.	Variable	Label	Missing Values	Values	Value labels
				5	‘longer than 2 hours’
				6	Not sure/cannot remember
				88	Multiple
13	S0413checkrxtse	‘did health professional check if you had any side effects'	55 through 99	1	‘Yes’
				2	‘Yes, but not as often as I would have liked’
				3	No
				4	‘not sure, cannot remember’
				88	Multiple
14	S0414rxthpevery	‘did health professionals do everything they could to manage side effects'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘I did not experience any side-effects ‘
				5	‘not sure, cannot remember’
				88	Multiple
15	S0415rxthpresp	‘did health professional treat you with respect and dignity'	55 through 99	1	‘Yes always'
				2	Yes sometimes
				3	no
				4	not sure cannot remember
				88	Multiple
16	S0416rxthpassist	‘did health professionals check if you needed help or assistant with things'	55 through 99	1	‘Yes ‘
				2	‘No’
				3	‘not sure, cannot remember’
				88	Multiple
17	S0417rxthpemot	'did health professionals check if you needed help with managing	55 through 99	1	‘Yes ‘
				2	‘No’

Question No.	Variable	Label	Missing Values	Values	Value labels
		emotional state'		3	‘not sure, cannot remember’
				88	Multiple
18	S0418rxthptravel	'did health professionals check if you needed help traveling to or from appointments'	55 through 99	1	‘Yes ‘
				2	‘No’
				3	‘not sure, cannot remember’
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
19	S0419rxthpcontact	'were you given a number to contact if you had concerns about your condition or treatment'	55 through 99	1	‘Yes ‘
				2	‘No’
				3	‘not sure, cannot remember’
				88	Multiple
20	S0420rxthpfam	‘did health professionals ask if your family or friends need support or information'	55 through 99	1	‘Yes, regularly’
				2	‘Yes, occasionally’
				3	‘No, never’
				4	‘No, as family or friends were not involved’
				5	‘not sure, cannot remember’
				88	Multiple
21	S0421rxtcarsat	‘how satisfied were you with car parking at radiotherapy centre'	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’
				5	‘Very dissatisfied’
				6	‘Not applicable ‘
				88	Multiple
22	S0422rxtsat	‘how satisfied were you with radiotherapy care overall?'	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’
				5	‘Very dissatisfied’
				88	Multiple

Module 5: Chemotherapy Experiences

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0501havechemo	‘did you have chemotherapy for cancer'	55 through 99	1	yes
				2	no
				88	Multiple
2	S0502whenchemo	‘when did you start chemotherapy for first time'	55 through 99	1	‘Within the last 3 months’
				2	‘More than 3 months ago, but less than 6 months ago’
				3	‘More than 6 months ago, but less than 12 months ago’
				4	‘More than 12 months ago, but less than 2 years ago’
				5	‘More than 2 years ago’
				6	‘Not sure cannot remember’
				88	Multiple
3	S0503chemohosp	‘what hospital did you have chemotherapy at'	Alpha		Type in text provided
3	S0503chemohosppc	‘what was postcode of hospital had chemotherapy'	5555 through 9999		Type in postcode
4	S0504chemhospdec	‘who decided that you would have chemo at this hospital'	55 through 99	1	‘I made the decision with little or no input from my doctor’
				2	‘I made the decision after considering my doctor’s opinion’
				3	‘My doctor and I made the decision together’
				4	‘My doctor made the decision after considering my opinion’
				5	‘My doctor made the decision with little or no input from me’
				6	‘Other please specify’
				7	Not sure/cannot remember
				88	Multiple
4	S0504chemhospdeccf	comment flag	Alpha		Type in text provided
5	S0505chemobills	'did you have any bills	55 through 99	1	No, I did not have any bills associated with chemotherapy

Question No.	Variable	Label	Missing Values	Values	Value labels
		associated with your chemotherapy that you had to pay'		2	Yes, and my health insurance covered these costs completely
				3	Yes, and my health insurance covered only some of these costs
				4	Yes, I had bills to pay
				88	Multiple
	S0505chemobillcf	Comment flag what bills for chemotherapy	Alpha		Type in text provided
6	S0506chemocosts	‘were out of pocket costs explained to you'	55 through 99	1	‘Yes, I was fully informed of the costs I would have to pay’
				2	‘Yes, I was informed, but not of the full amount’
				3	‘No, I was not informed of the costs involved ‘
				4	‘not sure, cannot remember’
				88	Multiple
7a	S0507chemoaway	‘did you have to stay away from home when had chemo'	55 through 99	1	‘Yes’ '
				2	no
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
7b	S0507bchemoarrange	‘who arranged this accommodation if you had to stay away'	55 through 99	1	I did or family friends did
				2	staff at hospital
				3	staff associated with my doctor
				4	not sure
				5	Other
				88	Multiple
7b	S0507bchemoarrangecf	comment flag	Alpha		Type in text provided
8a	S0508startchemo	‘how long did you wait before you had your first chemo treatment'	55 through 99	1	‘Less than 2 weeks’
				2	‘More than 2, but within 4 weeks’
				3	‘More than a month ‘
				4	‘not sure, cannot remember’
				5	‘Other’
				88	Multiple
8a	S0508astartchemocf	comment flag	Alpha		Type in text provided
8b	S0508bychemo2wk	‘why did you have to wait longer than 2 weeks'	55 through 99	1	‘Personal decision to wait’
				2	‘Chemotherapy waiting times I was kept updated’
				3	‘Chemotherapy waiting times I was not updated’
				4	Other
				88	Multiple
8b	S0508bychemo2wkcf	comment flag	Alpha		Type in text provided
9a	S0509aprepchemo	‘'how to prepare for chemo information given'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
9b	S0509bmanchemostrss	'how to manage anxiety or stress'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9c	S0509cfeelchemo	‘how you would feel at end of chemotherapy'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9d	S0509dchemoeffect	‘information about side effect you might experience'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
9e	S0509emanagechemo	‘information about how to manage any side effects'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
9f	S0509fpossemdept	‘possibility of going to the emergency department'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure, cannot remember’
				88	Multiple
10	S0510chemohpunder	‘did health professional check you understood information'	55 through 99	1	‘Yes'
				2	‘No'
				3	‘not sure, cannot remember’
				88	Multiple
11	S0511chemohptrav	‘staff take into account how far you had to travel when arranging chemotherapy appointments '	55 through 99	1	‘Yes, definitely’
				2	‘Yes, as much as they could’
				3	‘No, not at all’
				4	‘Travel times or other commitments were not a problem for me’
				5	‘not sure, cannot remember’
				88	Multiple
12	S0512waitchemoapp	‘how long did you wait at your chemotherapy appointments '	55 through 99	1	‘within 15 minutes of my appointment time’
				2	‘within 15-30 minutes of my appointment time’
				3	within 30-60minutes of my appointment time
				4	‘within 1-2 hours of my appointment time’

Question No.	Variable	Label	Missing Values	Values	Value labels
				5	‘longer than 2 hours’
				6	chemotherapy in tablet form, this wasn't a problem for me
				7	‘not sure, cannot remember’
				88	Multiple
13	S0513chemosechk	‘did health professionals check if you had any side effects or symptoms '	55 through 99,	1	‘Yes’
				2	‘Yes, but not as often as I would have liked’
				3	‘No'
				4	‘not sure, cannot remember’
				88	Multiple
14	S0514chemohpevery	‘health professionals involved in ' chemotherapy do everything they could to help manage any side effects '	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No’
				4	‘I did not experience any side-effects ‘
				5	‘not sure, cannot remember’
				88	Multiple
15	S0515chemorespect	‘health professionals involved in your chemotherapy treat you with respect and dignity?'	55 through 99	1	‘Yes always'
				2	Yes sometimes
				3	no
				4	not sure cannot remember
				88	Multiple
16	S0516chemohpchk	‘did health professionals check if you needed any help or assistance with things '	55 through 99	1	‘Yes ‘
				2	‘No'
				3	‘not sure, cannot remember’
				88	Multiple
17	S0517chemohpemot	'did health professionals check if	55 through 99	1	‘Yes ‘

Question No.	Variable	Label	Missing Values	Values	Value labels
		you needed assistance managing your emotional state'		2	‘No'
				3	‘not sure, cannot remember’
				88	Multiple
18	S0518chemohptravchk	'did health professionals check if you needed help with travelling to or from appointments	55 through 99	1	‘Yes ‘
				2	‘No'
				3	‘not sure, cannot remember’
				88	Multiple
19	S0519chemocontact	‘Were you given a telephone number to contact if you had concerns'	55 through 99	1	Yes
				2	No
				3	not sure cannot remember
				88	Multiple
20	S0520chemocard	‘Were you given a card that explained your chemotherapy if you needed to go to the Emergency Department'	55 through 99	1	Yes
				2	No
				3	not sure cannot remember
				88	Multiple
21	S0521chemohpfam	‘health professionals 'ask if your family or friends needed any information or support?'	55 through 99	1	‘Yes, regularly’
				2	‘Yes, occasionally’
				3	‘No, never’
				4	‘No, family or friends were not involved’
				5	‘not sure, cannot remember’
				88	Multiple
22	S0522chemocarsat	‘satisfied were you with the availability of car parking '	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’

Question No.	Variable	Label	Missing Values	Values	Value labels
				5	‘Very dissatisfied’
				88	Multiple
23	S0523chemosat	‘how satisfied were you with the treatment you received from all health professionals involved in chemo'	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’
				5	‘Very dissatisfied’
				88	Multiple

Module 6: Emergency Department

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0601emdeptatt	‘have you had to go to the emergency department cause you were sick from your treatment?'	55 through 99	1	‘Yes, only once’
				2	‘Yes, more than once’
				3	‘Yes, but it was before my cancer was properly diagnosed’
				4	‘No, never ‘
				88	Multiple
2	S0602emhosp	‘Which hospital emergency department did you last go to'	Alpha		Type in text provided
2	S0602emhosppc	‘emergency department hospital postcode'	5555 through 9999		Type in postcode
3	S0603emwait	‘about how long did you have to wait before you saw the doctor?'	55 through 99	1	‘less than 10 minutes’
				2	‘More than 10 minutes, but less than 30 minutes’
				3	‘More than 30 minutes, but less than 1 hour’
				4	‘Between 1-2 hours’
				5	‘Between 2-4 hours’
				6	‘More than 4 hours’
				7	‘not sure, cannot remember’
				88	Multiple
4	S0604emmanage	‘you feel that your condition was well managed while you were in the waiting '	55 through 99	1	‘Yes, my condition was managed well’
				2	‘No, my condition was not managed well ‘
				3	‘not sure, cannot remember’
				88	Multiple
5	S0605emhpskill	‘Did you think health professionals in the Emergency Department had the knowledge and skills needed to look after	55 through 99	1	Yes all or most of them did
				2	only a few of them did
				3	no
				4	not sure cannot remember

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
6	S0606emadmit	‘Were you admitted into hospital as a result of your consultation '	55 through 99	1	Yes
				2	No
				3	not sure cannot remember
				88	Multiple

Module 7: Follow-up care

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0701fusurg	'which doctor is mainly in charge of your follow-up care 1'	55 through 99	0	Not surgeon
				1	Surgeon in charge of follow up
1	S0701fuhaem	'which doctor is mainly in charge of your follow-up care 2'	55 through 99	0	Not haem
				1	Haematologist in charge of follow up
1	S0701furadonc	'which doctor is mainly in charge of your follow-up care 3'	55 through 99	0	No rad onc
				1	Radiation oncologist in charge of follow up
1	S0701fugp	'which doctor is mainly in charge of your follow-up care 4'	55 through 99	0	No GP
				1	GP in charge of follow up
1	S0701fufumedonc	'which doctor is mainly in charge of your follow-up care 5'	55 through 99	0	No medical oncologist
				1	Medical oncologist in charge of follow up
1	S0701fuother	'which doctor is mainly in charge of your follow-up care 6'	55 through 99	0	No
				1	Other in charge of follow up
1	S0701fuothercf	comment flag			
1	S0701fuoterdr	'which doctor is mainly in charge of your follow-up care 7'	55 through 99	0	No
				1	Other doctor in charge of follow up
1	S0701fuotherdrcf	comment flag			
1	S0701funocharge	'which doctor is mainly in charge of your follow-up care 8'	55 through 99	0	
				1	Not sure who is in charge of follow up
2	S0702fuhosp	'which hospital was the most involved in your follow-up care'	Alpha		Type in text provided
2	S0702fuhosppc	'follow-up care hospital postcode'	5555 through 9999		postode
3	S0703schappwork	‘was work or other commitments, or how far you had to travel taken into consideration when making appointments'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, as much as it could be’
				3	‘No, not at all’

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	‘Travel times or other commitments were not a problem for me’
				5	‘not sure, cannot remember’
				88	Multiple
4	S0704appcoored	‘Were your appointments and tests coordinated by health professionals '	55 through 99	1	‘Yes, definitely’
				2	‘Yes, sometimes’
				3	‘No’
				4	‘not sure, cannot remember’
				88	Multiple
5	S0705resultavail	‘how often have test results or other information needed for your appointment not been available to your doctor?'	55 through 99	1	‘Never’
				2	‘Once or twice’
				3	‘Three or four times’
				4	‘Five or more times’
				5	‘not sure, cannot remember’
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
6a	S0706afuplan	‘follow-up A written plan '	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6b	S0706bfutest	‘follow-up b. Information about what follow-up tests you would need'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6c	S0706cfuhealthy	‘follow-up--things you could do to stay healthy'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6d	S0706dfuinvest	‘follow-up which new symptoms need investigation'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6e	S0706efufeel	‘follow-up how people feel after finishing cancer treatment'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6f	S0706ffusupp	‘follow-up how to get extra	55 through 99	1	‘Yes, I was given this information’

Question No.	Variable	Label	Missing Values	Values	Value labels
		support if you or your family wanted it?'		2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
6g	S0706gfuoftenchk	‘follow-up how often you would need to have tests or check-ups?'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘Not sure cannot remember’
				88	Multiple
7	S0707manongoingself	‘given info about managing side-eff...‘	55 through 99	1	`Yes, I was given this information`
				2	`Yes, but I would have liked more`
				3	`No`
				4	`I did not have any side-effects or ongoing symptoms`
				5	`Not sure/cannot remember`
				88	Multiple
8	S0708gpfollowup	‘does your GP have a good understanding of the follow-up care you need '	55 through 99	1	‘Yes ‘
				2	‘No’
				3	‘I do not have a regular GP’
				4	‘not sure, cannot remember’
				88	Multiple

Module 8: Information Received

Question No.	Variable	Label	Missing Values	Values	Value labels
1a	S0801aimpactivity	‘a. The possible impact of treatment on your capacity to	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’

Question No.	Variable	Label	Missing Values	Values	Value labels
		work or do activities'		3	‘No, I was not given this information’
				4	‘I did not need this information’
				5	‘Not sure, cannot remember’
				88	Multiple
1b	S0801bimpenergy	‘b. The possible changes in your energy level? '	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘I did not need this information’
				5	‘Not sure, cannot remember’
				88	Multiple
1c	S0801cimpfertile	‘c. What you could do to preserve your fertility?'	55 through 99	1	‘Yes, I was given this information’
				2	‘Yes, but I would have liked more’
				3	‘No, I was not given this information’
				4	‘I did not need this information’
				5	‘Not sure, cannot remember’
				88	Multiple
2	S0802finsupp	‘health professionals talk to you about any financial support programs '	55 through 99	1	‘Yes, someone talked to me about financial support’
				2	‘No, but I would have liked someone to’
				3	‘No I did not need any financial support services’
				4	‘Not sure cannot remember’
				88	Multiple
3	S0803hpanyqn	'feel like you could ask the health professionals involved in your care any questions'	55 through 99	1	yes definitely
				2	yes to some extent
				3	no
				4	not sure cannot remember

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
4a	S0804asocwork	‘Social worker'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4b	S0804bpsych	‘Psychologist'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4c	S0804cdietitian	‘Dietitian'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4d	S0804dspeech	‘Speech Therapist'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4e	S0804eoccthery	‘Occupational Therapist'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
4f	S0804fpainman	‘Pain management specialist'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4g	S0804ghelpline	‘Cancer Helpline'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
4h	S0804hfinplanner	‘Financial planner	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
5a	S0805ahelpchores	‘Help with domestic chores (e.g. cooking or cleaning etc.)?'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
5b	S0805bhelpprob	‘Family problems?'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember

Question No.	Variable	Label	Missing Values	Values	Value labels
				88	Multiple
5c	S0805chelpchild	‘Working out childcare when you were having treatment?'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
5d	S0805dhelpfin	‘Your finances (accessing your superannuation, illness insurance, income protection etc.)?'	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
5e	S0805ehelpsuppg	‘Finding support groups or other services '	55 through 99	1	yes
				2	no but I would have liked them to
				3	no but I didn’t need them to
				4	not sure/cannot remember
				88	Multiple
6	S0806possresearch	did health professionals talk to you about taking part in any cancer research?"	55 through 99	1	‘Yes, and I was happy for them to do this’
				2	‘Yes, but I was not happy for them to do this’
				3	‘No, but I would have liked them to have done this’
				4	‘No, and I am glad they did not do this’
				5	‘Not sure cannot remember’
				88	Multiple
7	S0807alttherapy	feel you could talk with the health professionals involved in your care about complementary or alternative therapies	55 through 99	1	‘Yes, with all the health professionals ‘
				2	‘Yes, with some health professionals’
				3	‘No, not at all ‘
				4	‘I didn’t want to talk to staff about this issue’
				5	‘I was not interested in complementary or alternative therapies’
				6	‘Not sure cannot remember’
				88	Multiple

Module 9: Overall Care

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S0901hpcontact	has there been a health professional or a team of health professionals you could contact	55 through 99	1	'Yes, there was at least one health professional I could contact throughout my treatment'
				2	'Yes, there was someone I could contact but not all the time'
				3	'No'
				4	'Not sure cannot remember'
				88a	Multiple
2	S0902surgcharge	doctor/s were in charge of your care 1	55 through 99	0	
				1	Surgeon in charge
2	S0902haemcharge	doctor/s were in charge of your care 2	55 through 99	0	
				1	Haematologist in charge
2	S0902medonccharge	doctor/s were in charge of your care 3	55 through 99	0	
				1	Medical oncologist in charge
2	S0902radonccharge	doctor/s were in charge of your care 4	55 through 99	0	
				1	Radiation oncologist in charge
2	S0902gpcharge	doctor/s were in charge of your care 5	55 through 99	0	
				1	GP in charge
2	S0902othrdrcharge	doctor/s were in charge of your care 6	55 through 99	0	
				1	Other doctor in charge
2	S0902othrdrchgcf	comment flag			
2	S0902othrcharge	doctor/s were in charge of your care 7	55 through 99	0	
				1	Other is in charge
2	S0902notsurecharge	doctor/s were in charge of your care 8	55 through 99	0	
				1	Not sure who is in charge
3a	S0903aconflictinf	You received conflicting information from different	55 through 99	1	no never
				2	once

Question No.	Variable	Label	Missing Values	Values	Value labels
		doctors or health professionals?		3	2-3 times
				4	4 or more times
				5	not sure cannot remember
				88a	Multiple
3b	S0903bhpnotinf	You thought a health professional was not fully informed about your treatment and /or your progress?	55 through 99	1	no never
				2	once
				3	2-3 times
				4	4 or more times
				5	not sure cannot remember
				88a	Multiple
3c	S0903crepeattest	You thought tests or other assessments were being repeated unnecessarily	55 through 99	1	no never
				2	once
				3	2-3 times
				4	4 or more times
				5	not sure cannot remember
				88a	Multiple
3d	S0903dresultnotthr	The results of your tests, X-rays or scans were not available when needed for an appointment?	55 through 99	1	no never
				2	once
				3	2-3 times
				4	4 or more times
				5	not sure cannot remember
				88a	Multiple
3e	S0903enotpassinf	You thought the health professionals involved in your care were not passing on information to one another?	55 through 99	1	no never
				2	once
				3	2-3 times

Question No.	Variable	Label	Missing Values	Values	Value labels
				4	4 or more times
				5	not sure cannot remember
				88a	Multiple
	S0904Q3comm	any comments on things that happened	Alpha		Type in text provided
4	S0904canurse	were you given name of a clinical nurse specialist who would in charge of your care?	55 through 99	1	Yes
				2	No
				3	Not sure/can't remember
				88a	Multiple
5	S0905canursecontact	how easy is it for you to contact clinical nurse specialist"	55 through 99	1	Easy
				2	Sometimes easy, sometimes difficult
				3	Difficult
				4	I have not tried to contact him/her
				88a	Multiple
6	S0906canurselisten	the last time you spoke to your clinical nurse specialist, did he/she listen carefully to you?	55 through 99	1	Yes definitely
				2	Yes, to some extent
				3	No
				88a	Multiple
7	S0907Canurseunderst	how often do you get answers you can understand from clinical nurse specialist?	55 through 99	1	All or most of the time
				2	Some of the time
				3	Rarely or never
				4	I do not ask any questions
				88a	Multiple
8	S0908difftxtcent	different treatment centres involved in your care informed about the care you had	55 through 99	1	‘Yes, they seemed well informed about the care I had received at other places’
				2	‘Yes, although some information seemed to be missing’

Question No.	Variable	Label	Missing Values	Values	Value labels
		received at the other centres		3	‘No, there seemed to be little or no sharing of information’
				4	‘I only had treatment at one treatment centre’
				5	‘Not sure cannot remember’
				88a	Multiple
9	S0909interpreter	was a hospital/treatment centre interpreter available for you?	55 through 99	1	‘Yes, at most or all of my appointments’
				2	‘Yes, at some of my appointments’
				3	‘No, an interpreter was never available’
				4	‘No one talked to me about getting an interpreter, but I needed one’
				5	‘I did not need an interpreter’
				6	‘Not sure cannot remember’
				88a	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
10	S0910gpinformed	was your GP kept informed about your condition and your treatment?	55 through 99	1	‘Yes, my GP seemed very well informed'
				2	'Yes, to some extent'
				3	‘No, my GP did not know much about my cancer or the treatment I had’
				4	‘I do not have a regular GP’
				5	‘Not sure cannot remember’
				88a	Multiple
11	S0911hpworktog	How would you rate how well the doctors and nurses involved in your cancer care worked together?	55 through 99	1	‘Excellent’
				2	‘Very good’
				3	‘Good’
				4	‘Fair’
				5	‘Poor’
				88a	Multiple
12	S0912allhpsat	satisfied were you with the overall care you received from all health professionals involved in your treatment?	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’
				5	‘Very dissatisfied’
				88a	Multiple
13	S0913complaint	Was there a time when you were you wanted to or did complain about it care	55 through 99	1	‘Yes, there was at least one time ‘
				2	‘No, my care was generally fine’
				3	‘No, my care was excellent’
				4	‘Not sure cannot remember’
				88a	Multiple
13b	S0913bwhatcomplain	What was the issue complained about	Alpha		Type in text provided

Module 10: Background information

Question No.	Variable	Label	Missing Values	Values	Value labels
1	S1001Sex	Sex	55 through 99	1	Male
				2	Female
				88a	Multiple
2	S1002Age	Age	5555 through 9999		
3	S1003Livetown	What is the name or postcode of the town/suburb where you currently live?	Alpha		Type in text provided
3	S1003Livetownpc	postcode of town where live;	5555 through 9999		Type in postcode
4	S1004txtlive	Where were you living when you received your treatments for cancer?	55 through 99	1	Same as address above
				2	Different address
				88a	Multiple
4	S1004txtlivesuburb	suburb where living when treated for cancer	Alpha		Type in text provided
4	S1004txtlivepc	postcode of town where living when treated for cancer	5555 through 9999		Type in postcode
5	S1005language	language spoken at home	55 through 99	1	‘English’
				2	‘Italian’
				3	‘Greek’
				4	‘Cantonese’
				5	‘Arabic including Lebanese’
				6	‘Vietnamese’
				7	‘Mandarin’
				8	‘Other please specify’
5	S1005languagecf	Specify language	Alpha		Type in text provided
6	S1006Indig	indigenous or torres strait islander?	55 through 99	1	Yes aboriginal

Question No.	Variable	Label	Missing Values	Values	Value labels
				2	yes Torres Strait Islander
				3	yes both indigenous and TSI
				4	no
				88a	Multiple
7	S1007Health	In general, how would you rate your health?	55 through 99	1	'Excellent'
				2	'Very good'
				3	'Good'
				4	'Fair'
				5	'Poor'
				88a	Multiple

Brief Survey: Additional Questions

Question No.	Variable	Label	Missing Values	Values	Value labels
	s00_id	**patient id**			
1	S1101cancertype	‘what cancer diagnosed with'		1	breast
				2	leukaemia
				3	Prostate
				4	Colorectal
				5	Lung
				6	Brain
				7	Sarcoma
				8	Uterus
				9	Multiple myeloma
				10	Kidney
				11	Stomach cancer
				12	Mesothelioma
				13	Central nervous system
				14	Melanoma
				15	Ovarian
				16	Lymphoma
				17	Bladder cancer
				18	Pancreatic cancer
				19	Throat/mouth
				20	Other
				88	Multiple
1	S1101cancertycf	comment flag	Alpha		Type in text provided
2	S1102datedxdd	‘day of diagnosis'	55 through 99		Numeric 1 through 31

Question No.	Variable	Label	Missing Values	Values	Value labels
	S1102datedxmm	Month of diagnosis	55 through 99		Numeric 1 through 12
	S1102datedxyyy	Year of diagnosis	5555 through 9999		year
3a	S1103acancerinfo	'information in a format you were happy with '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘No I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
3b	S1103btctoptinfo	information about treatment options for your cancer '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘No I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
3c	S1103cmoreinfo	‘told how you could get more information '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘NO I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
3d	S1103dsupportinfo	‘information who you could contact for support '	55 through 99	1	‘Yes, definitely’
				2	‘Yes I think so’
				3	‘NO I do not think so’
				4	‘No, definitely not’
				5	Not sure/ Can't remember
				88a	Multiple
4	S1104atxtsurg	‘had surgery as treatment for cancer '	55 through 99	0	No surgery
				1	Surgery
	S1104atxtsurgcf	Where did you have surgery	Alpha		Type in text provided
4	S1104btxtradio	'had radiotherapy as treatment for cancer'	55 through 99	0	No radiotherapy
				1	Radiotherapy
	S1104btxtradiocf	Where did you have radiotherapy	Alpha		Type in text provided
4	S1104ctxtchemo	'had chemotherapy for cancer '	55 through 99	0	No chemo
				1	Chemotherapy/targetted therapies
	S1104ctxtchemocf	Where had chemotherapy	Alpha		Type in text provided
4	S1104dtxthorm	'had hormonal therapy'	55 through 99	0	No hormonal therapy

Question No.	Variable	Label	Missing Values	Values	Value labels
				1	Hormonal therapy
	S1104dtxthormcf	Where had hormonal therapy	Alpha		Type in text provided
4	S1104etxtother		55 through 99	1	Other treatment
	S1104etxtothercf	comment flag	Alpha		Type in text provided
5	S1105shortsideeff	‘possible short term side effects explained'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No, and I would have liked this information’
				4	‘No, but I researched this myself ‘
				5	‘Not sure cannot remember’
				88	Multiple
6	S1106longsideeff	‘possible long term side effects explained'	55 through 99	1	‘Yes, definitely’
				2	‘Yes, to some extent’
				3	‘No, and I would have liked this information’
				4	‘No, but I researched this myself ‘
				5	‘Not sure cannot remember’
				88	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
7	S1107hpcontact	has there been a health professional or a team of health professionals you could contact	55 through 99	1	‘Yes, there was at least one health professional I could contact throughout my treatment’
				2	‘Yes, there was someone I could contact but not all the time’
				3	‘No’
				4	‘Not sure cannot remember’
				88a	Multiple
				1	Not sure who is in charge
8	S1108canurse	were you given name of a clinical nurse specialist who would in charge of your care?	55 through 99	1	Yes
				2	No
				3	Not sure/can't remember
				88a	Multiple
9	S1109canursecontact	how easy is it for you to contact clinical nurse specialist"	55 through 99	1	Easy
				2	Sometimes easy, sometimes difficult
				3	Difficult
				4	I have not tried to contact him/her
				88a	Multiple
10	S1110hpworktog	How would you rate how well the doctors and nurses involved in your cancer care worked together?	55 through 99	1	‘Excellent’
				2	‘Very good’
				3	‘Good’
				4	‘Fair’
				5	‘Poor’
				88a	Multiple

Question No.	Variable	Label	Missing Values	Values	Value labels
11	S1111allhpsat	satisfied were you with the overall care you received from all health professionals involved in your treatment?	55 through 99	1	‘Very satisfied’
				2	‘Satisfied’
				3	‘Neither satisfied or dissatisfied’
				4	‘Dissatisfied’
				5	‘Very dissatisfied’
				88a	Multiple
12	S1112complaint	Was there a time when you wanted to or did complain about it care	55 through 99	1	‘Yes, there was at least one time ‘
				2	‘No, my care was generally fine’
				3	‘No, my care was excellent’
				4	‘Not sure cannot remember’
				88a	Multiple
12b	S1112bwhatcomplaint	What was the issue complained about	Alpha		Type in text provided

Appendix 11: Using SPSS to analyse the data from the survey

This Appendix provides information and instructions regarding use of the statistical software package SPSS for analysis of the data generated from the survey. The information provided relates to:

1) Importing data into SPSS
2) Declaring missing values
3) Recoding text data into a number format
4) Creating a variable to indicate if the patient was treated at your health service.
5) Joining data sets together
6) Creating a variable to indicate if the patient had all their treatment at your health service
7) Selecting cases for analysis.
8) Running frequencies to obtain response distributions

For more detailed information on using SPSS please refer to the SPSS user manuals.

The information below is based on the windows version of SPSS.

You can operate SPSS using a menu system, which operates like a Microsoft Windows menu system or through syntax. Syntax is an SPSS specific code used to run different procedures or functions. Syntax is saved in a file called *.sps. Below we provide instructions for using SPSS syntax or SPSS menus for the tasks listed above. In the syntax examples included in this Appendix, SPSS procedure words or text are shown in red. Words that you can change are shown in black.

1) Importing data into SPSS

As the data generated from the ACCESS database is a ".csv" file, it needs to be read into SPSS and the variables in the data need to be defined. This is done through a data specification or shell file. The specification files for each survey modules can be downloaded from https://www2.health.vic.gov.au/about/health-strategies/cancer-care/cancer-projects

The SPSS specification file assigns a variable name to each data item (eg, a survey question), a variable label that describes what the variable is (e.g. the wording of the survey question), labels for each value the variable has (eg, 1 for "yes" 2 "no"), declares values to be excluded from analyses (eg, missing values, multiple response values, invalid values). It also defines the type of data contained within each variable, with variables containing text (eg, name of hospital) defined as a string or alpha variable while variables containing numbers defined as numeric.

The data specifications (variable names, variable labels, variable type, values and labels and missing values) for each survey module are shown in Appendix 10.

The ".csv" files, their corresponding SPSS specification files and potential names for the saved SPSS data file are shown in Table 11A.

Table 11A: For each survey module, name of the output file from the data entry database and the corresponding SPSS specification file name and data file name.

Survey module	**Datafile name**	**SPSS specification file Name**	**SPSS data file names**
Module 1	PECS_Section01_find_out.csv	diagnosis_specification.sps	Diagnosis.sav
Module 2	PECS_Section02_deciding.csv	deciding_specification.sps	Deciding.sav
Module 3	PECS_Section03_Surgery.csv	surgery_specification.sps	Surgery.sav
Module 4	PECS_Section04_Radio.csv	radio_specification.sps	radio.sav
Module 5	PECS_Section05_chemo.csv	chemo_specification.sps	Chemo.sav
Module 6	PECS_Section06_Emerg.csv	ED_specification.sps	ED.sav
Module 7	PECS_Section07_FollowUp.csv	followUp_specification.sps	followUp.sav
Module 8	PECS_Section08_Info_Rec.csv	Info_recvd_specification.sps	Info_recvd.sav
Module 9	PECS_Section09_Overall.csv	Overallcare_specification.sps	Overallcare.sav
Module 10.	PECS_Section10_Back_Gnd.csv	Back_Gnd_specification.sps	Back_Gnd.sav
Brief Survey	PECS_Section11_Brief.csv	Briefsurvey_specification.sps	Briefsurvey.sav

To import the data into SPSS follow the following steps.

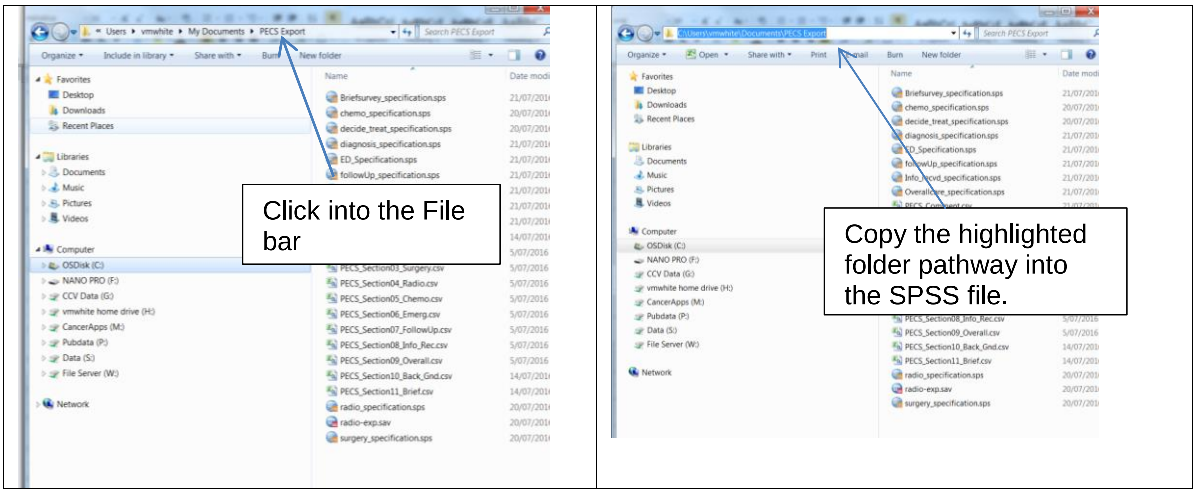
Step 1: Open up SPSS for windows

Step 2: By double clicking, open the SPSS specification file.
The specification file starts with the following text:

```
GET DATA
/TYPE=TXT
/FILE="C:\Users\vmwhite\Documents\PECS Export\PECS_Section01_Find_out.csv"
/DELCASE=LINE
/DELIMITERS=","
/QUALIFIER=""
/ARRANGEMENT=DELIMITED
/FIRSTCASE=2
/IMPORTCASE=ALL
/VARIABLES=
```

The text "C:\Users\vmwhite\Documents\PECS Export\" specifies the pathway to the file to be opened. This will need to be changed to reflect the location of the files exported from the Database.

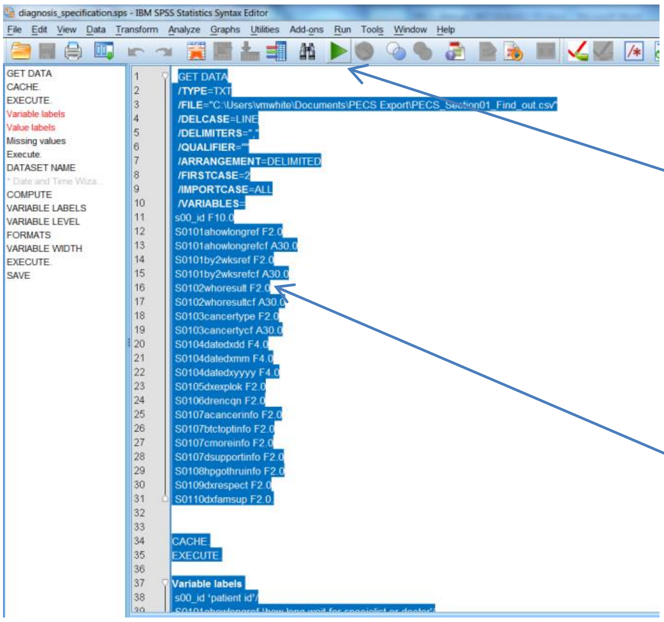
Step 3: Identify the file pathway: Open up the folder where the ".csv" files are located. In that folder, click on the file bar and the folder's pathway will be displayed (see images below). Copy this pathway into the SPSS file.



Click into the File bar

Copy the highlighted folder pathway into the SPSS file.

Step 4: Executing the file. In SPSS, after the file pathway has been changed, highlight all the text in the file and hit the run arrow (see images below). This will execute the syntax and import the '*.csv' file into SPSS, assign variable names and labels to the data, assign value labels to variables and define missing values.

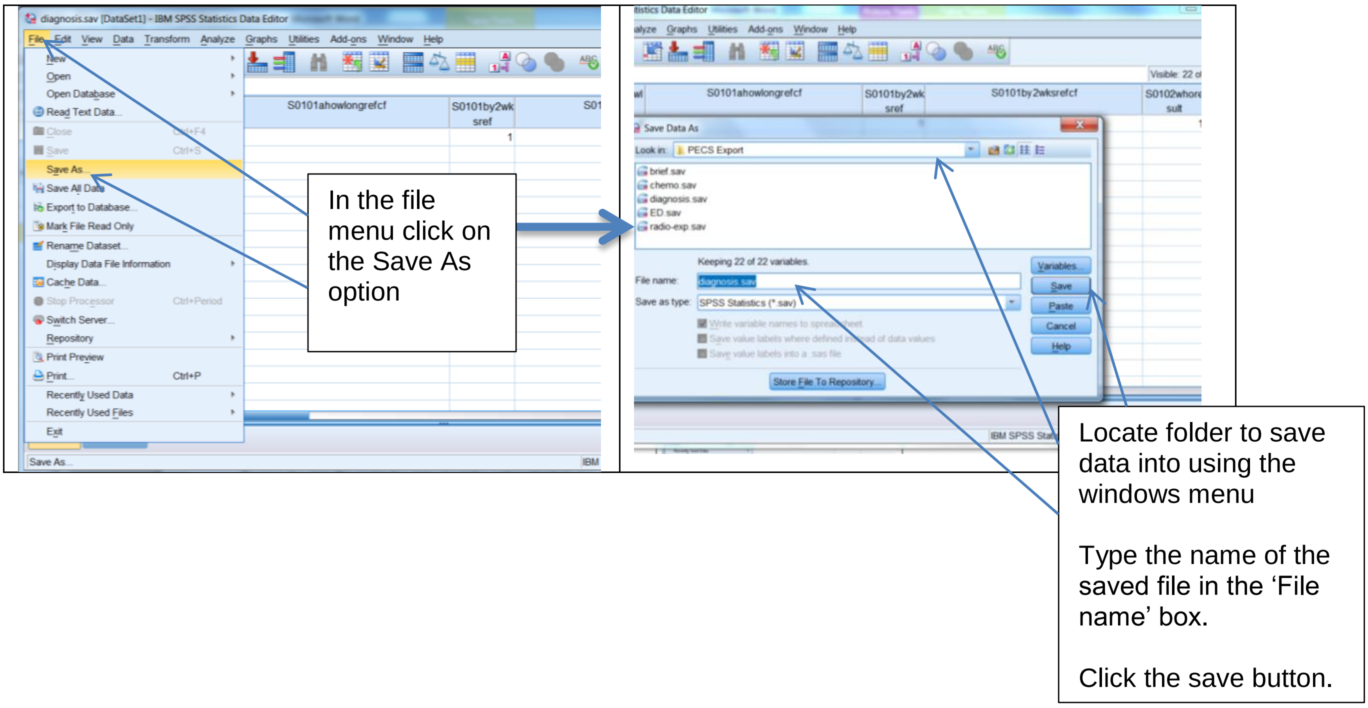


```
GET DATA
 /TYPE=TXT
 /FILE="C:\Users\vmwhite\Documents\PECS Export\PECS_Section01_Find_out.csv"
 /DELCASE=LINE
 /DELIMITERS=","
 /QUALIFIER='"'
 /ARRANGEMENT=DELIMITED
 /FIRSTCASE=2
 /IMPORTCASE=ALL
 /VARIABLES=
s00_id F10.0
S0101ahowlongref F2.0
S0101ahowlongrefcf A30.0
S0101by2wksref F2.0
S0101by2wksrefcf A30.0
S0102whoresult F2.0
S0102whoresultcf A30.0
S0103cancertype F2.0
S0103cancertycf A30.0
S0104datedxdd F4.0
S0104datedxmm F4.0
S0104datedxyyyy F4.0
S0105dxexplok F2.0
S0106drencqn F2.0
S0107acancerinfo F2.0
S0107btctoptinfo F2.0
S0107cmoreinfo F2.0
S0107dsupportinfo F2.0
S0108hpgothruinfo F2.0
S0109dxrespect F2.0
S0110dxfamsup F2.0.


CACHE.
EXECUTE.

Variable labels
s00_id 'patient id'/
```

Click the run arrow to execute all commands

Highlight all text in the file

<u>Step 5: Saving the data file</u>. Click into the data sheet labelled “Data View” in SPSS. In the File Menu, click on the ‘Save As’ option. This will open up a new dialogue box and you can save the file in a location of your choice following the usual windows procedures. SPSS data files have a .sav ending to their name. See below for screen images of this process.



In the file menu click on the Save As option

Locate folder to save data into using the windows menu

Type the name of the saved file in the ‘File name’ box.

Click the save button.

2) Declaring missing values

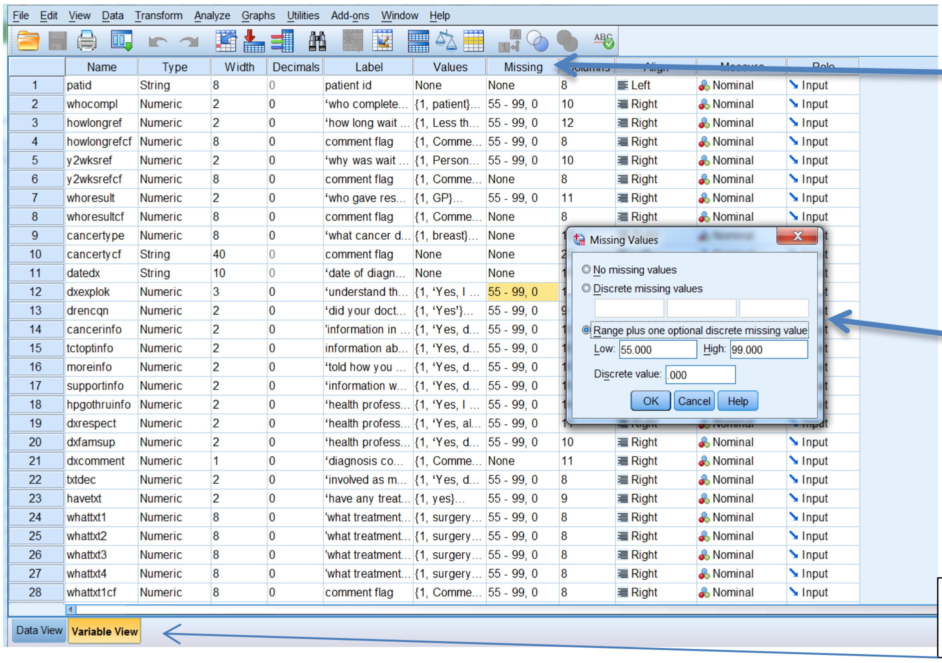
In SPSS, you are able to declare some values ‘missing’. This means that cases with a ‘missing’ data response will be excluded from analyses. As discussed above, the output from a frequency analysis will show the percentage calculated when all cases are included in the analyses and the percentage calculated when all the missing values are excluded.

For most questions the SPSS shellfile defines values of ‘99’, ‘55’, ‘88’ and ‘77’ as missing.

For age the missing value is 9999.

If you need to declare other values as missing, do this through the menu system from the data screen.

The follow screenshot describes the process:



	Name	Type	Width	Decimals	Label	Values	Missing	Columns	Align	Measure	Role
1	patid	String	8	0	patient id	None	None	8	Left	Nominal	Input
2	whocompl	Numeric	2	0	'who complete...	{1, patient}...	55 - 99, 0	10	Right	Nominal	Input
3	howlongref	Numeric	2	0	'how long wait ...	{1, Less th...	55 - 99, 0	12	Right	Nominal	Input
4	howlongrefcf	Numeric	8	0	comment flag	{1, Comme...	55 - 99, 0	8	Right	Nominal	Input
5	y2wksref	Numeric	2	0	'why was wait ...	{1, Person...	55 - 99, 0	10	Right	Nominal	Input
6	y2wksrefcf	Numeric	8	0	comment flag	{1, Comme...	None	8	Right	Nominal	Input
7	whoresult	Numeric	2	0	'who gave res...	{1, GP}...	55 - 99, 0	11	Right	Nominal	Input
8	whoresultcf	Numeric	8	0	comment flag	{1, Comme...	None	8	Right	Nominal	Input
9	cancertype	Numeric	8	0	'what cancer d...	{1, breast}...	None				
10	cancertycf	String	40	0	comment flag	None	None				
11	datedx	String	10	0	'date of diagn...	None	None				
12	dxexplok	Numeric	3	0	'understand th...	{1, 'Yes, I ...	55 - 99, 0				
13	drencqn	Numeric	2	0	'did your doct...	{1, 'Yes'}...	55 - 99, 0				
14	cancerinfo	Numeric	2	0	'information in ...	{1, 'Yes, d...	55 - 99, 0				
15	tctoptinfo	Numeric	2	0	information ab...	{1, 'Yes, d...	55 - 99, 0				
16	moreinfo	Numeric	2	0	'told how you ...	{1, 'Yes, d...	55 - 99, 0				
17	supportinfo	Numeric	2	0	'information w...	{1, 'Yes, d...	55 - 99, 0				
18	hpgothruinfo	Numeric	2	0	'health profess...	{1, 'Yes, I ...	55 - 99, 0				
19	dxrespect	Numeric	2	0	'health profess...	{1, 'Yes, al...	55 - 99, 0				
20	dxfamsup	Numeric	2	0	'health profess...	{1, 'Yes, d...	55 - 99, 0	10	Right	Nominal	Input
21	dxcomment	Numeric	1	0	'diagnosis co...	{1, Comme...	None	11	Right	Nominal	Input
22	txtdec	Numeric	2	0	'involved as m...	{1, 'Yes, d...	55 - 99, 0	8	Right	Nominal	Input
23	havetxt	Numeric	2	0	'have any treat...	{1, yes}...	55 - 99, 0	9	Right	Nominal	Input
24	whattxt1	Numeric	8	0	'what treatment...	{1, surgery...	55 - 99, 0	8	Right	Nominal	Input
25	whattxt2	Numeric	8	0	'what treatment...	{1, surgery...	55 - 99, 0	8	Right	Nominal	Input
26	whattxt3	Numeric	8	0	'what treatment...	{1, surgery...	55 - 99, 0	8	Right	Nominal	Input
27	whattxt4	Numeric	8	0	'what treatment...	{1, surgery...	55 - 99, 0	8	Right	Nominal	Input
28	whattxt1cf	Numeric	8	0	comment flag	{1, Comme...	55 - 99, 0	8	Right	Nominal	Input

Missing Values

○ No missing values

○ Discrete missing values

● Range plus one optional discrete missing value

Low: 55.000 High: 99.000

Discrete value: .000

In the Missing column click on row of relevant variable.

In the missing Values box specify the values you want to declare missing.

Variable view needs to be active.

3) Recoding text data into a number format

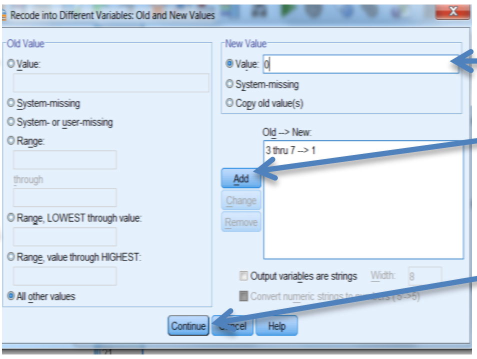
This section relates to short text responses, for example hospital name, other doctor seen.

SPSS has a facility to recode text variables into numeric responses. The procedure in SPSS is called AUTORECODE. AUTORECODE creates a new variable with all unique text responses coded into numbers.

The AUTORECODE function is both case and spelling specific. Each unique spelling of a word will be coded with a different number. For example the text "Fairfield"; "FairField", "fairfeld" "fair field" and "Fair Field" will be assigned 5 different numeric codes. For this reason careful typing of text, especially the names of treatment centres is recommended.

Running Autorecode in SPSS

The syntax for running the AUTORECODE function is shown below. You can type this into a SPSS syntax file.



Recode into Different Variables: Old and New Values

Old Value

○ Value:

○ System-missing

○ System- or user-missing

○ Range:

through

○ Range, LOWEST through value:

○ Range, value through HIGHEST:

● All other values

New Value

● Value: 0

○ System-missing

○ Copy old value(s)

Old --> New:

3 thru 7 --> 1

☐ Output variables are strings Width: 8

☐ Convert numeric strings to numbers ('5'->5)

Specify values or range of values to be recoded

Specify the new value and click Add.

When finished click Continue

Adding Value labels to a variable

The following syntax can be used to add value labels to a variable. The SPSS commands needed are shown in red.

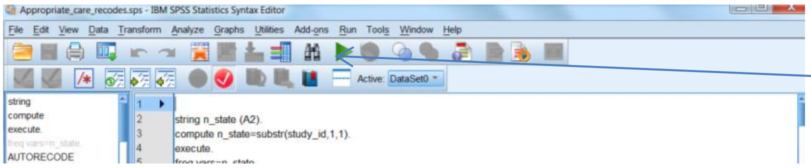
To add value labels in SPSS use the following syntax

```
Value labels Variable name             0 'didn't have surgery at hospital'
                                       1 'had surgery at hospital'.

Execute.
```

The inverted commas around the labels are needed. A full stop after the last label is needed.

'Execute.' is needed to run the procedure.

To run the procedure highlight the text and click on the green arrow at the top of the syntax window as shown below.



```
string n_state (A2).
compute n_state=substr(study_id,1,1).
execute.
```

Click on Arrow to run the syntax

This procedure needs to be repeated for surgery, chemotherapy, radiotherapy, follow-up care and for Emergency Department care.

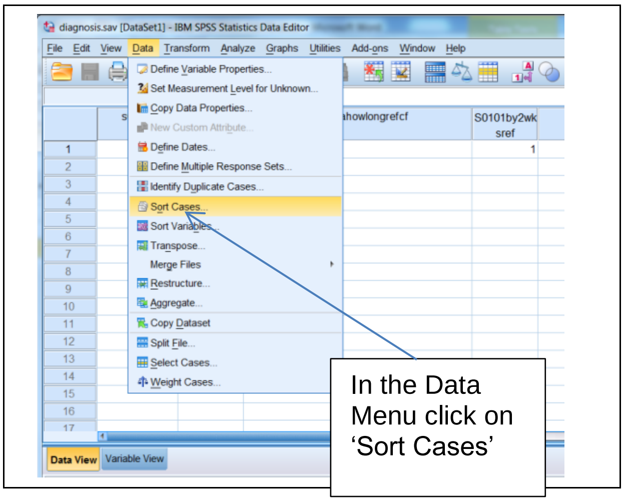
4) Joining data sets together

You may want to join two or more SPSS data files (.sav files) together. Data in the different files need to joined by the patient id variable (the ID variable is called s00_id). In SPSS, joining files together is called merging and because data comes from the same individuals, SPSS refers to this as 'adding variables' with a patient's data in one file joined to the end of their data in another file. Before files can be joined they need to be sorted so that IDs in a data file are in the same sequential order. The following syntax can be used for this

```
SORT CASES BY s00_id(A).
Execute.
```

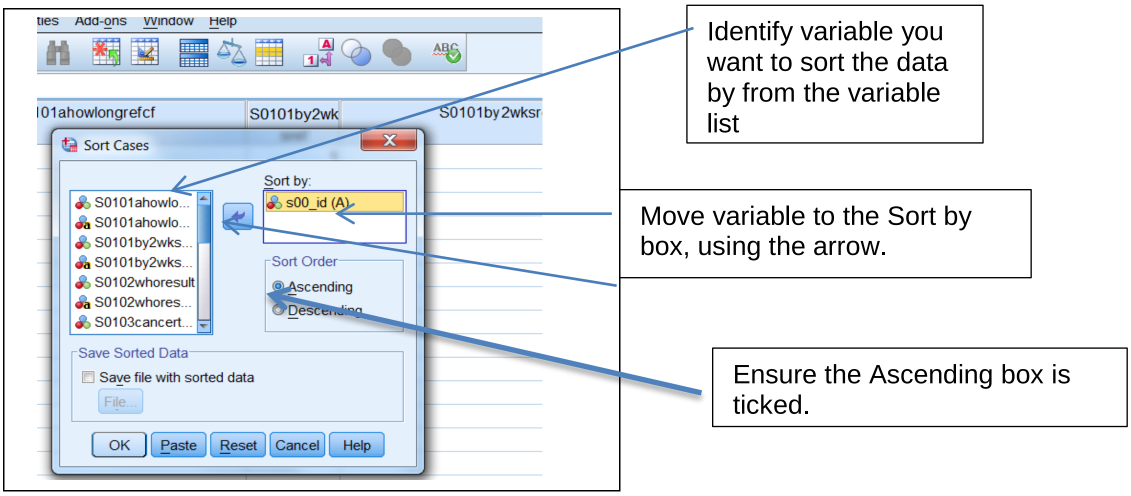
This can also be done through the menus.

Step 1: In the Data Menu, scroll down to the Sort Cases option.



In the Data Menu click on 'Sort Cases'

Step 2: Click on Sort Cases to open a new dialogue box containing the variable list and a box to indicate the variable you want to sort the data set by. Move the selected variable into this box using the arrow button. Tick the Ascending order button. This will mean the IDs will be ordered from the lowest to the highest in the data set.



Sort by: s00_id (A)

Sort Order
● Ascending
○ Descending

Identify variable you want to sort the data by from the variable list

Move variable to the Sort by box, using the arrow.

Ensure the Ascending box is ticked.

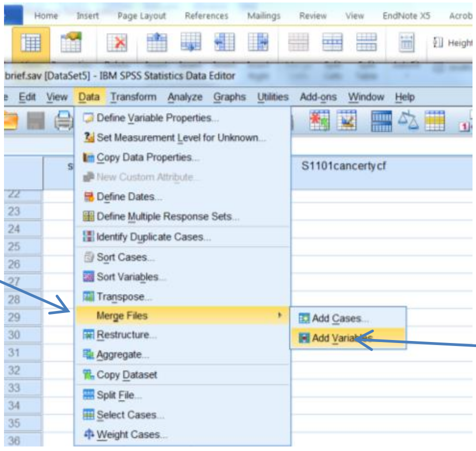
Step 3: Repeat this process for all data files you want to join.

Merging the data files using the Menus in SPSS

Step 1: Open the data sets you want to merge and ensure each data set is sorted by ID.

Step 2: Make one data set active by clicking on the data sheet.

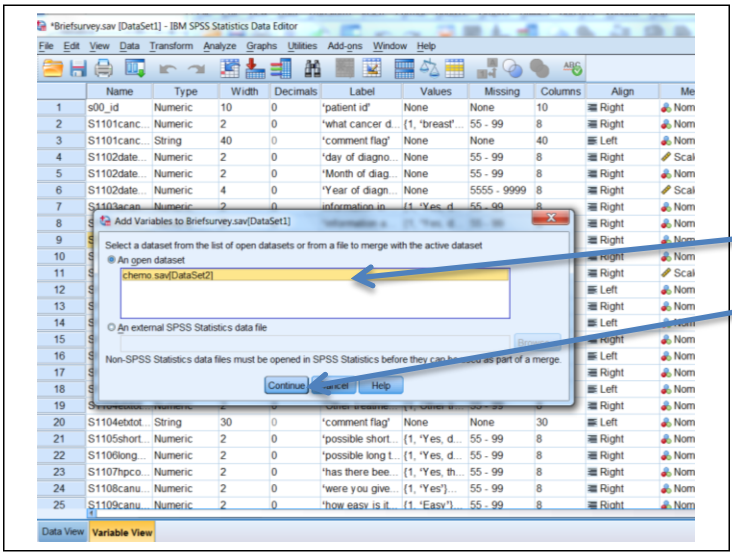
Step 3: In that active data set, pull down the Data menu and click on the Merge Files option and then click on Add Variables.



In the Data file, click on Merge Files.

Click on 'Add Variables'.

Step 4: In the new box that appears, in the 'An open dataset' a list of the SPSS data files open will appear. Click on the data file you want to merge.



Select a dataset from the list of open datasets or from a file to merge with the active dataset

● An open dataset

chemo.sav[DataSet2]

○ An external SPSS Statistics data file

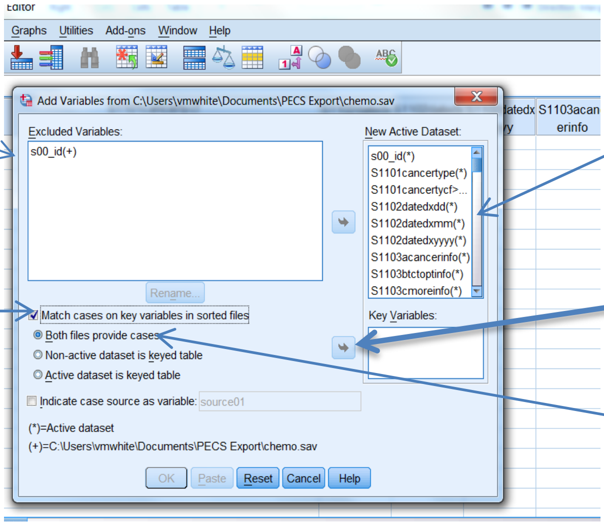
Non-SPSS Statistics data files must be opened in SPSS Statistics before they can be used as part of a merge.

In the 'An Open data set' box click on the data set you want to merge. Then hit the continue button.

Step 5: After hitting the Continue button, a new box will appear. This box will show a list of variables included in the new data file on the right side and a list of variables not included will be shown on the left. The excluded variables will include the patient ID variable which will be used to merge the files together-it is referred to as the Key variable. Click on the 'Match cases on key variables in sorted files' button. Click the 'Both files provide cases' button.

Patient ID is in the Excluded Variables box

Click the 'Match cases on Key variables in sorted files'



☑ Match cases on key variables in sorted files

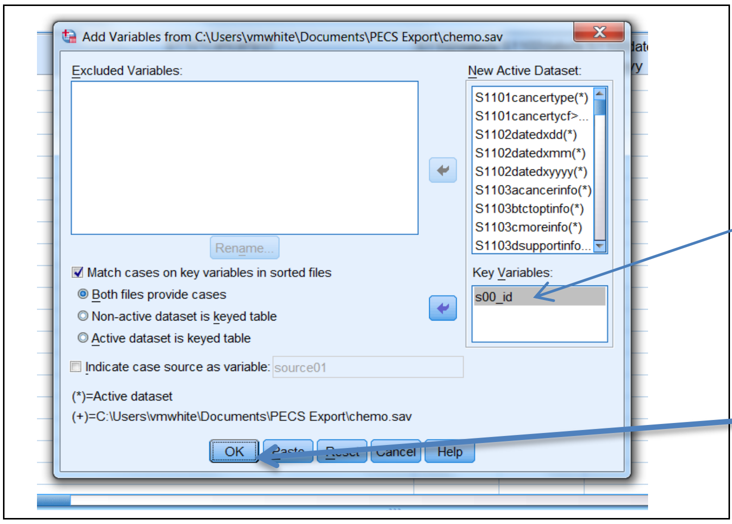
● Both files provide cases

List of variables included in the new merged data set

Arrow to use to move ID variable into Key variable box.

Click on button indicating 'Both files provide cases'.

Step 6: Highlight the patient id variable (s00_id) and move it to the Key variable box by ticking the arrow next to this box. Click on the OK button



☑ Match cases on key variables in sorted files

● Both files provide cases

Key Variables: s00_id

Highlight the ID variable and click on the arrow to move variable into the Key Variable box.

Click OK

A new data file will be created. Save this file for future use.

Repeat this procedure as needed for merging data files.

6) Creating a variable to indicate in the patient had all their treatment at your health service.

For 'whole of service' surveys, it is useful to identify patients that have had all their treatment at your service.

The syntax commands for identifying patients who had all their treatment at your centre at specified below.

Please note in the syntax below, '***yourhosp'*** stands for a variable name used to indicate the patient had the treatment at your treatment centre.

Creating this new variable involves determining how many different types of treatment the patient had and then determining if all these treatments were had at your treatment sentence.

Step 1: Count the number of treatments a patient had

```
count nrtreatments=S0301surgery S0401haveradio S0501havechemo (1).
execute.
```

Step 2: Create a new variable to indicate that the patient had all their treatments at your treatment centre. A 0 is assigned to this variable to indicate treatment not at your treatment centre.

```
compute alltxt_yourhosp=0.
execute.
```

Creates new variable indicating all treatment at your centre.

Step 3: For patients having only one treatment, this treatment needs to be at your treatment centre. Use the code below to identify patients only having one treatment and then assign a code of 1 to the alltxt_yourhosp variable if the surgery or chemotherapy or radiotherapy at your hospital.

```
do if nrtreatments=1.
if (yourhosp_surg=1) alltxt_yourhosp =1.
If (yourhosp_chemo =1 ) alltxt_yourhosp=1.
If (yourhosp_rxt=1)  alltxt_yourhosp=1.
end if.
execute.
```

For patients having only 1 treatment, this treatment needs to be at your centre. Assigns a value of 1 to alltxt_yourhosp, if they had surgery or radiotherapy or chemotherapy at your centre.

Step 4: For patients having 3 treatments (surgery, chemotherapy and radiotherapy), all treatments need to be at your hospital. The syntax for identifying these patients and assigning a value of 1 to the alltxt_yourhosp variable is below.

```
do if (nrtreatments=3).
if (yourhosp_surg=1 and yourhosp_chemo=1
     and yourhosp_rxtrh=1) alltxt_yourhosp=1.
end if.
execute.
```

For patients having 3 treatments: All treatments need to be at your centre. Assigns a value of 1 to alltxt_yourhosp if each of the three treatments at your centre. ‘And’ means all conditions need to be true.

Step 5: For patients having 2 treatments, both treatments need to be at your hospital. Create three possible combinations of treatment: (surgery and chemo), (surgery and radio); (radio and chemo).

Assign a value of 1 to alltxt_yourhosp if both treatments are at your hospital. The ‘OR’ in the syntax means any one of these conditions can be true.

The syntax is below.

```
do if (nrtreatments=2).
if (yourhosp_surg =1 & yourhosp_chemo =1)
  OR (yourhosp_surg =1& yourhosp_rxtrh=1)
  OR (yourhosp_chemo =1& yourhosp_rxtrh =1) alltxt_yourhosp =1.
end if.
```

For patients having only 2 treatments. Both treatments need to be at your centre.

```
execute.
```

Step 6: Assigning labels to your new variable. The following syntax assigns a variable label and value labels to your newly created variable. Assigning the labels will inform you about the variable and what its values mean.

```
Variable label alltxt_yourhosp  'patient's treatment was all at this hospital centre'.
execute.
Value labels alltxt_yourhosp  1 'all treatment at treatment centre'
                              0  'treatment at number of centres'.
execute.
```

Don't forget the Executes and the full stops are needed.

To run the syntax, highlight all the text and hit the green arrow in the menu bar from the syntax page.

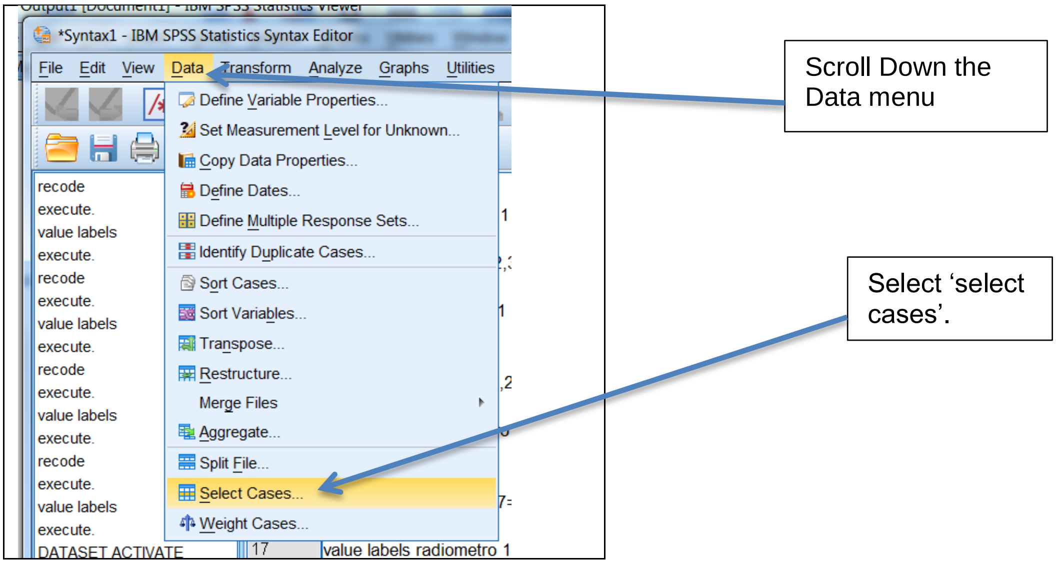
7) Selecting cases for analyses

After you have made the variable indicating whether a patient had their surgery, radiotherapy, chemotherapy or follow-up care at your treatment centre, you can use these variables to select cases for your analysis.

To select cases for specific analyses it is easiest to use the Filter function in SPSS. This function allows you to select cases that meet certain conditions (eg, those having surgery at your treatment centre) and run analyses only on those cases. These cases will be selected until you turn the Filter off.

Use the SPSS menus to turn on the Filter function. In the example below cases having surgery at the Alfred Hospital are selected. The variable indicating the patient had surgery at the Alfred is called "alfredsurg" with the value [1] indicating that someone had surgery at The Alfred.

Step 1: In the Data menu, select the "select cases" option



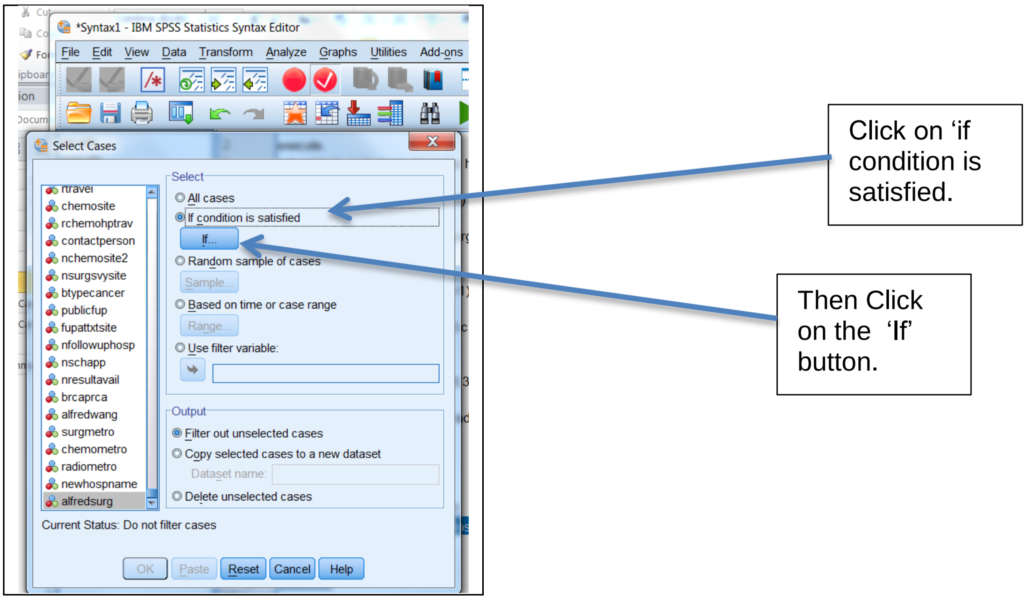
```
recode
execute.
value labels
execute.
recode
execute.
value labels
execute.
recode
execute.
value labels
execute.
recode
execute.
value labels
execute.
DATASET ACTIVATE
```

17 value labels radiometro 1

Scroll Down the Data menu

Select 'select cases'.

Step 2: In the pop-up window, select the “if condition is satisfied”. Clicking this will bring up a new window.



Select Cases

Select
○ All cases
● If condition is satisfied
○ Random sample of cases
○ Based on time or case range
○ Use filter variable:

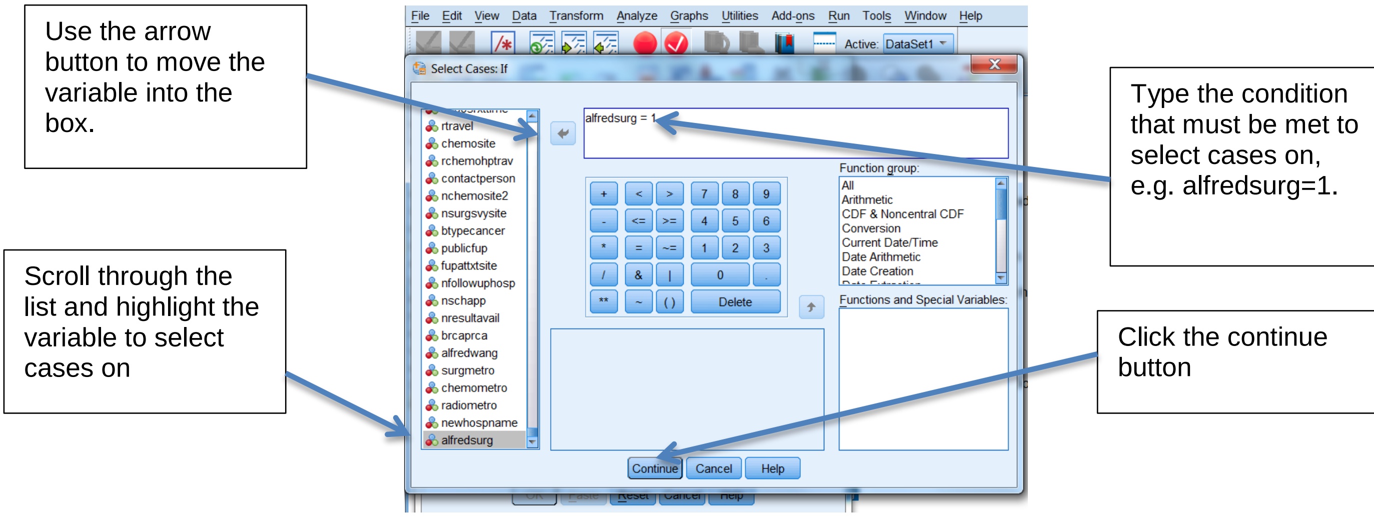
Output
● Filter out unselected cases
○ Copy selected cases to a new dataset
○ Delete unselected cases

Current Status: Do not filter cases

Click on ‘if condition is satisfied.

Then Click on the ‘If’ button.

Step 3: From the list of variables on the left of the window, scroll down to find the variable you want to use to select cases. Move this variable into the space using the arrow. Specify the condition that must be met for the case to be selected. In this example the variable ‘alfredsurg’ must equal 1. Click the continue button to go back to the previous window.



Select Cases: If

alfredsurg = 1

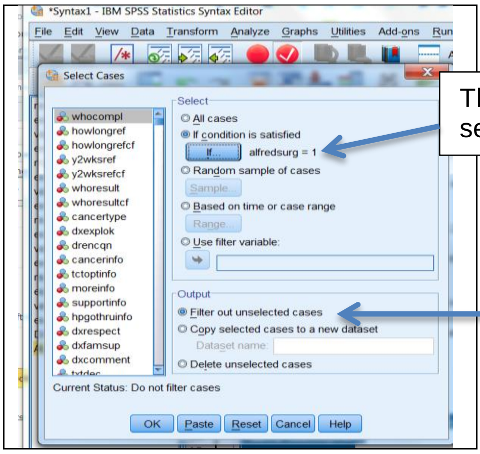
Use the arrow button to move the variable into the box.

Scroll through the list and highlight the variable to select cases on

Type the condition that must be met to select cases on, e.g. alfredsurg=1.

Click the continue button

Step 4: Click the “Filter out unselected cases” button. Then hit the “Ok” button for the procedure to run.

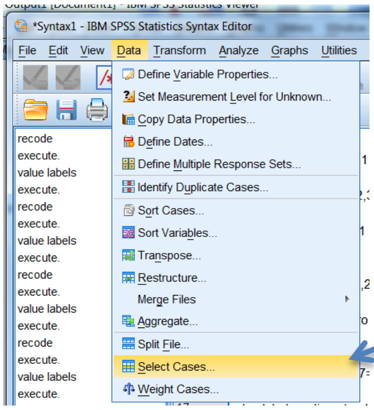


The condition being selected is specified.

Ensure the button 'Filter out unselected cases" is ticked.

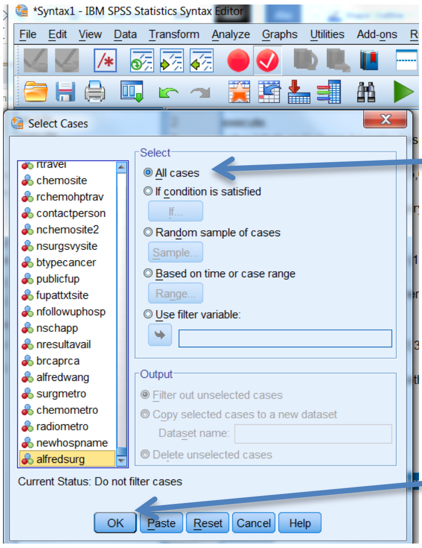
To turn the filter off using the menus:

Step 1: In the Data menu, select the 'Select Sases' option.



Select 'select cases'.

Step 2: In the new window click on the 'All cases" button, then hit the "OK" button.



Click on 'All cases' button.

Click the OK button to run

This will return your data set to the full number of cases.

8) Running frequencies to obtain response distributions

To determine the proportion of people completing the survey providing different responses to the different questions, the SPSS procedure ‘Frequencies’ can be run.

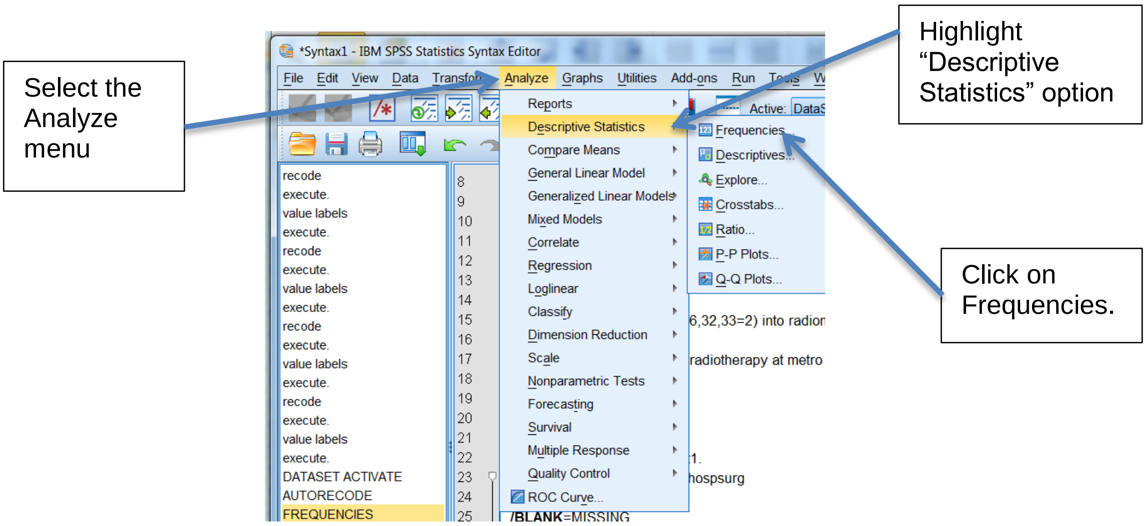
The data dictionary provided in Appendix 11 provides the list of variable names assigned to each question in the survey. Using this information you can identify the variables you want to analyse.

Below is an example of using syntax to run the Frequencies procedure. The variables in the example relate to chemotherapy component of the survey.

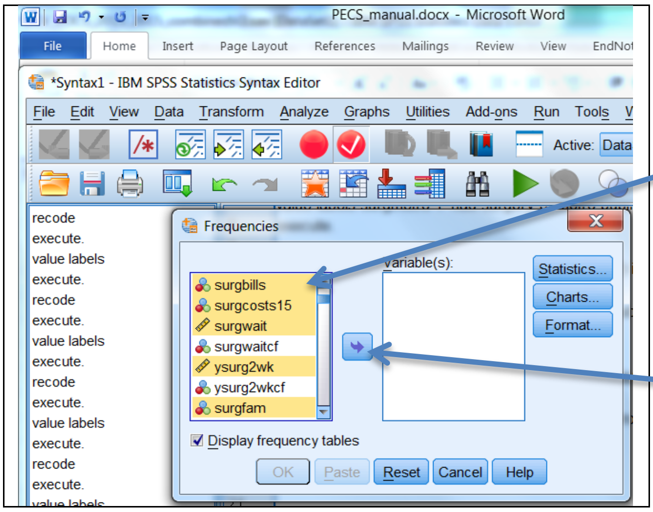
```
FREQUENCIES VARIABLES=S0501havechemo S0504chemhospdec S0505chemobills
S0507achemoaway S0507bchemoarrange S0508astartchemo S0509aprepchemo
S0509bmanchemostrss S0509cfeelchemo S0509emanagechemo
 /ORDER=ANALYSIS.  /ORDER=ANALYSIS.
```

The following steps demonstrate how to run the Frequencies procedure using SPSS menus,

Step 1: In the Analyze menu, highlight the ‘Descriptive statistics’ option to display a second menu. In this menu click on the Frequencies option



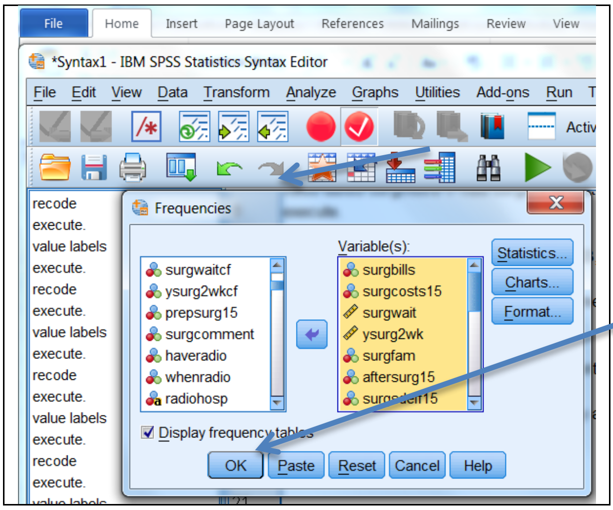
Step 2: In the new pop-up box, scroll down the variables listed on the right hand side to identify the variables you want in the analysis. Highlight these variables and click on the arrow button to move them to the box headed Variables.



Highlight variables of interest.

Click on arrow to move to Variables box.

Step 3: Once all the variables of interest have been moved to the variables box, click OK button to run the frequencies procedure.



Once variables of interest are in the variables box, click the OK button for frequencies to run.

Frequencies Output

Typical Frequencies output from SPSS is shown in below

Use % from the “Valid Percent’ column for reporting.

cleanwc ‘how clean were the toilets and bathrooms used in hospital?'

		Frequency	**Percent**	**Valid Percent**	**Cumulative Percent**
Valid	1 ‘Very clean’	770	43.9	72.7	72.7
	2 ‘Fairly clean’	233	13.3	22.0	94.7
	3 ‘Not very clean’	30	1.7	2.8	97.5
	4 ‘Not at all clean’	10	.6	.9	98.5
	5 ‘Not sure cannot remember’	16	.9	1.5	100.0

	Total	1059	60.4	100.0	
Missing	0	320	18.3		
	55	361	20.6		
	88 Multiple	2	.1		
	99	3	.2		
	System	8	.5		
	Total	694	39.6		
Total		1753	100.0		

The frequency tables will provide:

1) the number of cases choosing each response option (column headed “Frequency”).

2) the number of cases with missing data (shown in the section of the table with the side heading “Missing’).

3) the percent of all cases (including those with missing data) choosing each response;

4) the percent of all valid cases (excluding those with missing data) choosing each response.

5) the cumulative percent (a running total using each subsequent response) based on the valid cases.

Please note that some of the cases defined as missing may be those that did not have surgery so skipped the question (identified with the codes 55 and 0 in table above), those that should have answered the question but didn’t, those that provided multiple or invalid responses.

When reporting data from the survey, the percentage from the “Valid Percent” column would normally be used.

Excluding options indicating the event was not relevant to the participant.

While most questions in the survey are intended to be answered by everyone, there are some questions that may not be relevant to people. An example of questions that may not be relevant to everyone is the question asking about satisfaction with car parking at chemotherapy or radiotherapy treatment centres. These questions include a ‘not applicable’ response option that may be used by people who didn’t drive to the treatment centres, or who didn’t have to access car parking.

You can choose to include or exclude the ‘not applicable’ responses from the frequency counts.

The simplest way to exclude the response is to declare the value associated with the response ‘missing’ using procedures described above.

If you exclude these responses from your frequency analysis, please ensure that you indicate this when describing the percentages in the text and in descriptions of the graphs. Examples of how this might be phrased are shown below.

> ***Example:*** *excluding ‘not applicable’ responses from car parking satisfaction question.*
>
> “Of those needing car parking …’ OR
> “Of those indicating this question was relevant to them,…” OR
> “Excluding those indicating they didn’t need car parking …”