Willingness of cancer survivors to complete patient reported outcomes (PRO) surveys: a pilot study at Flinders Centre for Innovation in Cancer (FCIC), South Australia

Prof Marion Eckert
Rosemary Bryant AO Research Centre

University of South Australia

Acknowledgments

This work was supported by Flinders Centre for Innovation in Cancer, Flinders University, Cancer Council SA and The University of South Australia .

Dr Nadia Corsini	Cancer Council SA
Professor David Roder	University of South Australia
Professor Carlene Wilson	Flinders University of SA
Professor Bogda Koczwara	Flinders Centre for Innovation in Cancer
Ms Julie Marker	Cancer Voices SA
Dr Ingrid Flight	Flinders University of SA
Mr Michael Fitzgerald	Flinders Centre for Innovation in Cancer
Ms Imogen Ramsey	University of South Australia
Ms Bonnie Wiggins	Cancer Council SA
Mr Greg Sharplin	Cancer Council SA

FLINDERS CENTRE for INNOVATION in CANCER

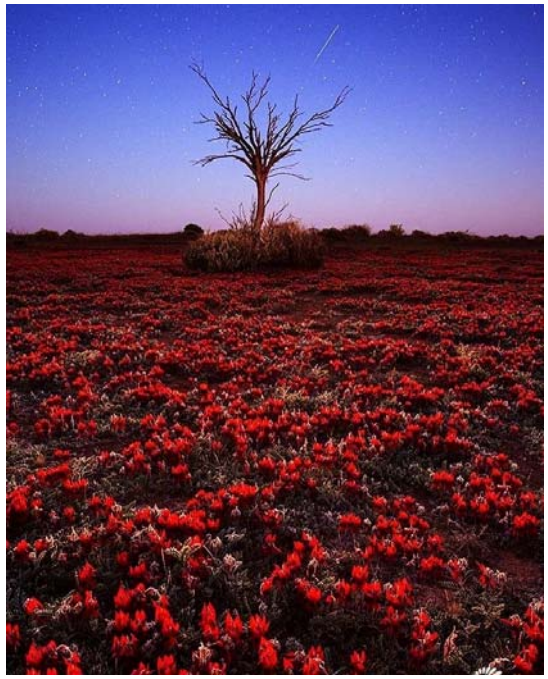
cancer voices sa

Cancer Council SA

University of South Australia

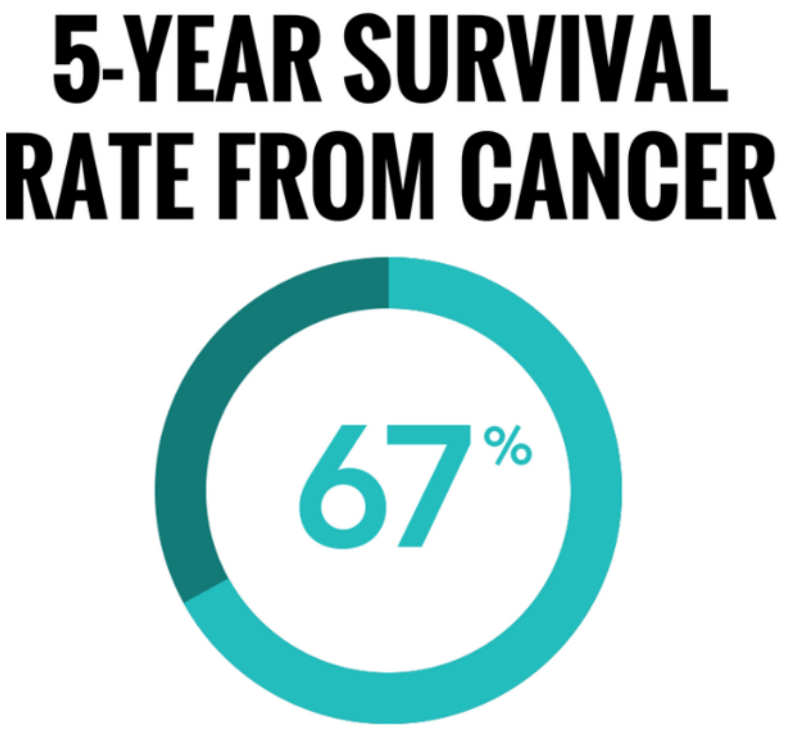
Presentation overview

- Context
- Challenges
- Defining Patient Reported Outcomes'
- International Approaches
- FCIC Pilot Study
- Method
- Results
- Discussion
- Conclusion



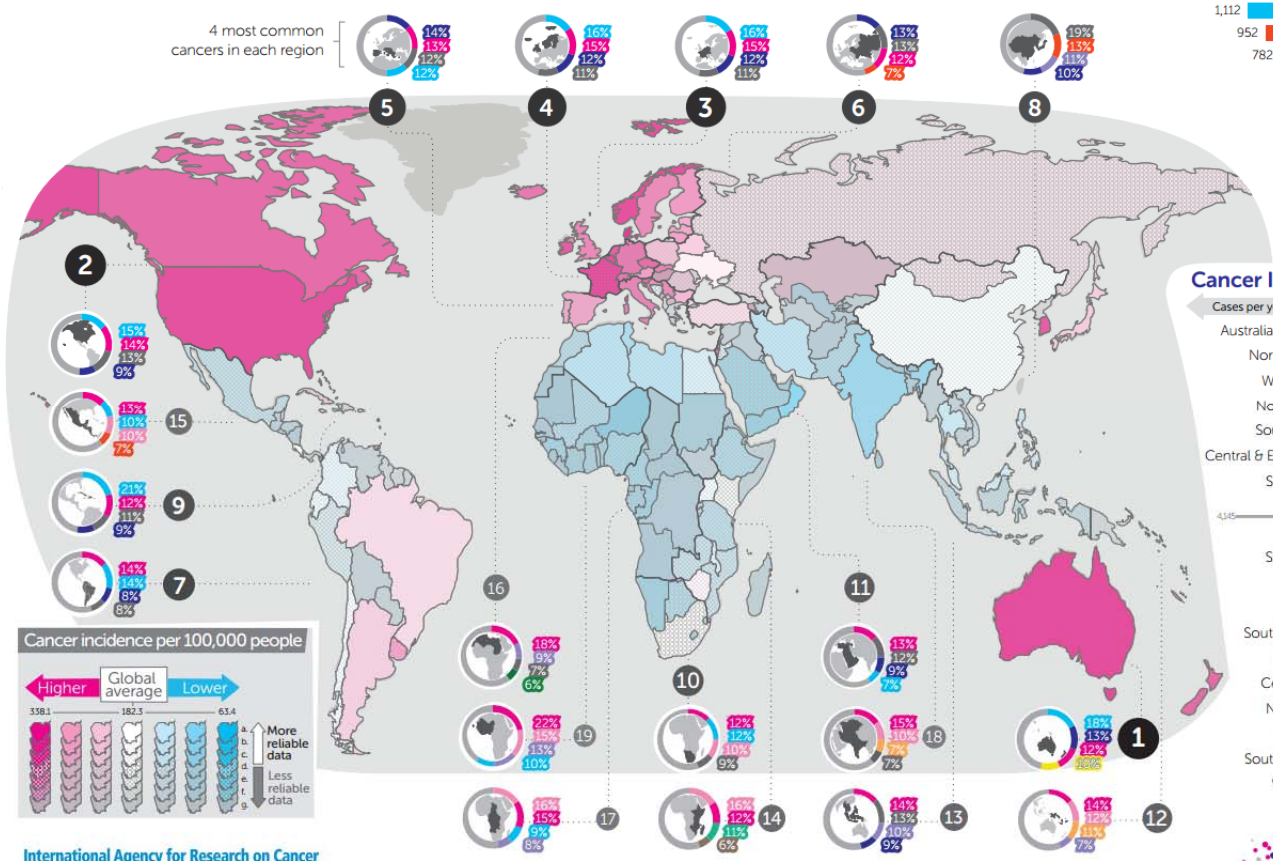
More people are living with cancer

Cancer in Australia

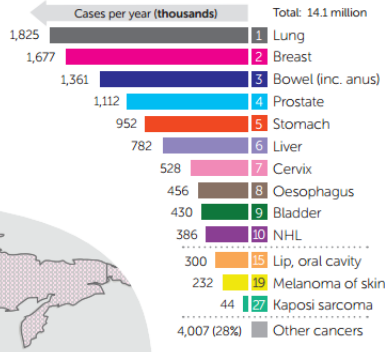


Worldwide Cancer Incidence

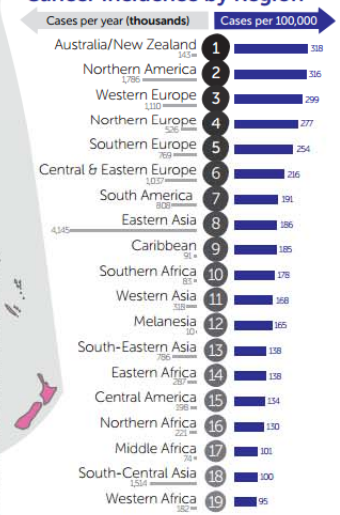
An estimated 14.1 million adults in the world were diagnosed with cancer in 2012. These cases were not spread evenly across the globe and the reliability of cancer statistics available for each country varies.



Most Common Cancers Worldwide



Cancer Incidence by Region



Source: GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC. NHL = Non-Hodgkin lymphoma. Region boundaries are standard United Nations groupings. Data quality classifications for incidence data: a. High quality national data or high quality regional (coverage greater than 50%) b. High quality regional (coverage between 10% and 50%) c. High quality regional (coverage lower than 10%) d. National data (rates) e. Regional data (rates) f. Frequency data g. No data. 'High quality' refers to Data included in Cancer incidence in Five Continents (CI5) volume IX1 or X2.

CANCER RESEARCH UK

University of South Australia

International cancer survivorship

Netherlands

- PROFILES Registry: population-based survivorship monitoring tool

United Kingdom

- eRAPID: acute monitoring tool for the safe delivery of cancer treatment
- HOPE program: self-management support
- Macmillan eHNA project: holistic needs assessment

United States

- Instapeer: mobile health platform providing anonymous peer support

Long-term challenges

Health-Related Quality of Life

Social

Practical

Emotional

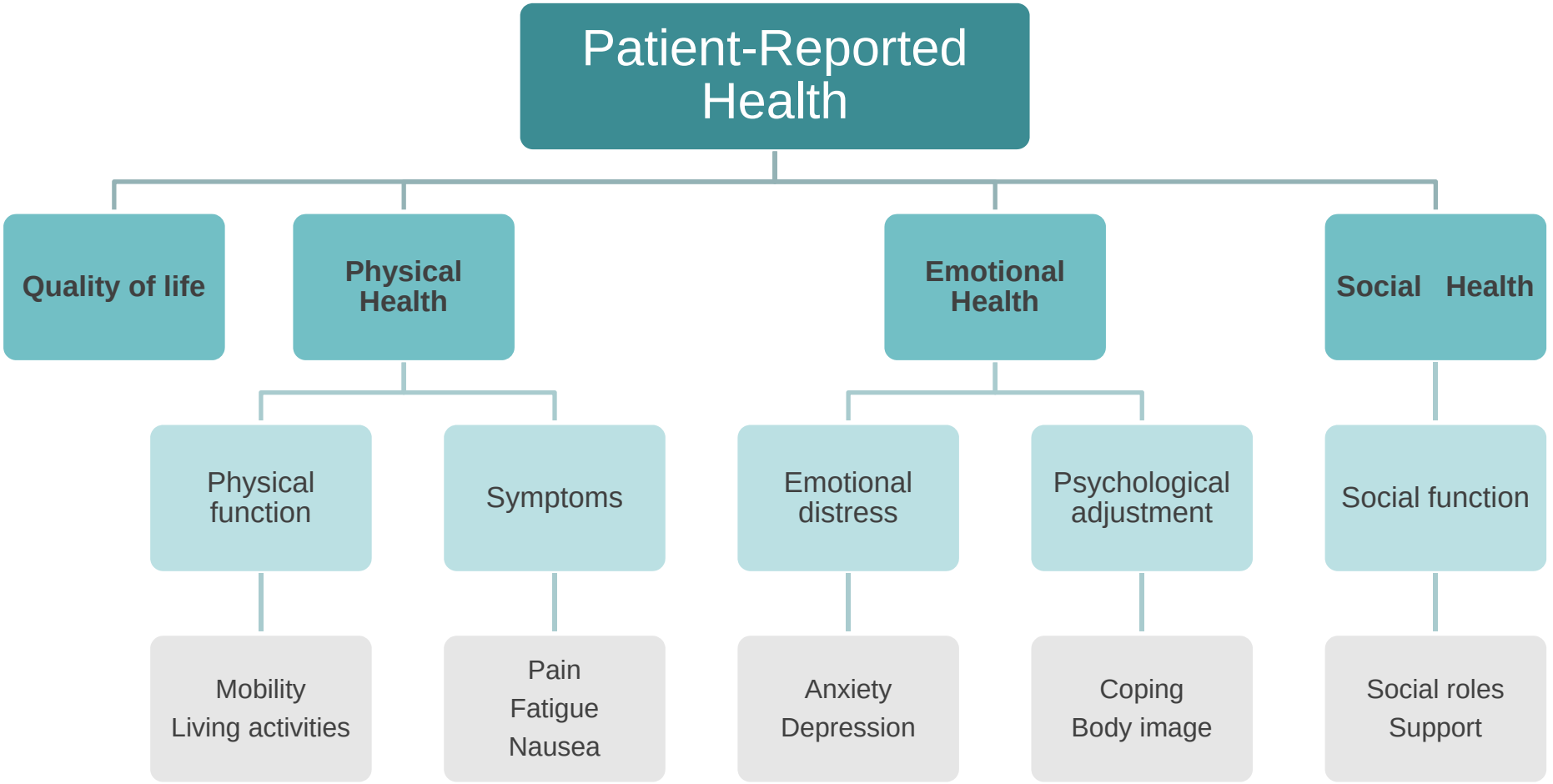
Physical

Spiritual

What is a patient-reported outcome?

“Any report of the status of a patient’s health condition that comes directly from the patient”

Source: http://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf


Patient-Reported Health
Quality of life
Physical Health
Emotional Health
Social Health
Physical function
Symptoms
Emotional distress
Psychological adjustment
Social function
Mobility
Living activities
Pain
Fatigue
Nausea
Anxiety
Depression
Coping
Body image
Social roles
Support

Gaps in monitoring survivorship

There is currently no mechanism in place for monitoring PRO among people with cancer at a population level in Australia.

PRO data collected routinely at a population level and linked with clinical data could improve our understanding of the burden of cancer on quality of life and inform health and support services, policy, research, and advocacy.

PRO data in Australia

Survivorship research projects and large surveys

- time limited
- often selected tumour(s)

Component of some clinical registries

No population-level data on long-term outcomes apart from date of death and cause of death.

Quality of life data is not routinely collected for surveillance
Unable to answer questions such as:

- When do problems occur, for how long, and for whom?
- Who is most at risk?
- What are the disparities in outcomes?

International approaches

Systematic narrative review

- to describe the development and operational approaches of patient-reported outcomes (PRO) surveillance systems (under review: Journal of Cancer Survivorship).

7 systems identified

- Clinical registries with long-term PRO collection
- Collects PRO exclusively

Varied approaches to recruitment

Limited information regarding consent rate or response rate

- Where reported consent rate ranged from 55% to 95%

PILOT STUDY

University of South Australia

Flinders Centre for Innovation (FCIC) in Cancer Survivorship Program

Operates at FCIC

Provides assessment and advice to patients at end of acute treatment

Opportunity to investigate patient willingness to provide PRO on an ongoing basis

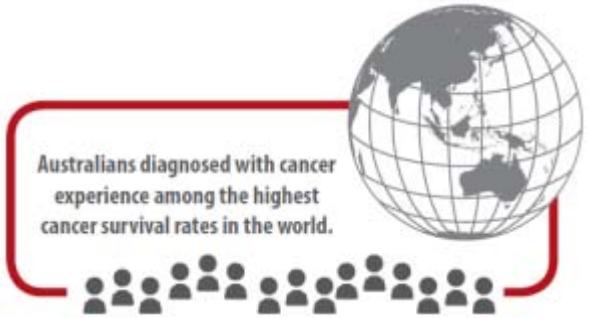
Other considerations

- Feasible to approach all patients
- Denominator could be determined for accurate consent and response rate calculation

FCIC Pilot Study

Aim: to determine the feasibility and acceptability of collecting PRO on two occasions (baseline and 12 months later) from people who have recently completed treatment for cancer.

Population: All eligible public and private cancer patients with appointments at the Flinders Centre for Innovation in Cancer (FCIC) Survivorship Clinic.



Methodology: Participants

Sample: 47 eligible patients with appointments at the FCIC Survivorship Clinic between 29 October 2015 – 20 July 2016.

Inclusion criteria: English-speaking adults (18+) that have completed cancer treatment within the previous 3 months, with curative intent.

Methodology: Procedure

- Eligible patients approached by the Nurse Practitioner Candidate (NPC) at the Survivorship Clinic for consent to be contacted
- Consenting patients contacted via telephone by a member of the research team.
- Study information, consent form, survey, and reply-paid envelope distributed to interested individuals.
- Survey completed at baseline and 12 months after (data collection for follow-up currently underway).

Methodology: Measures

Table 1. Validated PRO measures

Domain	Instrument	Items, *n*
Health-related quality of life (HRQOL)	EORTC Quality of Life Questionnaire (QLQ-C30)	30
Fear of cancer recurrence	Concerns about Recurrence Questionnaire (CARQ)	4
Psychological adjustment	Hospital Anxiety and Depression Inventory (HADS)	14
Positive outcomes resulting from cancer	Post-Traumatic Growth Inventory (PTGI)	10
Everyday challenges	Social Difficulties Inventory (SDI)	21

Methodology: Measures

Table 2. Cancer-specific supplementary modules

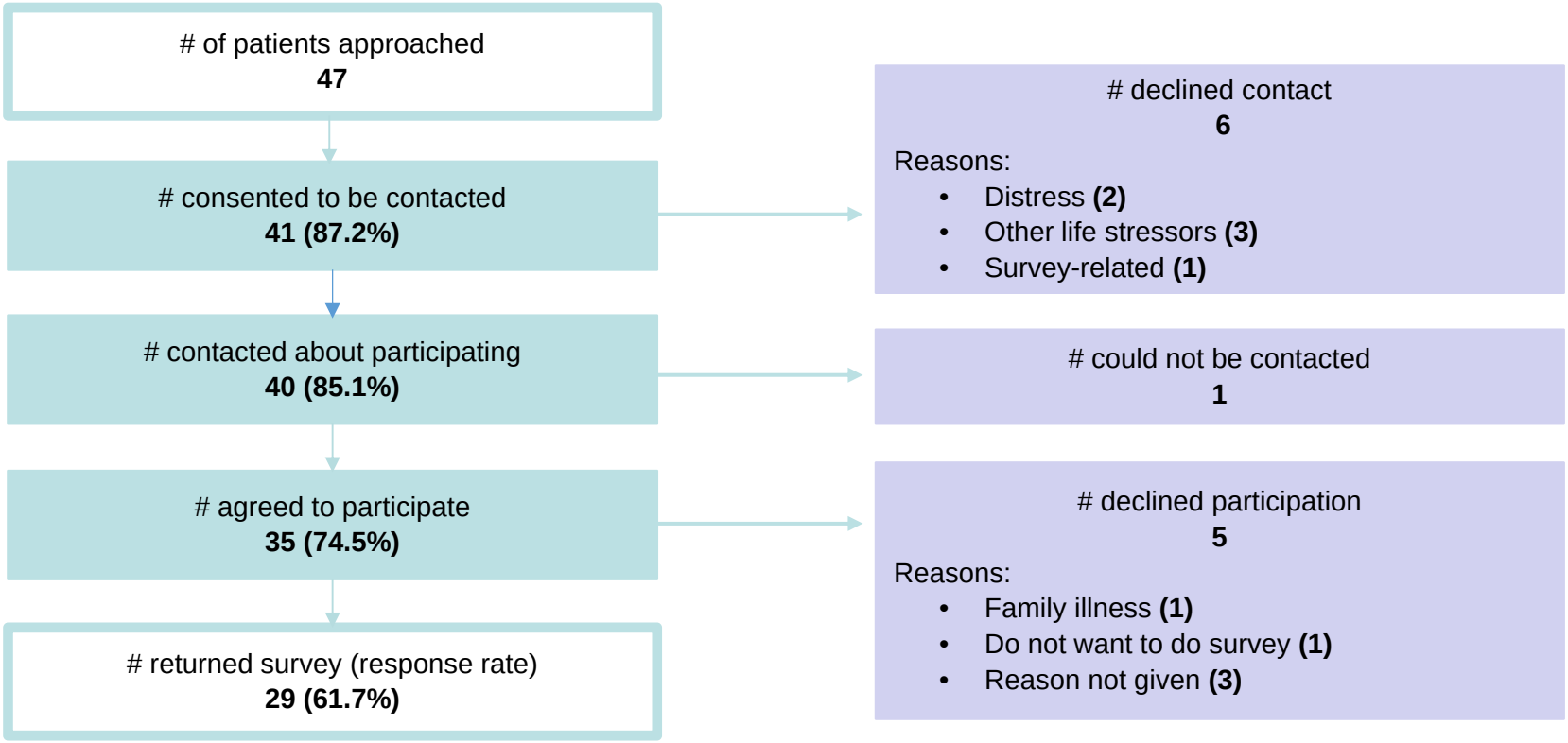
Cancer type	Instrument	Items, *n*
Breast	QLQ-BR23	23
Colorectal	QLQ-CR29	29
Head and neck	QLQ-H&N35	35
Oesophageal	QLQ-OES18	18
Ovarian	QLQ-OV28	28
Cholangiocarcinoma and gallbladder	QLQ-BIL21	21

Methodology: Measures

Table 3. Additional variables

Domain	Items, *n*
Participant demographics (gender, age, education, etc.)	10
Treatment and diagnosis information	4
Cancer risk factors (smoking, physical activity)	2
Post-treatment information and care	4
Service utilisation and preferences	10
Survey completion and preferences	3
Survey feedback (open-ended questions)	6

Results: Study participation (baseline)



Results: Participant characteristics

Twenty-nine participants completed the baseline survey (response rate = 61.7%)

- Mean age 57.7 years (SD = 10.3, range = 36–75 years).
- None identified as Aboriginal or Torres Strait Islander descent
- None reported speaking a language other than English at home.
- The sample was weighted towards females (86.2%) and breast cancer (72.4%).

Table 4. Participant characteristics

Variable		*n*	%
Gender (n=29)	Male	4	13.8
	Female	25	86.2
Birthplace (n=24)	Australia	13	44.8
	United Kingdom	10	34.4
	Italy	1	3.4
Education (n=29)	Some high school	7	24.1
	Completed high school	9	31.0
	Trade or TAFE	7	24.1
	University graduate	4	13.8
	Post-graduate studies	2	6.9

Table 4. Participant characteristics (cont.)

Variable		*n*	%
Cancer type (n=29)	Breast	21	72.4
	Head and neck	3	10.3
	Colorectal	3	10.3
	Cholangiocarcinoma	2	6.9
Employment status (n=29)	Full time employment	7	24.1
	Part time employment	5	17.2
	Full time parent or carer	3	10.3
	Retired	9	31.0
	Unable to work for health reasons	4	13.8
Living arrangement (n=29)	With partner/spouse/family/friend	24	82.8
	Alone	5	17.2
Smoking	Daily	4	13.8

Results: Factors influencing participation

The direct logistic regression model which included three independent variables (age, gender, cancer type) was not statistically significant:

χ^2 (3, N = 47) = 3.06, p = .38

Results: Data completeness

The majority (84.8%) of items were answered by all respondents. No trends in missing data were observed.

Missing data was recorded for 27 items, which were mostly single cases.

Only two PRO items had missing data for 2–3 respondents.

The section on survey completion and preferences recorded the highest number of missing items (4) and total missing responses per item (range = 1–5).

Results: Survey preferences

Mean completion time = 22 mins (SD = 9.6, range = 5–47 mins).

72% indicated they would be willing to complete a similar survey every year.

6% indicated they would be willing every 2-5 years

66% said they would prefer to complete the survey on paper (vs. online).

Feedback

Positive feedback:

- *I like this survey it reminds me that I am doing well.*
- *Congratulations on conducting this research*

Considerations for future models:

- *Include a section about other medical issues that impact on the cancer experience.*
- *Have had cancer twice and unsure which cancer to focus on for the survey*

Discussion

The response rate (61.7%) was lower than the 70% target (i.e. the response rate achieved by PROFILES). Factors that may have affected participation include:

- Closer proximity to completion of treatment (3 months) compared with PROFILES (12 months).
- Approach via the Survivorship Clinic rather than by letter from treating physician.
- Delay between initial approach at Survivorship Clinic and receiving survey.

Conclusions

- South Australian cancer survivors are willing to provide information on a range of psychosocial outcomes.
- The type of questions included in the pilot questionnaire appear to address important and relevant survivorship issues.
- The response rate is lower than what is required to obtain representative coverage of a population, but still promising.

Thank you

Questions?

University of South Australia