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
## Acknowledgments

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<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Dr Nadia Corsini</td>
<td>Cancer Council SA</td>
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<td>Professor David Roder</td>
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<td>Flinders University of SA</td>
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<td>Flinders University of SA</td>
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<td>Cancer Council SA</td>
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<tr>
<td>Mr Greg Sharplin</td>
<td>Cancer Council SA</td>
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Presentation overview

• Context
• Challenges
• Defining Patient Reported Outcomes'
• International Approaches
• FCIC Pilot Study
• Method
• Results
• Discussion
• Conclusion
More people are living with cancer

1 million in Australia
Cancer in Australia

1 IN 2 AUSTRALIAN MEN

1 IN 3 AUSTRALIAN WOMEN

WILL BE DIAGNOSED WITH CANCER BY THE AGE OF 85

5-YEAR SURVIVAL RATE FROM CANCER

67%
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.
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”

Patient-Reported Health

Quality of life
  - Physical function
    - Mobility
    - Living activities
  - Symptoms
    - Pain
    - Fatigue
    - Nausea
  - Emotional distress
    - Anxiety
    - Depression
  - Psychological adjustment
    - Coping
    - Body image

Social health
  - Social function
    - 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.

Health-Related Quality of Life → Patient-Reported Outcome → Informed decision-making for increased patient HRQOL
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%
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>
<thead>
<tr>
<th>Domain</th>
<th>Instrument</th>
<th>Items, $n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health-related quality of life (HRQOL)</td>
<td>EORTC Quality of Life Questionnaire (QLQ-C30)</td>
<td>30</td>
</tr>
<tr>
<td>Fear of cancer recurrence</td>
<td>Concerns about Recurrence Questionnaire (CARQ)</td>
<td>4</td>
</tr>
<tr>
<td>Psychological adjustment</td>
<td>Hospital Anxiety and Depression Inventory (HADS)</td>
<td>14</td>
</tr>
<tr>
<td>Positive outcomes resulting from cancer</td>
<td>Post-Traumatic Growth Inventory (PTGI)</td>
<td>10</td>
</tr>
<tr>
<td>Everyday challenges</td>
<td>Social Difficulties Inventory (SDI)</td>
<td>21</td>
</tr>
</tbody>
</table>
# Methodology: Measures

## Table 2. Cancer-specific supplementary modules

<table>
<thead>
<tr>
<th>Cancer type</th>
<th>Instrument</th>
<th>Items, $n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>QLQ-BR23</td>
<td>23</td>
</tr>
<tr>
<td>Colorectal</td>
<td>QLQ-CR29</td>
<td>29</td>
</tr>
<tr>
<td>Head and neck</td>
<td>QLQ-H&amp;N35</td>
<td>35</td>
</tr>
<tr>
<td>Oesophageal</td>
<td>QLQ-OES18</td>
<td>18</td>
</tr>
<tr>
<td>Ovarian</td>
<td>QLQ-OV28</td>
<td>28</td>
</tr>
<tr>
<td>Cholangiocarcinoma and gallbladder</td>
<td>QLQ-BIL21</td>
<td>21</td>
</tr>
</tbody>
</table>
# Methodology: Measures

## Table 3. Additional variables

<table>
<thead>
<tr>
<th>Domain</th>
<th>Items, $n$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant demographics (gender, age, education, etc.)</td>
<td>10</td>
</tr>
<tr>
<td>Treatment and diagnosis information</td>
<td>4</td>
</tr>
<tr>
<td>Cancer risk factors (smoking, physical activity)</td>
<td>2</td>
</tr>
<tr>
<td>Post-treatment information and care</td>
<td>4</td>
</tr>
<tr>
<td>Service utilisation and preferences</td>
<td>10</td>
</tr>
<tr>
<td>Survey completion and preferences</td>
<td>3</td>
</tr>
<tr>
<td>Survey feedback (open-ended questions)</td>
<td>6</td>
</tr>
</tbody>
</table>
Results: Study participation (baseline)

- # of patients approached: 47
- # consented to be contacted: 41 (87.2%)
- # contacted about participating: 40 (85.1%)
- # agreed to participate: 35 (74.5%)
- # returned survey (response rate): 29 (61.7%)
- # declined contact: 6
  - Reasons: 2 Distress, 3 Other life stressors, 1 Survey-related
- # could not be contacted: 1
- # declined participation: 5
  - Reasons: 1 Family illness, 1 Do not want to do survey, 3 Reason not given
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

<table>
<thead>
<tr>
<th>Variable</th>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (n=29)</td>
<td>Male</td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>25</td>
<td>86.2</td>
</tr>
<tr>
<td>Birthplace (n=24)</td>
<td>Australia</td>
<td>13</td>
<td>44.8</td>
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<tr>
<td></td>
<td>United Kingdom</td>
<td>10</td>
<td>34.4</td>
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<tr>
<td></td>
<td>Italy</td>
<td>1</td>
<td>3.4</td>
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<tr>
<td>Education (n=29)</td>
<td>Some high school</td>
<td>7</td>
<td>24.1</td>
</tr>
<tr>
<td></td>
<td>Completed high school</td>
<td>9</td>
<td>31.0</td>
</tr>
<tr>
<td></td>
<td>Trade or TAFE</td>
<td>7</td>
<td>24.1</td>
</tr>
<tr>
<td></td>
<td>University graduate</td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td></td>
<td>Post-graduate studies</td>
<td>2</td>
<td>6.9</td>
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</table>
### Table 4. Participant characteristics (cont.)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Cancer type (n=29)</th>
<th>Employment status (n=29)</th>
<th>Living arrangement (n=29)</th>
<th>Smoking</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Breast</td>
<td>Full time employment</td>
<td>With partner/spouse/family/friend</td>
<td>Daily</td>
</tr>
<tr>
<td></td>
<td>Head and neck</td>
<td>Part time employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Colorectal</td>
<td>Full time parent or carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cholangiocarcinoma</td>
<td>Retired</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Unable to work for health reasons</td>
<td></td>
<td></td>
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<td>n</td>
<td>n</td>
<td>n</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>7</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>72.4</td>
<td>24.1</td>
<td>82.8</td>
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<td></td>
<td>10.3</td>
<td>17.2</td>
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</tr>
<tr>
<td></td>
<td>10.3</td>
<td>10.3</td>
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<td></td>
<td>6.9</td>
<td>31.0</td>
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<tr>
<td></td>
<td>4</td>
<td>13.8</td>
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</tr>
</tbody>
</table>
Results: Factors influencing participation

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

\[ \chi^2 (3, N = 47) = 3.06, \ p = .38 \]
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?