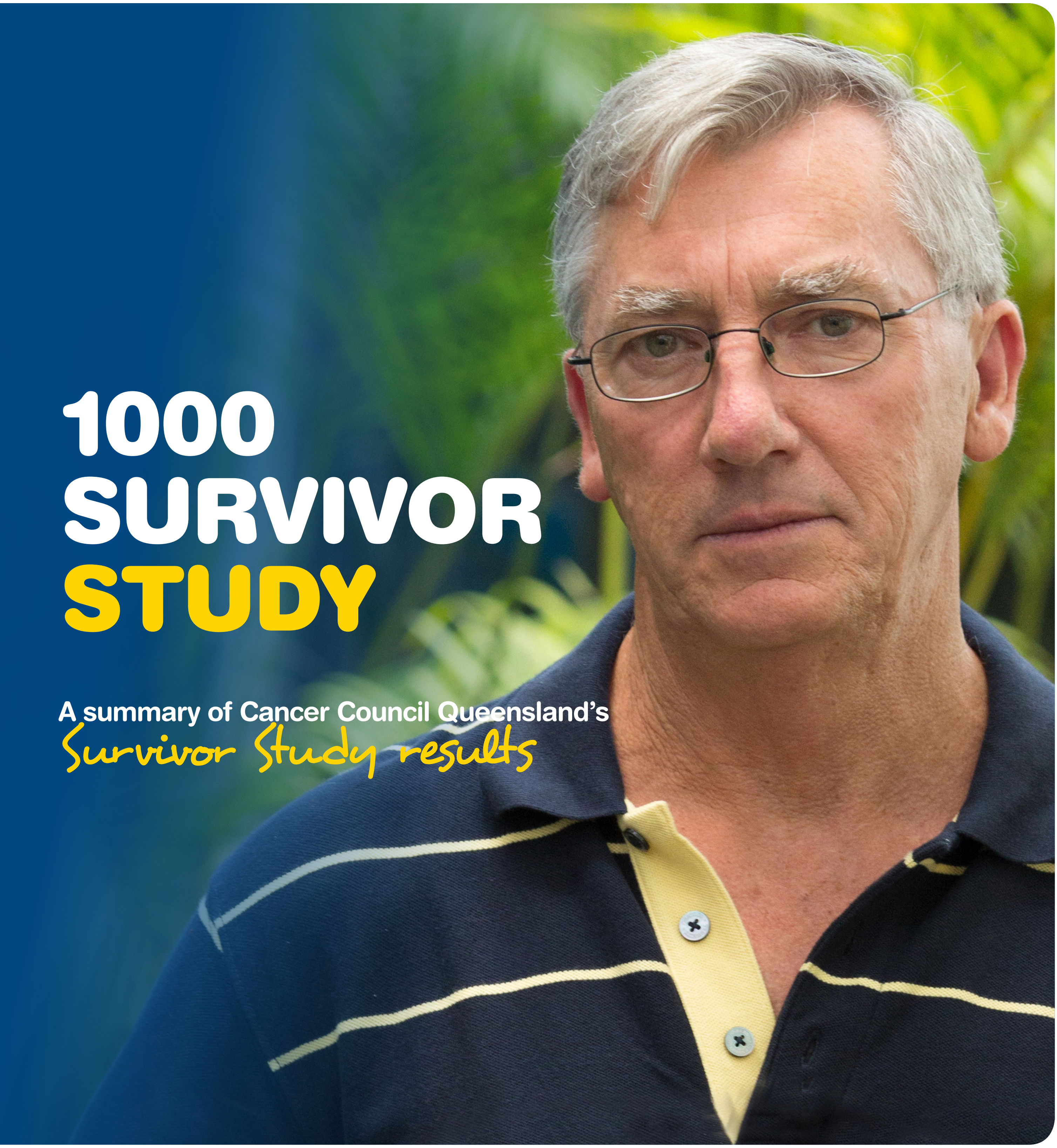

1000 SURVIVOR STUDY

A summary of Cancer Council Queensland's
Survivor Study results

Cancer Council
Queensland

SURVIVOR
STUDY

Acknowledgments

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Executive Summary

In Australia, the five year survival rate for cancer has steadily increased over the past three decades. This is largely due to improvements in diagnosis and available treatments. While this is encouraging, there is now a great need for more information about how people in their post-treatment phase cope in order to better support those affected by cancer.

Recognising this need, Cancer Council Queensland (CCQ) collaborated with the LIVESTRONG Foundation to utilise their national online survivorship survey, piloting it for a Queensland audience. The aim of the study was to better understand the concerns and support-use behaviour of cancer survivors in Queensland to further inform, develop and identify support mechanisms required to help improve quality of life, and to support advocacy efforts and provide an evidence base for CCQ's service provision strategy for survivorship.

The survey specifically addressed the physical, emotional, and practical challenges that Queenslanders with cancer, who have completed treatment, may face. The results are taken from 1031 Queenslanders who completed the online survey. The average age of the participants was 57.9 years at the time of survey completion. Just over half the participants were female (54.8%), 66.8% had completed a college / TAFE certificate or a university degree and 57.8% lived in major cities within Queensland. It had been less than five years post-treatment for 66.3% of the sample and the most common cancer types represented were breast, prostate and colorectal cancer.

The results show that almost all of the participants experienced at least one type of physical concern (94.6%). However, the proportion of participants who reported to receive care for each physical concern varied widely. Participants were more likely to seek care for less-common concerns e.g., thyroid issues (71 reported the concern and 85.9% received care) and lymphoedema (239 reported the concern and 70.7% received care). Care was sought less often for more common physical concerns including

concentration issues (557 reported the concern and 18.1% received care), sexual dysfunction (549 reported the concern and 30.4% received care) and incontinence (309 reported the concern and 37.9% received care).

For emotional concerns the story is different. Almost all of the participants experienced emotional worries (94.4%), however, participants consistently did not receive care. On average, more than 70% of participants who reported a particular emotional concern did not receive care. The most common concerns that participants did not receive care for were cancer-related stigma (323 reported the concern and 79.6% did not receive care), personal appearance (372 reported the concern and 78.6% did not receive care) and family member risk (545 and 75.6% did not receive care). Help was most likely to be sought for sadness and depression, however more than half of the participants who reported this concern still did not receive care (644 and 52.6% did not receive care).

Practical issues included being negatively affected at work because of cancer (45% of 686 employed) and financial difficulties (29.7%). Participants reported being unable to work in the same way as prior to their cancer diagnosis, experiencing difficulties returning to work and being unable to work full-time. Of the participants who reported work-related problems, 66.1% did not receive help.

Across each of the three areas of concern, the foremost reason participants did not receive care was that they 'have learned to live with' their physical, emotional or practical issue. Further investigation is needed to identify the meaning behind this response, in order to fully understand the longer term circumstances of people who have been diagnosed with cancer and are living with it as a chronic disease.

The results of this survey do not represent the views and experiences of all post-treatment cancer survivors in Queensland due to the sampling methods. However, this study shows clearly that the concerns cancer survivors encounter are wide-ranging and many do not receive or seek care for concerns they are experiencing. It will be important to identify the relationships between these concerns, in addition to the facilitators and barriers surrounding receipt of care, in order to provide the most effective and appropriate services and support after treatment has finished.

"I feel that cancer has changed my life forever, and that I will never return to being the person I was before, but that is not a bad thing." *CANCER SURVIVOR*

Survivor study highlights

1031

participants who were diagnosed with cancer and finished treatment took part in the survey

Participants

- **Breast** (26%), **prostate** (22%), **colorectal** (10%) , **all lymphomas** (8%) and **gynaecological** (6%) cancers represented the most common cancer types on the sample
- **66%** completed their treatment less than five years ago
- **The most common types of treatment** were surgery (69%), chemotherapy (45%), and radiation (45%)

"I learned to live with it"

Was the most common reason participants did not receive care for their physical, emotional and practical concerns following completion of treatment

Physical

- **95%** experienced at least one physical concern following treatment
- **72%** received care for at least one of their physical concerns
- **82%** did not receive care for at least one of their physical concerns

Emotional

- **94%** experienced at least one emotional concern following treatment
- **46%** received help for at least one emotional concern
- **87%** did not receive help for at least one emotional concern

Practical

- **30%** reported being negatively affected at their job as a result of their diagnosis and treatment for cancer
- **More highly educated** received help for their work concerns
- **30%** reported that they and/or their loved ones had financial problems because of cancer and younger participants struggled more with financial concerns compared to older participants

Meaning Making

- **70%** reported that they have been trying to take better care of their health following their cancer treatment, by being up to date with screening and partaking in more regular physical activity
- **10%** reported that their life would never be good again

Treatment Guidance & Quality of Care

- **81%** reported that they had received instructions about where to go for post-treatment care
- **58%** did not have a dedicated person to help guide them through their cancer experience
- **61%** never received a written summary of all the cancer treatments they received
- **45%** felt included (as much as they wanted) in their health care decisions
- **68%** were frequently offered the opportunity to ask questions of their health care team
- **30-40%** reported that their health team did not ask about their emotional well-being on a regular basis
- **15%** reported that health professionals never helped them deal with their feelings of uncertainty about their situation

Advocacy and Engagement

- **61%** felt there should be more funding directed towards cancer research
- **48%** wanted more resources for people affected by cancer
- **41%** believed Australia should have a national cancer plan

Alternative Treatments and Support

- **Exercise** (44%), **nutritional supplements** (29%), **massage** (23%) and **meditation** (19%) were common forms of alternative treatment
- **24%** did not use alternative treatments
- **53%** reported it was helpful to connect with others who had been diagnosed with cancer
- **40%** found it beneficial to receive emotional support from another person with cancer