

RESEARCH AGENDA FOR

Cancer Survivorship Care in Queensland



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Queensland Collaborative for Cancer Survivorship Executive Committee



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Acknowledgments

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OUR VISION

To optimise health and wellbeing for all people affected by cancer.

OUR MISSION

To develop and enable optimal survivorship care in Queensland and beyond.

WHO ARE WE

The Queensland Collaborative for Cancer Survivorship (QCCS) is a collaborative group of researchers, clinicians, and academics with a shared passion and interest in research to improve outcomes for people diagnosed with cancer in Queensland from the time of diagnosis, and for the remainder of their life.

Our collaborative involves consumers, and clinical and research leaders from the Children's Health Queensland, Mater Misericordiae Ltd., Metro North Hospital and Health Service, Metro South Health, QIMR Berghofer Medical Research Institute, Queensland University of Technology, University of Queensland, and partners.

WHY DO WE EXIST

The formation of the QCCS represents a significant opportunity for Queensland to drive an innovative cancer survivorship research agenda that will benefit people affected by cancer in Queensland and provide leadership at a national and international level.

The diverse geography and networked health system in Queensland provides an opportunity to critically review how survivorship care can best be planned and delivered across different service locations and types, incorporating primary and tertiary care, and public and private health systems.

Queensland benefits from significant expertise in cancer survivorship research and is home to several respected national and international leaders in this field. The QCCS provides an opportunity not only to harness these expertise for the benefit of patients in Queensland but to create a forum through which expertise can be shared and the next generation of research leaders developed.

Our vision is to build a true collaborative that can benefit the entire state, and not just one institution. Our key driver is to improve outcomes and experiences for people affected by cancer in Queensland. However, through our national and international links and partnerships, our work can and will influence change worldwide.

OUR GOALS

We have three main goals:

1

To facilitate high-quality, practice-changing cancer survivorship research relevant to the Queensland population

2

To translate survivorship research findings into clinical practice with an aim of improving outcomes and experience for people affected by cancer in Queensland

3

To raise awareness of the importance and value of cancer survivorship research and its translation into practice

OUR VALUES

Collaboration | Transparency | Integrity | Innovation | Inclusion

OUR APPROACH AND WHAT WE OFFER

Principles underpinning our cancer survivorship research

Our research is

- ✔ **Collaborative / multidisciplinary:** we bring together different disciplines, research expertise and perspectives with an interest in cancer survivorship research and its application
- ✔ **Strategic:** we focus on survivorship research that requires collaborative effort and that will make the biggest difference for people affected by cancer in Queensland
- ✔ **Measurable:** we use available data to identify areas of unmet need in survivorship care, define the baseline for our research activities and measure change
- ✔ **Relevant:** we consider clinical and patient needs, practice relevance and health system implications when designing our survivorship research questions and approach
- ✔ **Translatable:** our research generates outcomes that can be applied locally, nationally and internationally to improve cancer survivorship care
- ✔ **Inclusive:** our research considers the survivorship needs of everyone affected by cancer, regardless of cancer type, age, geography and culture

OBJECTIVE OF THE RESEARCH AGENDA

To provide targeted research directions on focused research efforts and collaborative opportunities that align with (1) the priority needs of cancer survivors and (2) identified areas of strengths in Queensland.

DEVELOPMENT OF THE RESEARCH AGENDA FOR CANCER SURVIVORSHIP CARE IN QUEENSLAND

Development of the research agenda comprises four phases. First, a research prioritisation workshop was held at the Brisbane Cancer Conference on 28 November, 2019. Sixty participants represented a wide range of disciplines and settings. The attendance list for this workshop is outlined in Appendix 1.

The discussions were conducted to generate potential research priorities under four broad research areas in four separate breakout groups: Models of Care, Symptom Science, Vulnerable and Small Populations, and Technology and Data Analytics. Second, based on the outcomes of discussions at the workshop, the Executive Committee developed a draft document including all priorities and brief explanation on the focus.

Third, the draft research agenda was then circulated to a number of key stakeholders via email for further input (see Appendix 1). Last but not least, taking all feedbacks into consideration, the Executive Committee finalised and endorsed the research agenda as the final document.

INITIAL WORKSHOP



Research prioritisation workshop at Brisbane Cancer Conference with researchers, clinicians, cancer services executives, NGO representatives, consumers (n=60)
NOVEMBER 2019

Development of Draft by the Executive Committee
JANUARY TO APRIL 2020

DRAFT DEVELOPMENT



FURTHER CONSULTATION



Wider consultation with key stakeholders via an electronic survey (researchers, clinicians, service executives and consumers)
MAY TO JULY 2020

Taking all feedback into consideration, the Executive Committee finalised and endorsed the research agenda as the final document
JULY TO AUGUST 2020

FINAL REVIEW & ENDORSEMENT

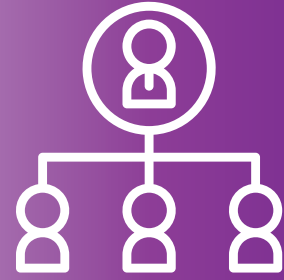


PRIORITY RESEARCH AREAS





MODELS OF CARE



- ✓ Cancer care coordination – defining and standardising roles while enhancing benefits and cost-effectiveness
- ✓ Cancer survivorship – addressing needs of those living with and beyond cancer in the community and associated health, financial and psychosocial issues
- ✓ Carers needs- enhancing services and care to address specific needs of carers
- ✓ Community services and referral pathways – increasing availability of and accessibility (through development and implementation of pathways) to individual or group-based, cancer-specific exercise, dietary and psychological support in the community
- ✓ Needs-based models of care– developing models of care addressing different needs specific to cancer type and stage, including models for cancer survivors with metastatic disease
- ✓ Self-management – incorporating self-management support (provided to patients and/or patient-carer dyads) into routine care to improve patient outcomes
- ✓ Shared-care and other alternative models of care– effectively transit cancer survivors back into the community with support from General Practitioners (GPs), other primary care providers (including nurses and allied health) and not-for-profit organisations



SYMPTOM SCIENCE

- ✓ Complex interventions that optimise multiple outcomes – including, mental, physical, social and spiritual health
- ✓ Personalised symptom management – taking into account a person's individual clinical, social, demographic, and biological factors (including genomics) to deliver care specific to them
- ✓ Patient-reported outcome measures (PROMs) – optimising the clinical utility and timing of PROMs data collection
- ✓ Integration of PROMs and interventions with established effectiveness into practice – including support for decision making, tailoring, self-management and education

VULNERABLE POPULATIONS & ENSURING EQUITABLE ACCESS TO CARE



- ✓ Equitable cancer care across the age continuum - optimising care, enhancing access, and increasing health literacy for
 - Aboriginal and Torres Strait Islanders
 - Culturally and linguistically diverse (CALD) populations
 - Geriatric populations
 - People with lower socio-economic status and those experiencing job insecurity, unstable housing or homelessness
 - People with multimorbidity
 - People living in regional and rural areas
 - People with cancers that are rare or have poorer prognosis
 - Prisoners
 - Refugees/asylum seekers

- ✓ Child and adolescent survivorship – optimising transition from paediatric to adult setting and improving outcomes for child and adolescent cancer survivors

- ✓ Financial toxicity – understanding, preventing and managing financial toxicity in all cancer survivors

- ✓ Telehealth – harnessing telehealth to promote evidence-based intervention uptake for all and address inequity in access to services, especially in regional areas and adapted for vulnerable populations

TECHNOLOGY & DATA ANALYTICS



- ✓ Tele/online support services (e.g. Cancer Council Helpline) – strategies for improving delivery of and access to service
- ✓ Communication – using technology to enhance communication between patient groups, researchers, and clinical sites
- ✓ Data sharing – optimising sharing of digital health data to enhance patient care
- ✓ Patient ownership – exploring the impact of patients having access to and taking ownership of their health data
- ✓ Psychological care – utilising technologically-driven care to enhance psychological care and minimise distress in both carer and patient
- ✓ Research translation of telehealth – integrating telehealth into clinical setting and Queensland Health systems – especially during the post-COVID era
- ✓ Management of side-effects through technology – embracing technology to increase reporting and enhance management of side effects
- ✓ Surveillance – incorporating technology into cancer surveillance practices

PRIORITY RESEARCH APPROACH

- ✔ Consumer and multidisciplinary engagement – prioritising partnership with consumers and multidisciplinary members in all aspects of research and enabling meaningful engagement and contribution (for example, co-design or experience-based co-design methods)
- ✔ Economic evaluations – evaluating costs in the implementation of all current and novel interventions
- ✔ Implementation science- addressing all facilitators and barriers, and measuring reach, implementation and maintenance (sustainability) of optimal care
- ✔ Patient-centred care – accommodating health literacy, cultural needs, patient preferences and decision making, especially regarding cancer treatment



AREA 1 : **MODELS OF CARE**

GROUP & CONTACT

Shared care follow-up models	MNHHS – Glen Kennedy
Optimisation of survivorship outcomes in people with advanced disease	QUT – Patsy Yates MNHHS – David Wyld UQ – Marina Reeves
Self-Management Support in Cancer Survivors	QUT/MSH – Ray Chan
Personalised post-BMT survivorship care	MNHHS – Glen Kennedy
Enhancing services and care to address specific needs of carers	QIMR Berghofer – Vanessa Beesley
Survivorship care for brain cancer survivors and families	GU – Tamara Ownsworth MSH – Mark Pinkham

AREA 2 : **SYMPTOM SCIENCE**

GROUP & CONTACT

Optimisation of personalised symptom management	QUT – Patsy Yates, Kim Alexander
Incidence, risk factors and prevention strategies of lower limb lymphoedema associated with gynaecological cancer	GU – Sandi Hayes

PROPOSED PRIORITY
AREAS FOR RESEARCH
HIGHER DEGREE STUDIES

AREA 3 : **VULNERABLE POPULATIONS & ENSURING EQUITABLE ACCESS TO CARE**

GROUP & CONTACT

Use of patient reported outcomes in vulnerable populations	GU-Laurelie Wishart
Geriatric oncology models of care	MNHHS – Darshit Thacker, David Wyld, Glen Kennedy
Child and adolescent survivorship transition model of care	QYCS – Rick Walker QUT – Natalie Bradford MNHHS/MSH – Glen Kennedy, David Wyld
Minimisation of the impacts of financial toxicity	QIMR Berghofer – Louisa Gordon
Safety, feasibility, acceptability and effect of exercise intervention in under-studied cancer cohorts (e.g., those residing in rural/regional areas, those with more advanced disease at diagnosis and poorer prognosis, those with complex medical history).	GU – Sandi Hayes
Understanding the needs of and access to care for those in rural/regional areas	UQ – Marina Reeves
Developing recommendations for modifiable behavioural risk factors in those with metastatic disease	UQ – Marina Reeves

AREA 4 : **TECHNOLOGY & DATA ANALYTICS**

GROUP & CONTACT

Use of patient reported outcomes in routine cancer care	QIMR Berghofer – Penny Webb MSH – Laurelie Wishart
Telehealth-delivered psychological support and rehabilitation to cancer survivors	GU – Tamara Ownsworth
Evaluation of technology – enabled interventions	QUT – Patsy Yates
Using telehealth to deliver exercise services to cancer survivors	GU – Sandi Hayes
Big data – using routinely – collected health data to improve patient outcomes	QIMR Berghofer – Penny Webb
Developing natural language processing algorithms to better use routinely collected data	UQ – Marina Reeves, Jason Pole

Please contact qccs@qut.edu.au if you are interested in conducting your Research Higher Degree in any of the priority areas

Abbreviations: GU = Griffith University; MNHHS = Metro North Hospital and Health Services; MSH = Metro South Health; QIMR Berghofer = QIMR Berghofer Medical Research Institute; QUT = Queensland University of Technology; QYCS = Queensland Youth Cancer Service; UQ = University of Queensland

APPENDIX 1

ATTENDANCE LIST FOR THE RESEARCH PRIORITISATION WORKSHOP AT THE BRISBANE CANCER CONFERENCE 2019

Kim Alexander, Helen Anderson, Anne Ary, Vanessa Beesley, Dawn Bedwell, Natalie Bradford, Minnie Brady, Bena Brown, Christine Carrington, Ray Chan, Louise Cooney, Mary Jane Courage, Elizabeth Coyne, Sarah Day, Kerrie Doupain, Kelly Dungey, Riley Elder Dunn, Elaine Robinson, Julie Evans, Simone Faulkner, Helen French, Louisa Gordon, Tracey Guan, Bethany Halpin, Brigid Hanley, Corrine Haugstetter, Jenny Job, Tamara Jones, Ria Joseph, Glen Kennedy, Mary Anne Kedda, Claire Kelly, Liz Knox, Wei-Hong (Wendy) Liu, Leah McIntyre, Emma McKinnell, Paul Moran, Hanh Nguyen, Jessica Nicholson, Jodie Nixon, Shoni Philpot, Elizabeth Pinkham, Mark Pinkham, Marina Reeves, Natasha Reid, Shelley Rumble, Marissa Ryan, Carolina Sandler, Leanne Stone, Rosa Spence, Laisa Teleni, Carla Thamm, David Theile, Dean Vuksanovic, Rina Waller, Euan Walpole, Sebastian Walpole, Martine Waters, Laurelie Wishart, Natasha Woodward

EXPERTS WHO PROVIDED ADDITIONAL FEEDBACK AND INPUT DURING THE FINAL CONSULTATION PROCESS

Elizabeth Eakin, Louisa Gordon, Sandi Hayes, Sandie McCarthy, Wayne Nicholls, Tina Skinner, Jolieke van der Pols, Jane Turner, Liz Ward, Patsy Yates



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