

Cancer Quality of Life  
Expert Service Team  
(CQUEST)

### Newsletter contents

Message from the Executive

CQUEST welcomes new  
Research Fellow

Spotlight on paediatric  
research

Estimands workshop

Joint CQUEST and CREST  
workshop on quality-of-life in  
cancer research

Research invitation:  
Development of a quality-of-life  
questionnaire for people with  
metastatic uveal melanoma

CCTG upcoming events

# CQUEST Newsletter Issue 2

## Message from the Executive

Welcome to the second CQUEST newsletter. Since the previous newsletter we have continued to support the [Cancer Cooperative Trials Groups \(CCTGs\)](#) in developing the quality of life components of trials and other research studies in development.

Highlights include attending and presenting at a number of Annual Scientific Meetings, and conducting virtual workshops about choosing patient-reported outcomes measures (PROMs) for use in clinical trials, and meeting with research managers across the groups to discuss using conceptual frameworks in the design of the quality of life elements of studies. We have also welcomed Carrie-Anne Ng as our new Research Fellow.

Upcoming events (described further below) include a workshop on the Estimands framework, and a joint workshop with [CREST](#) (Cancer Research Economics Support Team) on quality of life measurement for trials and economic evaluation.

As the year draws to a close, the CQUEST Executive would like to wish you all the best for the new year, and we look forward to continuing to work with you.

**Associate Professor Brendan Mulhern**  
**Dr Tim Luckett**

## CQUEST welcomes new Research Fellow

CQUEST is excited to have [Ms Carrie-Anne Ng](#) join [Associate Professor Brendan Mulhern](#) and [Dr Tim Luckett](#) on the core executive team! Carrie is a Research Fellow at the Centre for Health Economics Research and Evaluation (CHERE) at the University of Technology Sydney (UTS). She has submitted her PhD on evaluating the effects of exercise on bone health through clinical trial interventions. Carrie will become a key collaborator with the CCTGs, and looks forward to providing you with continued support to ensure the optimal inclusion of quality of life and other PROMs in cancer clinical trials.



**Presenters:**

[Dr Jessica Roydhouse](#),  
Select Foundation Senior  
Research Fellow in Health  
Services Research, Menzies  
Institute for Medical  
Research, University of  
Tasmania

[Sabine Braat](#), Senior  
Research Fellow  
(Biostatistics), Melbourne  
School of Population and  
Global Health, University of  
Melbourne

[Dr Anna Grobler](#), Senior  
Research Fellow, Clinical  
Epidemiology & Biostatistics  
(CEBU), Murdoch Children's  
Research Institute



## Estimands workshop

### What are estimands?

Trials in cancer have numerous challenges, such as worsening function, high mortality and treatment discontinuation. These post-randomisation events are particularly salient for patient-reported outcomes (PROs). Even with identical objectives, different trials produce variable results due to inconsistencies in how these events are handled. Appropriate reporting of treatment effects is critical for the translation of findings to practice and policy. There has been a new effort to align trial objectives, design and analysis, improve communication, and clarify interpretation of the effect of treatment known as the **estimand framework**. Estimands offer researchers the opportunity to address these well-known issues.

### The workshop

This workshop will include two sessions:

- Morning session (via Zoom or in-person at UTS) - introduction to estimands, covering how to define and document trial estimands based on internationally agreed guidelines.
- Afternoon session (in-person at UTS only, with attendance at the morning session a requirement) - an opportunity to apply the estimand framework to example trials in hands-on exercises. Attendees can bring their own concepts for trials or use examples provided.

This is a joint workshop between CQUEST and Cancer Symptom Trials (CST).

- 📅 Date: Wednesday 8 February 2023
- 🕒 Time: 9.30AM to 4.00PM AEDT
- 📍 Where: UTS Building 10, Level 7, Seminar Room 2 (CB10.07.102)
- 📧 RSVP: <https://bit.ly/3g0CWLM>
- ✉ Contact: [cquest@uts.edu.au](mailto:cquest@uts.edu.au)

For an introduction to estimands and their application to a palliative care clinical trial, please see the following recent article by the workshop presenters: Roydhouse J, Floden L, Braat S, Grobler A, Kochovska S, Currow DC, *et al.* [Missing data in palliative care research: estimands and estimators](#). *BMJ Supportive & Palliative Care*. 2022;bmjspcare-2022-003553.

## Joint CQUEST and CREST workshop on quality of life in cancer research

CQUEST and the Cancer Research Economics Support Team (CREST) are hosting a joint workshop on quality of life in cancer research. This one-day face-to-face workshop will:

- explain the rationale for assessing health related quality of life (HRQL) in clinical studies;
- describe methods of measuring and valuing HRQL, and how these differ;
- describe the role of HRQL in economic evaluation; and
- introduce quality-adjusted life-years (QALYs) and the use of generic and cancer specific measures for estimating QALYs. The workshop includes lecture-based learning and group exercises.

- 📅 Date: Friday 10 February 2023
- 🕒 Time: 9.00AM to 4.00PM AEDT (tentative)
- 📍 Where: UTS (venue to be confirmed)
- 📄 RSVP: <https://bit.ly/3fX77KR>
- ✉ Contact: [cquest@uts.edu.au](mailto:cquest@uts.edu.au)

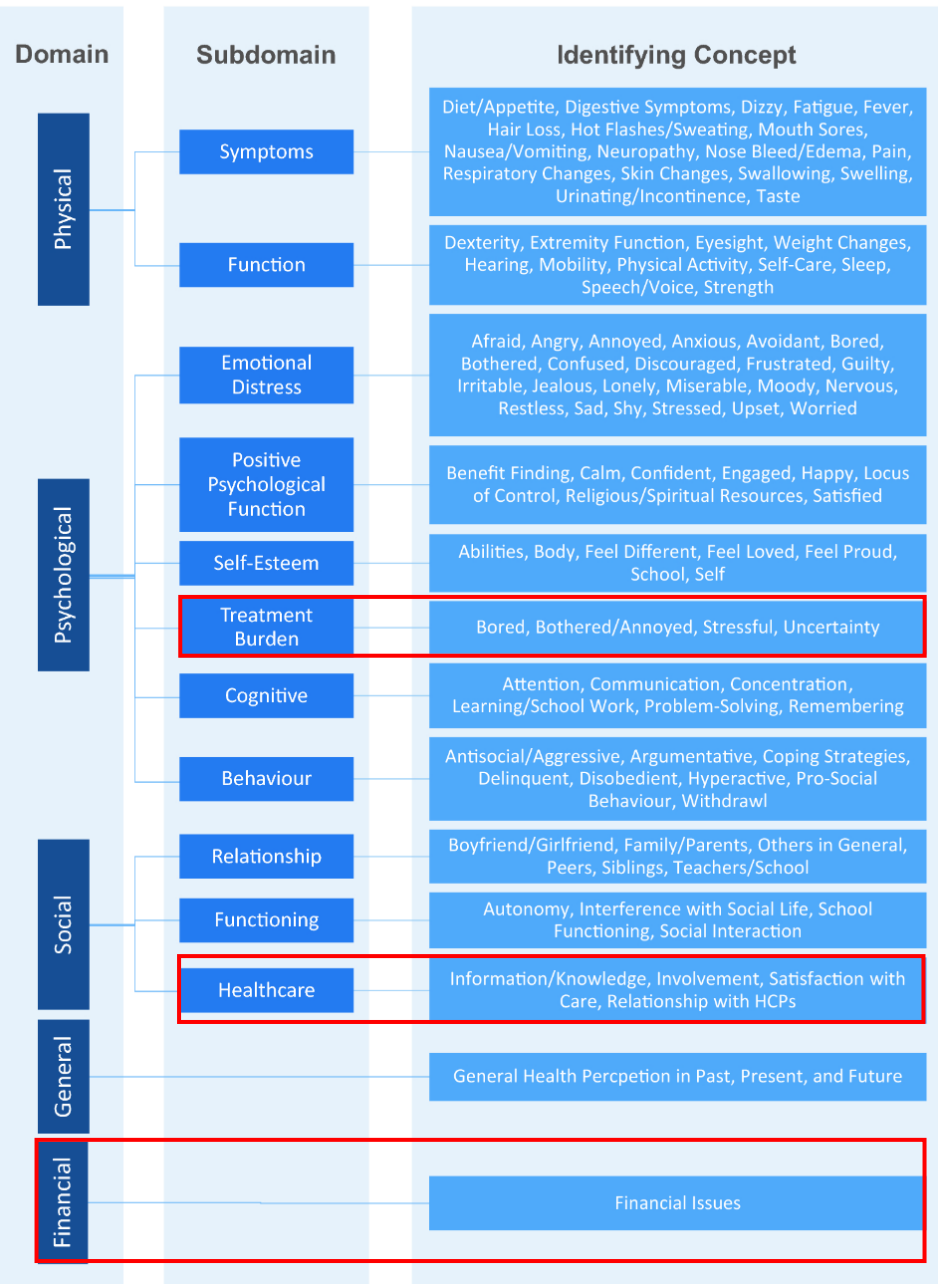


## Spotlight on paediatric research

### **Updating our understanding of health-related quality of life issues in children with cancer: a systematic review of patient-reported outcome measures and qualitative studies**

The survival rates of children with cancer have improved over decades, but children still experience substantial symptoms and side-effects from their disease and treatment. Many PROMs have been developed to assess health-related quality of life (HRQL) from children's perspective. However, these PROMs differ considerably in terms of content and how they measure the HRQL, of children with cancer.

This [systematic review by Rothmund and colleagues \(2022\)](#) provides a comprehensive overview of age- and disease-specific HRQL issues in children with cancer (8-14 years). From 4 databases, 96 PROMs from 45 qualitative studies were identified. The items from PROMs and quotations from interviews of children or their parents reported in these studies were mapped onto a conceptual model. The findings were compared with an [earlier conceptual model of HRQL published in 2014](#).



The updated conceptual model (Fig 1) largely reflected the domains and subdomains identified by the earlier work. Overall, 5.2% of items and quotations in the current study were assigned to three newly introduced sub(domains): ‘treatment burden’ (e.g., fear of needles), ‘treatment involvement’ (e.g., shared decision-making), and ‘financial issues’. Physical and psychological aspects were also more frequently covered than social issues.

These findings serve as an impetus to refine our understanding of how to measure HRQL in children with cancer. While this comprehensive overview identified the HRQL issues investigated in children with cancer, the relevance of the domains and the comprehensibility of the instruments from children’s perspectives are still unknown. This raises questions about when self and/or proxy reported approaches are most relevant. Further qualitative research involving children with cancer, their parents, caregivers and healthcare professionals are needed to provide clarification of the conceptual model and improve its relevance to children with cancer.

Contributed by: Carrie-Anne Ng

<sup>1</sup> From: “Updating our understanding of health-related quality of life issues in children with cancer: a systematic review of patient-reported outcome measures and qualitative studies” by M. Rothmund et al., 2022, Quality of Life Research, Figure 2. (<https://doi.org/10.1007/s11136-022-03259-z>).

Fig 1 Updated Model of Health-Related Quality of Life Issues in Children with Cancer<sup>1</sup>. Newly identified (sub)domains are highlighted in red.

### Paediatric Multi Instrument Comparison (P-MIC)

As described above in the summary of the work by Rothmund et al (2022), measuring HRQL in paediatric populations is challenging. There are a range of generic and condition specific measures of HRQL for children. Alongside differences in the content of the instruments, there is a lack of psychometric evidence about the extent to which the instruments are valid



and reliable. This is a key research gap, as valid and reliable instruments are required to facilitate accurate outcome measurement and clinical decision making. Therefore, it is crucial that we generate further evidence to understand the measurement performance and characteristics of the instruments.

The “[QUality OF Life in Kids: Key evidence to strengthen decisions in Australia \(QUOKKA\)](#)” programme (funded by the Medical Research Futures Fund) is tackling this issue. The programme has developed a Paediatric Multi Instrument Comparison (P-MIC) dataset including data from more than 7,000 children from the general population, across 11 conditions and 3 hospital settings (outpatients, urgent care and intensive care) with 4 week follow up. A protocol paper is published (Jones *et al.*, 2021). A range of generic instruments such as the EQ-5D-Y, CHU-9D, PedsQL and PROMIS Paediatric-25 are included alongside disease specific instruments for each condition sample.

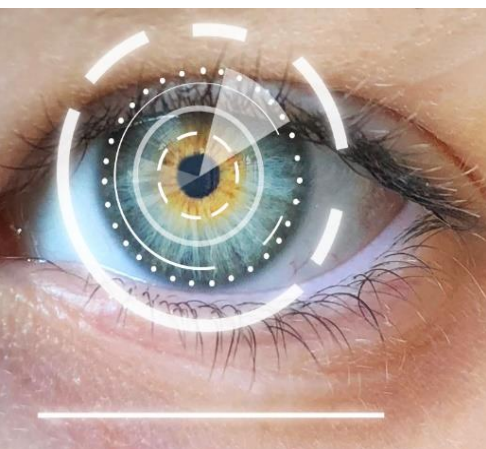
Analysis of P-MIC is currently ongoing, but initial analysis suggests that many of the widely used generic instruments overlap and diverge in the concepts measured, and they can detect differences in HRQL across populations with different severities of health concerns.

Further information can be found on the website:

<https://www.quokkaresearchprogram.org/> or by contacting the [CQUEST team](#).

Contributed by: Brendan Mulhern

Reference: Jones R, Mulhern B, McGregor K, Yip S, O’Loughlin R, Devlin N, Hiscock H. (2021). Psychometric Performance of HRQoL Measures: An Australian Paediatric Multi-Instrument Comparison Study Protocol (P-MIC). *Children*, 20(8): 714.



## Research invitation – Development of a quality-of-life questionnaire for people with metastatic uveal melanoma

Medical oncologist and Melanoma and Skin Cancer (MASC) Trials investigator Prof Anthony Joshua and collaborators at UTS are conducting a study to develop a questionnaire to measure impacts on quality of life from metastatic uveal melanoma and its treatment for use in future clinical trials.

Clinicians (from all disciplines – medical, nursing, and allied health) and metastatic uveal melanoma patients are invited to participate.

Participation will involve a 30-minute interview conducted via video conference (Zoom or Skype) in which you will be asked about the impacts on quality of life you have observed (clinicians) or experienced (patients) from metastatic uveal melanoma and its treatment.

If you would like further information, please contact the co-ordinating investigator, Dr Tim Lockett, at [tim.lockett@uts.edu.au](mailto:tim.lockett@uts.edu.au) or 02 9514 4861.

This study has been approved by the St Vincent's Hospital Human Research Ethics Committee 2022/ETH01013.

## CCTG upcoming events

Australasian Gastro-Intestinal Cancer Trials Group (AGITG) | [AGITG Annual Scientific Meeting 2022](#) | 14-17 November 2022

Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) | [Cancer Survivorship Conference](#) | 9-10 March 2023

Cancer Symptom Trials (CST) | PACSC & CST Annual Research Forum 2023 | 15-16 March 2023

Australia New Zealand Gynaecological Oncology Group (ANZGOG) | ANZGOG Annual Scientific Meeting 2023 | 22-24 March 2023

Melanoma and Skin Cancer (MASC) Trials | [MASC Trials Annual Scientific Meeting 2023](#) | 23 March 2023

Trans-Tasman Radiation Oncology Group (TROG) | TROG Annual Scientific Meeting 2023 | 19-22 June 2023

Australian & New Zealand Urogenital and Prostate (ANZUP) | [#ANZUP23 ASM](#) | 9-11 July 2023

Thoracic Oncology Group Australia (TOGA) | [TOGA Annual Scientific Meeting](#) | 20-21 July 2023

Breast Cancer Trials (BCT) | [BCT 44th Annual Scientific Meeting](#) | 26-28 July 2023



[uts.edu.au/cquest](https://uts.edu.au/cquest)

UTS CRICOS Provider Code: 00099F

This email was sent by University of Technology Sydney, PO Box 123 Broadway NSW 2007, Australia