

CQUEST NEWSLETTER

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Cancer Quality of Life
Expert Service Team
(CQUEST)

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Message from the Executive

The end of 2024 was a busy time for CQUEST both professionally and personally, with the launch of our [conceptual framework to guide the selection of patient reported outcome measures \(PROMs\) in cancer clinical trials](#); a consumer workshop held in November; and research fellow, Dr Carrie-Anne Ng getting married in Melbourne!

2025 is already well-and-truly underway, and we look forward to the exciting opportunities ahead. See below for what we have planned in the first part of the year.

Don't forget, our team is here to support you at any time with any PROM-related questions you may have: cquest@uts.edu.au.

Upcoming CQUEST workshop

WORKSHOP

CQUEST & CREST Quality of life in cancer research



Friday, 4 April 2025



9 AM - 4 PM (AEDT)



University of Technology Sydney



Cancer Quality of Life
Expert Service Team
(CQUEST)



CQUEST and CREST Workshop: Quality of Life in Cancer Research

Friday, 4 April 2025 | 9 AM - 4 PM AEDT

Back by popular demand!

CQUEST is joining forces with CREST to host this in-person workshop on quality of life in cancer research. It has been specifically developed for clinicians, researchers and investigators.

The workshop will:

- describe the role of assessing health-related quality of life (HRQL) in clinical studies;
- describe the role of HRQL in economic evaluation;
- introduce quality-adjusted life-years (QALYs)
- describe methods of measuring HRQL and obtaining QALYs; and
- explore approaches to reduce questionnaire burden in trials

For more information or to register, [click here](#).

[Register today](#)



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Reaching consensus on core patient-reported outcome (PRO) set for brain cancer clinical trials: A collaboration with COGNO

A Cooperative Trials Group for Neuro-Oncology (COGNO) [2022 Delphi study](#) identified inclusion of relevant patient-reported outcomes (PROs) to be the top priority for ANZ brain cancer research, especially for consumers.

In response, key COGNO members and CQUEST have been working on a project to establish a core set of PROs for use in ANZ clinical trials involving adults with primary brain tumours. This effort will ensure that trials measure aspects of health that are most important and likely to be affected across different interventions, enabling comparison between trials to determine the most effective treatments.

In late 2024, we completed two rounds of surveys and two workshops with consumers, clinicians and researchers. Since trials are expected to add PROs specific to their aims, populations and interventions, our challenge has been to keep the core PRO set as brief and concise as possible. Another workshop is planned for the end of March, to be followed by further consultation with consumers. Stay tuned for the results!

If you're interested in exploring undertaking a similar consensus process for your CCTG, please get in touch with our team.

Highlight from ISOQOL 2024



The International Society for Quality of Life Research (ISOQOL) annual conference was held in Germany in October 2024, with the theme 'All different together: Showcasing variety of QOL research'.

It was an exciting opportunity for Carrie-Anne Ng to share CQUEST's latest findings on the performance of computer adaptive testing (CAT) in cancer clinical trials. CAT has been of growing interest among CCTG members as a way to reduce questionnaire burden, and CQUEST is developing this work to help inform the performance and selection of CAT.

Carrie also took part in several thought-provoking workshops and attended presentations on emerging topics in QoL research, such as the validity of a single question on treatment tolerability, and the use of artificial intelligence (AI) to analyse responses to open-ended questions.

CQUEST will continue engaging in these international conversations and share our takeaways and insights with the CCTGs.



Perspectives on using the modular approach

Our latest publication

There is growing concern among international stakeholders that the cancer clinical trial community has often relied on specific full-length questionnaires, which may not always measure the QoL issues relevant for specific studies, contexts, populations, and stakeholders.

The potential to reduce questionnaire burden while improving the relevance of questions in a more flexible manner has also been a key area of interest for both CCTG investigators and consumers alike.

In response, there has been recent interest in a **“modular approach”**, where only a subset of domains (i.e. subscales) from multi-scaled questionnaires are administered. In CQUEST’s latest publication, we build upon recent guidance from the Food and Drug Administration (FDA) and questionnaire developers regarding the use of PROMs, as well as position statements from various international stakeholders. We also provide practical examples of how to apply the modular approach and demonstrate how it can improve PRO data quality.

This article has been accepted by the Medical Journal of Australia. Additionally, Carrie-Anne Ng will be delivering an oral presentation titled “Perspectives For and Against a ‘Modular Approach’” at the Trans-Tasman Radiation Oncology Group (TROG) ASM 2025 held in Brisbane in March 2025.

Keep an eye out for our updates!

Exploring consumers’ perspectives of the modular approach

Despite detailed recommendations from international stakeholders and PROM developers, we have yet to see uptake of the modular approach in cancer clinical trials. It is possible that despite emerging evidence supporting the modular approach, stakeholders will continue to prefer the traditional approach as the least risky option.

This qualitative study seeks to explore the acceptability of the modular approach in administering PROMs from the perspective of cancer consumers.



You are eligible to participate in this research if you are a patient, family member and/or caregiver who had experience with cancer.

Participants will be asked to take part in a 40-minute interview.

For more information and to register your interest, please visit: <https://bit.ly/3Xdnh4k>

Human Research Ethics Committee approval: UTS HREC #ETH21-6090

Upcoming CCTG scientific meetings

**MARCH
5-7**

ANZGOG ASM
Canberra
<https://www.anzgogasm.org.au>

**MARCH
18-21**

TROG ASM
Brisbane
<https://www.trogasm.com.au>

**MARCH
27-28**

PaCCSC and CST Research Forum
Sydney
[Click here for event page](#)

**JULY
20-22**

ANZUP ASM
Sydney
<https://anzup.org.au/asm2025>

**JULY
23-25**

BCT ASM
Hobart
[Click here for event page](#)

**JUL-AUG
30-1**

ANZCHOG ASM
Brisbane
<https://asm-anzchog.com>

**JUL-AUG
30-1**

TOGA ASM
Brisbane
[Click here for event page](#)

**SEPT
14-16**

COGNO ASM
Gold Coast
[Click here for event page](#)

**NOV
24-27**

AGITG ASM
Tarntanya Adelaide
<https://asm.gicancer.org.au>