

CQUEST NEWSLETTER

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Cancer Quality of Life
Expert Service Team
(CQUEST)

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Message from the Executive

As 2024 progresses, CQUEST remains committed to delivering capacity-building activities and resources for CCTG members.

Earlier this year, we hosted an in-person workshop for consumers and community representatives, alongside webinars in April and May for clinicians and researchers.

We are pleased to announce that Cancer Australia has extended the CQUEST contract until June 2025, enabling us to continue providing PROM-related services to the CCTGs.

If you have any questions about quality of life measurement, please feel free to get in touch with our team any time: cquest@uts.edu.au.

Upcoming CQUEST workshops



Choosing the right PROMs for cancer clinical research

Wednesday, 21 August 2024 | 12 - 1.30 PM AEST

Run annually, this workshop is for CCTG members who:

- want to learn more about the conceptual frameworks for guiding choice of patient reported outcome measures (PROMs)
- are developing a concept and want advice on the right PROMs to include in their study (feel free to bring along a concept to discuss).

[Register today](#)



Maximising the value of quality-of-life assessment while minimising burden: A workshop for consumers

Thursday 28 November | 2 - 5 PM AEDT

This 3-hour online workshop is for consumers and community representatives. During the workshop, we'll cover the selection and implementation of patient reported outcome measures (PROMs) and examine how quality of life outcomes can impact decision-making and future clinical practice beyond the clinical trial.

[Register today](#)



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Using conceptual frameworks to guide the selection of patient reported outcome measures (PROMs) in cancer clinical trials - a CQUEST resource

The *Standard Protocol Items: Recommendations for Interventional Trials – patient-reported outcome* (SPIRIT-PRO) extension requires trial protocols to justify the selection of PROMs and hypothesise expected effects (1).

Ideally, the rationale for PROM selection should be supported by a conceptual framework, which provides an empirical and theoretical basis to ensuring the trial measures most to patients (2, 3). However, many protocols default to a standard set of widely-used PROMs, resulting in important outcomes being missed, unnecessary respondent burden, and difficulty interpreting findings.



Following discussions with the CCTG research managers, CQUEST has developed [a resource](#) to help investigators establish a conceptual framework and associated measurement model for their trial protocol.

In this online resource, we outline the definition and rationale of a conceptual framework and include a ste-by-step guide on developing one (**Figure 1**).

[Scan the QR code or click here to view resource](#)

1. Determine the content for the conceptual model

- Patient-reported concepts expected to be affected
- Expected directions of effects
- Expected relationships between concepts

2. Organise concepts as 'proximal' or 'distal'

- Proximal concepts are directly impacted by the disease and/or treatment
- Distal concepts are more likely to be affected by factors *beyond the intervention*

3. Select PROMs (or sub-scales) for the measurement model

- Select measures which best assess concepts
- (Contact CQUEST if you need additional support)

4. Draft the conceptual framework

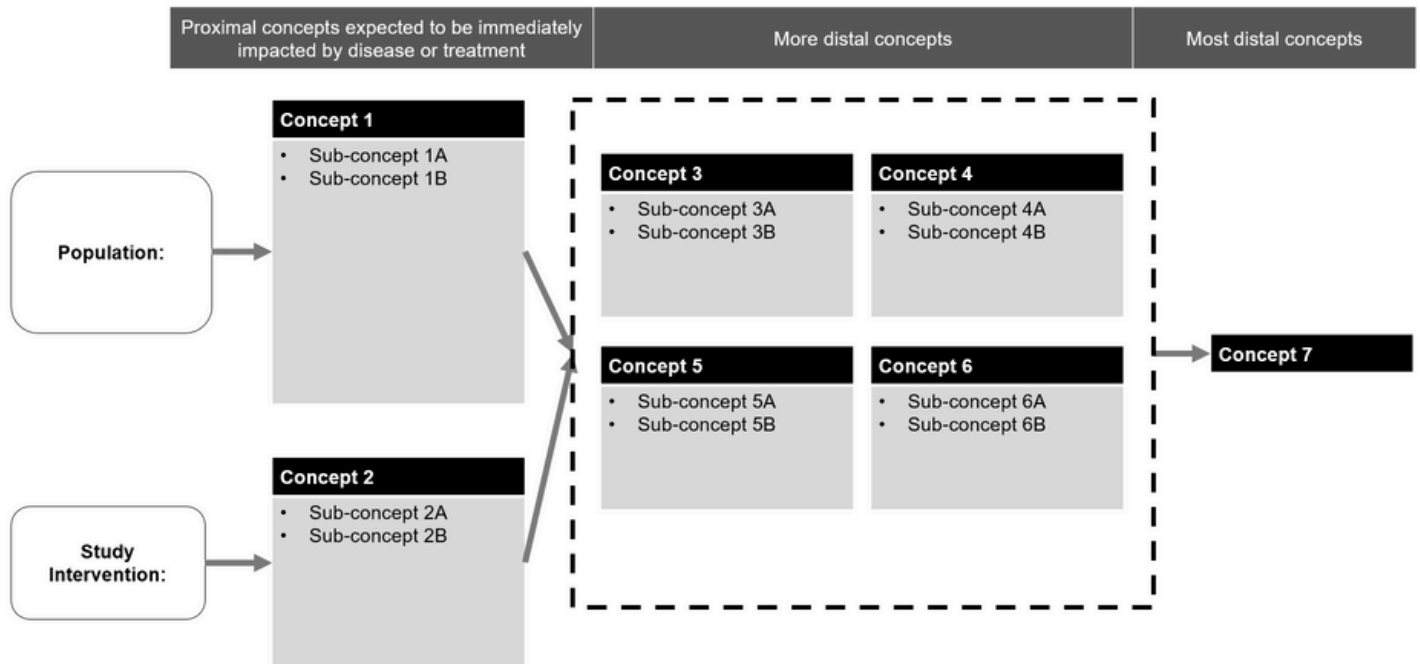
- The [template](#) on our resource webpage can help you create a figure to insert into your study concept or protocol

Figure 1 Summary of step-by-step guide on developing a conceptual framework

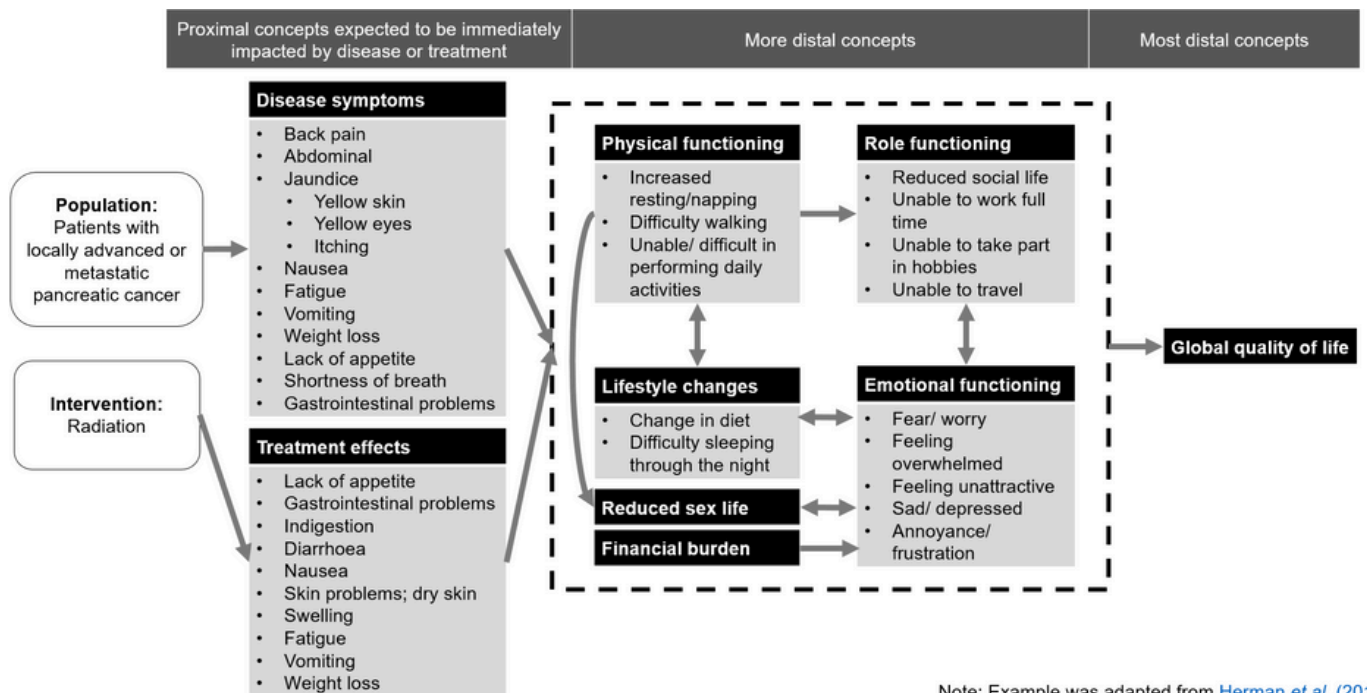


CCTG investigators are invited to utilise the conceptual framework template (**Figure 2**) to inform PROM selection in their trials. CQUEST can collaboratively build this with investigators and then assist with the choice of PROMs after key concepts of interest have been identified. The framework template is adaptable to various trial settings, thereby addressing the diverse needs of cancer clinical trials and other study types involving PROMs.

A)



B)



Note: Example was adapted from [Herman et al. \(2019\)](#)

Figure 2 A) Template and B) example of a conceptual model

References:

- Melanie C, Madeleine K, Rebecca M-B, Olalekan A, Derek K, Anita S, et al. SPIRIT-PRO Extension explanation and elaboration: guidelines for inclusion of patient-reported outcomes in protocols of clinical trials. *BMJ Open*. 2021;11(6):e045105.
- Food and Drug Administration (FDA). Patient-focused drug development: Selecting, developing, or modifying fit-for-purpose clinical outcome assessments. Guidance for Industry [draft] 2022
- Reeve BB, Wyrwich KW, Wu AW, Velikova G, Terwee CB, Snyder CF, et al. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Qual Life Res*. 2013;22(8):1889-905.

CQUEST Online Resources

CQUEST has developed a suite of online resources designed to assist CCTG members in implementing patient-reported outcome measures (PROMs) in cancer clinical trials. On our website, you'll find resources including:

- PROMs translations and cross-cultural validations
- A tool to calculate norm-based T-scores for QLQ-C30 and FACT-G data
- A fact sheet for patients on understanding questionnaires in clinical trials
- A best-practice guide for clinical trials staff on administering questionnaires to patients
- ...and more

We welcome your input and ideas for new resources. Share your feedback through our dedicated feedback form on the resource webpage or via email at cquest@uts.edu.au

[CQUEST Resources](#)



Recap: Consumer workshop, February 2024

On Friday, 2 February, CQUEST held an in-person workshop for community and consumer representatives from the CCTGs. This workshop was well attended with consumers flying in from around Australia, and even New Zealand!

The workshop provided attendees with a comprehensive overview of why quality of life is measured and the different PROMs that are commonly used in cancer clinical trials. Attendees were introduced to conceptual frameworks and their role in selecting PROMs.

Using the CQUEST-developed conceptual framework template, attendees had the opportunity to assess a concept's choice of patient-reported outcomes (PROs) and associated measures used. This gave attendees the chance to apply their learnings and determine how conceptual frameworks can be used within their trial group.

We thoroughly enjoyed delivering this workshop and would like to thank all the attendees for being so engaged throughout the day and sharing their own stories and lived expertise with us.



Upcoming CCTG scientific meetings

**JULY
21-23**

[Australian and New Zealand Urogenital and Prostate Cancer Trials Group \(ANZUP\) ASM](#)

**JULY
24-26**

[Breast Cancer Trials \(BCT\) ASM](#)

**AUG
1-2**

[Thoracic Oncology Group Australia ASM](#)

**AUG
1-3**

[Australian and New Zealand Children's Haematology and Oncology Group \(ANZCHOG\) ASM](#)

**OCT
10-11**

[Australian and New Zealand Sarcoma Association \(ANZSA\) ASM](#)

**OCT
13-15**

[Cooperative Trials Group for Neuro-Oncology \(CONGO\) ASM](#)

**OCT
10-11**

[Melanoma and Skin Cancer Trials \(MASC Trials\) ASM](#)

**AUG
1-3**

[Australian and New Zealand Children's Haematology and Oncology Group \(ANZCHOG\) ASM](#)

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