

Abstract for ISOQOL 2024

Design of the Cancer Symptom Rating Questionnaire (CancerSRQ)

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Aim: To design a Cancer Symptom Rating Questionnaire (CancerSRQ) for people with cancer.

Methods: The CancerSRQ format is based on established -SRQ measures (e.g. ThySRQ for hypothyroidism, HypoSRQ for diabetes: © Bradley). For an initial draft, items were selected from the -SRQ Item Library, modifying as needed, and new items drafted based on relevant literature, specialist cancer websites and input from two oncologists. Items have two parts: in part (a) respondents indicate if they have had the symptom in recent weeks ('yes' or 'no'), and, if 'yes', in part (b) rate how much the symptom has bothered them ('not at all', 'a little', 'moderately', or 'a lot'). Thirty-six interviews were conducted with UK English-speaking patients with a range of different cancers and experience of various cancer treatments. Participants (12 men, 24 women; mean age 58.5 years) were recruited from Barts Health NHS Trust (n=10), UK Maggie's Centres (n=10) and Cancer Research UK (n=16). Semi-structured interviews elicited spontaneous mention of symptoms of cancer and its treatment prior to completing a draft CancerSRQ. The CancerSRQ Design Team met between sets of 4-5 interviews and items were retained, modified, expanded or removed. Interviews continued until no further changes were required.

Results: The CancerSRQ now asks about 105 symptoms in 18 sections. There are 79 library items included, 48 of which remained unchanged while 31 were expanded or modified. There are 26 new items. Section 1 contains 27 individual symptom items for all respondents, followed by 15 sections (e.g. appetite and digestion, sexual problems) which respondents only complete if they respond to an initial question

indicating the section is applicable to them. Section 17 provides blank item templates for completion if a symptom has not been mentioned, and Section 18 is a free text box for comments.

Conclusions: The CancerSRQ design was facilitated by the existing questionnaire template and item library from other condition-specific -SRQs. The CancerSRQ will be useful in identifying, monitoring and managing symptoms of cancer and its treatment, in clinical trials of new and existing treatments and in routine clinical practice. Large-scale data collection is underway to evaluate the psychometric properties of the CancerSRQ.