

# Design of the Cancer Symptom Rating Questionnaire (CancerSRQ)

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## Background and Aims

The symptoms of cancer and its treatment can impact on a person's quality of life and well-being. Symptoms can be due to cancer, its treatment, co-morbidities, or a combination of all of these.

Symptoms can vary in frequency and severity. However, the symptoms which are of greatest severity are not always those which are most bothersome to the individual (McMillan et al., 2008). A symptom might also occur frequently, but not trouble the patient unduly or occur infrequently but be a major source of bother. Symptoms are subjective. Therefore, accurate assessment needs to consider the breadth of possible symptoms and the extent to which applicable symptoms impact on the individual.

The aim was to design a Cancer Symptom Rating Questionnaire (CancerSRQ). The CancerSRQ was designed to assess the presence of symptoms and the degree to which respondents are bothered by symptoms they have experienced. The CancerSRQ was also designed to be suitable for use with people with different types and stages of cancer, and on a range of different treatments.

## Methods

### Participants

Thirty-eight interviews were conducted, either via Microsoft Teams or telephone, with UK English-speaking patients with a range of different cancers and experience of various cancer treatments (Table 1). Participants (14 men, 24 women; mean age 59.1 years; range 30-83 years) were recruited from Barts Health NHS Trust (n=10), UK Maggie's Centres (n=10) and Cancer Research UK (n=18).

Table 1: Clinical characteristics of the sample

Cancer type(s)	N	Cancer treatment(s)	N	Cancer stage	N
Breast	12	Surgery	26	Stage I	3
Gastrointestinal	9	Chemotherapy	25	Stage II	11
Gastrointestinal	7	Radiotherapy	21	Stage III	7
Gynaecological	6	Hormone therapy	19	Stage IV	11
Lung	5	Immunotherapy	7	Unclear	6
Head and neck	3	Stem cell transplant	2	Co-morbid health problems	N
Myeloma	2	Active monitoring	2	Related to cancer	26
Lymphoma	2	Targeted therapy	1	Unrelated to cancer	17
Sarcoma	2	Brachytherapy	1	Cancer in remission	4
Skin melanoma	1	---	---	Yes	19
Liver	1	---	---	No	15
Brain	1	---	---	Unclear	4

NB: Cancer type(s) include primary and secondary cancers. Gastrointestinal (pancreatic, bowel, colorectal, stomach, oesophagus); Gynaecological (ovarian, bladder, kidney); Gynaecological (vulva, ovarian, uterine, endometrial); Head and neck (salivary, larynx, thyroid).

### Design

The stages involved in the design of the CancerSRQ are illustrated in Figure 1. The CancerSRQ format was based on established -SRQ measures (e.g. ThySRQ for hypothyroidism; McMillan et al., 2008; HypoSRQ for diabetes; Taylor et al., 2019; © Bradley). For an initial draft, items were selected from the -SRQ Item Library, modifying as needed. The initial draft was reviewed by two consultant oncologists to advise on the appropriateness and relevance of the items. New items were drafted based on clinician feedback, relevant literature and specialist cancer websites. CancerSRQ items have two parts: (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') (Figure 2).

### Interviews

Semi-structured interviews elicited spontaneous mention of symptoms of cancer and/or its treatment prior to completing a draft CancerSRQ. While completing the draft CancerSRQ, participants were asked to 'think aloud' and were encouraged to make suggestions for improvement or refinement of the questionnaire. The CancerSRQ Design Team met between sets of 4-5 interviews and items were retained, modified or removed. Interviews continued until no further changes were required.

## References

- McMillan, C., Bradley, C., Razvi, S., & Weaver, J. (2008). Evaluation of new measures of the impact of hypothyroidism on quality of life and symptoms: the ThyDQoL and ThySRQ. *Value in Health*, 11(2), 285-294.
- Taylor, M. D., Han, T. S., Ward, H., & Bradley, C. (2019). Design and development of the Hypoglycaemia Symptom Rating Questionnaire (HypoSRQ). *Diabetes Research and Clinical Practice*, 151, 187-197.

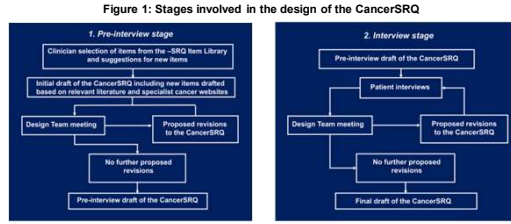


Figure 2: Example of a CancerSRQ item

1.01 (a) Have you felt generally tired, weak and/or lethargic during the daytime in recent weeks?

No  If 'no', go to next symptom

Yes  If 'yes', complete part (b)

(b) How much has this bothered you?

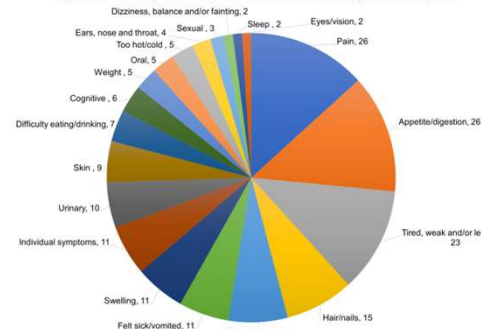
not at all  a little  moderately  a lot

## Results

### Spontaneous mentions of symptoms

Figure 3 shows the frequency with which different types/categories of symptoms were mentioned spontaneously by all 38 participants during the interviews before they were presented with the draft CancerSRQ.

Figure 3: Frequency of spontaneous mention of types/categories of symptoms



The most frequently mentioned types/categories of symptoms were *Pain*, *Appetite/digestion* (e.g. diarrhoea, constipation, loss of appetite, indigestion/heartburn), *Tired, weak and/or lethargic*, *Hair/nail problems* (e.g. hair loss, brittle nails), and *Psychological symptoms* (e.g. anxiety, depression, irritable, overwhelmed, symptoms of panic, confused).

There were 41 additional spontaneous mentions of specific diagnoses/conditions (e.g. amyloidosis, septic neutropenia, high blood pressure, etc.) which were not included in the CancerSRQ, where the focus is specifically on the experience of symptoms.

### Acknowledgements

We thank the participants who took part in this research. Thanks are due to Mara Budau, who assisted with extracting data from the patient interviews. Thanks to staff at Maggie's Cancer Centres and Cancer Research UK (CRUK) for advertising the research to patients.

Figure 4 shows the frequency with which specific individual symptoms were mentioned spontaneously by participants during the interviews before they were presented with the CancerSRQ. *Tired, weak and/or lethargic* was mentioned most frequently followed by *Swelling* and *Felt sick/vomited*. Figure 5 shows the different types/categories of symptoms that were spontaneously mentioned by participants as being most bothersome before they were presented with the draft CancerSRQ. The symptoms which were most frequently reported as being most bothersome were *Pain*, *Psychological symptoms* and *Tired, weak and/or lethargic*.

Figure 4: Frequency of spontaneous mentions of individual symptoms

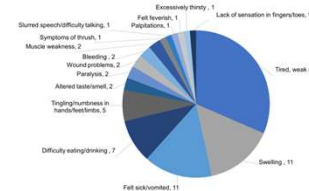
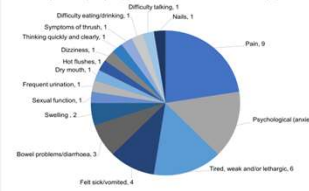


Figure 5: Frequency of spontaneous mentions of most bothersome symptoms



### Final draft of the CancerSRQ

The final draft of the CancerSRQ contained 104 symptom items (Figure 6), 81 originating from the -SRQ Item Library, of which 41 items remained unchanged (grey) and 40 items were expanded or modified (blue). There are 23 new items (orange). The CancerSRQ contains 18 sections. Section 1 contains 27 individual symptom items for all respondents, followed by 15 sections (e.g. *Appetite/digestion*, *Sexual*, *Skin*) 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 elsewhere in the questionnaire, and Section 18 is a free text box for comments and/or to elaborate on symptoms.

Figure 6: Cancer Symptom Rating Questionnaire (CancerSRQ): Symptom List

<b>Section 1: Individual symptoms</b> <ul style="list-style-type: none"> <li>Tired, weak and/or lethargic</li> <li>Felt sick/vomited</li> <li>Short of breath</li> <li>Cough</li> <li>Felt feverish</li> <li>Skin reaction at injection/infusion site</li> <li>Swelling</li> <li>Puffy face/cheeks</li> <li>Tingling/numbness in hands/feet/limbs</li> <li>Lack of sensation in fingers/toes</li> <li>Muscle weakness</li> <li>Paralysis</li> <li>Difficulty eating/drinking</li> <li>Altered taste/smell</li> <li>Excessively thirsty</li> <li>Wound problems</li> <li>Bleeding</li> <li>Symptoms of thrush</li> <li>Symptoms of jaundice</li> <li>Broken/fractured bone</li> <li>Restless legs</li> <li>Trembling/shaking</li> <li>Palpitations</li> <li>Slurred speech/difficulty talking</li> <li>Seizures</li> <li>Hallucinations</li> <li>Period problems</li> </ul>	<b>Section 2: Feeling too hot/cold</b> <ul style="list-style-type: none"> <li>Feeling too hot/too cold (e.g. hot flushes)</li> <li>Excessive sweating</li> <li>Cold hands/feet</li> <li>Felt colder than usual</li> </ul>	<b>Section 6: Cognitive</b> <ul style="list-style-type: none"> <li>Memory lapses</li> <li>Difficulty thinking quickly and clearly</li> <li>Problems making plans/solving problems</li> <li>Difficulty concentrating</li> </ul>	<b>Section 9: Oral</b> <ul style="list-style-type: none"> <li>Problems with gums/teeth</li> <li>Dry mouth</li> <li>Swollen/discooured lips</li> <li>Swollen/discooured tongue</li> <li>Discomfort/pain in mouth or throat</li> <li>Mouth ulcers/sores</li> <li>Other oral problems</li> </ul>	<b>Section 13: Nails/hair</b> <ul style="list-style-type: none"> <li>Hair loss/thin hair</li> <li>Hair regrowth - changes in appearance/colour/texture</li> <li>Hair problems</li> <li>Nail problems</li> </ul>		
<b>Section 3: Pain</b> <ul style="list-style-type: none"> <li>Muscle pains/cramps</li> <li>Pain/stiffness in joints</li> <li>Chest pain</li> <li>Abdominal pain</li> <li>Headaches</li> <li>Post-operative pain</li> <li>Breakthrough pain</li> </ul>	<b>Section 7: Weight</b> <ul style="list-style-type: none"> <li>Felt overweight</li> <li>Felt underweight</li> <li>Gained weight unintentionally</li> <li>Lost weight unintentionally</li> </ul>	<b>Section 10: Dizziness, balance and/or fainting</b> <ul style="list-style-type: none"> <li>Unsteady/uncoordinated</li> <li>Dizzy, lightheaded or faint</li> <li>Passed out/lost consciousness</li> </ul>	<b>Section 14: Skin</b> <ul style="list-style-type: none"> <li>Dry, sensitive, itchy or sore skin</li> <li>Acne, spots, warts or rashes</li> <li>Excessive bruising</li> <li>Skin that has been red/felt hot</li> <li>Scared skin</li> <li>Unusually pale skin</li> <li>Damaged skin</li> </ul>	<b>Section 15: Urinary</b> <ul style="list-style-type: none"> <li>Urinate frequently</li> <li>Urinary incontinence/urgency</li> <li>Difficulty urinating</li> <li>Discomfort/pain when urinating</li> <li>Discoloured urine</li> <li>Blood in urine</li> </ul>		
<b>Section 4: Psychological</b> <ul style="list-style-type: none"> <li>Anxious, worried or nervous</li> <li>Sad, low in mood or depressed</li> <li>Irritable, frustrated or angry</li> <li>Stressed/overwhelmed</li> <li>Symptoms of panic</li> <li>Confused/disorientated</li> </ul>	<b>Section 8: Appetite/digestion</b> <ul style="list-style-type: none"> <li>Poor appetite</li> <li>Excessive appetite</li> <li>Food cravings</li> <li>Felt full soon after starting a meal</li> <li>Indigestion, heartburn or acid reflux</li> <li>Felt bloated</li> <li>Flatulence or belching (wind)</li> <li>Loose stools/diarrhoea, with or without incontinence/urgency</li> <li>Constipation</li> </ul>	<b>Section 11: Ear, nose and/or throat</b> <ul style="list-style-type: none"> <li>Hearing problems</li> <li>Symptoms of tinnitus</li> <li>Other ear problems</li> <li>Difficulty swallowing</li> <li>Nasal problems</li> <li>Voice problems</li> </ul>	<b>Section 16: Sexual</b> <ul style="list-style-type: none"> <li>Unable/difficult to become sexually aroused</li> <li>Absence of interest in sex</li> <li>Avoidance of sexual activity</li> <li>Discomfort/pain during sex</li> <li>Other problems with sexual function</li> </ul>	<b>Section 5: Sleep</b> <ul style="list-style-type: none"> <li>Unpleasant/vivid dreams</li> <li>Problems falling asleep/staying asleep</li> <li>Sleeping more than usual</li> </ul>	<b>Section 12: Eyes/vision</b> <ul style="list-style-type: none"> <li>Eye problems</li> <li>Vision problems</li> </ul>	<b>Key:</b> <ul style="list-style-type: none"> <li>Unmodified -SRQ Item Library item</li> <li>Modified -SRQ Item Library item</li> <li>New item</li> </ul>

## Conclusions

- The CancerSRQ design was facilitated by the existing questionnaire template and item library from other condition-specific -SRQs, with 81 items in the final draft originating from the -SRQ Item Library.
- Accurate assessment of symptoms needs to consider the breadth of possible symptoms and the extent to which applicable symptoms are bothersome to the individual.
- Using the CancerSRQ as a patient-reported symptom measure will be useful in clinical trials of new and existing cancer treatments, and in routine clinical practice.
- Routine assessment and symptom management are important for people with cancer. The CancerSRQ will help clinicians to recognise, diagnose, treat and monitor symptoms over time.
- Large-scale data collection is underway to establish optimal scoring, quantitative validity and reliability of the CancerSRQ.

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For access to the CancerSRQ and other questionnaires please visit:  
www.healthpsychologyresearch.com

