Identifying Patient-Reported Outcome Measures that Assess Physical Symptoms for Childhood Cancer Survivors and Exploring Barriers and Facilitators for Clinical Implementation

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Preface

This thesis is written as the graduation assignment for my master's degree of the study Health Psychology and Technology at the University of Twente. The Princess Máxima Centre in Utrecht offered me a place where I could apply my passion for improving an individual's health, by using technology. I was able to apply this passion to childhood cancer survivorship care, which is a valuable field in healthcare that deserves attention and continuous improvements. Over there, I got the opportunity to conduct my own research, in which I could perform multiple studies to improve the focus on the patient's preferences and needs during the consult. I learned to identify a problem, formulate suitable studies to solve the problem, and conduct those studies in a proper way.

I would like to thank my supervisors from the University of Twente, Stans Drossaert and Sabine Siesling, who provided me with patient advice and guidance throughout the research process. I also want to thank Loraine Cahn, my supervisor from the Princess Máxima Centre, who always had time for my questions and gave valuable guidance and tips, applicable to my research but certainly to daily life as well. Lastly, I would like to thank my family, friends and boyfriend, who supported me during my graduation period with much appreciation and understanding.

I hope you will enjoy reading my thesis! Thank you for your time.

Maartje Vriens

Abstract

Background Improved survival rates for childhood cancer are accompanied by a majority of those survivors suffering from long-term physical symptoms, as a result of their previously received treatments. Patient-reported outcome measures (PROMs) have the potential to measure those symptoms in cancer survivors more accurately than merely physician assessment. The implementation of PROMs in daily clinical practice has appeared to be challenging. Moreover, it is unknown what validated PROMs can measure physical symptoms in childhood cancer survivors.

Aim This study focused on (1) identifying validated PROMs that can measure physical symptoms that are monitored in the follow-up care of childhood cancer survivors, and (2) exploring barriers and facilitators that can apply to childhood cancer survivors and their doctors in implementing and using digital PROMs in daily clinical practice.

Methods A systematic literature review was conducted to identify validated PROMs in literature that can assess physical symptoms in childhood cancer survivors. An umbrella review was performed to explore what barriers and facilitators for implementing and using digital PROMs in daily practice are available in literature that can apply to childhood cancer survivorship care. Lastly, a focus group interview was conducted with two childhood cancer survivor representatives to discuss what barriers and facilitators for completing PROMs can exist among childhood cancer survivors.

Results An overview was created with 91 PROMs that can assess physical symptoms in childhood cancer survivors. No validated instrument was found that can measure all physical symptoms that are monitored in childhood cancer survivorship care. PRO-CTCAE was found to cover most of the symptoms in childhood cancer survivors. No studies were found in the umbrella review that specifically focused on the target group of childhood cancer survivors. Still, an overview was created of barriers and facilitators that can exist in childhood cancer survivorship care for using PROMs. A lack of perceived value of PROMs was found to be the most prevalent barrier in literature that impedes both patients and healthcare professionals from using PROMs. Survivors in the focus group interview described additional barriers and facilitators that can apply specifically to childhood cancer survivors for completing PROMs.

Conclusion No validated questionnaire is available that can measure all physical symptoms in childhood cancer survivors. Future efforts are needed to establish a questionnaire for childhood cancer survivors, which can be done by combining validated instruments directed at other patient groups, or by creating a new questionnaire specifically focusing on the physical symptoms of childhood cancer survivors. In addition, the created overview with barriers and facilitators can be used as an indication of what factors can impede or facilitate childhood cancer survivors in completing PROMs. However, future research is needed to receive a complete overview of all barriers and facilitators for completing PROMs that exist among childhood cancer survivors. Eventually, using a suitable and comprehensive PROM in daily practice can be the way towards more patient-centred and ultimately better childhood cancer survivorship care.

Keywords Childhood cancer survivorship care, PROMs, implementation, barriers, facilitators

1. Introduction

Improvements in healthcare ensure that increasing numbers of childhood cancer patients survive their disease (Geenen et al., 2007). The five-year survival rate of paediatric cancer was 20% in the 1940s, while this survival rate is currently near 80% (Curry et al., 2006; Robison & Hudson, 2014). However, after this five-year milestone has been reached, 75% of the survivors experience adverse physical and psychological health outcomes due to previous intensive treatments (Geenen et al., 2007). Those survivors have an increased risk of adverse physical symptoms, such as dysfunctioning organs of which heart failure is the most frequent one (Feijen et al., 2019). Other adverse late effects are psychosocial and cognitive symptoms, such as anxiety and memory problems, that may negatively affect the lives of cancer survivors (Geenen et al., 2007; Robison & Hudson, 2014).

These late adverse health outcomes should be monitored, which can be realised by long-term follow-up care (Michel et al., 2019). Studies have shown that regulated long-term follow-up care can play a role in prevention, early diagnosis, and the initiation of interventions to provide care for adverse health outcomes (Michel et al., 2019; Signorelli et al., 2017). This type of care is provided in the Netherlands in three outpatient clinics to childhood cancer survivors from five years after their cancer diagnosis. The survivors are invited after five years, as those outpatient long-term follow-up clinics focus on the late effects of survivors, and not on the short-term effects of cancer treatments. The frequency of follow-up care varies from yearly to once every two or five years and depends on the treatment history of the survivor, as this is the main determinant for the risk of adverse health outcomes (Mud et al., 2012; SKION, 2010).

To provide long-term follow-up care in a structured and evidence-based way, clinical practice guidelines can be used (Kremer et al., 2012). Those guidelines include comprehensive, suitable, and accessible information on the organisation and provision of beneficial care practices. The outpatient clinics that provide childhood cancer survivorship care use guidelines that are composed of information concerning possible physical, psychosocial, and lifestyle symptoms of survivors (SKION, 2010). In addition, a symptom list is used including more than a hundred possible physical health outcomes for survivors that can assist clinicians in using the guidelines and is part of the European PanCare Follow-Up guidelines for childhood cancer survivorship care. Both the guidelines and symptom list are based on studies focusing on the occurrence of late effects by childhood cancer survivors. However, the guidelines are general-oriented and currently used according to a one-size-fits-all approach. Those should be specified to the individual patient, in which the personal risk of late effects and the patient's needs and preferences are included. When those are clear before the consult, the doctor can focus on aspects that are relevant to the patient.

One way to enable matching the follow-up care to the needs of the patient is by the use of patient-reported outcome measures (PROMs) (Gordon & Chen, 2017). PROMs are questionnaires that should be completed by patients to obtain a vision concerning their perceived health status, level of impairment, and health-related quality of life (Basch et al., 2014). Studies have shown that compared to physician assessments, PROMs can capture patient symptoms more accurately (Xiao et al., 2013). Moreover, the instruments can assist in obtaining a complete perception of the patient's subjective health experiences and can facilitate a more efficient anamnesis in the consult between clinician and patient (Gordon & Chen, 2017). Therefore, PROMs enable patient-centred care and better informed clinical decisions for both patients and doctors. Nevertheless, studies have shown that PROMs often involve many items that are not relevant to the patient (Briggs et al., 2020). There is the need to use a questionnaire that fits the target group of childhood cancer survivors, in which only questions are included that can be experienced by the survivors. However, it is unknown what validated

questionnaire can measure symptoms of childhood cancer survivors as an overview of available PROMs for survivors is lacking.

PROMs that are created for other patients may also be suited for childhood cancer survivors, such as PROMs directed at cancer patients, as similar symptoms may be experienced by both target groups. The extent to which questionnaires of other target groups can measure the physical symptoms of childhood cancer survivors should be explored. Furthermore, as described before, the clinical guidelines are composed of physical, psychosocial, and lifestyle symptoms. It is important to consider all aspects separately when exploring PROMs for survivorship care as a comprehensive questionnaire should be obtained, in which no symptoms are overlooked. This study focuses on the physical symptoms that can be experienced by survivors. In addition, childhood cancer survivorship care is provided to both children and adults. Different types of PROMs should be used for children and adults, as both target groups require another approach to questioning and can experience different symptoms. Therefore, separate studies have to be performed on those two target groups. This study focuses on adult childhood cancer survivors.

The implementation process of PROMs should also be considered as the integration of the instruments into daily practice has appeared to be challenging (Antunes et al., 2013; Gordon & Chen, 2017). Studies have shown that PROMs are often too long and too burdensome to complete (Briggs et al., 2020). Patients often do not complete the questionnaires, while healthcare professionals frequently fail to use the PROMs in the consultation room (Antunes et al., 2013). Many barriers and facilitators are identified in studies that can explain the lacking implementation of PROMs in daily clinical practice. However, the perspective of childhood cancer survivors is lacking in literature as most studies focus on other target groups, such as cancer patients (Foster et al., 2018). There are some interfaces in the barriers and facilitators between those target groups, but also some differences exist. Medical, social, ethical, and psychological concerns arise for childhood cancer survivors due to receiving treatment in their growth process (Steliarova-Foucher et al., 2017). In addition, technology offers opportunities for the digital completion of PROMs, such as a shorter time needed to complete, the possibility to complete the instruments at home, and more complete data of the patients as answers do not get lost (Meirte et al., 2020). However, completing PROMs digitally may also bring additional barriers, such as technical difficulties while accessing the questionnaires, and a larger financial investment needed for a technical infrastructure (Meirte et al., 2020). The barriers and facilitators that apply to digital PROMs for childhood cancer survivors should be identified, to ensure that a questionnaire will be implemented and used in daily clinical practice in childhood cancer survivorship care. Due to the lacking perspective of survivors in literature, an additional focus group interview should be conducted to ensure that barriers and facilitators that apply to childhood cancer survivors are included.

In sum, an overview of validated PROMs for measuring symptoms in childhood cancer survivors is lacking in literature. Besides, it is unknown what factors can impede or facilitate the completion of PROMs by childhood cancer survivors. Therefore, this study tried to answer the following three research questions:

(1) What validated PROMs can measure physical symptoms that are monitored in the follow-up care for adult childhood cancer survivors? (2) What barriers and facilitators are described in literature for implementing and using digital PROMs in daily clinical practice that can apply to adult childhood cancer survivors, their doctors and the organisation of care? (3) What barriers and facilitators for completing digital PROMs are experienced by the target group of adult childhood cancer survivors?

2. Method

Determining what validated PROMs are available in literature and how those can be implemented in daily clinical practice consisted of three sub-studies. First, a systematic literature review was conducted to identify available PROMs for assessing physical symptoms in childhood cancer survivors. Then, an umbrella review was performed to explore barriers and facilitators for implementing and using PROMs that can exist in childhood cancer survivorship care. Lastly, a focus group interview was conducted with childhood cancer survivor representatives to explore aspects that can impede or facilitate the completion of PROMs by childhood cancer survivors. This section elaborates on these three sub-studies separately.

2.1 Systematic literature review on available PROMs for assessing physical symptoms

A systematic literature review was conducted to identify validated PROMs that can assess physical symptoms in childhood cancer survivors. Articles were searched by defining search terms that were inserted in the PubMed database. Two searches were set up, in which one was focused on articles concerning childhood cancer survivors, and the other on articles related to cancer survivors. The search strategy was evaluated by two experts to ensure the search was exhaustive, in which one expert was specialised in guidelines for childhood cancer survivorship care, and the other expert was specialised in doing systematic literature reviews. The final search string concerned five main topics: “childhood cancer”, “cancer”, “PROMs”, “late effects”, and “survivors”. There are multiple ways to denote these main topics. Therefore, a search string was designed with an exhaustive list of synonyms for those five terms. This list was partially derived from search terms used by the international guideline harmonization group (IGHG, 2021). The main topics were inserted in PubMed as follows: [childhood cancer AND [survivors OR late effects] AND PROMs] OR [cancer AND survivors AND late effects AND PROMs]. The complete search string is available in Appendix A.

The inclusion criteria of the literature review were (1) article describes patient-reported outcomes, (2) article describes patient-reported outcome measures, and (3) article focuses on childhood cancer survivorship care or on cancer survivorship care. The exclusion criteria were (1) article has been written in languages other than English or Dutch and (2) article exclusively concerns PROMs that assess other aspects than physical outcomes, such as psychosocial and lifestyle symptoms. The inclusion and exclusion criteria were used to receive a selection of studies from the PubMed search. In order to apply the second exclusion criteria, the PROMs used in the study were extracted and the topic of each PROM question was assessed. All articles and PROMs were evaluated by one reviewer. If there was any doubt about including or excluding an article, then the article was included.

Data extraction

The data extraction consisted of three aspects, in which data were extracted from: (1) the articles, (2) the PROMs, and (3) a selection of PROMs that are more suitable for childhood cancer survivors.

First, all articles that used PROMs with questions that assess physical symptoms were noted.

Second, data were extracted from the PROMs that were used in the articles. The data that was derived consisted of (1) name of the PROM, (2) target group, (3) development year, (4) proportion of questions about physical symptoms, (5) symptoms allocated to physical domains, (6) answer options, (7) frequency of PROM occurring in different articles, (8) whether PROM is available in Dutch, (9) whether PROM has been validated, and lastly, (10) the full name of the abbreviated PROM. The overview of the data extraction was discussed with two experts that are specialised in guidelines for childhood cancer survivorship care. The experts reviewed

the overview and proposed additional questionnaires for self-assessment of symptoms in childhood cancer survivors that were lacking.

Third, the number of questions from PROMs were investigated that assess physical symptoms that are monitored in childhood cancer survivorship care. Those symptoms were derived from the symptom list that is included in the guidelines for childhood cancer survivorship care. The inclusion criterium for further exploration was that the PROM contained five or more questions that assess physical symptoms from the symptom list. This criterium was applied to receive a selection of questionnaires that are more suitable for assessing physical symptoms in childhood cancer survivors. From the instruments that met the inclusion criterium, the questions of the PROMs that assess physical symptoms in childhood cancer survivors were added to an overview with the symptom list.

2.2 Umbrella review of barriers and facilitators of implementing and using digital PROMs

An umbrella review was performed to explore what barriers and facilitators for implementing and using digital PROMs in daily clinical practice are available in other systematic reviews that can apply to childhood cancer survivorship care. Systematic reviews were searched in the Scopus database. The included main themes were “barriers”, “facilitators”, “PROMs”, “care”, and “systematic reviews”. Additional synonyms were used to receive a broader variety of results. The search terms were inserted in Scopus as follows: [barriers OR facilitators] AND PROMs AND care AND systematic review. The complete search string is available in Appendix B.

The inclusion criteria were (1) article describes barriers and/or facilitators of implementing or using PROMs in daily practice, (2) article describes PROMs focusing on use in healthcare, and (3) article is a systematic review. Articles were excluded when (1) article is not available in English or Dutch, (2) article concerns paper-based PROMs only, and (3) article exclusively concerns barriers and facilitators that do not apply to the general population of cancer survivors. The last exclusion criterium has been used as this umbrella review only focused on barriers and facilitators that apply to childhood cancer survivors in general. Differences in barriers and facilitators can exist for survivors that additionally need other types of care caused by co-morbidities such as diabetes and depression (Carfora et al., 2022). Inclusion and exclusion of articles were based on screening of the title and abstract. Then, the full texts of the remaining articles were evaluated by one reviewer.

Data extraction

The data extraction of the systematic reviews consisted of two aspects. First, characteristics of the included reviews were retrieved, including (1) authors, (2) title, (3) year of publication, (4) study design, (5) setting, (6) number of included studies in the review, (7) number of included studies that focus on cancer survivors as target group, and (8) level of barriers and facilitators on which the review mostly focused.

Second, barriers and facilitators of implementing and using digital PROMs that can apply to childhood cancer survivorship care were collected from the systematic reviews that were included in the data extraction. The derived barriers and facilitators were categorised at three different levels: patient level, healthcare professional level, and organisational level.

2.3 Focus group interview on barriers and facilitators for completing digital PROMs

A focus group interview was conducted to discuss what barriers and facilitators for completing digital PROMs can specifically apply to childhood cancer survivors. A focus group interview was considered an appropriate approach since this method has the potential to increase the understanding of factors that can influence individuals' behaviours (Krueger & Casey, 2014). Participants of the focus group were childhood cancer survivor representatives, who are familiar with barriers and facilitators that can exist among cancer survivors due to their experience in their working field. Besides, they are aware of the different types of survivors and their varying perspectives. The inclusion criteria for the survivor representatives consisted of individuals who (1) have had a diagnosis of cancer during childhood, (2) work professionally as childhood cancer survivor representatives in projects in healthcare, and (3) have capabilities of speaking and understanding Dutch. No exclusion criterium was formulated. A group was formed of two survivor representatives, who were invited via an information letter that is available in Appendix C. The focus group lasted approximately sixty minutes.

The procedure for evaluating barriers and facilitators for the completion of digital PROMs started with creating a topic list, based on the overview of barriers and facilitators that resulted from the umbrella review. The content was comprised of questions focusing on four topics: (1) experiences of completing a questionnaire in general in healthcare, (2) the medical difficulty level of a questionnaire and accompanied challenges, (3) the possible deployment of a questionnaire in childhood cancer survivorship care, and (4) the content of included questions in the questionnaire. The topic list is available in Appendix D. During the focus group interview, we aimed to create an atmosphere in which participants felt like they could say everything. In order to increase the perceived open atmosphere, participants of the focus group were ensured that all opinions were accepted and nothing that was discussed in the focus group could be distributed to others. The focus group interview was conducted by two researchers, in which one researcher took minutes and summarised conclusions per topic to assure that stated comments were interpreted correctly. The other researcher facilitated the discussion, asked open questions, was in charge of the time, contributed to a safe and open atmosphere, and made sure that every participant could provide answers to questions.

The data analysis was based on the minutes taken during the focus group interview. Main themes and categories of the barriers and facilitators were defined that captured the manifest content of the focus group. The categories were grouped into the main themes to ensure structured results. Consequently, barriers and facilitators for completing digital PROMs could be defined that can specifically apply to childhood cancer survivors.

3. Results

3.1 Systematic literature review PROMs

3.1.1 Characteristics of selected articles

In PubMed, 805 articles were retrieved. After the title, abstract, and included PROMs were reviewed, 374 articles were assessed as relevant for this study. The other 431 articles were excluded since those did not meet the inclusion and exclusion criteria. The number of included and excluded studies are summarised in the flowchart in Figure 1. An overview of the included articles is available in Appendix E, in which links to the articles and PROMs used in the studies are presented.

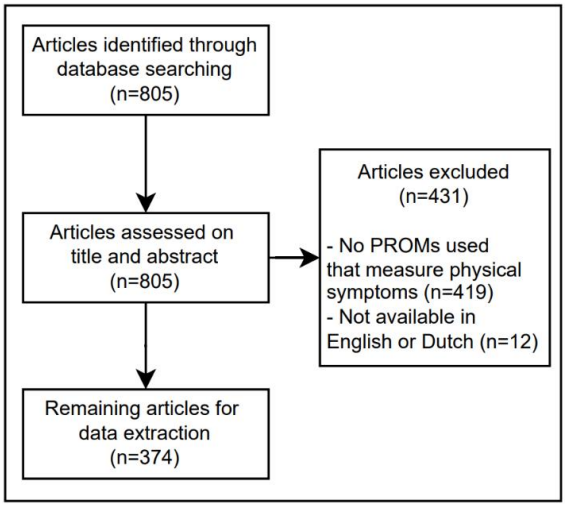

Figure 1: Flow of studies through systematic literature review

3.1.2 Overview of used PROMs in the selected articles

In the 374 articles that resulted from the literature review, 86 different PROMs were used. The overview with PROMs was discussed with two experts, who suggested five additional questionnaires for childhood cancer survivorship care that were lacking. Those instruments were the PanCare FollowUp questionnaire (PCFU), the Adolescent and Young Adult (AYA) anamnesis, the Dutch Childhood Oncology Group (DCOG)-LATER questionnaire, the St. Jude Life questionnaire, and the St. Jude Childhood Cancer Survivor Study (CCSS) questionnaire. Eventually, 91 PROMs were included in the overview of instruments that can assess physical symptoms in childhood cancer survivors, and the content of these questionnaires was explored.

No PROMs are available in literature that are validated and specifically created for assessing physical symptoms of childhood cancer survivors. PROMs were created for seven different target groups, also including the non-validated questionnaires: (1) the general population, (2) chronic disease patients, (3) cancer patients (who currently receive treatment for their cancer diagnosis), (4) childhood cancer patients, (5) adolescent and young adult cancer patients, (6) cancer survivors (who completed treatment for their cancer diagnosis), and (7) adult childhood cancer survivors (who completed treatment for their cancer diagnosis during childhood). Most of the PROMs are originally created for assessing symptoms in cancer patients (n=70).

The five questionnaires that were suggested by experts were not validated for any target group. Those PROMs were searched in scientific literature as no further information was yet known about the questionnaires. It was found that scientific publications were available on those questionnaires. Those publications were mostly written by employees from the organisation that created the questionnaire and did not concern with the validation of the questionnaire. In addition, all suggested PROMs are created for childhood cancer survivors. The questionnaires are composed of comprehensive lists of questions that assess varying types of symptoms in survivors, also involving questions about the background information of survivors such as their previous diagnosis and the presence of other diseases in the family.

The number of articles from the literature review in which the PROMs were used is presented in Figure 2, in which the fifteen most often used PROMs are included. As can be seen in the figure, QLQ-C30 is most frequently used in the studies from the literature review (n=141). In addition, from the total of 374 articles, 197 articles used multiple PROMs in their study (p=53%).

More information has been explored on the 91 PROMs that can assess physical symptoms in childhood cancer survivors. As an illustration, data is presented that is derived from the fifteen PROMs that were most

often used in the articles, available in Table 1. The complete overview of all 91 PROMs and their characteristics is presented in Appendix F, additionally including other characteristics concerning the allocation of symptoms to physical domains, the specific answer options, and the full name of the abbreviated PROM.

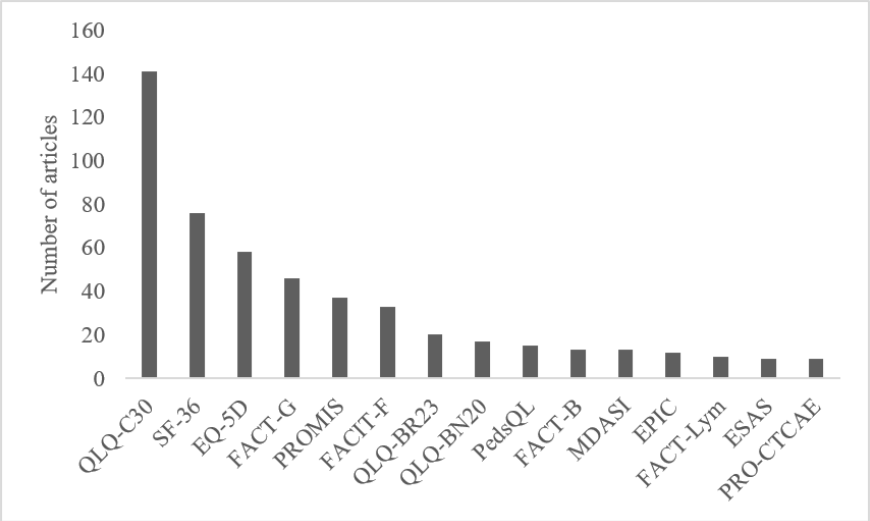

Figure 2: Number of articles from the literature review that used the fifteen most often used PROMs

Table 1

Characteristics of the fifteen most often used PROMs in the selected 374 articles

Questionnaire	Target group	Development year	Proportion questions about physical symptoms	Answer options	Assessment period	Articles that used the PROM	PROM available in Dutch	Validated
QLQ-C30	Cancer patients	1995	10/30	4	Last week	141	Yes	Yes
SF-36	General population	1990	1/36	5	Last month	76	Yes	Yes
EQ-5D	General population	1990	2/5	3	At the moment	58	Yes	Yes
FACT-G	Cancer patients	2007	2/27	5	Last week	46	Yes	Yes
PROMIS	General population	2018	1/29	5	Last week	37	No	Yes
FACIT-F	Chronic disease patients	2007	0/13	5	Last week	33	Yes	Yes
QLQ-BR23	Cancer patients	1996	12/23	4	Last week	20	Yes	Yes
QLQ-BN20	Cancer patients	2010	14/20	4	Last week	17	Yes	Yes
PedsQL	Young adults	1998	7/27	5	Last month	15	Yes	Yes
FACT-B	Cancer patients	2007	5/10	5	Last week	13	Yes	Yes
MDASI	Cancer patients	2000	13/28	11	Last day	13	No	Yes
EPIC	Cancer patients	2002	22/31	5	Last month	12	Yes	Yes
FACT-Lym	Cancer patients	2007	7/15	5	Last week	10	Yes	Yes
ESAS	Cancer patients	2010	5/9	11	At the moment	9	No	Yes
PRO-CTCAE	Cancer patients	2014	76/80	5	Last week	9	Yes	Yes

3.1.3 Overview of a selection of PROMs that are more suitable for childhood cancer survivors

After the 91 PROMs were assessed on the number of questions about physical symptoms from the symptom list from the guidelines used in childhood cancer survivorship care, twelve PROMs were selected for additional data extraction. The other 79 PROMs were excluded since those did not assess any physical symptoms from the symptom list (n=12), or contained less than five questions (between one and four questions) that measure physical symptoms of the symptom list (n=67). The number of included and excluded PROMs is presented in the flowchart in Figure 3.

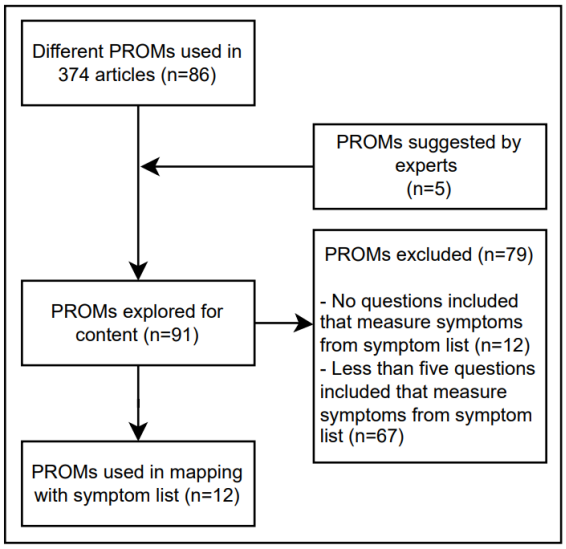

Figure 3: Flow of PROMs through selection process

The questions of the selected twelve PROMs that assess physical symptoms in childhood cancer survivors were connected to the symptom list from the guidelines. The symptoms that are covered by questions from PROMs are indicated with an x in Table 2. A complete overview, also indicating what question is involved about the symptom, is available in Appendix G.

The proportion of physical symptoms from the symptom list that is assessed by questions from the PROMs is presented in Figure 4. As can be seen in the figure, no PROM was available that measures all physical symptoms in childhood cancer survivors. PRO-CTCAE covers most of the symptoms from the symptom list (p=38%), and is originally created for cancer patients. Instruments that cover the second and third most symptoms in survivors are PCFU and St. Jude CCSS, which are two non-validated questionnaires that were suggested by experts. Symptoms of the urinary domain of the symptom list are mostly lacking in those three questionnaires. Those symptoms are measured by the EPIC questionnaire, which includes a sub-domain of questions specifically focusing on urinary symptoms.

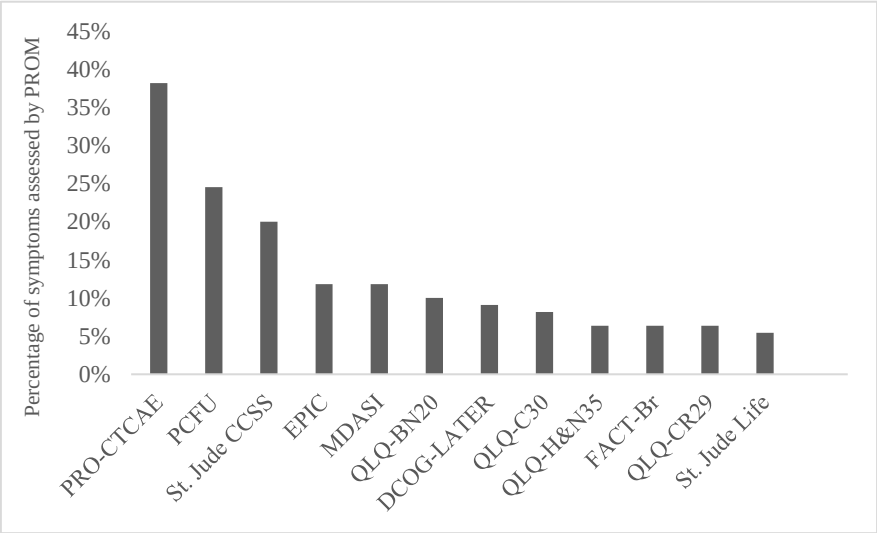

Figure 4: Percentage of physical symptoms from the symptom list that are assessed by questions from the PROMs (n=12)

Table 2

Overview of what physical symptoms of childhood cancer survivors are assessed by the twelve PROMs

Symptoms from guidelines	**PRO-CTCAE**	**PCFU**	**EPIC**	**MDASI**	**QLQ-BN20**	**QLQ-H&N35**	**QLQ-C30**	**FACT-Br**	**QLQ-CR29**	**DCOG-LATER**	**St. Jude CCSS**	**St. Jude Life**
Cough	x					x				x		
Constant cough				x								
Difficulty swallowing or breathing	x	x				x					x	x
Lump or swelling in the neck												
Hoarseness	x					x						
Extreme thirst		x										
Polydipsia												
Aphasia		x			x			x			x	
Intra-oral pain						x						
Suspicious intra-oral lesions												
Heartburn	x	x										
Abdominal distention	x		x	x					x			
Constipation	x	x		x			x					
Chronic diarrhoea	x	x	x				x					
Persistent change in bowel habits				x								
Blood in stool			x						x			
Feeling that the bowel does not empty completely			x									
Unexplained weight loss												
Light-coloured bowel movements												
Shortness of breath	x	x		x			x				x	
Orthopnoea												
Wheezing	x											
Palpitations	x	x								x		
Tachycardia												
Dizziness	x	x									x	
Fainting												
Chest pain		x				x				x	x	x
Swelling	x	x										
Ankle or lower leg oedema				x								
Paraesthesia	x	x		x							x	x
Hyperreflexia												
Weakness												
Pallor												
Skin irritation	x	x			x							
Purpura	x											
Suspicious new skin lesions and changing moles												
Dry skin	x											
Muscle weakness	x	x			x							
Muscle cramping												
Decreased strength and exercise tolerance							x			x	x	
Tetany												
Low blood pressure												
Hemiparesis/hemiplegia												
Behavioural changes					x							
Balance problems		x										
Falling												
Areflexia												
Motor or sensory changes								x				
Lack of coordination					x			x			x	
Seizures					x			x		x	x	
Fractures											x	
Limited range of motion												
Bone mass												
Bone pain	x											

Symptoms from guidelines	PRO-CTCAE	PCFU	EPIC	MDASI	QLQ-BN20	QLQ-H&N35	QLQ-C30	FACT-Br	QLQ-CR29	DCOG-LATER	St. Jude CCSS	St. Jude Life
Visual changes		x		x	x			x			x	
Decreased acuity	x											
Halos	x											
Difficulties in reading or focusing images					x							
Diplopia					x						x	
Dry eyes											x	
Persistent eye irritation												
Excessive tearing	x											
Light sensitivity												
Poor night vision												
Painful eye												
Pain	x	x		x			x			x	x	x
Headache	x				x			x				x
Progressively worsening, severe headaches											x	
Abdominal pain	x	x							x			
Nausea	x			x			x				x	x
Vomiting	x			x			x					
Uneven shoulder blades												
Hump or curve in the back												
Back pain												
Lack of appetite	x			x			x					
Hyperphagia												
Hearing difficulties		x						x			x	
Tinnitus	x	x								x	x	
Polyuria (frequent urination)	x	x							x			
Nocturia		x							x			
Reduced amount of urine												
Dark-coloured urine	x											
Polyuria			x									
Dysuria	x		x						x			
Haematuria			x								x	
Urinary urgency or frequency	x		x		x				x		x	
Abnormal urinary stream												
Sexual dysfunction	x	x	x							x		
Reduced libido	x		x									
Vaginal dryness	x											
Reduced fertility												
Early sexual development												
Night sweats	x											
Icterus												
Reduced growth velocity												
Weight gain		x	x	x		x						
Weight loss						x						
Cold intolerance	x	x										
Heat intolerance												
Brittle hair	x						x				x	
Hypocalcemia												
Hyperphosphatemia												
Missed menstrual periods	x	x								x		
Irregular menstrual periods	x	x								x		
Hot flushes	x		x									
Lump or mass in the breast											x	
Breast or nipple pain	x		x									
Nipple retraction												
Nipple discharge or bleeding												

3.2 Umbrella review of barriers and facilitators

3.2.1 Characteristics of selected reviews

In Scopus, 70 literature reviews were retrieved, of which 49 were excluded based on title and abstract since those did not meet the inclusion and exclusion criteria. Two main reasons for exclusion were because a review was about PROMs in general without a focus on barriers or facilitators (n=29), or a review described barriers and facilitators that did not apply to the general population of cancer survivors (n=10). Afterwards, 21 reviews were assessed based on full-text, from which nine systematic reviews were included for data extraction. The number of included and excluded reviews is presented in the flowchart in Figure 5. An overview of the characteristics of the included systematic reviews is available in Table 3.

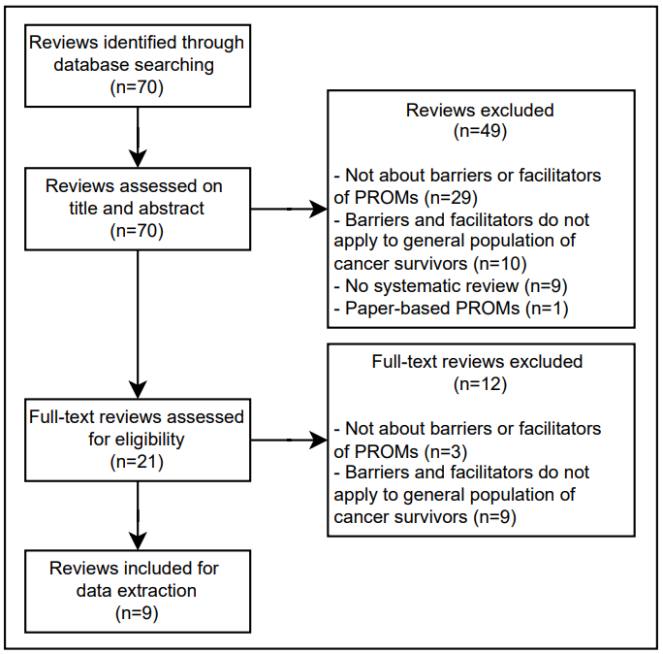

Figure 5: Flow of literature reviews through umbrella review

In total, 281 studies were used in the nine literature reviews. Eight of those studies had cancer survivors as their target group, and none of those studies was directed at cancer survivors that received their diagnosis during childhood. The eight studies all concerned randomised controlled trials, in which a new digital instrument was introduced in cancer survivorship care, such as a web-based system for symptom management by survivors. The studies compared the difference in health outcomes among patients using the new digital instrument, to patients receiving the usually provided care. Seven of the eight studies did not describe any barriers or facilitators for using such an instrument. The other study by Handberg et al. (2018) described one barrier to using PROMs, which is included in the literature review by Easpaig et al. (2020).

Most of the reviews focused on barriers and facilitators at the level of healthcare professionals (HCP) (n=7). Other levels of focus were the patient and the organisation (org). In addition, the reviews focused on four different settings in healthcare: cancer care, clinical care, outpatient rehabilitation care, and palliative care.

Table 3

Characteristics of the included literature reviews from the umbrella review (n=9)

Authors	Title	Year of publication	Setting	Included studies in review	Included studies on cancer survivors	Level of focus
Aapro et al.	Digital health for optimal supportive care in oncology: benefits, limits, and future perspectives	2020	Cancer care	66	5	Patient
Antunes et al.	Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers	2013	Palliative care	31	0	Patient & HCP & org

Briggs et al.	Implementing Patient-Reported Outcome Measures in Outpatient Rehabilitation Settings: A Systematic Review of Facilitators and Barriers Using the Consolidated Framework for Implementation Research	2020	Outpatient rehabilitation care	15	0	HCP & org
Carfora et al.	Patients' experiences and perspectives of patient reported outcome measures in clinical care: A systematic review and qualitative meta-synthesis	2022	Clinical care	14	0	Patient
Easpaig et al.	What are the attitudes of health professionals regarding patient reported outcome measures (PROMs) in oncology practice? A mixed-method synthesis of the qualitative evidence	2020	Cancer care	34	1	HCP
Howell et al.	Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors	2015	Cancer care	30	0	HCP & patient
Nguyen et al.	A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care	2020	Cancer care	14	0	Patient & HCP & org
Yang et al.	Patient-reported outcome use in oncology: a systematic review of the impact on patient clinician communication	2018	Cancer care	43	0	HCP & patient
van Egdom et al.	Implementing Patient-Reported Outcome Measures in Clinical Breast Cancer Care: A Systematic Review	2019	Cancer care	34	2	HCP

3.2.2 Barriers and facilitators from literature reviews

The barriers and facilitators that were identified in the nine systematic reviews are presented using three levels: patient level, healthcare professional level, and organisational level. Barriers and facilitators that were often mentioned are described in this section. The overview of all identified barriers and facilitators is presented in Table 4, divided into three sub-tables with the barriers and facilitators described per level.

Patient-level

The ***lack of perceived value*** *(Aapro et al., 2020; Antunes et al., 2013; Carfora et al., 2022; Howell et al., 2015; Nguyen et al., 2020; Van Egdom et al., 2019)* and the ***lack of knowledge*** *(Aapro et al., 2020; Antunes et al., 2013; Howell et al., 2015; Nguyen et al., 2020; Van Egdom et al., 2019)* are prevalently mentioned barriers for patients to completing PROMs. Besides, ***PROMs involving items that are not perceived as relevant to patients*** hinder their use *(Antunes et al., 2013; Briggs et al., 2020; Carfora et al., 2022; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019)*.

Major facilitators for patients include PROMs assessing ***issues that are relevant to clinical care*** *(Antunes et al., 2013; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019)* and PROMs having the ***ability to be adapted to local needs*** *(Antunes et al., 2013; Yang et al., 2018)*. Moreover, beliefs of patients can facilitate the use of PROMs, such as their perception that they are ***taken more seriously*** *(Aapro et al., 2020; Carfora et al., 2022)* when completing PROMs, or their belief that PROMs can ***facilitate preparation for consults since PROMs let patients consider their condition*** *(Aapro et al., 2020; Carfora et al., 2022)*.

Table 4a

Barriers and facilitators of using and implementing PROMs from umbrella review at patient level

Barriers	Facilitators
● Lack of perceived value of PROMs (e.g. because patients don't understand purpose) (Aapro et al., 2020; Antunes et al., 2013; Carfora et al., 2022; Howell et al., 2015; Nguyen et al., 2020; Van Egdom et al., 2019) ● PROMs involve items that are not relevant to patients (Antunes et al., 2013; Briggs et al., 2020; Carfora et al., 2022; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019) ● Lack of knowledge about completing PROMs (Aapro et al., 2020; Antunes et al., 2013; Howell et al., 2015; Nguyen et al., 2020; Van Egdom et al., 2019) ● Inability to complete: ○ Too burdensome: takes too much time and takes too long (Antunes et al., 2013; Briggs et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Van Egdom et al., 2019) ○ Difficult independently (Briggs et al., 2020; Nguyen et al., 2020) ○ Too confusing (e.g. due to no consistent symptom recall period) (Briggs et al., 2020; Van Egdom et al., 2019) ○ Require too high reading level (Briggs et al., 2020; Howell et al., 2015; Nguyen et al., 2020) ● Belief of patients that PROMs: ○ Cannot accurately capture the patient's symptoms and cannot reflect the patient's situation (Antunes et al., 2013; Carfora et al., 2022; Van Egdom et al., 2019) ○ Cannot be answered by patients as they are no doctors (Carfora et al., 2022) ○ May compromise the HCP to patient relationship (Nguyen et al., 2020) ○ Are not used during consultations, which leads to lower perceived value (Carfora et al., 2022) ○ Are only useful for HCPs or research (Carfora et al., 2022) ● Language restriction when PROMs are not translated (Aapro et al., 2020; Antunes et al., 2013; Briggs et al., 2020; Howell et al., 2015) ● PROMs can distress patients by self-reflection (Briggs et al., 2020; Carfora et al., 2022) ● Patient expectations: want treatment, not PROMs (Briggs et al., 2020) ● Lack of reminders to complete PROMs (Yang et al., 2018)	● PROMs involve items that are relevant to clinical care (Antunes et al., 2013; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019) ● Use of PROMs that can be adapted to local needs (Antunes et al., 2013; Yang et al., 2018) ● Use of PROMs that need a short time to complete with consistent instructions (Antunes et al., 2013; Carfora et al., 2022) ● Data of PROMs is shown during consult (Antunes et al., 2013) ● Belief of patients that PROMs: ○ Let patients be taken more seriously (Aapro et al., 2020; Carfora et al., 2022) ○ Facilitate preparation for consultations, because PROMs let patients self-reflect on their condition (Aapro et al., 2020; Carfora et al., 2022) ○ Increase understanding of their condition (Carfora et al., 2022) ○ Lead to improved communication with HCPs (Aapro et al., 2020) ○ Help for patient empowerment (Aapro et al., 2020; Carfora et al., 2022) ○ Can enable shared-decision making (Carfora et al., 2022) ○ Can lead to individualised approach to patients since there is more focus on symptoms that bother the patient (Carfora et al., 2022) ● Provide information on: ○ How to complete PROMs (Antunes et al., 2013; Yang et al., 2018) ○ PRO score results (Van Egdom et al., 2019) ○ How to interpret scales (Antunes et al., 2013; Yang et al., 2018) ○ Purpose of PROMs (Briggs et al., 2020)

<u>Healthcare professional-level</u>

A barrier that was present in cancer survivorship care for healthcare professionals in using PROMs was the ***belief that PROMs require performing additional tasks on top of other competing demands*** *(Handberg et al., 2018; Easpaig et al., 2020)*. Other key barriers for healthcare professionals include a ***lack of perceived value*** *(Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Yang et al., 2018)*, and a ***lack of knowledge*** *(Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Yang et al., 2018)*.

A major facilitator for healthcare professionals is using ***simple graphics to present results, which allows for easy and quick interpretation*** *(Aapro et al., 2020; Antunes et al., 2013; Carfora et al., 2022; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019)*. Moreover, the ***provision of training prior to the implementation of PROMs on how to use, analyse and interpret data resulting from PROMs*** *(Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020)* facilitates the use of PROMs.

Table 4b

Barriers and facilitators of using and implementing PROMs from umbrella review at healthcare professional level

Barriers	Facilitators
● Lack of perceived value of PROMs (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Yang et al., 2018) ● Lack of knowledge about using PROMs (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Yang et al., 2018) ● Lack of training on how to use, analyse and integrate PROMs (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020) ● Time constraints: ○ Too much of HCP's time (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020; Yang et al., 2018) ○ Not enough time to address issues during consult that arise from PROMs (Easpaig et al., 2020; Howell et al., 2015; Nguyen et al., 2020) ○ Not enough staff (Antunes et al., 2013) ○ Fear of added work (Antunes et al., 2013) ● Belief of HCPs that PROMs: ○ Are used as a substitute for direct care, instead of as an adjunct to care (Antunes et al., 2013; Howell et al., 2015; Yang et al., 2018) ○ Are intrusive in the clinical setting and disrupt current routine (Antunes et al., 2013; Howell et al., 2015; Yang et al., 2018) ○ Do not help direct patient care (Briggs et al., 2020; Yang et al., 2018) ○ Are too subjective (Antunes et al., 2013; Briggs et al., 2020) ○ Require performing additional tasks on top of other competing demands (Easpaig et al., 2020) ○ Are only useful for research (Briggs et al., 2020) ● HCPs resistance to behavioural change: ○ Headstrong in own method (Briggs et al., 2020) ○ Fear of change (Antunes et al., 2013) ● Overload of information since too much redundant information is included (Briggs et al., 2020; Van Egdom et al., 2019) ● Lack of incentives for HCPs (Yang et al., 2018) ● Lack of personal interest (Briggs et al., 2020)	● Use of simple graphics to present results, which allows for easy and quick interpretation (e.g. present data in the form of histograms, bar charts and line graphs with comparison data (Yang et al., 2018)) (Aapro et al., 2020; Antunes et al., 2013; Carfora et al., 2022; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019) ● Training before implementation on how to use, analyse and integrate PROMs (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020) ● Benefits of PROMs are easy noticeable (Aapro et al., 2020; Antunes et al., 2013; Easpaig et al., 2020) ● Convinced of the benefits and value of PROMs (Aapro et al., 2020; Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Yang et al., 2018) ● Belief of HCPs that PROMs: ○ Contribute to an increased understanding of the patient's condition (Carfora et al., 2022; Van Egdom et al., 2019) ○ Lead to improved communication between patients and HCPs since PROMs can provide opening-up to discuss broader issues (Antunes et al., 2013; Carfora et al., 2022) ○ Contribute to real-time reporting of symptoms (Aapro et al., 2020) ○ Contribute to a higher quality of care (Briggs et al., 2020) ○ Are integral component of clinical care (Antunes et al., 2013) ○ Lead to increased efficiency for patient visits (Carfora et al., 2022) ● Use of reminders to use PROMs, explicitly requested during consults (Antunes et al., 2013; Yang et al., 2018) ● Readiness to change (Briggs et al., 2020)

Organisational-level

The key barrier at the organisational level is the ***lack of integration of PROMs into clinical practice*** *(Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Nguyen et al., 2020; Van Egdom et al., 2019)*. Besides, ***problems with technology*** *(Aapro et al., 2020; Antunes et al., 2013; Nguyen et al., 2020; Yang et al., 2018; Van Egdom et al., 2019)* can impede the use of PROMs in daily practice.

A major facilitator is the ***integration of PROMs in daily routine*** *(Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019)*. Another prevalent facilitator is ***assigning a coordinator to lead the implementation process of PROMs*** *(Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Yang et al., 2018; Van Egdom et al., 2019)*, who is performing facilitating tasks such as encouraging the patient's acceptance of PROM collection and guiding healthcare professionals through PROM results.

Table 4c

Barriers and facilitators of using and implementing PROMs from umbrella review at organisational level

Barriers	Facilitators
● Lack of integration of PROMs into clinical practice (e.g. when HCPs have to use an extra computer program to use PROMs) (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Nguyen et al., 2020; Van Egdom et al., 2019) ● Problems with technology (e.g. generation of false alerts to complete PROM) (Aapro et al,. 2020; Antunes et al., 2013; Nguyen et al., 2020; Yang et al., 2018; Van Egdom et al., 2019) ● Cost constraints (Antunes et al., 2013; Briggs et al., 2020; Nguyen et al., 2020; Van Egdom et al., 2019) ● Lack of a user-friendly infrastructure (Briggs et al., 2020; Nguyen et al., 2020; Yang et al., 2018) ● Absence of practice policy *(Briggs et al., 2020; Easpaig et al., 2020; Nguyen et al., 2020)* ● Concerns about privacy and security of patient data *(Nguyen et al., 2020; Van Egdom et al., 2019)* ● Lack of meetings with discussions among HCPs (Briggs et al., 2020) ● Lack of knowledge in what PROMs to choose for clinical practice (Briggs et al., 2020)	● Integrate PROMs in daily routine (e.g. by embedding PROM results in EHR) (Briggs et al., 2020; Easpaig et al., 2020; Howell et al., 2015; Yang et al., 2018; Van Egdom et al., 2019) ● Assign coordinator to lead implementation (Antunes et al., 2013; Briggs et al., 2020; Easpaig et al., 2020; Yang et al., 2018; Van Egdom et al., 2019), tasks: ○ Encourage patient's acceptance of PROM collection ○ Guide HCPs through PROM results and ensure that appropriate actions are taken to address patient issues ○ Appreciate the impact of PROMs, to encourage HCPs to use them ○ Provide ongoing support at departmental and organisational levels ● Presence of practice policy (Briggs et al., 2020; Easpaig et al., 2020; Yang et al., 2018; Van Egdom et al., 2019) ● Use of implementation strategies (Antunes et al., 2013; Briggs et al., 2020) ● Involve HCPs in the development process: ○ Prior meeting to explore the feasibility of implementation (Antunes et al., 2013) ○ Regular meetings with feedback from HCPs (Howell et al., 2015) ● Content of PROMs: ○ Comment boxes to specify items (Carfora et al., 2022; Van Egdom et al., 2019) ○ Ability to flag important items (Carfora et al., 2022; Howell et al., 2015) ○ Consistency in scale meaning and PROM score (Howell et al., 2015; Van Egdom et al., 2019) ○ Ideal length of up to 20 questions (Yang et al., 2018) ○ Ideal administer time up to 10 minutes (Yang et al., 2018) ● Characteristics of PROMs: ○ Completion moment coincides with consultations in the hospital (Carfora et al., 2022; Yang et al., 2018) ○ Notifications to patients and/or managers when HCPs have reviewed PROM results (Van Egdom et al., 2019) ○ Ability to monitor PROM scores by patients (Van Egdom et al., 2019) ○ Circulate PROM data to all HCPs involved in the care pathway of a single patient (Yang et al., 2018) ● Fast response to system alerts (Aapro et al., 2020)

3.3 Focus group interview with childhood cancer survivor representatives

Nineteen categories were identified through the focus group interview (n=2) that can serve as barriers or facilitators for childhood cancer survivors to complete PROMs in daily clinical practice. Those categories were grouped into three main themes: (1) barriers for childhood cancer survivors to complete PROMs, (2) facilitators for childhood cancer survivors to complete PROMs, and (3) suggested approaches to facilitate the use of PROMs by childhood cancer survivors. A selection of barriers and facilitators is described in this section and the overview of all barriers and facilitators is available in Table 5.

Barriers for childhood cancer survivors to complete PROMs

A *lack of perceived value* of PROMs was comprehensively discussed by the survivor representatives as being a barrier to complete PROMs. The representatives indicated this was caused by the fact that they have encountered many types of questionnaires in their working field, while a majority of those instruments are not used by doctors. Other described barriers were the *time required* to complete PROMs, *involved items that are not relevant* to survivors, *the same questions being asked* during the consult, the doctor *not coming back to the answers*, and *PROMs distressing survivors by self-reflection*. Moreover, the *inability to complete PROMs* impedes the completion of PROMs, which can be caused by multiple reasons, including *a confusing way of asking questions*, *a distracting format*, *reading difficulties*, *visual limitations*, *technology issues*, *dyslectic people*, *non-native Dutch readers*, and *cognitive difficulties*.

Facilitators for childhood cancer survivors to complete PROMs

The survivor's *understanding of the purpose* of PROMs can facilitate the completion of PROMs. Besides, the survivor representatives mentioned that the *ability to monitor health conditions through the years* contributes to completion, as survivors can see differences in their health conditions if they have completed PROMs multiple times. Another facilitator is the *doctor taking time to discuss the answers of PROMs during the consult*. The *use of reminders* to complete PROMs is also useful for completion. Lastly, the beliefs of survivors can contribute to the completion of PROMs, including beliefs that PROMs are *interesting to complete*, *facilitate preparation for consultations through self-reflection*, and *facilitate performing research on their own health situation*.

Suggested approaches to facilitate the use of PROMs by childhood cancer survivors

Survivor representatives suggested approaches that can facilitate the completion of PROMs. Features that the content should contain include *a clear elaboration about what symptoms the question assesses*, *a simple way of asking questions*, and *clear differentiation between answer options*. Besides, characteristics of PROMs can contribute to completing PROMs, including *the completion moment coinciding with consults in the hospital*, *the ability to make letters larger*, *the ability to let the questions be read out loud*, and *a completion time of twenty minutes*. Another suggested approach was *involving an introduction text in the questionnaire*, in which aspects are included about the *purpose of completing PROMs*, and *a time indication*. Lastly, the survivor representatives discussed the useful addition to create a *video with a short explanation* about PROMs.

Table 5

Barriers, facilitators and suggested approaches to complete PROMs for childhood cancer survivors

Barriers for survivors to complete PROMs	Facilitators for survivors to complete PROMs
● Lack of perceived value of PROMs: survivors do not understand the purpose, as many questionnaires are already existing that are not used ● PROMs take a long time to complete ● PROMs involve items that are not relevant to survivors: extra topics could be wanted to be discussed as well (e.g. side effects of current medication, or effects of drugs/alcohol on medication) ● Same questions are asked during consult ● Doctor does not come back to the answers of completed PROMs ● PROMs can distress survivors by self-reflection ● Belief of survivors that PROMs:	● Understand the purpose of PROMs ● Ability to monitor health conditions through the years, as the survivor can see differences in health condition through PROM results ● Doctor takes time to discuss the answers of completed PROMs during consult ● Use of reminders to complete PROMs ● Belief of survivors that PROMs: ○ Are interesting to complete ○ Facilitate preparation for consultations, because PROMs let survivors self-reflect on their own health situation

○ Cannot be answered by survivors since they are not qualified to ○ Are not useful to complete when survivor has (almost no) complaints ○ Have to be answered consistently, which takes more time to do ● Inability to complete, possible reasons: ○ Confusing way of asking questions ○ Distracting format ○ Reading difficulties ○ Visual limitations ○ Technology issues, caused by challenges to complete PROMs with computers ○ Dyslectic people ○ Non-native Dutch reader ○ Cognitive difficulties (e.g. light mental disorder)	○ Facilitate performing research on own health condition ○ Can provide a complete understanding of health condition ○ Contribute to a more patient-centred consult, as topics can be discussed that the survivor considers relevant

Suggested approaches to facilitate the use of PROMs by childhood cancer survivors

● Content of PROMs:
- ○ Clear elaboration about what symptoms the question assesses
- ○ Simple way of asking questions
- ○ Clear differentiation between answer options (*e.g. difference between 'a little bit' and 'somewhat' is vague*)
- ○ Answer option 'I don't know'
- ○ No unrequired information involved to ensure a simple format
- ○ No questions about the frequency of symptom occurrence as the frequency is challenging to remember (i.e. 'how often')
- ○ Include pictures to support the questions
- ○ Comment box at end of the questionnaire to discuss aspects that were not asked in the questionnaire, which provides the feeling that the survivor matters to the doctor
- ○ Use of objective questions (*e.g. 'how bad' is subjective: when you don't possess the symptom, you can't indicate that you don't have the symptom. First a question should be included about whether you possess the symptom)*

● Characteristics of PROMs:
- ○ Completion moment coincides with consultations in the hospital
- ○ Ability to make letters larger
- ○ Ability to let the computer read the questions out loud
- ○ Ideal completion time of up to 20 minutes
- ○ PROMs are distributed two to three weeks prior to the consult
- ○ Interesting format: not only black and white, but light colours
- ○ Ability to pause while completing PROMs
- ○ Ability to complete PROMs via multiple platforms: via computer or on paper

● Involve introduction text, including:
- ○ Purpose of completing
- ○ Time indication
- ○ That emotions can be included when completing the questionnaire
- ○ That the questionnaire can be completed with family

● Include a video in the introduction with a short explanation about PROMs, which should take a maximum of 30 seconds

● Consider gender specifications when asking about whether someone is male/female

4. Discussion

This study aimed to (1) identify what validated PROMs are available in literature for assessing physical symptoms in childhood cancer survivors, and (2) explore barriers and facilitators that can apply to childhood cancer survivors and their doctors in implementing and using PROMs in daily clinical practice. To the author's knowledge, this is the first study that has focused on the identification of suitable PROMs, barriers and facilitators in the setting of childhood cancer survivorship care. In this section, key findings are discussed separately for the three research questions. Afterwards, limitations and an overarching conclusion for this study are made.

4.1 What validated PROMs can measure physical symptoms that are monitored in the follow-up care for adult childhood cancer survivors?

No validated questionnaire was found that can measure all physical symptoms that are monitored in adult childhood cancer survivorship care. Still, the systematic literature review and suggested PROMs by experts resulted in an overview of 91 PROMs that can be used in childhood cancer survivorship care, but all validated instruments are originally created for other target groups than childhood cancer survivors. The findings of the literature review are in line with other reviews that examined the use of PROMs in clinical cancer care and found that the EORTC QLQ-C30 questionnaire is most often used in studies (Ahmed-Lecheheb & Joly, 2016; Giesinger et al., 2021; Shisler et al., 2018). This finding can be explained by the fact that QLQ-C30 is a questionnaire created for the general population, so is broadly applicable to different types of patients. It is still relevant to use questionnaires not specifically created for childhood cancer survivors as the overall health of survivors can also be measured with general-oriented instruments, and symptoms of other patients might also be experienced by survivors. However, the questionnaires are not validated in childhood cancer survivors, implying it is unknown whether the instruments can accurately measure the symptoms and overall health in survivors. The questionnaire that covers most of the physical symptoms in childhood cancer survivorship care (38%) is PRO-CTCAE, but this questionnaire still does not cover all symptoms as the instrument is created for measuring physical symptoms in cancer patients who currently receive treatment for their diagnosis. To ensure that all physical symptoms are measured that are monitored in follow-up care, additional questionnaires should be used. EPIC could be considered in addition, as this questionnaire measures many symptoms in the urinary domain that are lacking in PRO-CTCAE. Using multiple questionnaires to let patients measure their health is common in PROM use as a majority of the included studies from the literature review use multiple instruments to let patients assess their overall health.

The suggested PROMs by experts were non-validated instruments, created by organisations for their own use and their own specific target group of childhood cancer survivors. The PROMs did not result from the search of the literature review as almost no studies have been published about the questionnaires, which can be caused by the fact that the instruments include extensive lists of questions about varying domains exclusively relevant to childhood cancer survivorship care. As childhood cancer survivors are an underrepresented target group in literature, the questionnaires are not often used by other studies, making it less relevant to publish about the instruments (Steliarova-Foucher et al., 2017). Furthermore, the instruments are not validated, making them also less relevant to publish about. A choice should be made in childhood cancer survivorship care between using a non-validated questionnaire that is specifically created for childhood cancer survivors, or using a validated questionnaire that may be less fitting for the target group. Future research should (1) investigate the feasibility of using non-specific questionnaires in childhood cancer survivorship care

and validate those instruments in survivors, (2) validate existing instruments created for survivors, or (3) create and validate a new questionnaire including all physical symptoms that are monitored in childhood cancer survivorship care.

4.2 What barriers and facilitators are described in literature for implementing and using digital PROMs in daily clinical practice that can apply to adult childhood cancer survivors, their doctors and the organisation of care?

No literature reviews and no studies included in those reviews focused specifically on the target group of childhood cancer survivors. Therefore, the created overview of barriers and facilitators can only be used as an indication of what factors might impede or facilitate the use and implementation of PROMs for childhood cancer survivors. Yet, the found barriers and facilitators will apply to a great extent to childhood cancer survivorship care as the identified factors are generally applicable to multiple clinical settings. Besides, a comprehensive overview was created by combining literature reviews describing barriers and facilitators for completing PROMs in varying care settings. However, the barriers and facilitators may not be completely applicable to childhood cancer survivorship care, as childhood cancer survivors can experience other difficulties in completing PROMs compared to other cancer survivors or patients (Steliarova-Foucher et al., 2017). An example is having social difficulties in daily life caused by receiving cancer treatments during the growth process in childhood (Steliarova-Foucher et al., 2017). In addition, childhood cancer survivors only come to the hospital for follow-up care yearly or once every two or five years, so they receive another type of care than many other patients receive (Mud et al., 2012). The missing perspective of childhood cancer survivors in literature can be explained by the fact that paediatric cancer occurs less frequently than other chronic diseases, making it less tempting to perform research on that topic (Ayanian & Jacobsen, 2006; Steliarova-Foucher et al., 2017). Future research should be performed on barriers and facilitators that specifically apply to childhood cancer survivorship care.

More barriers and facilitators were found for healthcare professionals, compared to patients. This finding is in line with a majority of the literature reviews from the umbrella review focusing on the level of healthcare professionals. Furthermore, the findings show that healthcare professionals should be involved when implementing PROMs (Antunes et al., 2013). No reviews indicated that patients have to be included in the implementation process, which contradicts another study, that explicitly reports the need to involve patients in the whole process of designing and implementing PROMs (Haywood et al., 2016). Still, many studies do not include the patient's perspective, illustrating the need for future PROM development to further incorporate the patient in the process of implementing PROMs.

The findings on the barriers and facilitators that can hinder the implementation of PROMs are in line with studies that explored another field in healthcare: the implementation of clinical performance measures (Kondo et al., 2016). Those measures are indicators of the quality of provided care in healthcare organisations rendered by clinicians. Similar findings in both studies were found, such as the importance of including the instruments in daily routine and the importance of a strong infrastructure that can facilitate the implementation (Kondo et al., 2016). The similarity of the findings is mostly present in the structural characteristics that need to be considered to enable the implementation and utilisation of those instruments. It can be concluded that the findings concerning barriers and facilitators of PROMs are broader generalisable in healthcare than merely PROM use, and offer valuable insight for the development and implementation of other instruments in healthcare.

4.3 What barriers and facilitators for completing digital PROMs are experienced by the target group of adult childhood cancer survivors?

The barriers and facilitators that were found for childhood cancer survivor representatives provide an indication of what factors should receive greater emphasis in childhood cancer survivorship care. Besides, extra consideration should be given to barriers and facilitators that were mentioned by survivors and were lacking in literature, as those factors can be experienced specifically by childhood cancer survivors. A barrier that was described by childhood cancer survivor representatives, but was not mentioned in literature, includes the belief that PROMs are not useful to complete when the patient does not have complaints. A newly described facilitator was the ability to monitor the PROM results throughout the years, to be able to see differences in health conditions. Those factors can arise specifically for survivors as they receive long-term follow-up care, in which they rarely come to the hospital and may not experience any complaints when they come (Mud et al., 2012). In addition, multiple reasons were found why childhood cancer survivors would not be able to complete PROMs, such as visual and cognitive limitations, possibly caused by treatments in their growth process. Suggested approaches were found that can assist survivors in completing PROMs, such as the ability to make letters larger, or the ability to let questions be read out loud. Future research that explores barriers and facilitators for childhood cancer survivors should consider the variety of additional complications that can be present among survivors, possibly leading to different factors that impede or facilitate the completion of PROMs.

The findings of the focus group interview only provide an indication of what barriers and facilitators can specifically apply to childhood cancer survivors, as it was performed with only two participants. A focus group interview was performed due to the absence of studies in literature focusing on barriers and facilitators of completing PROMs for childhood cancer survivors, but due to time constraints, no additional focus groups could be conducted. Performing more focus groups is preferred as multiple perspectives and different group dynamics can be included. When other focus groups would have been conducted, participants may have more frequently disagreed with each other, leading to more discussion and a broader variety of results. Future research is needed to explore all barriers and facilitators for completing PROMs that can exist in childhood cancer survivors, which can be conducted by performing multiple focus groups with childhood cancer survivors.

4.4 Limitations

The systematic literature review includes some study-specific limitations that need to be acknowledged. First, the search was restricted to one database, so more PROMs may have been found when exploring other databases as well. Second, articles were only included when those were written in English or Dutch, whereas a PROM developed for measuring symptoms in childhood cancer survivors might exist in other languages. Third, one reviewer did the inclusion and exclusion of articles, as well as the exploration of the content of PROMs, making the data extraction error-prone. Fourth, the focus of this study has been on the identification of PROMs that can assess physical symptoms in childhood cancer survivors. However, this overview does not provide the complete picture as the guidelines used in childhood survivorship care also include information about the provision of care based on psychosocial and lifestyle symptoms. A future study is needed to investigate what PROMs are suitable for assessing psychosocial and lifestyle aspects in childhood cancer survivors.

The umbrella review also includes some study-specific limitations that should be acknowledged. First, systematic reviews have been identified in the study. However, useful individual studies about barriers and facilitators in cancer survivors may exist that are recently conducted, so are not yet included in systematic reviews, and are therefore not involved in this study. Second, only one database has been searched, so other possible useful reviews may have been missed that were included in other databases. Third, the results of the umbrella review are rather homogenous, as all included studies are derived from Western countries. Therefore, the identified barriers and facilitators are only applicable to similar healthcare organisations. Fourth, only one reviewer included, excluded, and synthesised the data, making the data extraction error-prone. Fifth, the umbrella review only counted the frequency of what barriers and facilitators are mentioned in the literature reviews, without any weighting. As a result, it is challenging to say what impact the different factors may have, and how independent components interact. Sixth, the wording in literature concerning barriers and facilitators can be confusing. For example, the disadvantages of using PROMs are not the same as the barriers to using PROMs. Consequently, some reviews might not have resulted from the literature search that used different words for barriers and facilitators.

4.5 Conclusion

Currently, no validated questionnaire is available that can measure all physical symptoms that are monitored in the follow-up care of childhood cancer survivors. Therefore, a new questionnaire should be established, in which a new instrument can be created that measures all physical symptoms in childhood cancer survivors, or validated instruments can be combined that were originally created for other patient groups. However, barriers can arise when using non-specific questionnaires that might impede childhood cancer survivors from completing PROMs, such as the involvement of non-relevant items as the instrument was originally created for another patient group. In addition, combining multiple questionnaires can result in a long, burdensome, and confusing task to complete, as different formats are used in the instruments. Those barriers could be partly overcome by using digital PROMs, in which features such as computer adaptive testing can be utilised that can decrease the length of a questionnaire by only involving items relevant to the patient's health situation (Meirte et al., 2020; Morris et al., 2017). The identified barriers and facilitators for completing PROMs can only be used as an indication of what factors can be present among childhood cancer survivors, as the perspective of survivors was obtained via a limited focus group interview. Future efforts are needed to validate the most suitable questionnaire(s) among childhood cancer survivors, and explore all barriers and facilitators for implementing and using PROMs that can apply in childhood cancer survivorship care. Eventually, using a suitable and comprehensive PROM in daily practice can be the way towards more patient-centred and ultimately better childhood cancer survivorship care.

References

Aapro, M., Bossi, P., Dasari, A., Fallowfield, L., Gascón, P., Geller, M., Jordan, K., Kim, J., Martin, K., & Porzig, S. (2020). Digital health for optimal supportive care in oncology: benefits, limits, and future perspectives. *Supportive Care in Cancer*, *28*(10), 4589–4612. https://doi.org/10.1007/s00520-020-05539-1

Ahmed-Lecheheb, D., & Joly, F. (2016). Ovarian cancer survivors' quality of life: a systematic review. *Journal of Cancer Survivorship*, *10*(5), 789–801. https://doi.org/10.1007/s11764-016-0525-8

Antunes, B., Harding, R., & Higginson, I. J. (2013). Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review of facilitators and barriers. *Palliative Medicine*, *28*(2), 158–175. https://doi.org/10.1177/0269216313491619

Ayanian, J. Z., & Jacobsen, P. B. (2006). Enhancing Research on Cancer Survivors. *Journal of Clinical Oncology*, *24*(32), 5149–5153. https://doi.org/10.1200/jco.2006.06.7207

Basch, E., Reeve, B. B., Mitchell, S. A., Clauser, S. B., Minasian, L. M., Dueck, A. C., Mendoza, T. R., Hay, J., Atkinson, T. M., Abernethy, A. P., Bruner, D. W., Cleeland, C. S., Sloan, J. A., Chilukuri, R., Baumgartner, P., Denicoff, A., St. Germain, D., O'Mara, A. M., Chen, A., Kelaghan, J., Bennett, A. V., Sit, L., Rogak, L., Barz, A., Paul, D. B., Schrag, D. (2014). Development of the National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE). *Journal of the National Cancer Institute*, *106*(9), 1–11. https://doi.org/10.1093/jnci/dju244

Briggs, M. S., Rethman, K. K., Crookes, J., Cheek, F., Pottkotter, K., McGrath, S., DeWitt, J., Harmon Matthews, L. E., & Quatman-Yates, C. C. (2020). Implementing Patient-Reported Outcome Measures in Outpatient Rehabilitation Settings: A Systematic Review of Facilitators and Barriers Using the Consolidated Framework for Implementation Research. *Archives of Physical Medicine and Rehabilitation*, *101*(10), 1796–1812. https://doi.org/10.1016/j.apmr.2020.04.007

Carfora, L., Foley, C. M., Hagi-Diakou, P., Lesty, P. J., Sandstrom, M. L., Ramsey, I., & Kumar, S. (2022). Patients' experiences and perspectives of patient-reported outcome measures in clinical care: A systematic review and qualitative meta-synthesis. *PLOS ONE*, *17*(4), https://doi.org/10.1371/journal.pone.0267030

Curry, H. L., Parkes, S. E., Powell, J. E., & Mann, J. R. (2006). Caring for survivors of childhood cancers: The size of the problem. *European Journal of Cancer*, *42*(4), 501–508. https://doi.org/10.1016/j.ejca.2005.11.003

Easpaig, B. N. G., Tran, Y., Bierbaum, M., Arnolda, G., Delaney, G. P., Liauw, W., Ward, R. L., Olver, I., Currow, D., Girgis, A., Durcinoska, I., & Braithwaite, J. (2020). What are the attitudes of health professionals regarding patient reported outcome measures (PROMs) in oncology practice? A mixed-method synthesis of the qualitative evidence. *BMC Health Services Research*, *20*(1). https://doi.org/10.1186/s12913-020-4939-7

Feijen, E. A. M. L., Font-Gonzalez, A., Van der Pal, H. J. H., Kok, W. E. M., Geskus, R. B., Ronckers, C. M., Bresters, D., Van Dalen, E. C., Van Dulmen-den Broeder, E., Van den Berg, M. H., Van der Heiden-van Der Loo, M., Van den Heuvel-Eibrink, M. M., Van Leeuwen, F. E., Loonen, J. J., Neggers, S. J. C. M. M., Versluys, A. B. B., Tissing, W. J. E., & Kremer, L. C. M. (2019). Risk and Temporal Changes of Heart Failure Among 5-Year Childhood Cancer Survivors: a DCOG-LATER Study. *Journal of the American Heart Association*, *8*(1). https://doi.org/10.1161/jaha.118.009122

Foster, A., Croot, L., Brazier, J., Harris, J., & O'Cathain, A. (2018). The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. *Journal of Patient-Reported Outcomes*, *2*(1). https://doi.org/10.1186/s41687-018-0072-3

Geenen, M. M., Cardous-Ubbink, M. C., Kremer, L. C. M., Van den Bos, C., Van der Pal, H. J. H., Heinen, R. C., Jaspers, M. W. M., Koning, C. C. E., Oldenburger, F., Langeveld, N. E., Hart, A. A. M., Bakker, P. J. M., Caron, H. N., & Van Leeuwen, F. E. (2007). Medical Assessment of Adverse Health Outcomes in Long-term Survivors of Childhood Cancer. *Journal of the American Medical Association*, *297*(24), 2705–2715. https://doi.org/10.1001/jama.297.24.2705

Giesinger, J. M., Efficace, F., Aaronson, N., Calvert, M., Kyte, D., Cottone, F., Cella, D., & Gamper, E. M. (2021). Past and Current Practice of Patient-Reported Outcome Measurement in Randomized Cancer Clinical Trials: A Systematic Review. *Value in Health*, *24*(4), 585–591. https://doi.org/10.1016/j.jval.2020.11.004

Gordon, B. B. E., & Chen, R. C. (2017). Patient-reported outcomes in cancer survivorship. *Acta Oncologica*, *56*(2), 166–173. https://doi.org/10.1080/0284186x.2016.1268265

Handberg, C., Thorne, S., & Maribo, T. (2018). When a policy decision meets practice realities: The case of cancer survivorship care and rehabilitation needs assessment. *European Journal of Oncology Nursing*, *33*, 70–77. https://doi.org/10.1016/j.ejon.2018.01.010

Haywood, K. L., Wilson, R., Staniszewska, S., & Salek, S. (2016). Using PROMs in Healthcare: Who Should Be in the Driving Seat—Policy Makers, Health Professionals, Methodologists or Patients? *The Patient - Patient-Centered Outcomes Research*, *9*(6), 495–498. https://doi.org/10.1007/s40271-016-0197-5

Howell, D., Molloy, S., Wilkinson, K., Green, E., Orchard, K., Wang, K., & Liberty, J. (2015). Patient reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Annals of Oncology*, *26*(9), 1846–1858. https://doi.org/10.1093/annonc/mdv181

International Guideline Harmonization Group (IGHG). (2021). *Handbook for Guideline Development* (version 4). accessible via: https://www.ighg.org/wp-content/uploads/2021/06/IGHG-Handbook-for-guideline-development_Version-4_April-2021.pdf

Kondo, K. K., Damberg, C. L., Mendelson, A., Motu'apuaka, M., Freeman, M., O'Neil, M., Relevo, R., Low, A., & Kansagara, D. (2016). Implementation Processes and Pay for Performance in Healthcare: A Systematic Review. *Journal of General Internal Medicine*, *31*(1), 61–69. https://doi.org/10.1007/s11606-015-3567-0

Kremer, L. C., Mulder, R. L., Oeffinger, K. C., Bhatia, S., Landier, W., Levitt, G., Constine, L. S., Wallace, W. H., Caron, H. N., Armenian, S. H., Skinner, R., & Hudson, M. M. (2012). A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: A report from the international late effects of Childhood Cancer Guideline Harmonization Group. *Pediatric Blood & Cancer*, *60*(4), 543–549. https://doi.org/10.1002/pbc.24445

Krueger, R. A., & Casey, M. A. (2014). Focus Groups. *A Practical Guide for Applied Research* (5th edition). SAGE Publications.

Meirte, J., Hellemans, N., Anthonissen, M., Denteneer, L., Maertens, K., Moortgat, P., & Van Daele, U. (2020). Benefits and Disadvantages of Electronic Patient-reported Outcome Measures: Systematic Review. *JMIR Perioperative Medicine*, *3*(1). https://doi.org/10.2196/15588

Michel, G., Mulder, R. L., Van der Pal, H. J. H., Skinner, R., Bárdi, E., Brown, M. C., Vetsch, J., Frey, E., Windsor, R., Kremer, L. C. M., & Levitt, G. (2019). Evidence-based recommendations for the organization of long-term follow-up care for childhood and adolescent cancer survivors: a report from the PanCareSurFup Guidelines Working Group. *Journal of Cancer Survivorship*, *13*, 759–772. https://doi.org/10.1007/s11764-019-00795-5

Morris, S., Bass, M., Lee, M., & Neapolitan, R. E. (2017). Advancing the efficiency and efficacy of patient reported outcomes with multivariate computer adaptive testing. *Journal of the American Medical Informatics Association*, *24*(5), 897–902. https://doi.org/10.1093/jamia/ocx003

Mud, M. S., Kremer, L. C. M., Sieswerda, E., Van der Pal, H. J. H. (2012). Zorg voor overlevenden van kinderkanker in Nederland. *Nederlands Tijdschrift Geneeskunde*

Nguyen, H., Butow, P., Dhillon, H., & Sundaresan, P. (2020). A review of the barriers to using Patient Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care. *Journal of Medical Radiation Sciences*, *68*(2), 186–195. https://doi.org/10.1002/jmrs.421

Robison, L. L., & Hudson, M. M. (2014). Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nature Reviews Cancer*, *14*(1), 61–70. https://doi.org/10.1038/nrc3634

Shisler, R., Sinnott, J. A., Wang, V., Hebert, C., Salani, R., & Felix, A. S. (2018). Life after endometrial cancer: A systematic review of patient-reported outcomes. *Gynecologic Oncology*, *148*(2), 403–413. https://doi.org/10.1016/j.ygyno.2017.11.007

Signorelli, C., Wakefield, C. E., Fardell, J. E., Wallace, W. H. B., Robertson, E. G., McLoone, J. K., & Cohn, R. J. (2017). The impact of long-term follow-up care for childhood cancer survivors: A systematic review. *Critical Reviews in Oncology/Hematology*, *114*, 131–138. https://doi.org/10.1016/j.critrevonc.2017.04.007

Steliarova-Foucher, E., Colombet, M., Ries, L. A. G., Moreno, F., Dolya, A., Bray, F., Hesseling, P., Shin, H. Y., & Stiller, C. A. (2017). International incidence of childhood cancer, 2001–10: a population-based registry study. *The Lancet Oncology*, *18*(6), 719–731. https://doi.org/10.1016/S1470-2045(17)30186-9

Stichting Kinderoncologie Nederland (SKION). (2010). *Richtlijn follow-up na kinderkanker meer dan 5 jaar na diagnose*. accessible via: https://www.skion.nl/workspace/uploads/richtlijn_follow-up_na_kinderkanker_deel_1_1.pdf

Van Egdom, L. S. E., Oemrawsingh, A., Verweij, L. M., Lingsma, H. F., Koppert, L. B., Verhoef, C., Klazinga, N. S., & Hazelzet, J. A. (2019). Implementing Patient-Reported Outcome Measures in Clinical Breast Cancer Care: A Systematic Review. *Value in Health*, *22*(10), 1197–1226. https://doi.org/10.1016/j.jval.2019.04.1927

Xiao, C., Polomano, R., & Bruner, D. W. (2013). Comparison Between Patient-Reported and Clinician-Observed Symptoms in Oncology. *Cancer Nursing*, *36*(6), 1–16. https://doi.org/10.1097/ncc.0b013e318269040f

Yang, L. Y., Manhas, D. S., Howard, A. F., & Olson, R. A. (2018). Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication. *Supportive Care in Cancer*, *26*(1), 41–60. https://doi.org/10.1007/s00520-017-3865-7

Appendix A: Search terms that were inserted in PubMed for the systematic literature review

Topic	Search terms
Childhood cancer (IGHG, 2021)	leukemia OR leukemi* OR leukaemi* OR AML OR (leukemia, lymphocytic, acute[Mesh]) OR (leukemia, lymphocytic, acute*) OR lymphoma OR lymphom* OR hodgkin OR hodgkin* OR "T-cell" OR "B-cell" OR nonhodgkin OR sarcoma OR sarcom* OR sarcoma, Ewing's OR Ewing* OR osteosarcoma OR osteosarcom* OR "wilms tumor" OR wilms* OR nephroblastom* OR neuroblastoma OR neuroblastom* OR rhabdomyosarcoma OR rhabdomyosarcom* OR teratoma OR teratom* OR hepatoma OR hepatom* OR hepatoblastoma OR hepatoblastom* OR PNET OR medulloblastoma OR medulloblastom* OR PNET* OR neuroectodermal tumors, primitive OR retinoblastoma OR retinoblastom* OR meningioma OR meningiom* OR glioma OR gliom* OR "brain tumor" OR "brain tumor*" OR "brain cancer*" OR "brain neoplasm*" OR "intracranial neoplasm*" OR "brain neoplasms" OR "central nervous system neoplasm" OR "central nervous system neoplasms" OR "central nervous system tumor" OR "central nervous system tumour" OR "central nervous system tumor*" OR "central nervous system tumour*" OR "pediatric oncology" OR "paediatric oncology" OR "childhood cancer" OR "childhood tumor" OR "childhood tumors" OR "childhood tumour" OR "childhood tumours" OR "pediatric cancer" OR "paediatric cancer"
Cancer (IGHG, 2021)	Cancer OR cancers OR cancer* OR oncology OR oncolog* OR neoplasm OR neoplasms OR neoplasm* OR carcinoma OR carcinom* OR tumor OR tumour OR tumor* OR tumour* OR tumors OR tumours OR malignan* OR malignant OR hematooncological OR hemato oncological OR hemato-oncological OR hematolo*
Survivors (IGHG, 2021)	Survivor OR survivors OR survivor* OR long term survivor OR long term survivors OR long term survivor* OR survivo* OR long term survival[tiab] OR survival[Mesh] OR survivorship
Late effects (IGHG, 2021)	"late effect" OR "late effects" OR "late effect*" OR "late side effect" OR "late side effects" OR "late side effect*" OR "late adverse effect" OR "late adverse effects" OR "late adverse effect*" OR "long term effect" OR "long term effect*" OR "long term adverse effects" OR "follow up study" OR "follow-up studies[Mesh]" OR aftercare[Mesh] OR aftercare* OR after treatment OR "health outcome" OR "health outcomes" OR "adverse health outcome" OR "adverse health outcomes" OR "long term follow up"

PROMs	"Patient Outcome Assessment"[Mesh] OR “patient outcome assessment” OR “patient outcome assessments” OR “patient centered outcome” OR “patient centered outcomes” OR “patient centred outcome” OR “patient centred outcomes” OR “patient reported outcome” OR “patient reported outcomes” OR “prom” OR “proms” OR “patient reported outcome measures” OR “patient reported outcome measure” OR “self report instruments” OR “self reported instruments” OR “self report instrument” OR “self reported instrument”
Search childhood cancer	[All Fields ‘childhood cancer’] AND [[All Fields ‘survivors’] OR [All Fields ‘late effects’]] AND [All Fields ‘PROMs’] = 383 results
Search cancer survivors	[All Fields ‘cancer’] AND [All Fields ‘survivors’] AND [All Fields ‘late effects’] AND [All Fields ‘PROMs’] = 461 results
Final search	[[All Fields ‘childhood cancer’] AND [[All Fields ‘late effects’] OR [All Fields ‘survivors’]] AND [All Fields ‘PROMs’]] OR [[All Fields ‘cancer’] AND [All Fields ‘survivors’] AND [All Fields ‘late effects’] AND [All Fields ‘PROMs’]] = 805 results

Appendix B: Search terms that were inserted in Scopus for the umbrella review

Topic	Search terms
Barriers	Barriers
Facilitators	Facilitators
PROMs	Proms OR prom OR "patient reported outcome" OR "patient reported outcomes" OR "patient reported outcome measure" OR "patient reported outcome measures"
Healthcare	Healthcare OR care OR "health services" OR "health related services"
Systematic review	"Systematic review" OR "systematic literature review"
Final search	TITLE-ABSTRACT-KEYWORDS [barriers OR facilitators] AND [PROMs] AND [healthcare] AND [systematic review] = 70 results

Appendix C: Information letter focus group

Goedendag,

Bij deze brief zit informatie over de commentaarronde die zal gaan over het gebruik van een vragenlijst voor in de zorg.

1. Achtergrondinformatie

Op dit moment wordt er een vragenlijst ontwikkeld die het fysieke welzijn van patiënten op de LATER-poli in kaart kan brengen. Deze *LATER-vragenlijst* is bedoeld om voorafgaand aan het consult te worden ingevuld door de patiënt, waarna de uitkomsten direct overzichtelijk beschikbaar komen voor de arts. Zo gaan beiden goed voorbereid het consult in: enerzijds heeft de patiënt al goed nagedacht over zijn of haar huidige klachten, en anderzijds heeft de arts een goed zicht op deze klachten. Daardoor kan het bezoek aan de LATER-poli optimaal worden afgestemd op de individuele behoeften van de patiënt, wat de kwaliteit van de geleverde zorg ten goede komt.

Uit onderzoek is gebleken dat patiënten dit soort vragenlijsten niet altijd invullen, en hier zijn al verschillende redenen voor bekend. Als we kunnen bepalen welke van deze bekende *barrières* en *facilitators* belangrijk zijn voor survivors op de LATER-poli, kunnen wij hier effectief op inspelen bij het ontwikkelen en implementeren van de *LATER-vragenlijst*.

2. Doel commentaarronde

Het doel van de commentaarronde is om inzicht te krijgen in de *barrières* en *facilitators* bij het invullen van vragenlijsten door patiënten, voorafgaand aan het consult op de LATER-poli.

Daarnaast zijn subdoelen om inzicht te krijgen in het standpunt van survivor vertegenwoordigers omtrent verschillende karakteristieken van de vragenlijst: algemene indrukken van een vragenlijst voor in de zorg, het geschikte (medische) taalniveau, timing en duur van invullen, en de vragenlijst inhoudelijk als geheel.

3. Wat wordt er van u verwacht?

De commentaarronde duurt ongeveer anderhalf uur. Als u meedoet aan deze commentaarronde, wordt van u verwacht dat u eenmalig voor anderhalf uur online aanwezig bent of fysiek naar het Princes Máxima Centrum komt (in overleg zijn beiden mogelijk, nog nader te bepalen).

De commentaarronde zal bestaan uit 2 tot 4 mensen en zij zullen tegelijkertijd meedoen aan de commentaarronde. Daarnaast zullen tijdens de commentaarronde twee onderzoekers aanwezig zijn die de commentaarronde leiden. Zij zullen vragen aan u en de andere deelnemers stellen, waarop u kan reageren.

4. Uw gegevens

De gegevens die u verstrekt tijdens de commentaarronde worden niet gepubliceerd, maar worden als inzichten meegenomen in het ontwikkelproces van de *LATER-vragenlijst*.

Daarnaast worden de gegevens vertrouwelijk behandeld. De gegevens die u tijdens de commentaarronde verstrekt, zullen binnen de groep blijven en worden anoniem genotuleerd.

Als u na het lezen van de informatie vragen heeft, dan kan u een mail sturen naar:
M.Vriens-5@prinsesmaximacentrum.nl

Met vriendelijke groet,
Maartje Vriens

Appendix D: Topic list focus group interview

1. Introductie (5 minuten)

- Voorstellen → woordvoerder & notulist
- Doel commentaarronde: inzicht krijgen in de barrières en facilitators bij het invullen van vragenlijsten door patiënten, voorafgaand aan het consult op de LATER-poli
- Aantal praktische zaken (privacy):
  - Er zijn geen goede of foute antwoorden: alle meningen worden gerespecteerd.
  - Alle gegevens worden vertrouwelijk behandeld, dus de informatie die wordt verstrekt tijdens dit gesprek mag niet aan andere mensen worden verteld.
  - Alle gegevens die je tijdens het gesprek verstrekt, worden anoniem genotuleerd. Deze gegevens worden niet gepubliceerd, maar worden als inzichten meegenomen in het ontwikkelproces van de LATER-vragenlijst.
  - Er is ruimte voor open discussie, dus het is niet nodig om dichtbij de gestelde vraag te blijven. Daarnaast kunnen jullie ook op elkaars antwoorden ingaan.
- Duur: commentaarronde zal ongeveer anderhalf uur (70 minuten) duren
- Nog vragen voorafgaand aan de commentaarronde?
- Agenda
  - 20 minuten voor het gebruik van een zorg-vragenlijst in het algemeen
  - 20 minuten voor het niveau van de vragenlijst
  - 10 minuten voor de inzet van de vragenlijst
  - 20 minuten voor de inhoud van de vragenlijst

2. Algemeen vragenlijst voor in de zorg (20 minuten)

- Heb je ervaring met het invullen van een vragenlijst voorafgaand aan een consult?
  - Zo ja: wat zijn je ervaringen daarmee?
- Wat zouden survivors als voordelen kunnen zien voor het invullen van een vragenlijst voorafgaand aan een consult?
- Wat zouden survivors als nadelen kunnen zien voor het invullen van een vragenlijst voorafgaand aan een consult?
- Wat zijn barrières waarom een survivor de vragenlijst niet zou invullen?
- Wat zijn redenen (facilitators) waarom een survivor de vragenlijst wel zou invullen?

3. Niveau vragenlijst (20 minuten)

- *Laten zien van een voorbeeld vragenlijst (PRO-CTCAE) en eerste pagina laten zien*
- Wat zijn je eerste indrukken rondom deze vragenlijst?
- Wat voor moeilijkheden kan een patiënt hebben tijdens het invullen van deze vragenlijst?
- Welke doelgroepen kunnen een dergelijke vragenlijst niet invullen?
  - Door welke moeilijkheden?
- Denk je dat mensen extra hulp nodig hebben voor het invullen van de vragenlijst?
  - Waarom wel/niet?
  - Zo ja: wat voor extra hulp?

- *Voorbeelden: uitleg door arts (bellen), uitlegvideo, uitleg in introductietekst, extra training*

- De vragenlijst zal veel symptomen omvatten: denk je dat dit als confronterend wordt ervaren door de patiënt?
  - Waarom wel/niet?

4. Inzet vragenlijst (10 minuten)

- Hoeveel dagen voor het consult zou een patiënt een uitnodiging moeten ontvangen voor het invullen van de vragenlijst?
  - *Door een arts is geopperd dat een maand van tevoren handig is, zodat extra fysieke metingen nog kunnen worden aangevraagd*
- Hoeveel minuten zou een patiënt maximaal bezig moeten zijn met het invullen van de vragenlijst?

5. Inhoud vragen (20 minuten)

- Welke optie lijkt je het beste?
  - 1. Lange vragen waarin voorbeelden van een symptoom worden gegeven
    - Voorbeeld: *Had je gezichtsproblemen, zoals wazig zien, lichtflitsen of zwevende vlekken zien, het hebben van droge of waterige ogen, tranende ogen, moeite met lezen of dubbelzien?*
  - 2. Korte vragen zonder voorbeelden van een symptoom
    - Voorbeeld: *Had je gezichtsproblemen?*
- Sommige vragen zijn specifiek gericht op mannen of vrouwen (*bijvoorbeeld bij symptomen omtrent menstruatie*).

Welke optie lijkt je het beste?
  - 1. Aan het begin van de vragenlijst de vraag toevoegen of iemand man of vrouw is
  - 2. Geen onderscheid maken tussen man en vrouw, en bij specifieke symptomen (zoals menstruatie) de optie 'niet van toepassing' toevoegen
- Denk je dat het nuttig is voor de patiënt als er de antwoordoptie 'weet ik niet' wordt toegevoegd?
  - Waarom wel/niet?
- Wat vind je van een leeg invulveld waar patiënten zelf aanvullende klachten kunnen invullen?
  - Moet dat wel of niet in de vragenlijst? Waarom wel/niet?

6. Afronding (5 minuten)

- Heb je nog verdere vragen of aanvullingen?
- Bedankt voor je tijd voor het deelnemen aan deze commentaarronde!

Appendix E: Overview of articles that resulted from systematic literature review

Link to article	PROMs
https://pubmed.ncbi.nlm.nih.gov/29736007/	FACIT-F, SF-36
https://pubmed.ncbi.nlm.nih.gov/29150143/	QLQ-C30, SF-36, FACT-G, FSFI
https://pubmed.ncbi.nlm.nih.gov/28511129/	FACT-GOG-NTX, QLQ-CIPN20
https://pubmed.ncbi.nlm.nih.gov/33517431/	QLQ-C30, QLQ-BN20, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/28453627/	QLQ-C30, SF-36, PRO-CTCAE, PROMIS, DASH
https://pubmed.ncbi.nlm.nih.gov/31790025/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/31606419/	PedsQL, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/31848315/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/33339639/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/33411044/	QLQ-C30, QLQ-BR23, QLQ-CR29, QLQ-H&N35, QLQ-OES18, QLQ-OV28, QLQ-BIL21
https://pubmed.ncbi.nlm.nih.gov/26270597/	PRO-CTCAE, QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/33021013/	EQ-5D, QLQ-C30, QLQ-CR29
https://pubmed.ncbi.nlm.nih.gov/31012356/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32556712/	FACT-BMT
https://pubmed.ncbi.nlm.nih.gov/32451566/	MFI
https://pubmed.ncbi.nlm.nih.gov/31550465/	ESAS
https://pubmed.ncbi.nlm.nih.gov/32193960/	QLQ-C30, QLQ-OG25, QLQ-CAX24, QLQ-FA12
https://pubmed.ncbi.nlm.nih.gov/30680843/	QLQ-C30, SF-36, EQ-5D, FACT-G, ESAS
https://pubmed.ncbi.nlm.nih.gov/31033073/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/28748716/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28249651/	MDASI-HN
https://pubmed.ncbi.nlm.nih.gov/34325946/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/34125642/	QLQ-C30, SF-36, MDASI, FACIT-F, FACT-G
https://pubmed.ncbi.nlm.nih.gov/34658160/	FACT-L, FACT-G, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/32423926/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/33482771/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/34582319/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/30926057/	MDASI, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32344296/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/29388275/	SF-36, FACT-C
https://pubmed.ncbi.nlm.nih.gov/30120002/	ESAS, QLQ-C30, QLQ-PAN26
https://pubmed.ncbi.nlm.nih.gov/31938965/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/31591636/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/32120228/	ESAS
https://pubmed.ncbi.nlm.nih.gov/30852760/	FACT-B
https://pubmed.ncbi.nlm.nih.gov/29969807/	QLQ-C30, QLQ-STO22, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/35028721/	QLQ-SH-C22, QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/33755805/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/32362277/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28918186/	QLQ-C30, QLQ-BR23, FACT-G
https://pubmed.ncbi.nlm.nih.gov/23907613/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/29856903/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/25448227/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/32152222/	QLQ-C30, EQ-5D, PRO-CTCAE
https://pubmed.ncbi.nlm.nih.gov/32243495/	SF-36
https://pubmed.ncbi.nlm.nih.gov/31028212/	QLQ-C30, QLQ-BR23, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/31028525/	PROMIS-GH
https://pubmed.ncbi.nlm.nih.gov/33534429/	FSFI
https://pubmed.ncbi.nlm.nih.gov/34904948/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/31045429/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/29466412/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28434095/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/34157084/	QLQ-C30, QLQ-OG25

https://pubmed.ncbi.nlm.nih.gov/31253733/	QLQ-C30, QLQ-MY20
https://pubmed.ncbi.nlm.nih.gov/33437925/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/30191868/	FACT-HN, FACIT-F, EQ-5D, MDASI-HN
https://pubmed.ncbi.nlm.nih.gov/21355946/	FACT-B
https://pubmed.ncbi.nlm.nih.gov/31834818/	QLQ-C30, QLQ-BR23, QLQ-FA12
https://pubmed.ncbi.nlm.nih.gov/30553942/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/33956062/	MDASI-HN
https://pubmed.ncbi.nlm.nih.gov/25567673/	FSFI
https://pubmed.ncbi.nlm.nih.gov/25597493/	QLQ-C30, QLQ-PR25, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/30716524/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/23031071/	FACT-An, FHNSI-22, ESAS
https://pubmed.ncbi.nlm.nih.gov/21394821/	PROMIS-SF
https://pubmed.ncbi.nlm.nih.gov/26926320/	FACT-Cx, PROMIS
https://pubmed.ncbi.nlm.nih.gov/29288122/	EPIC
https://pubmed.ncbi.nlm.nih.gov/32546796/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/35091512/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/30139347/	QLQ-C30, QLQ-PR25
https://pubmed.ncbi.nlm.nih.gov/30625479/	FACIT-F, FACT-G
https://pubmed.ncbi.nlm.nih.gov/30149935/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/34415790/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/28068158/	FACT-C
https://pubmed.ncbi.nlm.nih.gov/31916092/	BREAST-Q
https://pubmed.ncbi.nlm.nih.gov/34278531/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/32220543/	BREAST-Q
https://pubmed.ncbi.nlm.nih.gov/29072787/	PROMIS-GH, PROMIS, SF-36
https://pubmed.ncbi.nlm.nih.gov/21944095/	EPIC
https://pubmed.ncbi.nlm.nih.gov/32735463/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/22367682/	FACT-G, SF-36
https://pubmed.ncbi.nlm.nih.gov/29436144/	QLQ-SH-C22
https://pubmed.ncbi.nlm.nih.gov/28084867/	QLQ-C30, FACT-G, SF-36
https://pubmed.ncbi.nlm.nih.gov/31537562/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32775464/	QLQ-C30, CFQ
https://pubmed.ncbi.nlm.nih.gov/33058000/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/31309977/	DASH
https://pubmed.ncbi.nlm.nih.gov/34277024/	MDASI-BT, MDASI-SP, PROMIS
https://pubmed.ncbi.nlm.nih.gov/34904181/	EQ-5D, EPIC
https://pubmed.ncbi.nlm.nih.gov/34023744/	QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/34412527/	FACT-G, SF-36
https://pubmed.ncbi.nlm.nih.gov/28285980/	FACT-G, PROMIS-PF
https://pubmed.ncbi.nlm.nih.gov/31913509/	SF-36
https://pubmed.ncbi.nlm.nih.gov/30859650/	SF-36
https://pubmed.ncbi.nlm.nih.gov/29537491/	PROMIS-SF, FACT-BMT
https://pubmed.ncbi.nlm.nih.gov/34387856/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/31060822/	EPIC
https://pubmed.ncbi.nlm.nih.gov/32337778/	BREAST-Q
https://pubmed.ncbi.nlm.nih.gov/30798774/	QLQ-C30, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/28060691/	FACT-An
https://pubmed.ncbi.nlm.nih.gov/34304292/	FACT-En, PROMIS
https://pubmed.ncbi.nlm.nih.gov/23052918/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/24083543/	FACT-An, SF-36, QLQ-C30, MDASI
https://pubmed.ncbi.nlm.nih.gov/34408062/	BREAST-Q, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/28859042/	PROMIS-GH
https://pubmed.ncbi.nlm.nih.gov/34670600/	MDASI-BMT, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/32917486/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/22990056/	EPIC

https://pubmed.ncbi.nlm.nih.gov/27998215/	FACT-M
https://pubmed.ncbi.nlm.nih.gov/34400137/	QLQ-C30, QLQ-EN24
https://pubmed.ncbi.nlm.nih.gov/23578682/	EQ-5D, FACT-B, FACT-C, FACT-Lym, FACT-P
https://pubmed.ncbi.nlm.nih.gov/25953059/	QLQ-C30, QLQ-CR29
https://pubmed.ncbi.nlm.nih.gov/31227537/	MDASI-MM, QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/29191598/	ESAS, QLQ-C30, QLQ-LC13, QLQ-BM22, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/29198729/	FACT-B, FACT-G
https://pubmed.ncbi.nlm.nih.gov/32487574/	QLQ-C30, FACT-G
https://pubmed.ncbi.nlm.nih.gov/26464337/	QLQ-C30, SF-36
https://pubmed.ncbi.nlm.nih.gov/29451059/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/32781287/	PROMIS-PF
https://pubmed.ncbi.nlm.nih.gov/30652562/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/22829446/	PROMIS-PF, PROMIS-F
https://pubmed.ncbi.nlm.nih.gov/30041626/	FACIT-F
https://pubmed.ncbi.nlm.nih.gov/32374469/	PROMIS-F
https://pubmed.ncbi.nlm.nih.gov/25047397/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/32859572/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/32405965/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/32059728/	SF-36, FACT-B, FACIT-F, FACT-Es, FACT-Taxane
https://pubmed.ncbi.nlm.nih.gov/32664052/	PROMIS-SF
https://pubmed.ncbi.nlm.nih.gov/31615476/	EPIC
https://pubmed.ncbi.nlm.nih.gov/32599411/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/28916897/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/34645411/	MDADI, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/35230209/	SF-36
https://pubmed.ncbi.nlm.nih.gov/26715295/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/29656290/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/30470622/	QLQ-C30, QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/20454867/	SF-36
https://pubmed.ncbi.nlm.nih.gov/19967410/	FACT-G, FACT-Lym, SF-36
https://pubmed.ncbi.nlm.nih.gov/28574866/	SF-36
https://pubmed.ncbi.nlm.nih.gov/32361832/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/29753161/	SF-36
https://pubmed.ncbi.nlm.nih.gov/24634396/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/25469673/	MSAS, SF-36
https://pubmed.ncbi.nlm.nih.gov/28457651/	SF-36
https://pubmed.ncbi.nlm.nih.gov/25522692/	SF-36
https://pubmed.ncbi.nlm.nih.gov/27440393/	MDADI
https://pubmed.ncbi.nlm.nih.gov/33146572/	QLQ-C30, QLQ-BR23, PRO-CTCAE
https://pubmed.ncbi.nlm.nih.gov/31755917/	CFQ, MFI, QLQ-BN20, SF-36
https://pubmed.ncbi.nlm.nih.gov/29459102/	SF-36
https://pubmed.ncbi.nlm.nih.gov/31862171/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/27749474/	SF-36
https://pubmed.ncbi.nlm.nih.gov/28969611/	PROMIS-SF, EQ-5D, EPIC, FSFI
https://pubmed.ncbi.nlm.nih.gov/33407797/	FACT-Lym, MSAS
https://pubmed.ncbi.nlm.nih.gov/28758822/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/23845102/	QLQ-C30, QLQ-CR29
https://pubmed.ncbi.nlm.nih.gov/23632469/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/27379565/	FACT-G, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/17262196/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/27105196/	SF-36, FACT-C, FACT-G, FACT-D, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/20925920/	FACT-B, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/16614882/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27956540/	FACT-G, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/31313128/	FACT-Cog
https://pubmed.ncbi.nlm.nih.gov/24036439/	PROMIS

https://pubmed.ncbi.nlm.nih.gov/25713429/	PROMIS, FACT-Cx, FACT-G
https://pubmed.ncbi.nlm.nih.gov/27442677/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/21496339/	SF-36, FACT-G, FACIT-F, RSC
https://pubmed.ncbi.nlm.nih.gov/21715041/	SF-36, FACT-L, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/27993906/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/26926678/	EQ-5D, QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/29485067/	BREAST-Q, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/34387856/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27793125/	PROMIS, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/29858505/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/33237602/	PROMIS-GH
https://pubmed.ncbi.nlm.nih.gov/23153358/	SF-36, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/20409311/	FACT-L, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/24885258/	FACT-B, MDASI-BT, RSC
https://pubmed.ncbi.nlm.nih.gov/22141750/	QLQ-C30, QLQ-EN24, QLQ-OV28
https://pubmed.ncbi.nlm.nih.gov/25139241/	QLQ-C30, QLQ-LMC21
https://pubmed.ncbi.nlm.nih.gov/30925511/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/31957499/	SF-36
https://pubmed.ncbi.nlm.nih.gov/30648277/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/30527856/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/26884372/	SF-36, QLQ-C30, FACT-G, QLQ-OV28, FACT-O, FACIT-F, MFI
https://pubmed.ncbi.nlm.nih.gov/25873249/	EQ-5D, QLQ-C30, QLQ-STO22
https://pubmed.ncbi.nlm.nih.gov/33484565/	FACT-Cog
https://pubmed.ncbi.nlm.nih.gov/23578681/	EQ-5D, FACT-G
https://pubmed.ncbi.nlm.nih.gov/31014282/	EPIC, FACT-G
https://pubmed.ncbi.nlm.nih.gov/31605820/	PROMIS, PROMIS-GH
https://pubmed.ncbi.nlm.nih.gov/28197722/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/33515106/	FACIT-F, FACT-G
https://pubmed.ncbi.nlm.nih.gov/32997334/	EQ-5D, FACT-B
https://pubmed.ncbi.nlm.nih.gov/11338757/	SF-36
https://pubmed.ncbi.nlm.nih.gov/31792879/	FACT-Br, QLQ-C30, QLQ-BN20, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/25820683/	SF-36, PedsQL
https://pubmed.ncbi.nlm.nih.gov/30508641/	QLQ-C30, QLQ-LC13
https://pubmed.ncbi.nlm.nih.gov/26645111/	QLQ-C30, FACT-An, FACIT-F, FACT-G, FACT-Leu, MDASI
https://pubmed.ncbi.nlm.nih.gov/29411314/	SF-36, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/30694978/	FACT-B
https://pubmed.ncbi.nlm.nih.gov/33136468/	PROMIS-SF
https://pubmed.ncbi.nlm.nih.gov/12509953/	MFI
https://pubmed.ncbi.nlm.nih.gov/30573776/	SF-36, MDASI
https://pubmed.ncbi.nlm.nih.gov/25639748/	QLQ-CIPN20
https://pubmed.ncbi.nlm.nih.gov/23212603/	SF-36, QLQ-C30, FACT-B, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/25354481/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/25413127/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27435322/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/28441148/	FACT-Br, PROMIS-P
https://pubmed.ncbi.nlm.nih.gov/30639801/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/29799149/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/29775389/	QLQ-C30, QLQ-CR29, MSAS, SF-36, EPIC
https://pubmed.ncbi.nlm.nih.gov/33187543/	QLQ-C30, FACT-Cog
https://pubmed.ncbi.nlm.nih.gov/29799906/	QLQ-C30, QLQ-CIPN20
https://pubmed.ncbi.nlm.nih.gov/32000559/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/23175474/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27868156/	FSFI
https://pubmed.ncbi.nlm.nih.gov/27927667/	EQ-5D, EPIC, QLQ-PR25, QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/24355521/	SF-36, FACT-G, RSC
https://pubmed.ncbi.nlm.nih.gov/29866185/	QLQ-C30

https://pubmed.ncbi.nlm.nih.gov/28351354/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/26078203/	SF-36, FACT-P, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/30192384/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28537498/	QLQ-C30, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/31870331/	PROMIS-P, PROMIS-F, PROMIS-C
https://pubmed.ncbi.nlm.nih.gov/25190633/	PRO-CTCAE
https://pubmed.ncbi.nlm.nih.gov/26275239/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/28490558/	FACT-G, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/27178143/	QLQ-C30, QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/19358230/	SF-36
https://pubmed.ncbi.nlm.nih.gov/26227655/	QLQ-C30, QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/23338490/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/23542954/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/23704198/	QLQ-C30, SF-36
https://pubmed.ncbi.nlm.nih.gov/18648958/	SF-36, QLQ-C30, QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/34582267/	PRO-CTCAE, FACT-G, PROMIS
https://pubmed.ncbi.nlm.nih.gov/28627275/	PROMIS-F
https://pubmed.ncbi.nlm.nih.gov/34339099/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/28454583/	QLQ-C30, QLQ-HL27, QLQ-NHL-HG29, QLQ-NHL-LG20, QLQ-CLL17, MFI
https://pubmed.ncbi.nlm.nih.gov/34651082/	PROMIS-PF, PROMIS-GH
https://pubmed.ncbi.nlm.nih.gov/34492684/	QLQ-C30, FACT-A, SF-36, FACT-BMT
https://pubmed.ncbi.nlm.nih.gov/29762195/	DASH, PROMIS
https://pubmed.ncbi.nlm.nih.gov/32443312/	MDASI
https://pubmed.ncbi.nlm.nih.gov/29936066/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/34778941/	EQ-5D, QLQ-C30, PROMIS, MFI, FACT-G, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/27634326/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/33454225/	SF-36
https://pubmed.ncbi.nlm.nih.gov/34648119/	SF-36, FACT-Leu, QLQ-CML24, MDASI-CML
https://pubmed.ncbi.nlm.nih.gov/28039363/	SF-36, QLQ-C30, QLQ-BN20, FACT-G, FACT-Br
https://pubmed.ncbi.nlm.nih.gov/27565521/	SF-36
https://pubmed.ncbi.nlm.nih.gov/25834471/	SF-36, EPIC, QLQ-C30, FACT-G, FACT-P, QLQ-PR25
https://pubmed.ncbi.nlm.nih.gov/32005112/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27830957/	QLQ-C30, QLQ-CLL17
https://pubmed.ncbi.nlm.nih.gov/34638375/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/32074277/	FACT-Lym, SF-36
https://pubmed.ncbi.nlm.nih.gov/24560709/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/26816824/	QLQ-OV28, QLQ-CX24, QLQ-CR29, QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28265818/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/34524631/	PROMIS-P, PROMIS-F, PROMIS-PF, QLQ-CIPN20
https://pubmed.ncbi.nlm.nih.gov/30362974/	SF-36
https://pubmed.ncbi.nlm.nih.gov/29789774/	PROMIS-F, SF-36
https://pubmed.ncbi.nlm.nih.gov/34452710/	QLQ-C30, EQ-5D, QLQ-BR23, FACT-B, FACT-P
https://pubmed.ncbi.nlm.nih.gov/32537177/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/34439229/	SF-36
https://pubmed.ncbi.nlm.nih.gov/30249389/	FACIT-F, QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/33641257/	SF-36, PROMIS, PRO-CTCAE
https://pubmed.ncbi.nlm.nih.gov/22350378/	FACT-Br, QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/30989330/	FACT-Leu, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/28679417/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/31555487/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/30500439/	SF-36, EQ-5D, PROMIS, QLQ-C30, FACT-G, PRO-CTCAE, QLQ-MY20, QLQ-BN20, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/34051880/	QLQ-C30, QLQ-HCC18
https://pubmed.ncbi.nlm.nih.gov/33109665/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/31692481/	QLQ-C30, QLQ-BN20, FACT-Br, MDASI-BT
https://pubmed.ncbi.nlm.nih.gov/33411204/	PROMIS

https://pubmed.ncbi.nlm.nih.gov/29515973/	MFI, QLQ-C30, FACT-GOG-NTX
https://pubmed.ncbi.nlm.nih.gov/29858386/	SF-36, PROMIS-GH, PROMIS
https://pubmed.ncbi.nlm.nih.gov/25534576/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/31503332/	MDASI
https://pubmed.ncbi.nlm.nih.gov/29609532/	PROMIS, QLQ-CML24
https://pubmed.ncbi.nlm.nih.gov/28426375/	PROMIS-F, PROMIS-PF
https://pubmed.ncbi.nlm.nih.gov/34283381/	QLQ-C30, FACT-Hep, SF-36, QLQ-HCC18, EQ-5D, FACT-G, MDASI, ESAS, MDASI-GI
https://pubmed.ncbi.nlm.nih.gov/23666388/	QLQ-C30, QLQ-BN20, FACT-G, FACT-Br, MDASI-BT
https://pubmed.ncbi.nlm.nih.gov/34265479/	MDASI, PROMIS, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/23829800/	FACT-Hep
https://pubmed.ncbi.nlm.nih.gov/32862317/	EPIC, PRO-CTCAE, FACT-Cx, QLQ-C30, QLQ-CX24, QLQ-H&N35, MDADI, SF-36, QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/32506371/	MDASI-BT
https://pubmed.ncbi.nlm.nih.gov/31421371/	FACT-H, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/25034656/	QLQ-C30, QLQ-BN20, FACT-Br
https://pubmed.ncbi.nlm.nih.gov/32975600/	QLQ-C30, QLQ-HCC
https://pubmed.ncbi.nlm.nih.gov/34841461/	MDASI, QLQ-C30, QLQ-CR29
https://pubmed.ncbi.nlm.nih.gov/34253083/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/29556695/	MDASI-L
https://pubmed.ncbi.nlm.nih.gov/35032648/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/28410178/	SF-36
https://pubmed.ncbi.nlm.nih.gov/33650694/	DASH
https://pubmed.ncbi.nlm.nih.gov/34297613/	PedsQL, SF-36
https://pubmed.ncbi.nlm.nih.gov/32417351/	MDASI-HN, MDADI, FACT-HN
https://pubmed.ncbi.nlm.nih.gov/35279769/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32840417/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/29429817/	FACT-MM
https://pubmed.ncbi.nlm.nih.gov/34914683/	PROMIS-C
https://pubmed.ncbi.nlm.nih.gov/33469658/	MDASI
https://pubmed.ncbi.nlm.nih.gov/34389213/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/26430849/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/30268565/	SF-36
https://pubmed.ncbi.nlm.nih.gov/32859662/	FACT-G, MDASI
https://pubmed.ncbi.nlm.nih.gov/34732099/	PROMIS-F
https://pubmed.ncbi.nlm.nih.gov/28945870/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/18056649/	FACT-G, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/25605841/	FACT-G, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/34836730/	BREAST-Q
https://pubmed.ncbi.nlm.nih.gov/33105807/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/33233437/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/33855868/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27045164/	FACT-Leu, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/33153355/	QLQ-CML24
https://pubmed.ncbi.nlm.nih.gov/29103883/	QLQ-C30, QLQ-LC13, MDASI-L
https://pubmed.ncbi.nlm.nih.gov/34667840/	UW-QoL
https://pubmed.ncbi.nlm.nih.gov/34799785/	QLQ-CIPN20
https://pubmed.ncbi.nlm.nih.gov/34674981/	QLQ-C30, QLQ-CLL17
https://pubmed.ncbi.nlm.nih.gov/30593513/	FACT-B, MDASI-BT, RSC
https://pubmed.ncbi.nlm.nih.gov/34135651/	SF-36, QLQ-C30, QLQ-TC26, QLQ-CIPN20, MSAS-SF, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/21435899/	QLQ-C30, SF-36, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32741098/	SF-36
https://pubmed.ncbi.nlm.nih.gov/25248883/	MDASI-MM
https://pubmed.ncbi.nlm.nih.gov/34709389/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/27913477/	FACT-BRM, EQ-5D, SF-36, FACIT-F, FACT-Leu, MDASI-CML
https://pubmed.ncbi.nlm.nih.gov/35190938/	FACT-B, FACT-Cog
https://pubmed.ncbi.nlm.nih.gov/34529768/	QLQ-C30, QLQ-CIPN20, SF-36

https://pubmed.ncbi.nlm.nih.gov/23177797/	FACT-Leu, SF-36, MSAS-SF, FACT-BRM, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/31236462/	QLQ-C30, QLQ-H&N35
https://pubmed.ncbi.nlm.nih.gov/33180106/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/23531324/	SF-36
https://pubmed.ncbi.nlm.nih.gov/33687463/	SF-36, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/30380358/	EQ-5D, QLQ-C30, QLQ-MY20
https://pubmed.ncbi.nlm.nih.gov/32205155/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/29992040/	FACT-G, QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/22871884/	SF-36, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/34690090/	EQ-5D, FACT-Lym
https://pubmed.ncbi.nlm.nih.gov/35183476/	QLQ-C30, EQ-5D, FACIT-F, FACT-MM, QLQ-MY20, QLQ-CIPN20, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/35247394/	PROMIS
https://pubmed.ncbi.nlm.nih.gov/33851349/	FACT-Leu, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/32297435/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/28296257/	SF-36, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/34164353/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/34521609/	FACT-Leu
https://pubmed.ncbi.nlm.nih.gov/35279508/	QLQ-C30, QLQ-BR23
https://pubmed.ncbi.nlm.nih.gov/15897941/	MDASI-BT
https://pubmed.ncbi.nlm.nih.gov/30458340/	QLQ-C30
https://pubmed.ncbi.nlm.nih.gov/27629548/	MDASI-HF, ESAS
https://pubmed.ncbi.nlm.nih.gov/28843942/	FSFI
https://pubmed.ncbi.nlm.nih.gov/32187457/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/33890580/	QLQ-C30, QLQ-CLL17, QLQ-CML24
https://pubmed.ncbi.nlm.nih.gov/34206149/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/34196962/	PROMIS-P, PROMIS-F
https://pubmed.ncbi.nlm.nih.gov/31681134/	QLQ-C30, QLQ-BN20, QLQ-FA12
https://pubmed.ncbi.nlm.nih.gov/33493697/	SF-36
https://pubmed.ncbi.nlm.nih.gov/32181374/	ESAS
https://pubmed.ncbi.nlm.nih.gov/34491344/	PROMIS-PF, PROMIS-C, PROMIS-SF
https://pubmed.ncbi.nlm.nih.gov/34672349/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/32764261/	QLQ-C30, QLQ-BN20
https://pubmed.ncbi.nlm.nih.gov/33132304/	SF-36
https://pubmed.ncbi.nlm.nih.gov/34371214/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/34644372/	QLQ-C30, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/33121439/	EQ-5D
https://pubmed.ncbi.nlm.nih.gov/31005941/	PedsQL, EQ-5D
https://pubmed.ncbi.nlm.nih.gov/31868271/	MDASI-BT
https://pubmed.ncbi.nlm.nih.gov/25445473/	FACT-G, FACT-BMT, FACIT-F
https://pubmed.ncbi.nlm.nih.gov/25068290/	SF-36, PedsQL
https://pubmed.ncbi.nlm.nih.gov/29209525/	QLQ-C30, QLQ-LC13
https://pubmed.ncbi.nlm.nih.gov/31697365/	FACT-G
https://pubmed.ncbi.nlm.nih.gov/33442015/	PedsQL
https://pubmed.ncbi.nlm.nih.gov/26378033/	FACT-BMT, SF-36

Appendix F: Overview of data extraction from 91 PROMs

Questionnaire	Target group	Development year	Proportion physical symptoms	Symptoms allocated to domains	Answer options	Assessment period	Articles that involved the PROM	PROM available in Dutch	Validated	Abbreviation
PRO-CTCAE	Cancer patients	2014	76/80	Oral: 6 - Gastrointestinal: 12 - Respiratory: 3 - Cardio: 2 - Cutaneous: 15 - Neurological: 2 - Visual: 5 - Pain: 4 - Genitourinary: 9 - Sexual: 5 - Miscellaneous: 9	Five options: none / mild / moderate / severe / very severe	Last week	9	Yes	Yes	Patient Reported Outcomes version of the Terminology Criteria for Adverse Events
PCFU	Childhood cancer survivors	2021	33/35	Oral: 5 - Gastrointestinal: 4 - Respiratory: 3 - Cardio: 2 - Cutaneous: 3 - Neurological: 2 - Visual: 2 - Genitourinary: 2 - Sexual: 2 - Pain: 1 - Miscellaneous: 6	Six options: no, never / yes, rarely / yes, occasionally / yes, frequently / yes, almost constantly / not sure	Last month	0	Yes	No	PanCare FollowUp
EPIC	Cancer patients	2002	22/31	Urinary: 5 - Gastrointestinal: 7 - Sexual: 6 - Hormonal: 4	Five options: more than once a day / about once a day / more than once a week / about once a week / rarely or never	Last month	12	Yes	Yes	Expanded Prostate Cancer Index Composite
QLQ-BN20	Cancer patients	2010	14/20	Pain: 1 - Visual: 3 - Cutaneous: 1	Four options: not at all / a little / quite a bit / very much	Last week	17	Yes	Yes	QLQ-Brain Neoplasm
QLQ-H&N35	Cancer patients	1994	14/35	Oral: 10 - Swallowing: 4	Four options: not at all / a little / quite a bit / very much	Last week	8	Yes	Yes	QLQ-Head & Neck
QLQ-C30	Cancer patients	1995	10/30	Short of breath: 1 - Pain: 1 - Nausea: 3 - Gastrointestinal: 2	Four options: not at all / a little / quite a bit / very much	Last week	141	Yes	Yes	European Organisation for Research and Treatment of Cancer, Quality of Life
FACT-Br	Cancer patients	2020	7/23	Vision: 1 - Cutaneous: 2 - Pain: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	7	Yes	Yes	FACT-Brain Neoplasm
QLQ-CR29	Cancer patients	2006	11/29	Urinary: 4 - Gastrointestinal: 5 - Oral: 2	Four options: not at all / a little / quite a bit / very much	Last week	7	Yes	Yes	QLQ-Colorectal Cancer
AYA-anamnese	Adolescent and young adult cancer patients	2018	1/72	Sexual: 1	None (open questions)	In general (not specified)	0	Yes	No	Adolescent and Young Adult-anamnesis
BREAST-Q	Cancer patients	2017	11/99	Pain: 4 - Cardio: 7	Three options: none of the time / some of the time / all of the time	Last week	6	No	Yes	BREAST-questionnaire
CFQ	General population	1982	0/29	-	Five options: very often / quite often / occasionally / very rarely / never	Last 6 months	2	Yes	Yes	Cognitive Failure Questionnaire
DASH	General population	1996	5/30	Pain: 5	Five options: no difficulty / mild difficulty / moderate difficulty / severe difficulty / unable	Last week	4	Yes	Yes	Disabilities of the Arm, Shoulder and Hand
DCOG-LATER	Cancer survivors	2013	11/143	Oral: 1 - Cardio: 4 - Visual/hearing: 1 - Pain: 1 - Genitourinary: 2 - Sexual: 2	Two options: yes / no (presence of symptom)	At the moment	0	Yes	No	Dutch Childhood Oncology Group-LATER
EQ-5D	General population	1990	2/5	Pain: 1 - Cardio: 1	Three options: level 1 / level 2 / level 3	At the moment	58	Yes	Yes	EuroQoL 5 dimensions
ESAS	Cancer patients	2010	5/9	Pain: 1 - Nausea: 1 - Appetite: 1 - Miscellaneous: 2	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	At the moment	9	No	Yes	Edmonton Symptom Assessment Scale
FSFI	General population	2014	0/19	-	Five options: almost never or never / a few times / sometimes / most times / almost always or always	Last month	6	No	Yes	Female Sexual Function Index
MDASI-HN	Cancer patients	2000	13/28	Pain: 1 - Oral: 4 - Pain: 1 - Gastrointestinal: 1 - Miscellaneous: 6	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	4	No	Yes	MDASI-Head and Neck
MFI	Cancer survivors	1995	0/20	-	Five options: yes, that is true - no, that is not true (select number from 0 to 5)	In general (not specified)	7	Yes	Yes	Multidimensional Fatigue Index
MSAS	Cancer patients	2000	11/32	Pain: 1 - Nausea: 2 - Oral: 3 - Gastroinestinal: 3 - Cutaneous: 2	Four options: rarely / occasionally / frequently / almost constantly	Last week	3	No	Yes	Memorial Symptom Assessment Scale
PedsQL	Young adults	1998	7/27	Pain: 2 - Nausea: 5	Five options: never / almost never / sometimes / often / almost always	Last month	15	Yes	Yes	Pediatric Quality of Life Inventory
RSC	Cancer patients	1996	11/39	Pain: 5 - Nausea: 2 - Sexual: 1 - Gastrointestinal: 3	Four options: not at all / a little / somewhat / very much	Last week	4	Yes	Yes	Rotterdam Symptom Checklist
SF-36	General population	1990	1/36	Pain: 1	Five options: not at all / slightly / moderately / quite a bit / extremely	Last month	76	Yes	Yes	Short Form
St. Jude CCSS	Childhood cancer survivors	2011	37/266	Oral: 3 - Respiratory: 5 - Neurological: 6 - Visual/hearing: 14 - Pain: 2 - Genitourinary: 3 - Miscellaneous: 4	Four options: no / yes, and the condition is still present / yes, but the condition is no longer present / not sure	In general (not specified)	0	No	No	St. Jude Childhood Cancer Survivor Study
St. Jude Life	Childhood cancer survivors	2018	6/98	Respiratory: 1 - Cardio: 1 - Neurological: 1 - Pain: 2 - Nausea: 1	Six options: none / very mild / mild / moderate / severe / very severe	In general (not specified)	0	No	No	St. Jude Life (children hospital)
UW-QoL	Cancer patients	2012	6/16	Pain: 1 - Oral: 3 - Miscellaneous: 2	Five options: no 'symptom' - worst possible 'symptom' (answers written in statement)	Last week	6	No	Yes	University of Washington Quality of Life
FACT-An	Cancer patients	2007	4/20	Cardio: 1 - Miscellaneous: 2 - Short of breath: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	4	Yes	Yes	FACT-Anemia
FACT-B	Cancer patients	2007	5/10	Short of breath: 1 - Cutaneous: 2 - Pain: 1 - Miscellaneous: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	13	Yes	Yes	FACT-Breast
FACT-BMT	Cancer patients	2013	6/23	Appetite: 1 - Visual: 1 - Taste: 1 - Short of breath: 1 - Cutaneous: 1 - Gastrointestinal: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	5	Yes	Yes	FACT-Bone Marrow Transplantation
FACT-BRM	Cancer patients	2007	5/13	Appetite: 1 - Pain: 1 - Miscellaneous: 3	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Biologic Response Modifiers
FACT-C	Cancer patients	2007	4/11	Gastrointestinal: 4	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	4	Yes	Yes	FACT-Colorectal
FACT-Cog	Cancer patients	2008	0/10	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	4	Yes	Yes	FACT-Cognitive Function
FACT-Cx	Cancer patients	2007	7/12	Genitourinary: 5 - Gastrointestinal: 1 - Appetite: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	3	Yes	Yes	FACT-Cervical
FACIT-D	Chronic disease patients	2013	5/11	Gastrointestinal: 5	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	FACIT-Diarrhea

Questionnaire	Target group	Development year	Proportion physical symptoms	Symptoms allocated to domains	Answer options	Assessment period	Articles that involved the PROM	PROM available in Dutch	Validated	Abbreviation
FACT-En	Cancer patients	2015	9/16	Gastrointestinal: 1 - Genitourinary: 3 - Cuteanous: 3 - Sexual: 1 - Short of breath: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	No	No	FACT-Endometrial
FACT-Es	Cancer patients	2015	10/19	Cutaneous: 3 - Vaginal: 4 - Sexual: 2 - Vomiting: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	FACT-Endocrine Symptoms
FACIT-F	Chronic disease patients	2007	0/13	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	33	Yes	Yes	FACIT-Fatigue
FACT-G	Cancer patients	2007	2/27	Nausea: 1 - Pain: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	46	Yes	Yes	Functional Assessment of Cancer Therapy-General
FACT-GOG-NTX	Cancer patients	2007	8/11	Cutaneous: 4 - Pain: 1 - Hearing: 2 - Cardio: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Peripheral Neuropathy
FACT-HN	Cancer patients	2007	6/12	Oral: 6	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Head & Neck
FACT-Hep	Cancer patients	2007	8/18	Gastrointestinal: 8	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Hepatobiliary
FACT-L	Cancer patients	2007	3/9	Respiratory: 3	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	3	Yes	Yes	FACT-Lung
FACT-Leu	Cancer patients	2007	9/17	Pain: 1 - Swelling: 1 - Weight: 1 - Appetite: 1 - Miscellaneous: 5	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	8	Yes	Yes	FACT-Leukemia
FACT-Lym	Cancer patients	2007	7/15	Pain: 1 - Swelling: 1 - Weight: 1 - Appetite: 1 - Miscellaneous: 3	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	10	Yes	Yes	FACT-Lymphoma
FACT-M	Cancer patients	2007	8/24	Pain: 2 - Short of breath: 1 - Swelling: 1 - Appetite: 1 - Miscellaneous: 3	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	FACT-Melanoma
FACT-MM	Cancer patients	2009	3/14	Pain: 1 - Walking: 1 - Weight: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Multiple Melanoma
FACT-O	Cancer patients	2007	7/12	Swelling: 1 - Weight: 1 - Appetite: 1 - Gastrointestinal: 2 - Miscellaneous: 2	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	FACT-Ovarian
FACT-P	Cancer patients	2007	8/12	Pain: 2 - Gastrointesinal: 1 - Genitourinary: 2 - Sexual: 1 - Miscellaneous: 2	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	2	Yes	Yes	FACT-Prostate
FACT-Taxane	Cancer patients	2007	10/16	Cutaneous: 4 - Pain: 1 - Hearing: 2 - Cardio: 1 - Swelling: 2	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	FACT-Taxane
NFHNSI-22	Cancer patients	2010	12/22	Pain: 2 - Weight: 1 - Oral: 4 - Taste: 2 - Miscellaneous: 3	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	1	Yes	Yes	Functional Assessment of Cancer Therapy Head & Neck Cancer Symptom Index
MDASI	Cancer patients	2000	7/19	Pain: 1 - Oral: 2 - Miscellaneous: 4	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	13	No	Yes	MD Anderson Symptom Inventory
MDASI-BMT	Cancer patients	2000	10/24	Pain: 1 - Oral: 2 - Gastrointestinal: 1 - Miscellaneous: 6	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	1	No	Yes	MDASI-Bone Marrow Transplant
MDASI-BT	Cancer patients	2000	12/28	Pain: 1 - Oral: 2 - Visual: 1 - Gastrointestinal: 1 - Miscellaneous: 7	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	7	No	Yes	MDASI-Brain Tumour
MDASI-CML	Cancer patients	2000	13/26	Pain: 1 - Oral: 2 - Gastrointestinal: 1 - Swelling: 1 - Cutaneous: 2 - Miscellaneous: 6	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	2	No	Yes	MDASI-Chronic Myeloid Leukemia
MDASI-GI	Cancer patients	2000	11/19	Pain: 1 - Oral: 2 - Gastrointestinal: 2 - Oral: 1 - Taste: 1 - Miscellaneous: 4	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	1	No	Yes	MDASI-Gastrointestinal Cancer
MDASI-HF	Cancer patients	2000	12/27	Pain: 1 - Oral: 2 - Gastrointestinal: 1 - Swelling: 1 - Cardio: 1 - Miscellaneous: 6	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	1	No	Yes	MDASI-Heart Failure
MDASI-L	Cancer patients	2000	9/22	Pain: 1 - Oral: 2 - Gastrointestinal: 1 - Coughing: 1 - Miscellaneous: 4	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	2	No	Yes	MDASI-Lung
MDASI-MM	Cancer patients	2000	13/26	Pain: 2 - Oral: 3 - Gastrointestinal: 2 - Miscellaneous: 6	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	2	No	Yes	MDASI-Multiple Myeloma
MDASI-SP	Cancer patients	2000	11/24	Pain: 1 - Oral: 2 - Gastrointestinal: 2 - Sexual: 1 - Miscellaneous: 5	Eleven options: symptom not present - as bad as you can imagine (select number 0-10)	Last day	1	No	Yes	MDASI-Spine Tumour
MDADI	Cancer patients	2001	0/20	-	Five options: strongly agree / agree / no opinion / disagree / strongly disagree	Last week	4	No	Yes	MD Anderson Dysphagia Inventory
PROMIS	General population	2018	1/29	Pain: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	37	No	Yes	Patient-Reported Outcomes Measurement Information System
PROMIS-C	General population	2020	0/8	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	3	No	Yes	PROMIS-Cognitive
PROMIS-F	General population	2020	0/8	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	9	No	Yes	PROMIS-Fatigue
PROMIS-PF	General population	2016	0/0	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	7	No	Yes	PROMIS-Physical Function
PROMIS-GH	General population	2004	0/10	-	Five options: excellent / very good / good / fair / poor	In general (not specified)	7	No	Yes	PROMIS-Global Health
PROMIS-P	General population	2017	1/20	Pain: 1	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last week	4	No	Yes	PROMIS-Pain
PROMIS-SF	General population	2018	0/14	-	Five options: not at all / a little bit / somewhat / quite a bit / very much	Last month	6	No	Yes	PROMIS-Sexual Function
QLQ-BIL21	Cancer patients	2011	8/21	Oral: 1 - Taste: 1 - Cutaneous: 2 - Pain: 2 - Gastrointestinal: 2	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	Yes	QLQ-cholangiocarcinoma and gallbladder cancer
QLQ-BM22	Cancer patients	2008	14/22	Pain: 14	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	Yes	QLQ-Bone Metastases
QLQ-BR23	Cancer patients	1996	12/23	Oral: 1 - Taste: 1 - Visual: 1 - Sexual: 1 - Pain: 2 - Swelling: 2 - Miscellaneous: 4	Four options: not at all / a little / quite a bit / very much	Last week	20	Yes	Yes	QLQ-Breast Cancer

Questionnaire	Target group	Development year	Proportion physical symptoms	Symptoms allocated to domains	Answer options	Assessment period	Articles that involved the PROM	PROM available in Dutch	Validated	Abbreviation
QLQ-CAX24	Cancer patients	2015	6/24	Taste: 1 - Weight: 1 - Swallow: 1 - Dry mouth: 1 - Miscellaneous: 2	Four options: not at all / a little / quite a bit / very much	Last week	1	No	No	QLQ-Cachexia Cancer
QLQ-CLL17	Cancer patients	2015	6/17	Cardio: 1 - Pain: 2 - Oral: 2 - Miscellaneous: 1	Four options: not at all / a little / quite a bit / very much	Last week	4	Yes	No	QLQ-Chronic Lymphocytic Leukemia
QLQ-CML24	Cancer patients	2011	13/24	Pain: 3 - Weight: 1 - Cutaneous: 1 - Genitourinary: 1 - Visual: 1 - Miscellaneous: 6	Four options: not at all / a little / quite a bit / very much	Last week	4	No	No	QLQ-Chronic Myeloid Leukemia
QLQ-CIPN20	Cancer patients	2013	14/20	Pain: 2 - Cutaneous: 4 - Cardio: 5 - Visual: 1 - Miscellaneous: 2	Four options: not at all / a little / quite a bit / very much	Last week	8	No	No	QLQ-Peripheral Neuropathy
QLQ-CX24	Cancer patients	2003	14/24	Gastrointestinal: 3 - Genitourinary: 5 - Pain: 1 - Sexual: 2 - Miscellaneous: 3	Four options: not at all / a little / quite a bit / very much	Last week	2	Yes	Yes	QLQ-Cervical Cancer
QLQ-EN24	Cancer patients	2010	14/24	Pain: 1 - Genitourinary: 4 - Gastrointestinal: 4 - Miscellaneous: 3 - Sexual: 2	Four options: not at all / a little / quite a bit / very much	Last week	2	Yes	Yes	QLQ-Endometrial Cancer
QLQ-FA12	Cancer patients	2016	0/12	-	Four options: not at all / a little / quite a bit / very much	Last week	3	Yes	Yes	QLQ-Fatigue
QLQ-HCC18	Cancer patients	2002	9/18	Taste: 2 - Cardio: 1 - Swelling: 1 - Cutaneous: 1 - Pain: 2 - Miscellaneous: 2	Four options: not at all / a little / quite a bit / very much	Last week	3	Yes	Yes	QLQ-Hepatocellular Carcinoma
QLQ-HL27	Cancer patients	2015	6/27	Cardio: 1 - Pain: 2 - Taste: 1 - Cutaneous: 1 - Short of breath: 1	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	No	QLQ-Hodgkin's Lymphoma
QLQ-LC13	Cancer patients	2002	8/13	Respiratory: 3 - Swallowing: 1 - Pain: 3 - Miscellaneous: 1	Four options: not at all / a little / quite a bit / very much	Last week	4	Yes	Yes	QLQ-Lung Cancer
QLQ-LMC21	Cancer patients	2002	7/21	Weight: 1 - Taste: 1 - Dry mouth: 2 - Miscellaneous: 1 - Pain: 2	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	Yes	QLQ-Liver Metastases Colorectal Cancer
QLQ-MY20	Cancer patients	1999	12/20	Pain: 5 - Dry mouth: 1 - Visual: 1 - Miscellaneous: 5	Four options: not at all / a little / quite a bit / very much	Last week	4	Yes	Yes	QLQ-Multiple Myeloma
QLQ-NHL-HG29	Cancer patients	2015	10/29	Muscles: 1 - Pain: 2 - Dry mouth: 2 - Taste: 1 - Cardio: 2 - Miscellaneous: 2	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	No	QLQ-High-Grade Non-Hodgkin's Lymphoma
QLQ-NHL-LG20	Cancer patients	2015	6/20	Muscles: 1 - Pain: 1 - Dry mouth: 1 - Taste: 1 - Cardio: 1 - Miscellaneous: 1	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	No	QLQ-Low Grade Non-Hodgkin's Lymphoma
QLQ-OES18	Cancer patients	1999	14/18	Swallow: 2 - Oral: 4 - Taste: 1 - Pain: 3 - Miscellaneous: 4	Four options: not at all / a little / quite a bit / very much	Last week	1	Yes	Yes	QLQ-Oesophageal Cancer
QLQ-OG25	Cancer patients	2007	13/25	Oral: 5 - Miscellaneous: 2 - Pain: 2 - Taste: 1 - Miscellaneous: 3	Four options: not at all / a little / quite a bit / very much	Last week	2	Yes	Yes	QLQ-Gastroesophageal Cancer
QLQ-OV28	Cancer patients	1997	16/28	Pain: 2 - Gastrointestinal: 3 - Genitourinary: 1 - Cutaneous: 1 - Sexual: 1 - Miscellaneous: 8	Four options: not at all / a little / quite a bit / very much	Last week	4	Yes	Yes	QLQ-Ovarian Cancer
QLQ-PAN26	Cancer patients	1999	11/26	Gastrointestinal: 5 - Pain: 2 - Taste: 1 - Muscles: 1 - Dry mouth: 1 - Cutaneous: 1	Four options: not at all / a little / quite a bit / very much	Last week	1	No	No	QLQ-Pancreatic Cancer
QLQ-PR25	Cancer patients	1999	14/25	Genitourinary: 4 - Pain: 1 - Gastrointestinal: 2 - Weight: 2 - Sexual: 2 - Miscellaneous: 3	Four options: not at all / a little / quite a bit / very much	Last week	4	Yes	Yes	QLQ-Prostate Cancer
QLQ-SH-C22	Cancer patients	2014	9/22	Sexual: 9	Four options: not at all / a little / quite a bit / very much	Last month	2	No	Yes	QLQ-Sexual Health Questionnaire
QLQ-STO22	Cancer patients	1999	11/22	Oral: 3 - Pain: 1 - Gastrointestinal: 3 - Dry mouth: 1 - Taste: 1 - Miscellaneous: 2	Four options: not at all / a little / quite a bit / very much	Last week	2	Yes	Yes	QLQ-Gastric Cancer
QLQ-TC26	Cancer patients	1994	9/26	Taste: 1 - Pain: 1 - Cutaneous: 2 - Sexual: 2 - Miscellaneous: 3	Four options: not at all / a little / quite a bit / very much	Last week	1	No	Yes	QLQ-Testicular Cancer

Appendix G: Questions from PROMs that assess physical symptoms connected to symptom list

The twelve PROMs are divided into two overviews.

Symptoms from LATER-guidelines	PRO-CTCAE	PCFU	EPIC	MDASI	QLQ-BN20	QLQ-H&N35
Cough	Hoe ERG was uw HOEST op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					Heeft u gehoest?
Constant cough				Your problem with choking/coughing at its WORST?		
Difficulty swallowing or breathing	Hoe ERG was de MOEITE die u had MET SLIKKEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Moeite met slikken?				Heeft u moeite gehad met slikken bij het eten van vast voedsel?
Lump or swelling in the neck						
Hoarseness	Hoe ERG was uw HESE STEM op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					Bent u hees geweest?
Extreme thirst		Hevige dorst?				
Polydipsia						
Aphasia		Spraakproblemen, zoals onduidelijk of vertraagd spreken, veranderingen in je stem of weten wat te zeggen maar niet in staat zijn om het te zeggen?			Had u moeite met het vinden van de juiste woorden om uzelf uit te drukken?	
Intra-oral pain						Heeft u pijn in uw mond gehad?
Suspicious intra-oral lesions						
Heartburn	Hoe VAAK hebt u BRANDEND MAAGZUUR gehad in de afgelopen 7 dagen?	Zure oprispingen?				
Abdominal distention	Hoe VAAK hebt u een OPGEBLAZEN GEVOEL IN UW BUIK gehad in de afgelopen 7 dagen?		Hoe vaak had u, in de afgelopen 4 weken, buik- of darmkrampen?	Your problem with abdominal bloating at its WORST?		
Constipation	Hoe ERG was uw VERSTOPPING op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Moeizame of harde ontlasting (constipatie)?		Your problem with constipation at its WORST?		
Chronic diarrhoea	Hoe VAAK hebt u DUNNE OF WATERIGE STOELGANG (DIARREE) gehad in de afgelopen 7 dagen?	Papperige of waterige ontlasting (diarree)?	Hoe vaak was de ontlasting, in de afgelopen 4 weken, dun of vloeibaar?			
Persistent change in bowel habits				Your change in bowel pattern (diahrrea or constapation) at its WORST?		
Blood in stool			Hoe vaak had u, in de afgelopen 4 weken, bloed bij de ontlasting?			
Feeling that the bowel does not empty completely			Hoe vaak had u, in de afgelopen 4 weken, drang tot ontlasting, maar zonder dat er iets kwam?			
Unexplained weight loss						
Light-coloured bowel movements						
Shortness of breath	Hoe ERG was uw KORTADEMIGHEID op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Kortademigheid tijdens inspanning of activiteiten? & Kortademigheid in rust, dat wil zeggen zonder inspanning en wanneer je geen fysieke activiteit aan het doen was? & Kortademigheid bij platliggen, bijvoorbeeld om een dutje te doen of om te slapen?		Your shortness of breath at its WORST?		
Orthopnoea						
Wheezing	Hoe ERG was uw PIEPENDE ADEMHALING (FLUITEND GELUID IN DE BORST BIJ HET ADEMHALEN) op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					
Palpitations	Hoe VAAK hebt u een BONZENDE OF JAGENDE HARTSLAG (HARTKLOPPINGEN) gehad in de afgelopen 7 dagen?	Een bonzende, gejaagde of onregelmatige hartslag (hartkloppingen)?				
Dizziness	Hoe ERG was uw DUIZELIGHEID op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Last van duizeligheid?				
Fainting						
Chest pain		Pijn op de borst?				Had u pijn in uw borst?
Swelling	Hoe VAAK hebt u een GEZWOLLEN ARM OF BEEN gehad in de afgelopen 7 dagen?	Zwelling door vocht in je armen, benen of enkels?				
Ankle or lower leg oedema				Your problem with ankle swelling at its WORST?		
Paraesthesias	Hoe ERG was uw GEVOELLOOSHEID OF HET TINTELEN IN UW HANDEN OF VOETEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Een verdoofd gevoel of tintelingen in je handen of voeten?		Your numbness or tingling at its WORST?		

Symptoms from LATER-guidelines	PRO-CTCAE	PCFU	EPIC	MDASI	QLQ-BN20	QLQ-H&N35
Hyperreflexia						
Weakness						
Pallor						
Skin irritation	Hebt u enige vorm van HUIDUITSLAG gehad in de afgelopen 7 dagen?	Onderhuidse oneffenheden of huidproblemen?			Had u last van een jeukende huid?	
Purpura	Kreeg u GEMAKKELIJK BLAUWE PLEKKEN in de afgelopen 7 dagen?					
Suspicious new skin lesions and changing moles						
Dry skin	Hoe ERG was uw DROGE HUID op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					
Muscle weakness	Hoe VAAK hebt u SPIERPIJN gehad in de afgelopen 7 dagen?	Problemen met je spierkracht?			Had u last van spierslapte aan één kant van uw lichaam? & Had u last van spierslapte in beide benen?	
Muscle cramping						
Decreased strength and exercise tolerance						
Tetany						
Low blood pressure						
Hemiparesis/hemiplegia						
Behavioural changes					Voelde u zich onzeker om op uw benen te staan?	
Balance problems		Problemen bij het lopen, zoals mank lopen, of slepen met een been of voet?				
Falling						
Areflexia						
Motor or sensory changes						
Lack of coordination					Had u problemen met uw coördinatievermogen?	
Seizures					Had u plotselinge aanvallen/toevallen?	
Fractures						
Limited range of motion						
Bone mass						
Bone pain	Hoe VAAK hebt u PIJNLIJKE GEWRICHTEN (ZOALS ELLEBOGEN, KNIEËN, SCHOUDERS) gehad in de afgelopen 7 dagen?					
Visual changes		Gezichtsproblemen, zoals wazig zien, lichtflitsen of zwevende vlekken zien, of het hebben van droge of waterige ogen?		Your vision at its WORST?	Zag u onscherp?	
Decreased acuity	Hoe ERG was uw WAZIG ZICHT op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					
Halos	Hebt u ZWEVENDE VLEKJES OF SLIERTJES DIE VÓÓR UW OGEN BEWEGEN gehad in de afgelopen 7 dagen?					
Difficulties in reading or focusing images					Had u moeite met lezen?	
Diplopia					Zag u dubbel?	
Dry eyes						
Persistent eye irritation						
Excessive tearing	Hoe ERG waren uw TRANENDE OGEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					
Light sensitivity						
Poor night vision						
Painful eye						
Pain	Hoe VAAK hebt u PIJN gehad in de afgelopen 7 dagen?	Ergens pijn die anders was dan de alledaagse pijn die we allemaal wel eens ervaren (zoals lichte hoofdpijn, een verrekking of kiespijn)?		Your pain at its WORST?		
Headache	Hoe VAAK hebt u HOOFDPIJN gehad in de afgelopen 7 dagen?				Had u hoofdpijn?	
Progressively worsening, severe, unrelenting headaches						
Abdominal pain	Hoe VAAK hebt u BUIKPIJN gehad in de afgelopen 7 dagen?	Buikpijn?				
Nausea	Hoe VAAK bent u MISSELIJK geweest in de afgelopen 7 dagen?			Your nausea at its WORST?		
Vomiting	Hoe VAAK hebt u GEBRAAKT in de afgelopen 7 dagen?			Your vomiting at its WORST?		
Uneven shoulder blades						
Hump or curve in the back						
Back pain						
Lack of appetite	Hoe ERG was uw VERMINDERDE EETLUST op het SLECHTSTE MOMENT in de afgelopen 7 dagen?			Your problem with lack of appetite at its WORST?		
Hyperphagia						

Symptoms from LATER-guidelines	PRO-CTCAE	PCFU	EPIC	MDASI	QLQ-BN20	QLQ-H&N35
Hearing difficulties		Gehoorproblemen, zoals problemen met het onderscheiden van woorden in een luidruchtige omgeving, of het vaak moeten vragen wat er tegen je werd gezegd?				
Tinnitus	Hoe ERG was UW OORSUIZEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?	Last van oorsuizen?				
Polyuria (frequent urination)	Waren er momenten waarop u VAAK MOEST PLASSEN in de afgelopen 7 dagen?	Problemen met plassen, zoals een pijnlijk of brandend gevoel, of plots nodig of vaak moeten plassen?				
Nocturia		Last van 's nachts wakker worden om te plassen?				
Reduced amount of urine						
Dark-coloured urine	Is de KLEUR VAN UW URINE VERANDERD in de afgelopen 7 dagen?					
Polyuria			Hoe goed kon u, in de afgelopen 4 weken, de urine ophouden?			
Dysuria	Hoe ERG was uw PIJN OF BRANDENDE GEVOEL BIJ HET PLASSEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?		Hoe vaak had u, in de afgelopen 4 weken, pijn of een branderig gevoel bij het plassen?			
Haematuria			Hoe vaak had u, in de afgelopen 4 weken, bloed in de urine?			
Urinary urgency or frequency	Hoe VAAK hebt u VERLIES VAN CONTROLE OVER UW URINE (URINEVERLIES) gehad in de afgelopen 7 dagen?		Hoe vaak verloor u, in de afgelopen 4 weken, urine zonder dat u dat wilde?		Had u moeite om uw plas te beheersen?	
Abnormal urinary stream						
Sexual dysfunction	Hoe ERG waren uw PROBLEMEN MET HET KRIJGEN OF BEHOUDEN VAN EEN ERECTIE op het SLECHTSTE MOMENT in de afgelopen 7 dagen? Let op: andere antwoordmogelijkheden	Problemen met seksueel functioneren of seksuele interesse, zoals een gebrek aan verlangen of interesse in seks, het laattijdig of niet verkrijgen van een orgasme, of pijn tijdens gemeenschap?	Hoe zou u de kwaliteit van uw erecties omschrijven in de afgelopen 4 weken?			
Reduced libido	Hoe ERG was uw VERMINDERD SEKSUEEL VERLANGEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?		Hoe vaak was u seksueel actief, in welke vorm dan ook, in de afgelopen 4 weken?			
Vaginal dryness	Hoe ERG was uw VAGINALE DROOGHEID op het SLECHTSTE MOMENT in de afgelopen 7 dagen?					
Reduced fertility						
Early sexual development						
Night sweats	Hoe VAAK hebt u ONVERWACHT OF OVERMATIG GEZWEET OVERDAG OF 'S NACHTS (NIET IN VERBAND MET OPVLIEGERS) in de afgelopen 7 dagen?					
Icterus						
Reduced growth velocity						
Weight gain		Gewichtsschommelingen, gewichtstoename of gewichtsverlies van meer dan 5 kg?	Is uw gewicht veranderd in de afgelopen 4 weken?	Your problem with sudden weight gain at its WORST?		Bent u aangekomen?
Weight loss						Bent u afgevallen?
Cold intolerance	Hoe VAAK hebt u GEBIBBERD OF KOUDE RILLINGEN gehad in de afgelopen 7 dagen?	Een ongewone gevoeligheid voor warmte of kou?				
Heat intolerance						
Brittle hair	Hebt u HAARUITVAL gehad in de afgelopen 7 dagen?					
Hypocalcemia						
Hyperphosphatemia						
Missed menstrual periods	Hebt u een VERWACHTE MENSTRUATIE OVERGESLAGEN in de afgelopen 7 dagen?	Menstruaties overgeslagen die je wel had verwacht?				
Irregular menstrual periods	Hebt u ONREGELMATIGE MENSTRUATIE gehad in de afgelopen 7 dagen?	Onregelmatige menstruaties? & Hevige menstruaties met veel bloedverlies?				
Hot flushes	Hoe VAAK hebt u OPVLIEGERS gehad in de afgelopen 7 dagen?		In de afgelopen 4 weken, hoe vaak had u last van opvliegers?			
Lump or mass in the breast						
Breast or nipple pain	Hoe ERG was de ZWELLING OF GEVOELIGHEID IN UW BORSTEN op het SLECHTSTE MOMENT in de afgelopen 7 dagen?		In de afgelopen 4 weken, hoe vaak had u last van gevoelige borsten?			
Nipple retraction						
Nipple discharge or bleeding						

See the next page for the questions from the other six PROMs connected to the symptom list.

Symptoms from LATER-guidelines	QLQ-C30	FACT-Br	QLQ-CR29	DCOG-LATER	St. Jude CCSS	St. Jude Life
Cough				Heeft u in het afgelopen jaar een periode gehad waarin u meer dan 6 weken aaneengesloten hoestte?		
Constant cough						
Difficulty swallowing or breathing					Problems chewing or swallowing solids or liquids?	Trouble getting your breath
Lump or swelling in the neck						
Hoarseness						
Extreme thirst						
Polydipsia						
Aphasia		I am able to find the right word(s) to say what I mean & I have difficulty expressing my thoughts			Stammering or stuttering? & Any other speech defects?	
Intra-oral pain						
Suspicious intra-oral lesions						
Heartburn						
Abdominal distention			Heeft u een opgeblazen gevoel gehad in uw buik?			
Constipation	Had u last van obstipatie? (was u verstopt?)					
Chronic diarrhoea	Had u diarree?					
Persistent change in bowel habits						
Blood in stool			Heeft u bloed in uw ontlasting gehad?			
Feeling that the bowel does not empty completely						
Unexplained weight loss						
Light-coloured bowel movements						
Shortness of breath	Was u kortademig?				Chronic cough or shortness of breath for more than one month? & Problems with breathing while at rest that lasted for more than 3 months? & Trouble getting your breath?	
Orthopnoea						
Wheezing						
Palpitations				Hartritmestoornissen		
Tachycardia						
Dizziness					Persistent dizziness or vertigo? & Faintness or dizziness?	
Fainting						
Chest pain				Pijn op de borst (bij inspanning en/of rust)	Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? & Pains in heart or chest?	Pains in heart or chest
Swelling						
Ankle or lower leg oedema						
Paraesthesias					Numbness or tingling inparts of your body	Numbness or tingling in parts of your body
Hyperreflexia						
Weakness						
Pallor						
Skin irritation						
Purpura						
Suspicious new skin lesions and changing moles						
Dry skin						
Muscle weakness						
Muscle cramping						
Decreased strength and exercise tolerance	Heeft u zich slap gevoeld?			Problemen met het bewegingsapparaat (bijvoorbeeld arm/been/elleboog/knie)?	Decreased sense of touch or feeling in hands, fingers, arms or legs?	
Tetany						
Low blood pressure						
Hemiparesis/hemiplegia						
Behavioural changes						
Balance problems						
Falling						
Areflexia						
Motor or sensory changes		I have trouble feeling sensations in my arms, hands, or legs & I have weakness in my arms or legs				
Lack of coordination		I have trouble with coordination			Problems with balance, equilibrium, or ability to reach for or manipulate objects?	
					Epilepsy, repeated seizures.	
Fractures					Osteoporosis or osteopenia (thin, brittle, or fragile bones)? & Have you ever broken a bone?	
Limited range of motion						
Bone mass						
Bone pain						
Visual changes		I have trouble with my eyesight			Any other trouble seeing with one or both eyes even when wearing glasses? & A detached retina or any other condition of the retina? & Cataracts? & Crossed or turned eyes (strabismus)? & Lazy eye (amblyopia)?	

Symptoms from LATER-guidelines	QLQ-C30	FACT-Br	QLQ-CR29	DCOG-LATER	St. Jude CCSS	St. Jude Life
Decreased acuity						
Halos						
Difficulties in reading or focusing images						
Diplopia					Problems with double vision?	
Dry eyes					Very dry eyes requiring eye drops or ointment?	
Persistent eye irritation						
Excessive tearing						
Light sensitivity						
Poor night vision						
Painful eye						
Pain	Heeft u pijn gehad?			Hoeveel pijn had u de afgelopen 4 weken?	How much bodily pain have you had during the past 4 weeks?	For pain that you have had during the past 4 weeks, where has this pain been located?
Headache		I get headaches				How much bodily pain have you had during the past 4 weeks?
Progressively worsening, severe, unrelenting headaches					Other severe headaches?	
Abdominal pain			Heeft u buikpijn gehad?			
Nausea	Heeft u zich misselijk gevoeld?				Nausea or upset stomach	Nausea or upset stomach
Vomiting	Heeft u overgegeven?					
Uneven shoulder blades						
Hump or curve in the back						
Back pain						
Lack of appetite	Heeft u gebrek aan eetlust gehad?					
Hyperphagia						
Hearing difficulties		I have trouble hearing			Hearing loss requiring a hearing aid? & Deafness in both ears not completely corrected by hearing aid? & Deafness in only one ear not completely corrected by hearing aid? & Hearing loss, not requiring a hearing aid?	
Tinnitus				Heeft u last van oorsuizen?	Tinnitus or ringing in the ears?	
Polyuria (frequent urination)			Heeft u overdag vaak geplast?			
Nocturia			Heeft u 's nachts vaak geplast?			
Reduced amount of urine						
Dark-coloured urine						
Polyuria						
Dysuria			Heeft u pijn gehad bij het plassen?			
Haematuria					Blood in your urine?	
Urinary urgency or frequency			Heeft u ongewild urine verloren?		Urinary incontinence?	
Abnormal urinary stream						
Sexual dysfunction				Ervaart u problemen op seksueel gebied? & Welke problemen ervaart u?		
Reduced libido						
Vaginal dryness						
Reduced fertility						
Early sexual development						
Night sweats						
Icterus						
Reduced growth velocity						
Weight gain						
Weight loss						
Cold intolerance						
Heat intolerance						
Brittle hair	Had u last van haaruitval?				Persistent hair loss	
Hypocalcemia						
Hyperphosphatemia						
Missed menstrual periods				Bent u de afgelopen 12 maanden tenminste 1 maal ongesteld geweest?		
Irregular menstrual periods				Wat is de gemiddelde lengte van uw natuurlijke menstruele cyclus?		
Hot flushes						
Lump or mass in the breast					How often do you perform monthly breast self-examinations?	
Breast or nipple pain						
Nipple retraction						
Nipple discharge or bleeding						