Cancer Survivors’ Participation in Meaningful Life Activities, A Mixed Methods Approach

Allison Jean L'Hotta
Washington University in St. Louis

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Cancer Survivors’ Participation in Meaningful Life Activities,
A Mixed Methods Approach
by
Allison Jean L’Hotta

A dissertation presented to
The Graduate School
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

May 2022
St. Louis, Missouri
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List of Abbreviations

ACS\textsubscript{m}: Activity Card Sort, Modified Version

AACS: Adolescent Activity Card Sort

AYAPS: Adolescent and Young Adult Participation Sort

CDSR: Cochrane Database of Systematic Reviews

CIQ: Community Integration Questionnaire

CPI: Community Participation Indicators

CPIB: Communicative Participation Item Bank

DARE: Database of Abstracts of Reviews of Effects

DASH: Disabilities of the Arm, Shoulder and Hand

EMA: Ecological Momentary Assessment

ICC: Intraclass Correlation Coefficient

ICF: International Classification of Functioning, Disability and Health

ICPAS: Iranian Children Participation Assessment

IPA: Impact on Participation and Autonomy Scale

IRT: Item Response Theory

LIFE-H: Assessment of Life Habits

Lymph-ICF: Lymphoedema Functioning, Disability, and Health Questionnaire

Lymph-ICF-UL: Lymphoedema Functioning, Disability, and Health Questionnaire—Upper Limb

MAPA: Meaningful Activity Participation Assessment

OGQ: Occupational Gaps Questionnaire

OGQ-M/OPQ-M: Occupational Gaps Questionnaire—Malay Version/Occupational Participation Questionnaire

OT: Occupational Therapy
PActS: Possibilities for Activities Scale
PASE: Physical Activity Scale for the Elderly
PIPP: Perceived Impact of Problem Profile
PM-3D4D: Participation Measure—3 Domains, 4 Dimensions
PRISMA-SeR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
PRO: Patient-Reported Outcome
PROMIS: Patient-Reported Outcomes Measurement Information System
PSM: Prospective Surveillance Model
PT: Physical Therapy
QOL: Quality of Life
RNL: Reintegration to Normal Living Index
SEM: Structural Equation Modeling
SF: Short Form
SLP: Speech Language Pathology
WHODAS: World Health Organization Disability Assessment Schedule 2.0
WSAS: Work and Social Adjustment Scale
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I spoke with many individuals as a part of this study and I value each of them. I was in awe of how open people were with me during the interview portion of the study, sharing very personal, and often emotional, details about their lives. They reminded me how important relationships are in our life and encouraged me to make the most of each day I am given. I was also amazed by how willing people were to participate in the longitudinal study. I was often meeting individuals during their first appointment with their oncologist, a day that is undoubtedly overwhelming, but most were willing to stay, hear information about the study, and enroll in the study. Their engagement in my research was remarkable and I thank each of them.

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Allison Jean L’Hotta

Washington University in St. Louis

May 2022
To all the warriors, whether small in size and age or abundant in life experiences, you changed my life in a profound way.

“Many people are alive but don’t touch the miracle of being alive.”

-Thich Nhat Hanh
ABSTRACT OF THE DISSERTATION

Cancer Survivors’ Participation in Meaningful Life Activities,
A Mixed Methods Approach

by

Allison Jean L’Hotta

Doctor of Philosophy in Rehabilitation and Participation Science

Washington University in St. Louis, 2022

Professor Allison A. King, Chair

A new cancer diagnosis dramatically impacts an individual’s daily life. While data describing cancer-related symptoms (e.g. fatigue) and impairments (e.g. weakness) are abundant, there remains limited data detailing the impact of cancer on survivors’ daily life participation. Advancement in participation research is challenged by the lack of a universally accepted definition of participation and a standard approach to measurement. Previous research evaluating participation among cancer survivors is limited by small sample sizes, cross-sectional data including only a single disease group, and assessing participation exclusively among individuals who have completed active cancer treatment. The purpose of the presented dissertation was to advance the field of cancer rehabilitation and participation science by 1) identifying what assessments are used to measure participation among cancer survivors; 2) characterize how cancer survivors define participation; and 3) determine how participation is impacted in the first six-months following a new cancer diagnosis.

In synthesizing the current state of evidence for participation measurement in oncology through a scoping review, the vast heterogeneity in assessments used to measure participation
among cancer survivors was revealed. To address the second aim of this dissertation, we conducted interviews with 40 cancer survivors to add to the body of evidence seeking to broaden the conceptualization of participation. Findings confirmed core characteristics of participation identified in previous research including control, relationships, community engagement, and value, and highlighted that participation is an important construct to evaluate among cancer survivors.

Participation was then prospectively evaluated in a cohort of 123 survivors newly diagnosed with brain, breast, colorectal, or lung cancer for the first six-months post diagnosis. Patient-reported outcome (PRO) data were collected at three time points and included the Community Participation Indicators as the primary participation outcome and Patient-Reported Outcome Measurement Information System (PROMIS) ability to participate in social roles and activities as the secondary participation outcome. Additional PROs were collected on various health domains, such as physical function, fatigue, and anxiety. While there were no significant changes in participation over this six-month period, survivors demonstrated, on average, mildly impaired participation within six months of diagnosis. The colorectal group reported mild impairments as early as one-month post diagnosis. Approximately half the sample reported moderate impairments in participation, physical function, and mental health, indicating they may benefit from rehabilitation services. However, only 20-36% of individuals reporting moderate impairments in these health domains were previously referred to appropriate rehabilitation services by their medical team. PROs assessing participation and other domains of health relevant to rehabilitation (e.g. physical function, anxiety) were an effective method to identify survivors who may benefit from physical or occupational therapy or mental health support. Future work needs to measure participation among survivors from the point of diagnosis and
follow them for longer periods of time during their multi-year cancer journeys. Evaluating participation from diagnosis can support the prevention, early detection, and treatment of cancer-related disability.
Chapter 1: Introduction

Participation is a complex construct critical to understanding the daily lives of all individuals. In the presented dissertation, the following definition of participation is proposed: doing what an individual finds important or meaningful in their daily life, which helps establish life satisfaction. Previous research supports that participation establishes meaning, purpose, and life satisfaction and provides opportunities for social interaction and skill development.\textsuperscript{1-3} Each individual’s participation profile is unique because participation focuses on what an individual chooses to do versus what they have to do.\textsuperscript{4}

Activities are the building blocks of participation.\textsuperscript{4} An individual is engaging in an activity when they are brushing their teeth or getting dressed. Participation typically involves a sequence of multiple occupations or activities (e.g. brushing teeth, dressing, driving)\textsuperscript{4} to do something that is meaningful to or valued by the individual, such as picking up their children from school. While not all activities are meaningful to an individual, those that are help people form their identity through participation.\textsuperscript{5}

Participation is critical to promoting health and well-being.\textsuperscript{6} When diagnosed with a serious or life-threatening illness, participation remains important.\textsuperscript{7} Maintaining participation can help retain a sense of normalcy and purpose in life,\textsuperscript{1} promote feelings of joy, and enhance well-being in the face of illness.\textsuperscript{7} Participation and social connection have been associated with decreased mortality and protection against cognitive decline in older adults.\textsuperscript{8-10}

The potential health benefits of participation are striking. Consequently, it is critical that we investigate how daily life participation is impacted among individuals with chronic health
conditions. The presented work details the participation experiences of a large subset of individuals with at least one chronic health condition—cancer. The purpose of this dissertation is to 1) identify what assessment tools are used to measure participation among cancer survivors, 2) characterize how cancer survivors define participation, and 3) determine how participation changes during the first six months following a new cancer diagnosis.

1.1 Theoretical Basis of Participation
To better understand participation, key factors relevant to participation must be explored. Factors relevant to participation include motivation, competence, and self-efficacy\(^\text{11}\) along with the role of the environment in enabling or hindering participation in chosen occupations.\(^1\) The concepts of personal choice, satisfaction, and meaning are also essential to participation.\(^4,12\)

1.1.2 Self-Determination Theory
Motivation, informed by self-determination theory, is a key underpinning of participation. Self-determination theory outlines the importance of three concepts—competence, autonomy, and relatedness.\(^13\) Each of these factors is also discussed in literature on the conceptualization of participation:

- Competence: relates to an individual’s capacity and performance, which are directly relevant to activity and participation.\(^4\)
- Autonomy: incorporated into definitions\(^14\) and measures\(^15\) of participation. Self-determination theory defines autonomy as having a feeling of choice in one’s actions.\(^13\) Choice is another key component of participation.\(^16\)
- Relatedness/social connection: some definitions explicitly state that participation is intrinsically social and occurs in a societally defined context.\(^17\)
Self-determination theory delineates between intrinsic and extrinsic motivation. Intrinsically motivated behaviors are described as activities that are inherently valuable, interesting, enjoyable, and done for satisfaction. Intrinsically motivated behaviors are the most valued activities in an individual’s life, highlighting the direct connection to participation.

The majority of activities people do are extrinsically motivated by social pressures or other externally motivating factors. While there are a wide range of underlying reasons people participate in extrinsically motivated behaviors, Ryan and Deci (2000) identified the desire for relatedness as the primary influencing factor. Extrinsically motivated behaviors are internalized and integrated into behavior to different degrees based on social, environmental, and personal factors. While some behaviors remain extrinsically motivated by other individuals, such as a child doing their homework because their parents require they do so, others are done as a choice based on an individual’s self-accepted values and beliefs. For example, a father performs an activity for his child (e.g. changing the child’s diaper) because he recognizes the importance of performing this activity to help his child, yet he may not be intrinsically motivated by this task. Behaviors such as changing a child’s diaper have an ascribed value and personal importance and would fall under the concept of fulfilling a social role (father), a core component included in definitions of participation. Because extrinsically motivated behaviors are often socially motivated, social role fulfillment likely aligns with extrinsically motivated behaviors. While individuals ascribe value to these extrinsically motivated behaviors, they are not necessarily performed for their own pure interest and enjoyment as in intrinsically motivated behaviors.
1.1.3 Social Cognitive Theory

Social cognitive theory outlines how an individual’s perceived self-efficacy, or belief in their ability to organize and carry out actions, gives individuals an incentive to act.\textsuperscript{21} The concepts of competence and self-efficacy are often intertwined in the literature,\textsuperscript{18,22} but each construct likely has a unique impact on participation. Despite having the underlying skills/competence needed to participate, an individual may not perceive they are competent to do so. Self-efficacy can impact activity choices and how long people persist in difficult environments.\textsuperscript{21,22} Previous research demonstrates that self-efficacy explains a proportion of the variability in participation outcomes.\textsuperscript{23}

1.1.4 Locus of Control

Locus of control refers to an individual’s beliefs about the relationship between their actions and outcomes.\textsuperscript{24} The previously discussed concepts of competence and efficacy beliefs are related to both locus of control and participation.\textsuperscript{11,12,24} Similar to self-efficacy, examining locus of control can help explain why some people act or fail to act in challenging circumstances.\textsuperscript{24} In the scope of participation, this can translate to why some cancer survivors continue to participate fully after their diagnosis and others struggle to do the things they enjoy.

With an internal locus of control an individual perceives they have behavioral control over an outcome; they feel responsible and believe their actions and abilities determine their experiences.\textsuperscript{24,25} With an external locus, an individual believes outcomes are not determined by their own personal efforts but instead by external factors such as chance or their social context.\textsuperscript{24,25} When survivors perceive factors as outside of their control, even when it is something that is a part of them (e.g. physical weakness), there is an external locus of control.\textsuperscript{26}
Locus of control is an important construct to consider given that control is identified as a defining characteristic of participation.\textsuperscript{27}

1.1.5 Bronfenbrenner’s Ecological Systems Theory

To facilitate participation it is essential to understand the influence of environmental factors on the expression of disability.\textsuperscript{28} Throughout life, people are constantly interacting with novel and shifting environments. Bronfenbrenner’s ecological systems theory describes the mutual accommodation between developing individuals and their changing environments.\textsuperscript{29} Understanding the interactions between environments is key to informing the complex person-environment relations among survivors. Bronfenbrenner’s theory depicts the individual in the center of a series of interacting systems (Figure 1.1).\textsuperscript{29}

Figure 1.1. Bronfenbrenner’s Ecological Systems Theory Representing Survivors’ Environments
The primary environments in which adult cancer survivors participate include the home, work, hospital, and the broader community. These environments make up the microsystem, or immediate setting.\textsuperscript{29} The mesosystem describes the interrelationships between major settings and can include interactions with family, friends, peers, and medical professionals.\textsuperscript{29} The mesosystem is the environmental system representing social support, which is critical in person-environment-participation relationships.\textsuperscript{30,31} The exosystem indirectly impacts survivors through formal and informal social structures such as workplace policies, local, state, and national laws, and informal social networks.\textsuperscript{29} The macrosystem represents cultural values, attitudes, and institutional patterns.\textsuperscript{29} Bronfenbrenner’s ecological systems theory clearly synthesizes the interactions and interrelationships between the multi-level contexts of survivors. This environmental theory should be used in conjunction with self-determination, social cognitive, and control theories to investigate the construct of participation.

Due to the scope of this dissertation research, it was not feasible to address all of the theoretical underpinnings of participation. The qualitative portion of the dissertation is the main area where theoretical constructs were more critically analyzed. The focus was primarily on self-determination theory and secondarily on control theory.

1.2 Defining Participation

While occupational therapists have focused on participation for decades, the concept of participation garnered increased interest in scientific communities after its integration into the International Classification of Functioning, Disability and Health (ICF) in 2001.\textsuperscript{19} The ICF is a classification system designed with the goal of creating a standard language for addressing various domains of health.\textsuperscript{19} The ICF was an important step forward for how disability is viewed and classified because disability is no longer centered as a problem within an individual,\textsuperscript{32} as was
the case in the International Classification of Impairments, Disability and Health. The ICF outlines how disability is an interaction between health conditions, the person, and the environment and how health conditions can impact body functions and structures, activity, and participation. However, the ICF’s broad definition of participation as *involvement in a life situation* lacks conceptual clarity and has presented challenges for rehabilitation researchers and measurement development. The broad ICF definition of participation is insufficient to clearly define this complex construct. More than 20 years after the inception of the ICF we still lack a comprehensive, clear, and universally accepted definition of participation.

### 1.2.1 Differentiation of Activity, Performance, and Participation

To improve the conceptualization of participation there needs to be a clear distinction between activity and participation. Much of the confusion between the two concepts stems from the ICF including activity and participation in the same chapter. While the ICF does provide recommendations on how to distinguish between activity and participation, such as assigning certain domains to activity and others to participation, the lack of clear differentiation between the two concepts offers limited guidance for researchers. Although the ICF blended these constructs, activity and participation do have distinct definitions. Activities are concrete tasks which can lead to participation while participation is a more complex process of combining multiple tasks/activities to perform a life role or engage in something an individual finds personally meaningful. Until this distinction is made, assessments will continue to measure concepts in addition to or instead of participation, such as activity, function, and symptoms, which further confounds our ability to clearly define and make conclusions about participation.
Performance and participation are also frequently discussed concurrently by researchers and clinicians and the ICF again blends these concepts. Within the ICF activity and participation have performance and capacity qualifiers. “The performance qualifier describes what an individual does in his or her current environment. Since the current environment always includes the overall societal context, performance can also be understood as ‘involvement in a life situation’ or ‘the lived experience’ of people in their actual context” (pg. 12). Here the ICF suggests that performance can be seen as participation, resulting in confusion about the difference between the two constructs. The ICF contains a footnote associated with the definition of performance which states that although the only way to code participation is through performance, this does not indicate that participation is always connected to performance.19

The concept of performance is action-oriented, directly observable, linked with executing tasks or activities, and tends to lack meaning.12,19 For example, when a person is climbing stairs they are active in a task, it is observable, and climbing stairs likely is not a source of meaning in the person’s life. Participation goes beyond what an individual does and considers the subjective experiences of participating such as the meaning, value, or importance of engaging in an activity.34

1.2.2 Participation Beyond the ICF

Researchers have worked on further refining the definition of participation beyond the ICF definition. Below are examples of more expansive definitions of participation proposed since the publication of the ICF. Similarities and differences in terminology used to define participation are summarized in Table 1.1.

- “Involvement in life situations, which includes being autonomous to some extent or being able to control your own life, even if one is not actually doing things themselves.” Not
only should performance be a key indicator of participation, but also the fulfillment of personal goals and societal roles (Perenboom & Chorus, 2003).14

- “Engagement in activities that are intrinsically social, that are part of household or other occupational role functioning, or that are recreational activities occurring in community settings” (Brown et al., 2004).43
- “Participation not only includes active engagement in life situations at the societal level, but it also includes the personal meaning and satisfaction resulting from that engagement” (Hammel et al., 2008).27
- “Participation occurs at the societal level, and to participate is to fulfill social roles.”
  “Participation gains its societal perspective by performing with or for others” (Whiteneck & Dijkers, 2009).4
- “Active involvement in activities that are intrinsically social and occur in a societally-defined context” (Chang, Coster, & Helfrich, 2013).41

While each proposed definition is an improvement from the ICF, many still include ambiguous language (e.g. intrinsically social, societally-defined context). Further, engagement at the societal level is never explicitly defined and it is unclear if each definition is using this language in the same way. Last, all but one definition (Hammel et al., 2008)27 lack information about the subjective nature of participation (meaning, satisfaction), which researchers propose are critical components of participation.4,17 The objective and subjective aspects of participation are further discussed in the measurement section.
### Table 1.1 Terminology Used in Definitions of Participation

<table>
<thead>
<tr>
<th>Study</th>
<th>Involvement, engagement, doing</th>
<th>Life situations, activities</th>
<th>Autonomy, control</th>
<th>Societal context, level, or roles</th>
<th>Performance</th>
<th>Setting: household, community</th>
<th>Personal meaning, satisfaction</th>
<th>With others, social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perenboom &amp; Chorus, 2003</td>
<td>Involvement, doing things</td>
<td>Life situations</td>
<td>Autonomy, control</td>
<td>Societal roles</td>
<td>Performance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brown et al., 2004</td>
<td>Engagement</td>
<td>Activities</td>
<td>Occupational role functioning</td>
<td>Household, recreational activities in community settings</td>
<td>Intrinsically social</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hammel et al., 2008</td>
<td>Active engagement</td>
<td>Life situations</td>
<td>Societal level</td>
<td></td>
<td>Personal meaning &amp; satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whiteneck &amp; Dijkers, 2009</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chang, Coster, &amp; Helfrich, 2013</td>
<td>Active involvement</td>
<td>Activities</td>
<td>Societally-defined context</td>
<td>Performing with or for others</td>
<td>With or for others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Intrinsically social</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Leaders in the field have reported: “there continues to remain a critical need for participatory research that involves people with diverse disabilities and participation experiences in the grounded conceptualization of participation” (pg. 1446). Through qualitative methods we can conceptualize how cancer survivors view and define participation. Informed by previous research and the work presented in this dissertation, the following definition of participation is proposed: *doing what an individual finds important or meaningful in their daily life, which helps establish life satisfaction.* In the proposed definition, the term doing was used rather than involvement or engagement because this is the term survivors used most frequently when defining participation, as discussed in Chapter 3. The term activity was excluded to avoid blending of the concepts of activity and participation. Additionally, “life situations” and “societal context/level” were not included because this language is vague and is not easily understood by a broad audience. By stating that participation includes what an individual finds important or meaningful in their life, the proposed definition includes components of previous definitions such as household and community activities and the social nature of participation, but it does not provide specific examples. The proposed definition of participation is more comprehensive than the ICF definition and uses clear language than can be easily understood by a variety of audiences including clinicians, researchers, healthy individuals, and individuals living with chronic or disabling conditions.

1.3 Participation Measurement

The lack of consensus on a clear definition of participation leads to considerable variability in measurement approaches. Assessments vary in number and types of domains measured, how participation is evaluated (e.g. frequency of occurrence, importance, satisfaction, etc.), and scoring approaches. Participation measures are often developed and/or critically
analyzed through the lens of the ICF which identified nine domains of activity and participation: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social, and civic life. Assessments vary widely in their coverage of the nine ICF domains, and very few assessments cover all domains. The specific ICF domains that pertain specifically to participation versus activity remains widely debated.

Assessment tools also vary in the extent to which participation is measured. Some assessments include multiple domains specific to participation (e.g. productivity, social, leisure) while others focus on a specific aspect of participation such as work or social participation. Participation-specific measures vary widely in number of items, ranging between 11 and 240. Another group of assessments contains a single domain or question specific to participation integrated within larger global health or quality of life (QOL) assessments. These measures contain as few as a single item examining participation and do not examine the complexity of participation. Whether participation should be evaluated as a global construct or as individual domains remains unresolved. Additionally, drawing conclusions about participation from global health measures is scrutinized because these measures do not comprehensively evaluate the construct.

1.3.1 Objective and Subjective Components of Participation
Most measures include only an objective evaluation of whether or not an activity was done and lack questions about the subjective nature of participation. Measures need to include both objective and subjective components of participation to comprehensively evaluate the construct. Objective components include frequency and duration of participation. Subjective factors include satisfaction, importance, and/or meaning, among other factors.
An individual’s subjective participation experience can be measured in a variety of ways, further contributing to the variability in participation measurement approaches. In a systematic review of participation measures, only 9% of items measured satisfaction with participation. An assumption of assessments that only measure objective participation is that a greater sum frequency of participation indicates better participation, but this is not necessarily true. Understanding an individual’s subjective evaluation of their participation is essential, because personal preferences and choice play a key role in participation. People may not want to participate in certain activities, yet in assessments that only evaluate objective participation, they are penalized in their score for not participating.

1.3.2 Application of Modern Measurement Techniques

Modern measurement techniques, such as item response theory (IRT) and Rasch analysis, have a number of advantages. Assessments developed with Rasch analysis support the comparison of scores on a single latent trait by aligning the items on a linear scale in order of difficulty. A primary benefit of modern measurement approaches within a clinical context is the ability to use a smaller number of items to measure a construct with comparable reliability to a longer measure developed with classical test theory. However, the applicability of IRT to participation measures is widely debated. Some researchers explicitly state that participation is not a concept that follows the assumptions of IRT, particularly the assumption of having a linear trait that follows a hierarchical pattern.

To understand hierarchical ordering, first consider three facets of mobility: standing, walking, and running. These three forms of mobility follow a clear difficulty hierarchy with running denoting the most advanced form of mobility. Now, consider three life roles as potential participation items: worker, student, and homemaker. While the level of difficulty between these
roles can certainly be debated, there is not a clear expectation or accepted standard for which is a more advanced form of participation. This challenge is further illustrated within a single item of participation. Consider the idea of playing a game as a form of participation. The level of difficulty varies greatly based on the specific game (card game versus bingo versus memory game) and the context (playing with one individual versus a group at home versus at a community center). The difficulty of each of these scenarios is different, even within one facet of participation. The role personal preference plays in choosing to participate also presents challenges for IRT. Activities that are infrequently performed may be interpreted as more advanced forms of participation when in reality they are simply activities that an individual does not want to do.

Another assumption of IRT is trait unidimensionality, which means a single latent trait is measured (e.g. physical function, math skills). Participation is typically defined as a multidimensional construct; thus, the unidimensionality of participation is questioned. Not only do objective and subjective aspects of participation need to be distinctly measured, but participation may be further divided by areas of participation (e.g. productivity, social, and leisure). The dimensionality assumption is a common concern among health measures and is not unique to participation.

Whether the construct of participation meets the assumptions of IRT remains unclear, but the field is beginning to test its application. A team that previously critiqued the use of IRT for participation measures went on to develop the Participation Assessment with Recombined Tools—Objective using modern measurement techniques. The Participation Measure—3 Domains, 4 Dimensions (PM-3D4D) was developed using factor analysis and IRT. Notably,
participation was treated as a multidimensional construct in the development of PM-3D4D and there is no overall summary score, only individual domain and dimension scores.\(^{53}\)

### 1.3.3 Challenges with Scoring and Normative Values

Assessment developers continue to struggle with how to incorporate both objective and subjective evaluations of participation to create a meaningful score.\(^{4}\) Scoring is further confounded by differing approaches to domain-specific versus aggregate summary score calculation and the lack of normative values to which scores can be compared.\(^{41}\) While PM-3D4D is a rigorously developed measure, the complexity of scoring may render the scores too difficult to use because participation experiences are not clearly summarized.

To gather meaningful data from participation measures, a scoring system that can incorporate preference for activities or other subjective components of participation should be generated.\(^{37}\) This could be accomplished by developing an importance-weighted objective participation score.\(^{37}\) The Participation Objective, Participation Subjective includes importance-weighted scoring where areas of participation rated as more important receive a higher weight in the overall score in terms of an individual’s level of satisfaction.\(^{43}\) Importance-weighted scoring systems can help ensure data critical to the construct of participation are not lost and can support meaningful interpretations of assessment results by clinicians and researchers.

Another challenge in interpreting participation measures is understanding whether an individual’s participation is deemed “good” or fits an established social norm.\(^{41}\) There is no standard for what normal participation looks like because no large cohort studies of participation have been conducted using comprehensive measures of participation.\(^{12}\) Whether population normative values for participation are even appropriate is questioned.\(^{44}\) While the individual nature of participation is clear, lacking a comparator or a standard for participation limits our
ability to communicate the extent of participation restrictions and effectiveness of rehabilitation services.

In summary, areas to further explore to advance participation measurement and establish consensus include:

- Identify a clear and consistent definition of participation, including methods to differentiate between activity and participation.
- Determine the domains of participation.
- Identify if there is a minimum number of questions needed to comprehensively evaluate participation and inform clinical care.
- Determine if a single domain measuring participation within broader general health or quality of life (QOL) measures is sufficient to measure participation and inform clinical decision making.
- Ascertain how to combine scoring of objective and subjective components of participation to create meaningful scoring systems.
- Evaluate if IRT and the collection of normative data are applicable to the construct of participation.

While two systematic reviews of adult participation measures have been completed, these studies focus on a broad group of individuals with disabilities and include assessments that are not relevant to many cancer survivors, such as the Craig Handicap Assessment and Reporting Technique, used primarily amongst individuals with spinal cord injury. To examine the state of participation measurement amongst cancer survivors, scoping review methods can be used to investigate this broad topic where heterogeneity in findings is expected.
1.4 Application to Cancer Survivors

The population of cancer survivors, who are identified as survivors from the time of diagnosis,\textsuperscript{56} living in the United States is projected to increase to 26.1 million by 2040.\textsuperscript{57} Cancer is the result of uncontrolled cellular growth and malignant changes to cells.\textsuperscript{58} Treatment approaches such as surgery, chemotherapy, radiation therapy, and immunotherapy aim to remove or destroy cancerous cells in the body.\textsuperscript{58,59} In the process of destroying cancer cells, rapidly dividing healthy cells are frequently destroyed as well, resulting in a variety of side effects.\textsuperscript{58,60} Side effects can occur acutely, at the time of treatment, persist over time, or arise for the first time months or even years after treatment completion (known as late effects).\textsuperscript{61} Table 1.2 provides examples of how performance and participation can be impacted by disease-related, person-specific, and common biopsychosocial side effects of treatment. While the side effects listed in Table 1.2 are based on evidence, this is not an exhaustive list but serves as an overview of common challenges. Further, the performance and participation restrictions outlined are primarily theoretical to illustrate the differences between these concepts and provide ideas on how these areas can be impacted. Additionally, it is acknowledged that many of the presented factors have both biologic and psychologic underpinnings, but they are classified in only one category in the table.
Table 1.2 Impact of Biopsychosocial Factors on Performance and Participation

<table>
<thead>
<tr>
<th>Overarching Factor</th>
<th>Specific Factor</th>
<th>Impact on Performance</th>
<th>Impact on Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biologic (disease-specific)</td>
<td>Diagnosis &amp; disease stage</td>
<td>Bone tumor impacts ability to stand.⁶²</td>
<td>Stops playing basketball with friends.</td>
</tr>
<tr>
<td></td>
<td>Medical treatment (e.g. chemotherapy)</td>
<td>See below for performance limitations due to side effects of treatment.</td>
<td>Increased time spent in hospital, unable to maintain employment.⁶³</td>
</tr>
<tr>
<td>Biologic (person)</td>
<td>Age, sex</td>
<td>Female sex and older age at time of diagnosis are associated with higher levels of frailty, impacting both capacity and performance to perform physical activities.⁶⁴</td>
<td>Decreased participation in leisure time physical activity; doesn’t visit family friend’s apartment because they live on the 3rd floor.</td>
</tr>
<tr>
<td>Biologic (treatment side effects)</td>
<td>Comorbid conditions</td>
<td>Chemotherapy related cardiotoxicity⁶⁵ decreases heart function which impacts strength and ability to perform endurance activities.</td>
<td>Decreased endurance to perform volunteer activities at local arboretum (e.g. lawn mowing).</td>
</tr>
<tr>
<td></td>
<td>Peripheral neuropathy⁶⁶</td>
<td>Hand cramping limits ability to hold writing instrument.</td>
<td>Difficulty writing down orders on a notepad at work as a waiter.</td>
</tr>
<tr>
<td></td>
<td>Fatigue⁶⁷</td>
<td>Decreased endurance throughout day; can’t sustain standing in the afternoon.⁶⁸</td>
<td>Unable to coach swim team.</td>
</tr>
<tr>
<td></td>
<td>Pain⁶⁹</td>
<td>Post-operative neck pain impacts ability to hold head in neutral.</td>
<td>Limits participation in social activities due to difficulty maintaining typical social norms such as looking at</td>
</tr>
<tr>
<td>Strength</td>
<td>Decreased arm strength, unable to hold arm straight and resist pressure.</td>
<td>Unable to hold leash to walk dog.</td>
<td></td>
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<tr>
<td>----------</td>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Range of motion</td>
<td>Decreased shoulder range of motion post mastectomy.</td>
<td>Decreased ability to reach ingredients and baking materials in cabinets to bake with grandchild.</td>
<td></td>
</tr>
<tr>
<td>Coordination</td>
<td>Difficulty walking.</td>
<td>Unable to walk independently at grocery store.</td>
<td></td>
</tr>
<tr>
<td>Cognition</td>
<td>Difficulty following multi-step tasks. Concern about driving safety.</td>
<td>Difficulty learning and executing new complex activities at work. Unable to drive independently to medical appointments.</td>
<td></td>
</tr>
<tr>
<td>Swallowing</td>
<td>Decreased oral intake.</td>
<td>Not involved in family mealtime.</td>
<td></td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td>Vaginal dryness due to radiation.</td>
<td>Decreased sexual intimacy.</td>
<td></td>
</tr>
<tr>
<td>Lymphedema</td>
<td>Difficulty raising arms due to weight of limb - cannot sustain arm position on car steering wheel.</td>
<td>Does not drive to visit their child who lives an hour away.</td>
<td></td>
</tr>
<tr>
<td>Hair loss</td>
<td>N/A</td>
<td>Decreased interaction with peers due to discomfort with body image.</td>
<td></td>
</tr>
<tr>
<td>Language</td>
<td>Expressive aphasia.</td>
<td>Engaging in conversation with family and friends decreases due to</td>
<td></td>
</tr>
<tr>
<td>Domain</td>
<td>Category</td>
<td>Description</td>
<td>Impact</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Psychologic</td>
<td>Baseline mental health diagnosis</td>
<td>Difficulty with organization.</td>
<td>Difficulty attending medical appointments.</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>Difficulty maintaining attention on present moment.</td>
<td>Reduced engagement in conversation with friends.</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Takes hours to get out of bed and perform morning routine.</td>
<td>Difficulty driving children to school, attending work.</td>
</tr>
<tr>
<td></td>
<td>Coping approach</td>
<td>Unable to focus on anything other than cancer diagnosis and treatment.</td>
<td>Stops attending pottery classes.</td>
</tr>
<tr>
<td>Social</td>
<td>Socioeconomic status*</td>
<td>Lower socioeconomic status is associated with lower physical activity—does not exercise</td>
<td>Lower participation in sports or other leisure activities.</td>
</tr>
<tr>
<td></td>
<td>Education*</td>
<td>Lower education is associated with lower physical performance and strength—cannot lift heavy materials.</td>
<td>Difficulty participating in preferred hobby of woodworking.</td>
</tr>
<tr>
<td></td>
<td>Race, ethnicity</td>
<td>Newly diagnosed female African American survivors are more likely to have deficits in one or more activities of daily living (ADLs) (e.g. showering) than other races. Racial differences in disability were explained in part by lower income and education among</td>
<td>Due to inability to perform self-care, unable to maintain employment.</td>
</tr>
</tbody>
</table>
| Social support | In a broad sense, no impact on performance. When considering specific tasks that an individual needs physical assistance with, having instrumental support can help them for example get out of a chair. | Broadly, having social support encourages survivors to participate in a variety of activities, such as getting out of the house to exercise. 
Support provided for the performance of specific tasks can support participation in home (cooking) or in the community (going to a play). |

*Cited findings are not from cancer population.*
Qualitative studies explore the participation experiences of survivors with breast cancer, brain tumors, and post stem cell transplantation.\textsuperscript{68,73,89-91} Many survivors are limited to engaging in only basic activities of daily living due to extreme fatigue following transplant.\textsuperscript{68} They often forego more complex and energy-taxing activities, such as instrumental ADLs (e.g. household chores) and leisure activities, to conserve energy for the things they have to do.\textsuperscript{68,89} Survivors tend to gradually resume IADLs over time,\textsuperscript{68} but a standard pace of return to participation is not identified across qualitative studies.

Some survivors also restructure their priorities and limit relationships that did not enhance their life.\textsuperscript{92} However, maintaining social networks is important. Social support is critical to supporting participation amongst survivors and is particularly important when an individual needs to adapt to a change in functional status.\textsuperscript{89}

A common finding in qualitative studies is the potential healing power of participation and the use of participation as a coping mechanism to deal with cancer.\textsuperscript{68,89,90} While the available body of literature provides important information on activity and participation challenges among a few subgroups of survivors, there is still a paucity of evidence examining the participation experiences of a broad group of cancer survivors.

Despite the widespread impact of cancer on survivors’ daily lives, participation is rarely addressed in oncology care.\textsuperscript{93} While symptom and impairment screenings are fairly common,\textsuperscript{94,95} measuring and intervening in these domains does not necessarily translate to improved participation.\textsuperscript{20} Advancements in the field are constrained by the lack of consensus on how to screen survivors for participation restrictions and performance challenges.\textsuperscript{96,97}
A large cohort study of cancer survivors revealed prevalence rates for physical performance limitations are approximately 53% and approximately 31% for participation restrictions. While this work is widely cited, there are methodological flaws in how participation was measured. Conclusions were drawn about participation based on seven questions, several of which focused on activity-level limitations (e.g. use of fork, knife, or cup; dressing), rather than true participation restrictions.

Four studies used a modified version of the Activity Card Sort (ACSm) to evaluate participation amongst survivors. Findings consistently demonstrate that participation restrictions persist over time, sometimes for years post treatment, and that survivors report the greatest reduction in high-demand leisure activities (e.g. playing sports). Studies measuring participation with the ACSm had small sample sizes, between eight and 43 participants, and two focused exclusively on women with breast cancer.

Experts in the fields of participation and cancer rehabilitation recently outlined the need to longitudinally evaluate participation amongst survivors. Most studies that measure participation amongst survivors are cross-sectional and include only those who have completed treatment. Three studies have followed survivors over time, including in individuals post stem cell transplant (n= 36), breast cancer (n= 8), and extremity soft tissue sarcoma (n= 247), but none have measured participation starting from the point of diagnosis. By measuring participation we can begin to understand the variability in survivor experiences and identify individuals who may benefit from rehabilitation. PROs can be used to support measurement over time without increasing clinical burden.
The guiding conceptual model for this study is the prospective surveillance model. The prospective surveillance model is a proactive model of therapy that aids in early identification and treatment of impairments through routine assessment of function and participation across the cancer continuum (Figure 1.2). Following this model, assessments of participation start at the point of diagnosis, which is accomplished in the quantitative phase of the presented research.

Figure 1.2 Prospective Surveillance Model. The model incorporates assessments of body structures, activity, and participation throughout the entire cancer care continuum. Figure recreated for image clarity and reprinted with permission from Wolters Kluwer Health, Inc. License Number 5278410295132. Catherine Alfano & Mackenzi Pergolotti (2018). Next-Generation Cancer Rehabilitation: A Giant Step Forward for Patient Care. Journal of Rehabilitation Nursing, 43(4), 186-194. doi: 10.1097.rnj.0000000000000174

1.5 Summary

Cancer survivors experience debilitating side effects that make it difficult for them to participate in daily life, but we lack data explaining the extent of survivors’ participation restrictions. To determine how survivors’ daily lives are impacted by cancer we need to take a mixed methods approach, integrating both qualitative and quantitative data, to understand their experiences and perspectives of participation. To progress towards measuring participation
amongst cancer survivors, we need to first understand how participation was measured amongst survivors in previous research. The body of work outlined in this dissertation fills critical gaps in participation research amongst cancer survivors by 1) identifying what assessment tools are used to measure participation among cancer survivors, 2) characterizing how cancer survivors define participation, and 3) determining how participation changes during the first six months following a new cancer diagnosis.
Chapter 2: Assessments Used to Measure Participation in Life Activities in Individuals with Cancer: A Scoping Review

Reprinted by permission from [Copyright Clearance Center]: [Springer Nature] [Supportive Care in Cancer] [Assessments Used to Measure Participation in Life Activities in Individuals with Cancer: A Scoping Review, L’Hotta, AJ, Varughese, TE, Lyons, KD, Simon, L, & King, AA, 2020]

2.1 Abstract

Purpose: Individuals with cancer are at high risk for restricted participation in meaningful life activities such as work, school, and social activities. Evaluating participation in life activities is identified as a critical component of rehabilitation referral and triage systems. This scoping review investigates what assessments are used to measure participation in life activities in individuals with cancer.

Methods: Six databases were systematically searched using keywords and controlled vocabulary through February 2020. Eligible studies used the term participation in the context of life situations and had an assessment with at least 5 participation-specific questions.

Results: A total of 4,604 unique articles were identified and screened for eligibility. Thirty-two studies were included; 20 unique assessments of participation were identified. Assessments were developed with the primary purpose of measuring participation (n= 8); global or physical
function (n=9); community integration (n=1); social activity (n=1); or occupational gaps (n=1). Most assessments (12/20) were not developed with the purpose of measuring participation and only 4 assessments measured key components of participation other than frequency.

**Conclusion:** Measuring participation in life activities is a developing area in oncology research. Most studies do not accurately or comprehensively measure this construct. The heterogeneity in assessments used indicates no clear consensus on a gold-standard participation measure for use among cancer survivors. Comprehensively measuring participation will help identify individuals in need of rehabilitation services and is an essential first step to inform the development of targeted interventions to enhance participation.

**Keywords:** Participation; rehabilitation; survivorship; measurement; cancer care

### 2.2 Background

Approximately 38% of individuals in the United States will be diagnosed with cancer during their lifetime. Medical advances have improved survival trends from 1999 to 2016 for men and women with the majority of the most common cancer diagnoses. While survival rates vary widely depending on cancer type, 67% of individuals with cancer survive 5 or more years after diagnosis.

Individuals with cancer typically undergo an assortment of intensive medical treatments such as surgery, chemotherapy, and radiation therapy in an effort to eradicate the disease. The side effects of treatment are multifaceted and impact a variety of domains such as physical, cognitive, and psychosocial functioning. However, little is known about how such widespread and diverse challenges interplay to impact participation in life activities in individuals with cancer.
The International Classification of Functioning, Disability and Health (ICF) identified participation restrictions as one of the key components by which disability should be classified.\textsuperscript{110} Participation was defined by the ICF as involvement in a life situation.\textsuperscript{110} More recent definitions of participation refer to a person’s satisfaction with and ability to fulfill social roles within the home, community, and society.\textsuperscript{4,17} Given the many side effects of cancer treatment and the challenges survivors face gaining or returning to employment,\textsuperscript{111} engaging in basic (e.g. dressing, showering) and instrumental (e.g. housework, shopping) activities of daily living,\textsuperscript{112} and the cost of treatment,\textsuperscript{113} evaluating participation is critical.

Conceptually, there are both objective and subjective dimensions of participation.\textsuperscript{17} Objectively, one can describe the frequency of various role-relevant activities and the settings in which they occur.\textsuperscript{17,41} Subjectively, an individual’s satisfaction, desire for change, perceived difficulty, and importance of participation in specific activities can be described.\textsuperscript{41,44} Because there is no standard for what is considered better or worse participation, personal preferences have an important role in the measurement of participation.\textsuperscript{4} The ultimate goal of measuring this construct is to assess if an individual can do the things that are meaningful to them, to the extent they wish, and in a way that is satisfactory to them.

There has been a call to action for the promotion of strategies that facilitate return to work, school, and life for survivors of cancer,\textsuperscript{114} which are among the core domains of participation. Qualitative and survey data demonstrate that survivors want to engage in typical life activities, such as work and school.\textsuperscript{5} These activities are a natural part of daily life, help establish a sense of normalcy, provide opportunities for socialization, and promote feelings of accomplishment.\textsuperscript{5} Being unable to participate in meaningful activities leads some to feel as if they have lost part of their identity.\textsuperscript{5} To better understand how participation is impacted in
survivors, we must consistently include measures of participation into functional assessments of individuals with cancer from the point of diagnosis through end of life care.\textsuperscript{93} With the push to integrate this concept into the continuum of cancer care,\textsuperscript{20,93} understanding how participation is currently measured in this population is essential.

While two systematic reviews of participation measures\textsuperscript{41,44} have focused on broader populations, narrowing the focus to cancer survivors can identify assessments that are unique to this population and highlight gaps in oncology measurement practices. As the field of participation measurement continues to advance, there is an opportunity to identify additional participation measures that did not exist when the previous reviews were published.

Scoping reviews are conducted to investigate the extent of available literature on broad topics, emerging evidence, and research concepts evaluated and discussed with high variability.\textsuperscript{55,115,116} Participation is an emerging concept within the field of oncology, and we sought to examine how and to what extent participation is measured in cancer survivors. Because of the broad research question and emerging evidence base, a scoping review is recommended to explore participation in this population.\textsuperscript{55} The objective of this review was to determine what assessment tools are currently used to evaluate participation in life activities in individuals with cancer. For the purpose of this study, we referred to Chang and Coster’s (2014) definition of participation as \textit{active involvement in activities that are intrinsically social and occur in a societally defined context}.\textsuperscript{17}
2.3 Methods
The methods for conducting systematic scoping reviews recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines were used in this study.\textsuperscript{115}

2.3.1 Protocol
The study protocol was developed based on the PRISMA-P guideline for protocols. The study protocol is available on request from the corresponding author.

2.3.2 Eligibility Criteria
Inclusion and exclusion criteria were established prior to database searches. Studies were eligible for inclusion if they (1) used the term “participation” or “participate” in the context of involvement in a life situation; (2) included individuals with cancer (any type of cancer, age, phase of treatment, or survivorship); (3) defined a specific assessment as a measure of participation and/or if the assessment contained at least 5 questions pertaining to participation; (4) reported results or conclusions about participation based on assessment results; (5) were published in any year or language; and (6) were peer-reviewed articles, dissertations, or book chapters.

Studies were excluded if (1) participation was not discussed in the context of a life situation; (2) participation was discussed in the context of life situations, but the focus was too narrow (e.g. only physical activity participation); (3) the term participation was only used in an assessment domain title or within an assessment item; (4) no results or conclusions were provided related to participation; (5) the population did not include individuals with cancer; (6) participants were a duplicate cohort represented in separate publications; (7) the assessment used was a questionnaire or survey developed only for the specific study; (8) the assessment used had
fewer than 5 questions pertaining to participation; (9) findings were qualitative as the focus of this study was to identify and describe specific assessments used; and (10) only conference abstracts were available as this did not allow us to gain enough in-depth information on the study.

2.3.3 Information Sources

Search strategies were generated by a medical librarian (L.S.) to locate published literature on the measurement of participation among individuals with cancer. A combination of keywords and controlled vocabulary were used to search the following databases: Ovid Medline, Embase, Scopus, Cochrane Database of Systematic Reviews (CDSR), and Database of Abstracts of Reviews of Effects (DARE). Additionally, instrumentation fields were used to search in EBSCOhost PsycINFO and EBSCOhost PSYCtests.

During the project planning phase, we identified three articles\textsuperscript{41,44,117} that conducted similar studies synthesizing and evaluating tools used to measure participation. However, these studies did not focus on the use of these tools in individuals with cancer. Therefore, we conducted an additional search in each of the databases to find literature mentioning the assessments listed in these three review articles with individuals with cancer. Reference and citation information for each of the non-cancer measurement tool studies was created using the Scopus database.

All databases were searched from their inception through February 2020. Retrieved records for each of the three searches were exported into separate EndNote libraries. Duplicate records were removed by the medical librarian following specific de-duplication methodology\textsuperscript{118}.
2.3.4 Search

Fully reproducible search strategies for each database and search are available in Online Resource 1/Appendix A.

2.3.5 Selection of Sources of Evidence

Titles and abstracts were screened by a single reviewer. Articles identified as needing full-text review were independently screened by two reviewers to determine if they met eligibility criteria. Discrepancies in studies identified for inclusion or in data charting (discussed below) were resolved through discussion and consultation with a third reviewer.

To establish consistent screening guidelines, a list of study inclusion criteria was created with specific examples provided for more abstract components (e.g., the context in which participation was discussed). The list was tested by a single reviewer for 50 full-text articles. Modifications were made for improved clarity and a decision tree was created. The decision tree was used to guide reviewers in identifying articles to include in the study. The two reviewers trialed use of the decision tree for article inclusion with 15 articles and had 100% agreement.

2.3.6 Data Charting Process

A data charting form was developed in Microsoft Excel specific to the needs of this study. The form was pilot-tested by a single reviewer on 20 full-text articles. Modifications were made to include more specific questions about how participation was discussed in the article, the number of participation-specific questions in the assessment, number of study participants, and to include more detailed descriptive terms on how to chart information. A second pilot test was performed with both reviewers on the modified form with five articles. Neither reviewer identified a need for additional modifications to the form. The two reviewers independently charted data from all included studies and compared results.
2.3.7 Data Items
Data were charted on article (title, year, and first author) and participant characteristics (sample size, specific cancer population, and age), how participation was discussed (the definition if provided), where participation was discussed in the article, and what participation conclusions were made, the study’s primary objective, and information on the assessment used (name, how the study characterized the purpose of the measure, and methods for measuring participation).

2.3.8 Critical Appraisal of Individual Sources of Evidence
Because scoping reviews provide a broader overview of the evidence, they do not typically assess studies for quality.115 This is an optional item in the PRISMA-ScR guidelines and was not completed for this study.

2.3.9 Synthesis of Results
Summary statistics were generated for assessment and study characteristics. A bubble plot was created to represent the frequency of assessment use over time. Original articles describing the development of each of the assessments included in the review were identified and reviewed to understand the intended purpose of each assessment. A summary chart of assessment characteristics was created. A summary table of studies included in the review is provided in Online Resource 2/Appendix B.

2.4 Results
The search yielded 4,604 unique articles. After initial screening, 576 full-text articles were assessed for eligibility, 32 of which were included in this review. The majority of full-text articles determined to be ineligible for the review did not discuss participation (n= 290). Other excluded articles discussed participation, but in a context different from involvement in life
situations, such as exclusively measuring participation in physical activity, examining participation in cancer screening programs, or participation in decision making in medical care (n= 65). Articles were also excluded if participation was discussed briefly, but there were no measures (n= 71) or results and conclusions (n= 55) pertaining to participation. Details on study selection are described in Figure 2.1.

While one study was published in 2000, all other studies were published between 2006 and 2020. Time trends, frequency of assessment use, and sample size are illustrated in Figure 2.2. In the 32 included studies, 20 different assessments were used to measure or draw conclusions about participation. The Patient-Reported Outcomes Measurement Information System (PROMIS) battery was most frequently used (6 of 32 studies, all published in the last 6 years). The Reintegration to Normal Living Index (RNL) was used in 3 studies across a wider timespan, from 2006 to 2014. All other assessments were used in only 1-2 studies. Only 4 of the 20 assessments included questions that asked about the meaning, satisfaction, or value of participation, which are key components to evaluate when measuring participation.\textsuperscript{4}

Seventy-eight percent of studies characterized the identified assessment as a measure of participation. However, after reviewing the intended purpose of the assessment when it was developed, only 28\% of studies used a tool that was developed with the primary purpose of measuring participation. For example, the RNL was described in all 3 studies as a measure of participation, but the assessment was developed with the purpose of measuring global function status, a distinct and separate construct from participation.

Differences in sample size were apparent when comparing studies that used one of the eight assessments developed with the purpose of measuring participation versus those that were
Figure 2.1 Selection of Sources of Evidence

- Records identified through database searching (n = 5,477)
- Additional records identified through other sources (n = 7)

Records after duplicates removed (n = 4,604)

Records screened (n = 4,604)

Records excluded (n = 4,028)

Full-text articles excluded (n = 544)
- Participation not discussed (n = 290)
- Wrong population (n = 7)
- Wrong context for participation (n = 65)
- No assessment identified (n = 71)
- No results or conclusions pertaining to participation (n = 55)
- < 5 participation questions (n = 6)
- Qualitative (n = 3)
- Abstract only (n = 20)
- Review articles, no new information provided (n = 10)
- Studies with same cohort of participants and same measures (n = 4)
- Registered or incomplete clinical trial; study protocol paper (n = 13)

Studies included in qualitative synthesis (n = 32)
Figure 2.2 Articles Published with Each Assessment by Year and Sample Size

Bubble size corresponds to the study sample size; larger bubbles indicate larger study sample size. Matching colors indicate the same assessment, or assessments in the same family (i.e. LIFE-H for adults and children). White bubbles denote assessments used in only one study. CPIB= communicative participation item bank and SF= short form; all other abbreviations are listed with Table 2.2.
not developed for that purpose. Sample size ranged from 8 to 192 participants (median: 30, interquartile range [IQR]: 19.5-128.5) for studies using a participation measure. Studies that used more general assessments not specific to participation ranged from 17 to more than 5,000 participants (median: 102, IQR: 53-245).

Fifty percent of studies were conducted outside of the United States, with a total of 13 different countries represented in this review. Three studies\textsuperscript{119,164,165} focused on participation in children; all other studies included only adults. Breast cancer was the most frequently studied group as the population of interest in 31\% (n= 10) of studies. Study and assessment summary characteristics are further described in Table 2.1.

<table>
<thead>
<tr>
<th>Study (n= 32) &amp; Assessment (n= 20) Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study defined participation</td>
<td>11 (34)</td>
</tr>
<tr>
<td>Primary objective of study included measuring participation</td>
<td>13 (41)</td>
</tr>
<tr>
<td>Study characterized assessment as a measure of participation</td>
<td>25 (78)</td>
</tr>
<tr>
<td>Purpose of assessment when developed</td>
<td></td>
</tr>
<tr>
<td>Main purpose was to measure participation</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Studies in which these assessments were used</td>
<td>9 (28)</td>
</tr>
<tr>
<td>Specific domain(s) assessed participation</td>
<td>5 (25)</td>
</tr>
<tr>
<td>Measured global function/health or physical function</td>
<td>9 (45)</td>
</tr>
<tr>
<td>Assessment measured satisfaction, meaning, and/or value of participation</td>
<td>4 (20)</td>
</tr>
</tbody>
</table>

Assessments demonstrated high variability in domains measured (0-12), methods for administration, and number of items (between 5 and 240). Detailed information about assessment properties is provided in Table 2.2.
2.5 Discussion

2.5.1 Summary of Evidence

In this scoping review 32 studies were identified that used 20 different assessments to measure, describe, and draw conclusions about participation among individuals with cancer. The large majority of studies (29 of 32) were published in the last 10 years. This likely relates to the publication of the ICF in 2001 when participation was originally defined. After this time, the term participation became more commonly used in research across a variety of disciplines. Within oncology it took approximately 8 years from the publication of the ICF for the term participation to be more frequently incorporated into research.

Based on the findings of this review there is not strong evidence to draw conclusions about an ideal measure of participation for individuals with cancer. Comprehensive tools developed with the primary purpose of measuring participation that also provide objective and subjective evaluation of the concept should be used when possible. Only 4 (LIFE-H, LIFE-H for children, ICPAS, and MAPA) of the 8 assessments developed to measure participation had questions that asked about the value, satisfaction, or meaning of participation, which are essential components of comprehensive participation assessments. Of the assessments identified in this review, these 4 would provide the most comprehensive evaluation of the construct. There are additional comprehensive measures of participation (e.g. the Participation Measure—3 Domains, 4 Dimensions\(^4\)), however, that have not yet been used with cancer survivors. With the goal of incorporating participation measurement into routine care to inform rehabilitation referral and triage systems,\(^93\) the clinical utility of assessments needs to be appraised.
Table 2.2. Properties of Assessments used to Measure Participation in Individuals with Cancer

<table>
<thead>
<tr>
<th>Name</th>
<th>Purpose was to Measure/Evaluate</th>
<th>Domains</th>
<th>Total # of Items</th>
<th>Methods for Evaluating/Scoring Participation</th>
<th>Population(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACSm(^{a}) &amp; 99,100</td>
<td>Activity participation of adults in instrumental, leisure, and social activities.</td>
<td>4 categories: instrumental, low-physical-demand leisure, high-physical-demand leisure, and social activities</td>
<td>89</td>
<td>ACS was designed as a semi-structured interview but use in included studies was a modified checklist version.</td>
<td>Breast cancer survivors(^{105}) &amp; various cancer diagnoses(^{102}) Categorize items as: never done prior to transplant/diagnosis; do now (as often as before</td>
</tr>
</tbody>
</table>
transplant/diagnosis; do less or differently than before transplant/diagnosis; not done since transplant/diagnosis; or new activity since transplant/diagnosis.

<table>
<thead>
<tr>
<th>AACS&lt;sup&gt;b&lt;/sup&gt; Participation and activities</th>
<th>8 domains: self-care, sedentary leisure, vigorous leisure, education, work, chores, social interaction, and community access and mobility.</th>
<th>Semi-structured interview; asked “Do you participate in this activity?” If yes, provide level of assistance needed, if any. If not, provide personal, family, or environmental reason why.</th>
<th>Childhood cancer survivors with various diagnoses&lt;sup&gt;119&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;sup&gt;119,120&lt;/sup&gt; (Now AYAPS&lt;sup&gt;c&lt;/sup&gt;)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>LIFE-H</strong>&lt;sup&gt;d&lt;/sup&gt; Quality of social</td>
<td>12 categories of life habits: 240 (69)</td>
<td>Asoke about accomplishment</td>
<td>Breast cancer&lt;sup&gt;122&lt;/sup&gt;</td>
</tr>
</tbody>
</table>
participation, nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education, employment, & recreation

**LIFE-H** Social participation 11 categories: all in Life-H for adults except employment 197 (64 item short-form) Level of difficulty, type of assistance required; level of satisfaction

**IPA** Person-perceived handicaps, which authors state is participation according to the 8 subscales: self-care and appearance, mobility, leisure, social relationships, work, education, family role, and financial 41 Rate items from excellent (1) to very poor (5). Most items asked about the possibility of doing activities the way an individual wished. Other items

Children

Craniopharyngioma

Cancer survivors in Turkey
<table>
<thead>
<tr>
<th>Methodology</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICIDH-2</td>
<td>independence asked about frequency, ability, respect, contribution to activities, and contact with others.</td>
</tr>
<tr>
<td>ICPAS</td>
<td>Participation of children in Iranian context 8 sub-categories: ADL, IADL, play, leisure, social participation, work, education, and sleep/rest.</td>
</tr>
<tr>
<td>MAPA</td>
<td>Degree of meaning through participation in activities N/A Frequency of participation (in the last few months) and degree of personal meaningfulness experienced with each activity</td>
</tr>
</tbody>
</table>
What older adults feel they should and could be doing to understand participation from a social perspective: 7 activity categories: creative activities, spiritual activities, getting around town, communicating with others, doing physical exercise, keeping up with traditional media, and doing service activities. For each activity, asked “How much do you believe that a person of your age and diagnosis should be…” (1= very little to 5= quite a lot) and “How much confidence do you have…” (1= very little to 5= quite a lot).

<table>
<thead>
<tr>
<th>Assessments with Domain(s) Specific to Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymph-ICF&lt;sup&gt;131&lt;/sup&gt; Impairment in function, activity limitations, and participation</td>
</tr>
<tr>
<td>Restrictions</td>
</tr>
<tr>
<td>-----------------------</td>
</tr>
<tr>
<td>Lymph-ICF-ULj ^132</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>PIPPk ^133</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>PROMIS 1</td>
</tr>
<tr>
<td>WHODAS 2.0m 143</td>
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in society.

<table>
<thead>
<tr>
<th><strong>Global Function and Physical Function Assessments</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DASH</strong>\textsuperscript{146}</td>
</tr>
<tr>
<td><strong>PASE</strong>\textsuperscript{148}</td>
</tr>
<tr>
<td>Assessment</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>RNL&lt;sup&gt;p 150,151&lt;/sup&gt;</td>
</tr>
<tr>
<td>WSAS&lt;sup&gt;q 154&lt;/sup&gt;</td>
</tr>
<tr>
<td>CIQ&lt;sup&gt;r 156&lt;/sup&gt;</td>
</tr>
</tbody>
</table>
integration activities subscales of activities, or with whom an individual performs activities.

OGQs Occupational gaps; to what extent an adapted individual does/does not do what he or she does/does not want to do in cancer (OGQ-M/OPQ-M)

Instrumental ADLs, social, leisure, and work-related activities (original OGQ); 19 in the injury?; Did you want to perform the activity now? and Do you want to perform the activity now?

Version 1 OGQ: Did you perform the activity before the brain injury?; Did you want to perform the activity before the brain injury?; Do you perform the activity now? and Do you want to perform the activity now?

Adapted Malay version (OGQ-M/OPQ-M): Do you participate in colorectal cancer survivors & survivors with various diagnoses

Colorectal cancer survivors &

Scoring is dichotomous, yes/no.
this activity? If the response is ‘Yes,’ items were further evaluated using a 5-point Likert scale from 1 (very minimal participation) to 5 (very high participation) in rating the activity participation.

| Social Activity Log \(^\text{163}\) | Frequency and diversity of social activities outside of daily responsibilities. | N/A | 17 | Asks how many days in the past 7 days or month an individual participated in certain social activities. | Long-term cancer survivors who received hematopoietic stem cell transplantation\(^\text{163}\) |

Abbreviations: \(^a\)Activity Card Sort, modified; \(^b\)Adolescent Activity Card Sort; \(^c\)Adolescent and Young Adult Participation Sort; \(^d\)Assessment of Life Habits; \(^e\)Impact on Participation and Autonomy Scale; \(^f\)Iranian Children Participation Assessment Scale; \(^g\)Meaningful Activity Participation Assessment; \(^h\)Possibilities for Activity Scale; \(^i\)Lymphoedema Functioning, Disability, and Health
Questionnaire; 1Lymphoedema Functioning, Disability, and Health Questionnaire—Upper Limb; ²Perceived Impact of Problem Profile; ³Patient-Reported Outcome Measurement Information System; ⁴World Health Organization Disability Assessment Schedule; ⁵Disability of the Arm, Shoulder, and Hand; ⁶Physical Activity Scale for the Elderly; ⁷Reintegration to Normal Living Index; ⁸Work and Social Adjustment Scale; ⁹Community Integration Questionnaire; ¹⁰Occupational Gaps Questionnaire; ¹¹Occupational Gap Questionnaire—Malay version/Occupational Participation Questionnaire—Malay version
While the use of comprehensive participation measures is recommended, these measures tend to be more time consuming to complete. Assessments focusing on different (e.g. quality of life) or multiple (e.g. in a global health assessment) constructs contain fewer questions pertaining to participation and can be administered more rapidly, but the results of such assessments should be cautiously interpreted. One of the most widely cited publications describing participation in cancer survivors\textsuperscript{98} drew conclusions about participation based on seven questions, several of which asked about activity level impairments (e.g. difficulty using fork, knife, cup; difficulty dressing) and did not truly investigate the concept of participation. Results from general assessments can provide an overview of participation, but conclusions should not be made about participation because the items provide only a limited evaluation of this complex construct.\textsuperscript{166}

Although the PROMIS battery was the most frequently used assessment, there is emerging evidence that PROMIS participation short forms may lack sensitivity to identify impairments in participation detected with comprehensive participation measures.\textsuperscript{167} A potential for low sensitivity to detect impairments calls into question whether PROMIS is an adequate screening tool to identify participation restrictions.

The importance of measuring participation among cancer survivors is recognized globally. The field must work towards consistently measuring, interpreting, and making conclusions about participation restrictions from comprehensive and clinically useful participation measures. Future research should also focus on understanding what participation assessments are most relevant to survivors and if available participation measures meet the unique needs of this population. Our team is initiating a prospective study to understand survivors’ perspectives of participation and participation assessments. Information learned from survivors will inform the selection of a comprehensive participation measure to evaluate
participation over time. Comprehensively measuring participation can help researchers and healthcare providers gain a greater understanding of what is truly important to each individual with cancer. Surviving cancer is a massive feat; incorporating the concept of participation into oncology care can help survivors live a fulfilling and meaningful life during and after cancer and identify methods to reduce the societal cost of cancer.

2.5.2 Limitations
The specificity of our research question led to several potential limitations. Because we aimed to understand what assessment tools were used to measure participation in individuals with cancer, we excluded studies that described participation qualitatively or used surveys developed only for the purpose of their study. Additionally, review articles and position papers recommending assessments for use were excluded as these assessments had not yet been used with individuals with cancer. These strict eligibility criteria were necessary to appropriately answer our research question.

The abstract nature of participation was another potential limitation as this made it difficult to determine what assessments measured participation comprehensively. In an effort to move away from assessments that ask a very limited number of questions about participation, a cutoff of at least five participation-specific questions was selected. This was done a priori to determine study eligibility. While five questions specific to participation still does not represent a comprehensive measure of participation, this approach was taken to be as inclusive as possible while still eliminating assessments with very few questions pertaining to participation. A cutoff of 10 participation-specific questions was deemed too high based on findings from a prior systematic review which identified numerous participation assessments with less than 10 total items. With this approach we can begin to move away from the recommendation and use of
measures that ask few questions specific to participation and begin to critically evaluate what needs to be included in more comprehensive measures of participation. Measuring participation is a challenge in the field of rehabilitation overall, not just in the area of oncology. As this is the current state of the science, we sought to describe what assessments are currently used and identified areas for future research in the field.

2.5.3 Conclusions

Understanding survivors’ participation in activities that are meaningful to them is crucial to improving their daily experiences. More work is needed to identify clinically relevant measurement tools that capture changes in these important life activities. Participation has a widespread impact on individuals’ lives and needs to be comprehensively measured and included in outcome assessments of cancer survivors throughout the continuum of care.
Declarations

Funding: This work was funded by the Program in Occupational Therapy at Washington University School of Medicine in St. Louis.

Authors’ contributions: AL screened all articles, extracted data, and prepared the manuscript. TV was the secondary article reviewer, reviewing all full-text articles and assisted in writing the manuscript. KL assisted in writing the manuscript. LS generated and executed the search strategy and assisted in writing the methods section of the manuscript. AK guided the conceptualization of the research question, served as the third reviewer when discrepancies occurred, and assisted in writing the manuscript.

Conflict of Interest: The authors declare that they have no conflict of interest.

Acknowledgements: We greatly appreciate the expertise and guidance of Carolyn Stoll, Dr. Carolyn Baum, and Dr. Graham Colditz. We also thank all members of the Child Health & Education lab for their support and assistance with this project.

Funding: This work was funded by the Program in Occupational Therapy at Washington University School of Medicine in St. Louis.
Chapter 3:  
Cancer Survivors’ Perspectives of Participation:  
A Qualitative Synthesis


3.1 Abstract  
**Objective:** To characterize how cancer survivors define participation.  

**Design:** Prospective qualitative study.  

**Setting:** Participants were enrolled from an academic medical center and were located at home during the interview. Interviews were conducted over Zoom or phone.  

**Participants:** Cancer survivors (total n= 40) with brain, breast, colorectal, or lung cancer (n= 10 per group). Participants were purposively sampled to maximize variation in the study sample. Participant ages ranged from 26 to 83 with a mean age of 55 years. Seventy percent of participants were receiving active cancer treatment at the time of the interview.  

**Interventions:** Not applicable.
**Main Outcome Measure:** Participant perspectives gathered from a one-on-one semi-structured interview. Qualitative description and thematic analysis were used to analyze interview transcripts and develop themes from the data.

**Results:** Interviews revealed four themes that are common characteristics of participation: 1) control, 2) relationships, 3) engaging in your community, and 4) the value of participation. Survivors emphasized that fully participating in life was being able to do what they want to do without restrictions or limitations. The concept of control was complex and included multiple factors relevant to participation. Based on survivors’ perspectives, competence, choice, adaptations, and locus of control interact to influence broader feelings of control and participation.

**Conclusions:** Rehabilitation researchers and clinicians need to establish a standard and comprehensive definition of participation. Rehabilitation providers need to consistently evaluate how participation is impacted among cancer survivors and use measures that include the core participation characteristics of control, relationships, community engagement, and value. Comprehensively defining participation will improve the design and selection of measurement tools and support comprehensive assessment of survivor experiences.

**Keywords:** Cancer, rehabilitation, participation, qualitative research

**Abbreviations:**

ICF: International Classification of Functioning, Disability, and Health

### 3.2 Introduction
Cancer-related disability is widespread\textsuperscript{168-171} and a major cause of distress among survivors.\textsuperscript{172} Disability involves difficulty doing activities in any area of life and occurs when there is a gap between an individual’s ability and environmental and activity demands.\textsuperscript{32} Disability goes beyond basic and instrumental activities of daily living (e.g. showering and money management, respectively) to include challenges in facets of participation in daily life,\textsuperscript{4,11,34} such as caring for children, hobbies, and socialization.\textsuperscript{32}

Participation arose from the disability literature and was defined as ‘involvement in a life situation’ in the International Classification of Functioning, Disability and Health (ICF).\textsuperscript{110} Participation reflects the influence of the person and environment and replaced the more negative term, ‘handicap,’ which centered disability on the individual.\textsuperscript{19,33} Including participation in the ICF was a positive step, but the broad definition contributes to measurement challenges.\textsuperscript{41,44} There remains no universally accepted definition of participation or standard approach for measurement.\textsuperscript{4,17,44,45,173}

Researchers, clinicians, and survivors recognize the need to support survivors in returning to work, school, and life activities\textsuperscript{114}; but they do not name these domains participation. Cancer care prioritizes symptom management\textsuperscript{84} and quality of life,\textsuperscript{174} a related, but separate construct from participation.\textsuperscript{38,175} Within oncology, the term participation is typically used when discussing participation in clinical trials or cancer screening. While participation is a priority to address within oncology, the term is not used in the context of participating in daily life. How rehabilitation scientists explain participation to other disciplines may present challenges to its clinical integration.\textsuperscript{11}
As we work towards integrating participation into cancer care, we first need to understand what participation means to cancer survivors. To further elucidate this complex construct, we aimed to characterize how cancer survivors with brain, breast, colorectal, and lung cancer define participation.

### 3.3 Methods

The institutional review board and protocol review and monitoring committee at Washington University in St. Louis School of Medicine approved this cross-sectional study.

#### 3.3.1 Study Sample

Participants included adults (>18 years) with brain, breast, colorectal, or lung cancer. These groups were selected because they are the most common cancers in adults, with the exception of brain cancer, selected due to the high incidence of impairments that could affect participation. We aimed for 10 participants per stratum (total n= 40) to reach thematic saturation, the point at which we do not anticipate new themes will emerge with additional data. Individuals were excluded who were not English-speaking or aphasic, as their ability to engage in a conversation would be limited. Purposive sampling was used to maximize variation, identifying individuals on and off treatment and those with varying participation challenges. The sample was stratified by cancer type as participation experiences and perspectives were hypothesized to differ by cancer type.

The oncology treatment team approached patients about the study during clinic visits. Contact information of interested patients was shared with the study lead who then contacted potential participants. Informed consent was completed over the phone. One individual was recruited via snowball sampling.
3.3.2 Data Collection

Individual semi-structured interviews were conducted over zoom with video (n= 16), without participant video (n= 4), or over the phone (n= 20) between September and November 2020. A researcher trained in qualitative methods not part of the treatment team conducted all interviews (mean: 57 minutes, range: 30-81). An interview guide (Online Supplement/Appendix C) was developed based on previous research and clinical knowledge to understand the impact of cancer on survivors’ daily lives and to seek feedback on three participation measures. This study primarily focuses on responses to one of the opening questions: “What does it mean to you to be able to fully participate in life?” Thus, findings focus specifically on how survivors define participation. Interviews were audio recorded, transcribed verbatim, and de-identified.

Participants self-reported demographic characteristics and treatment history.

3.3.3 Protocol

Data were analyzed through an iterative team-based process by five researchers. Guided by qualitative description and thematic analysis, a primarily inductive approach to coding was used. Codes and definitions were documented in a codebook that was piloted, modified, and finalized by four team members. Two coders independently coded each transcript; one team member reviewed coded text and coding discrepancies. Themes were developed by continuously analyzing and reviewing coded text to identify data patterns. Data were coded using NVivo 12 software. For additional methodology, see Online Supplement/Appendix D.

3.4 Results

Sixty-one cancer survivors were contacted to participate. Ten could not be reached and six were no longer interested (reasons: request of spouse, too busy, did not feel their life was impacted by cancer). Forty-five consented to participate; three were lost to follow-up, one
withdrew due to time limitations, and one wanted an in-person interview, which was not possible due to COVID-19 research restrictions. Forty survivors ages 26-83 participated (Table 3.1).

Table 3.1. Participant Demographics

<table>
<thead>
<tr>
<th>Participant Characteristic</th>
<th>Total sample n= 40</th>
<th>Brain n= 10</th>
<th>Breast n= 10</th>
<th>Colorectal n= 10</th>
<th>Lung n= 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current age, mean (range)</td>
<td>54.8 (26-83)</td>
<td>47.1 (26-67)</td>
<td>53.2 (37-67)</td>
<td>54.2 (33-66)</td>
<td>64.6 (41-83)</td>
</tr>
<tr>
<td>Years since first diagnosed with cancer, mean (range)</td>
<td>5.9 (0-24)</td>
<td>2.2 (0-5)</td>
<td>9.3 (1-24)</td>
<td>4.3 (2-9)</td>
<td>7.8 (0-24)</td>
</tr>
<tr>
<td>Sex (female)</td>
<td>27 (68)</td>
<td>4 (40)</td>
<td>10 (100)</td>
<td>5 (50)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>6 (15)</td>
<td>2 (20)</td>
<td>2 (20)</td>
<td>0 (0)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Divorced</td>
<td>3 (7)</td>
<td>0 (0)</td>
<td>2 (20)</td>
<td>1 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Married</td>
<td>29 (73)</td>
<td>8 (80)</td>
<td>6 (60)</td>
<td>8 (80)</td>
<td>7 (70)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2 (5)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (10)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Race</td>
<td>6 (15)</td>
<td>1 (10)</td>
<td>4 (40)</td>
<td>0 (0)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1 (3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>White</td>
<td>33 (82)</td>
<td>9 (90)</td>
<td>6 (60)</td>
<td>10 (100)</td>
<td>8 (80)</td>
</tr>
<tr>
<td>Receiving treatment at</td>
<td>28 (70)</td>
<td>8 (80)</td>
<td>9 (90)</td>
<td>4 (40)</td>
<td>7 (70)</td>
</tr>
<tr>
<td>time of interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease Stage (total n=30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I  2 (6)</td>
<td>1 (10)</td>
<td>0 (0)</td>
<td>1 (10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>II 6 (20)</td>
<td>N/A</td>
<td>2 (20)</td>
<td>3 (30)</td>
<td>1 (10)</td>
<td></td>
</tr>
<tr>
<td>III 5 (17)</td>
<td>2 (20)</td>
<td>2 (20)</td>
<td>1 (10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV 17 (57)</td>
<td>5 (50)</td>
<td>5 (50)</td>
<td>7 (70)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment history,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>35 (88)</td>
<td>10 (100)</td>
<td>9 (90)</td>
<td>7 (70)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>Radiation</td>
<td>26 (65)</td>
<td>10 (100)</td>
<td>8 (80)</td>
<td>2 (20)</td>
<td>6 (60)</td>
</tr>
<tr>
<td>Surgery</td>
<td>21 (53)</td>
<td>6 (60)</td>
<td>6 (60)</td>
<td>7 (70)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>6 (15)</td>
<td>0 (0)</td>
<td>6 (60)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Survivors described participation as doing what they find important or meaningful in their daily lives. This included what they wanted to do and what they had to do in their life and is summarized as the central idea of ‘doing valued activities.’ Interviews revealed four characteristics of participation: 1) control, 2) relationships, 3) engaging in various contexts, and 4) generates meaning (Figure 3.1). The final theme highlights that participation is central to daily life among cancer survivors.

Figure 3.1. Participation Characteristics and Interactions Between Components of Control.
3.4.1 Control

Participants emphasized their desire to do what they want to do without restrictions or limitations. They wanted control and choice over what, how, and when they participate: “To physically be able to do whatever it is I want to do. Um, whatever that may be. Not to have any limitations.” [50/M/colorectal] Embedded within control were the concepts of competence, or the skills/abilities needed to participate, locus of control, adaptation, and choice.

*Competence (Skills/Abilities)*

Cancer took over the lives of many participants. Thus, their cancer experiences are often embedded within how they define participation. Survivors’ definitions emphasized treatment and disease side effects, and cancer-related limitations. Side effects (e.g. fatigue, colostomy issues, etc.) altered their competence level and perceived control over participation. Cancer-related concerns shaped how survivors defined participation:

“I did a lot of cooking and baking. Um I loved doing that for my family [voice cracks and gets high-pitched] and I can’t really do that now because—and all of this is difficult because my left side is affected. The motor function has been um affected…so a lot of things have been lost.” [62/F/brain]

Participation included doing valued activities of cooking and baking. Due to a loss of skills, she was unable to fully participate.

Participants felt they needed certain skills (e.g. physical, cognitive) to be competent and able to fully participate:
“To feel physically strong enough and um mentally strong enough [is what] I feel like I need to, to take part in life fully.” [67/F/breast]

Perceptions of what skills are needed to participate can be highly individual (Table 3.2) and yield different perspectives of participation. These differences are related in part to an individual’s locus of control.

**Locus of Control**

Two perspectives of control, internal and external loci of control, were apparent within participation definitions. With an external locus of control, cancer was often in control of the individual’s life and survivors felt unable to change their abilities: “I’d want to get rid of my physical restraints and go back to doing things.” [65/M/brain] Many felt that if they had specific abilities, they would be able to do what they wanted to do:

“More and more, I come to think up of, well, if I could breathe, I used to like to work in the yard… I used to plant bulbs and flowers… I just absolutely can’t do that anymore.”

[75/F/lung]

Here an external locus of control was dominant. She viewed her inability to breathe as outside of her control and a primary factor defining her participation.

With an internal locus of control some survivors had a “don’t let cancer stop me” mentality. Adaptations, putting forth effort, or making specific plans to participate, were the focus. While participants were often adapting to factors outside of their control, adapting was a way to take action, control a situation, and ultimately control their participation. One survivor
<table>
<thead>
<tr>
<th>Subtheme, topic</th>
<th>Example Quotations</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competence</td>
<td>“Now I wear a colostomy bag…it limits me in what I can do. Especially after the surgery, you know I’m limited to pickin’ up anything you know up to 50 pounds. So, other than that I try to do the best I can.”</td>
<td>61/M/colorectal</td>
</tr>
<tr>
<td>Locus of control, struggling with adaptations</td>
<td>“I’d love to see my friends more…I’d love to be physically able to do the things that we used to. Like one of them’s completely addicted to paintball, but there’s no way I could do that right now. Unless we just sit still and do target practice or something, which has been floated already, so that may happen, but, I can’t do that, I can’t [big sigh]…I don’t know if I could focus on a target.”</td>
<td>39/F/brain</td>
</tr>
<tr>
<td>Locus of control, adapting</td>
<td>“You have to adjust to those things that were normal for you in the past.</td>
<td>65/M/brain</td>
</tr>
</tbody>
</table>

Table 3.2. Illustrative Quotes of the Four Participation Characteristics
There’s a new normal…we go to some basketball games, volleyball games, uh, I can’t walk anymore but I can still go participate.”

Locus of control, stable disease & planning
“I need to figure out a plan to participate more. Um, you know, is that creating a schedule of which friends I’m going to call which days?”

Locus of control, resources & choices
“I was able to retire with a pension, um, after I was diagnosed and after it really became a struggle to keep working. But I know a lot of people don’t have that luxury. So you know for me being able to retire and still have an income um you know that gave me both the time and the resources, the financial resources, and the you know sort of leisure (laughter) resources um to be able to do a lot of the things um that I liked to.”

Locus of control, improve with time
“To have the energy um to get up, to you know go to the grocery store…bein’ able to take [my daughter] to all of her activities without bein’ tired…In my mind, I’m thinkin’ once this is over, then I will have that energy back, but I don’t even know if I’m using, if that’s a mental thing, and that’s why I stay so tired, because I think it is the chemo and
“If I can’t be useful in some way, uh it would be devastating. I want to be able to function to a point to where I’m useful and and gratified that I can do something, whether it’s it’s to help [my husband] split wood or take a walk and hold his hand.”

“Me getting back outside is fully participating in life. Uh meaning I’m able to socialize with my family and my friends, I’m able to do my foodie thing [laughs], I’m able to [play sports]…being able to get outside freely without the mask or the- or the stigma you may become sick again…being able to get outside, being able to do the things I need to do inside the house.”
“Having [a] routine keeps me going and gets me through those rough days or those low days…and I still felt like I accomplished something, that I didn't waste my day per se just because I didn't feel good or I didn't feel like it. So having a routine and getting those things accomplished just boosted I guess my morale.”

Theme: Participation is Central to Daily Life for Survivors

“Once I, uh, was diagnosed with my cancer, um, everything kind of, yeah, I realized how important everything in life really is…it was like, ‘this could be, you know, the end of everything.’”
needed to plan to protect himself from getting headaches. He also had a backup plan in case he experienced blurred vision and was unable to drive: “Part of it is just being prepared, making sure I have everything I need for what I'm going to be doing.”  [42/M/brain]

Survivors with an internal locus took ownership of situations and adapted it to their needs. Adapting helped survivors do the things they enjoyed. Some survivors struggled to figure out how/when/what to adapt to support participation (Table 3.2).

Participants felt personal control (internal locus) when they were in a more stable situation with their disease and had the skills and resources needed to participate. Resources provided choices and helped survivors participate in what they desired (Table 3.2).

The complexity of survivors’ experiences often highlighted both loci of control. Negative experiences altered perspectives of control:

“Most of it feels outside of my control. Yeah, I guess there’s always more you could do. You know you could be a lot more self-motivated… I could take more chances, you know with the getting out of the house than I do. But I mean even yesterday, like I ran to [store], which is probably 5 minutes from our house and I had an accident, you know, while I was out so so it kind of discourages you from wanting to get out.”  [59/F/colorectal]

While the potential for an internal locus is acknowledged through self-motivation and personally taking more chances, these ideas are dominated by an external locus due to the unpredictability of her diarrhea symptoms and frequent negative experiences. Highlighting co-
occurring loci of control, several participants contemplated whether their participation would naturally improve with time when they were no longer undergoing cancer treatment, but also acknowledged the importance of taking ownership of their participation (Table 3.2).

**3.4.2 Relationships**

Participation often involves doing activities for or with others, typically family and friends. Examples included cooking, going out with friends, or having a game night. Participation was discussed in the context of life roles, such as being a spouse, parent, grandparent, or friend: “To go for a walk with my husband at the end of the day...and to be able to cook dinner for my family.” [62/F/brain]

There was also a desire to be present for their children and family and visit or spend time with others: “Share time with family and stuff which I feel like I do do that. You know, my family, my son and granddaughters come over just about every weekend.” [59/F/colorectal]

Family members (spouse, children) were identified as survivors’ primary motivation and support to participate. Contributing and helping others was a common characteristic of participation (Table 3.2). Survivors wanted to feel useful and productive and some valued volunteering. The motivation behind volunteering varied from helping survivors feel better to providing opportunities to socialize and give back.

Communicating, socializing, and interacting were defining characteristics of participation. These were important for individuals throughout the entire cancer continuum: “To be able to interact with others and um being able to talk with them back and forth.” [67/M/brain, considering hospice]
3.4.3 Engaging in Various Contexts

Survivors discussed the importance of doing valued activities in various contexts such as the home, neighborhood, city, and work. For a subset of the sample, their concept of full participation included doing valued activities outside the home (Table 3.2). Examples included golfing, shopping, driving, walking outdoors, traveling, and going to restaurants and appointments. Survivors wanted to “go out” to do things with others and to enjoy life: “be able to travel and see things and experience the things in nature that I would like to enjoy.”

[49/M/colorectal]

While many participants expressed the desire to participate outside the home, some also acknowledged that their cancer experiences limited their participation outside the home due to physical challenges, body image or infection concerns, bathroom urgency, and shifts in what they found important in life. For some, their home environment became their place of safety during their cancer experience and they became hesitant to participate outside the home. When engaging less outside the home, social networks also became smaller:

“I used to be able to get up and do stuff, I was interacting with people, um you know, seeing them at the university, seeing them at church, you know what I mean? I was always interacting with people. Um, now I don’t at all, and it’s been [short pause, sounds emotional] something I really, I’m sorry about.” [75/F/lung]

Survivors rarely focused on engaging with the broader community as central to participation. While some discussed volunteering, as outlined in the previous theme, valued
activities outside the home were often done independently or with close family and friends with little emphasis on broader community-focused activities:

“[Being sick from chemotherapy was] when I realized how much I’d like to participate. Not necessarily in like group or or community activities but just just the basics, going to the store, uh you know, going shopping, taking the dog for a walk again, golfing with my kids, hanging out outside with my kids.” [50/M/colorectal]

3.4.4 Generates Meaning

Participation was described as meaningful and important. Survivors emphasized the personal value and satisfaction they derived from participating and how participation brought enjoyment to life:

“[It means everything, um, it’s extraordinarily, extraordinarily important…it’s what keeps you young and it’s what keeps you healthy, not to put any limits on yourself.” [66/F/colorectal]

Participation was linked to improved physical symptoms, self-satisfaction, and mental health. Participating helped survivors feel accomplished and could improve their mindset (Table 3.2). There are many mechanisms through which participation may impact mental health. Several participants suggested that participating served as a distraction from their cancer and improved their mental status: “Once I find myself getting up and getting out and not thinking about [cancer] and doing things…to take my mind off of it and I think once I do that, I feel a lot better.” [54/F/breast] Experiences such as this supported life satisfaction among survivors who sometimes felt they were unable to do anything during the day other than lay on the couch.
3.4.5 Participation Remains Central to Daily Life Among Cancer Survivors

Even when dealing with a variety of side effects and a life-threatening diagnosis survivors still prioritized participation because of how central participation was to their life. There were phases when participating was very limited for some, but it was still something they highly valued and fought to continue to do. When participation restrictions were experienced, distress was common.

Cancer changed many survivors’ perspectives of what was important in life and their participation priorities. Cancer was sometimes a catalyst to participate more fully:

“I think I’ve found my purpose... before I was just alive. And now I think I am living. I am doing more exciting things... and seeing different things that I’ve always wanted to see. And I love it, you know, it’s just like man, this is fun, I’ve been missing out on this for a very long time.” [54/F/breast]

Participating in life was identified as a priority amongst survivors. Survivors repeatedly emphasized their focus on not taking anything for granted in life, which was central to how they viewed and defined participation (Table 3.2).

As a summary, the presented word cloud (Figure 3.2) illustrates terms most frequently used by survivors when defining participation. Commonly used words including doing, able, going, important, limitations, and people support the primary characteristics of participation identified in this study.
Figure 3.2. Words Commonly Used When Defining Participation
Word size corresponds with frequency of use. Larger words are used more frequently. The word ‘things’ was typically used in the context of ‘doing things.’

3.5 Discussion

Research aiming to broaden the conceptualization of participation has historically focused on the perspectives of individuals who receive intensive rehabilitation following an injury or illness (e.g. spinal cord injury, stroke). This study is the first to investigate how cancer survivors conceptualize participation. Cancer survivors’ perspectives confirmed previous findings about core participation characteristics including control, choice, competence, relationships, community engagement, and value.4,17,27,181

Findings also highlight how perspectives of participation vary among individuals with different types of disabilities. Hammel et al.’s study examining what participation means to
individuals with disabilities primarily included individuals with spinal cord injury, stroke, or traumatic brain injury. Societal perceptions were emphasized in the participation values outlined by Hammel et al., including societal inclusion, rights to resources, and the meta theme of respect and dignity. The current study did not confirm these findings among cancer survivors. Participants in Hammel et al.’s work likely had more permanent and static disabilities compared to cancer survivors. Cancer is a dynamic process and can result in a disability experience that is constantly evolving. Instead of focusing on how society views them and can adapt to their needs, many survivors are occupied by their disease, treatment, and associated changes within their body. Survivors identify the source of their cancer-related impairments (e.g. fatigue) as coming from within; consequently, environmental adaptations and societal influences are underrecognized.

Disability and cancer survivor identities can further shape perspectives of participation and rehabilitation. Cancer-related disability is common, but it is unknown whether survivors see themselves as people living with disabilities. Many of the disabling conditions experienced by survivors (e.g. cognitive impairments) result in hidden disabilities. The hidden nature of these disabilities may explain why participants’ perspectives of participation did not reflect Hammel’s meta-theme of respect and dignity. Survivors may not see themselves as having disabilities, and neither does society, so survivors may not face the stigmatization experienced by people living with disabilities.

Survivors also frequently anticipate resolution of cancer-related symptoms once they have completed treatment. They expect, and are often told by medical providers, it may take time to get back to their ‘old self’ and return to normalcy. However, the complexities of cancer-related disability make it difficult to assess when and if patients will return to baseline and
resume participating. Participation is a critical outcome of rehabilitation and we have demonstrated it is important to cancer survivors.

Future research needs to further define participation for a broad group of individuals with varying disabilities. Participation characteristics identified in this study and previous research need to be systematically tested with key stakeholders to develop an accepted comprehensive definition of participation. Measurement tools can then be refined and tested to support the clinical integration of participation measurement and facilitate referrals to rehabilitation. Evaluating variability in participation experiences can help providers identify individuals who may benefit from rehabilitation.

3.5.1 Study Limitations

Environmental influences were rarely discussed by survivors. This may be due to the interview guide design; we were seeking to understand participation broadly and did not probe on environmental factors. However, survivors did not discuss environmental factors when asked about barriers or supports to participation, suggesting survivors may be less aware of environmental influences on participation. It is unclear how this conceptualization of participation by survivors translates to all cancer survivors and other populations. Our sample was intentionally broad to capture a wide range of experiences. It is encouraging that the core participation characteristics identified in this study are consistent with previous research.

3.6 Conclusions

Rehabilitation researchers and clinicians need to establish a standard and comprehensive definition of participation. Rehabilitation providers need to consistently evaluate how participation is impacted among cancer survivors and use measures that include the core participation characteristics of control, relationships, community engagement, and value.
Comprehensively defining participation will improve the design and selection of measurement tools.
Suppliers:

a NVivo Version 12

b REDCap
c IBM SPSS Version 25
Chapter 4: Trajectories of Participation in Daily Life Among Cancer Survivors: A 6-Month Longitudinal Study


4.1 Abstract

4.1.1 Purpose
Cancer-related disability is common, but assessing and treating disability is not a primary focus in oncology care. This study examined how participation in daily life, a construct related to disability, is impacted during the first six-months following a new cancer diagnosis. Secondarily, risk-factors for participation restrictions were explored and patient-reported outcomes (PROs) were used to suggest referrals to rehabilitation services, specifically physical and occupational therapy and mental health support.

4.1.2 Patients and Methods
Participants (n=123) were newly diagnosed adults (>18 years) with brain, breast, colorectal, or lung cancer. PROs were collected one, three, and six-months post diagnosis. Participation in daily life was assessed through the Community Participation Indicators (CPI) and secondarily by Patient-Reported Outcome Measurement Information System (PROMIS) ability to participate subscale. Mixed effect regression modeling with random intercept evaluated change in participation over time.
4.1.3 Results
On average, participants reported mildly impaired participation within the first six-months following a new cancer diagnosis. However, no statistically significant changes in participation were observed over the study period. Risk factors for lower participation included receiving chemotherapy, lower physical function and social support, higher anxiety and fatigue, and change in employment. Lung cancer was associated with higher participation. PROs indicated roughly half the sample may benefit from physical or occupational therapy or mental health support, but only 20-36% of these individuals were previously referred by their medical team.

4.1.4 Conclusion
To understand how survivors’ daily lives are impacted by cancer, evaluating participation must be prioritized. Survivors experience impaired participation as early as one-month post diagnosis, but they are infrequently referred to supportive services. The use of PROs is an effective method to assess participation and identify survivors who may benefit from rehabilitation services.

4.2 Introduction
Disability due to cancer is common, but its detection and treatment is underrecognized in cancer care. Cancer survivors experience challenges with physical function, cognition, mental health, and participation in daily life. The pervasive nature of impairments disrupts how people function and live, leading to lost productivity, large societal costs, and high levels of distress.

The primary focus of medical care is disease survival, but most patients value preservation of function and cognitive abilities more than survival. Daily life participation, defined as *engagement in activities that are personally meaningful to an individual*, is also a priority amongst survivors, but it is rarely included in outcome assessments or addressed in
clinical cancer care.\textsuperscript{20,45,104} When participation is measured, it is almost exclusively evaluated among survivors who have completed cancer treatment.\textsuperscript{101,102} Participation is important to address because it can help protect against cognitive decline,\textsuperscript{10,198} improve quality of life (QOL), health, and well-being,\textsuperscript{1} and even decrease mortality.\textsuperscript{8,9}

Within oncology care, the use of electronic patient-reported outcome (PRO) measures supports early detection and treatment of patient symptoms, and is associated with higher health-related QOL, improved treatment tolerance, and reduced hospitalization and mortality.\textsuperscript{94,199} Clinical integration of PROs needs to expand to domains relevant to disability and rehabilitation, specifically participation. Prospectively evaluating participation is urgently needed to understand what factors put survivors at higher risk for disability and participation restrictions and to support early intervention.\textsuperscript{20} The primary study aim was to determine how participation changes during the first six-months after a new cancer diagnosis. Secondarily, we aimed to identify risk factors for participation restrictions and use PRO findings to suggest referrals to rehabilitation services, specifically physical (PT) and occupational therapy (OT) and mental health support.

\textbf{4.3 Methods}

This prospective longitudinal study evaluated participation in daily life in a cohort of individuals newly diagnosed with brain, breast, colorectal, or lung cancer. These disease groups were selected because they are amongst the most common cancers in adults,\textsuperscript{168} with the exception of brain cancer, selected due to the high incidence of impairments\textsuperscript{176} that can impact participation. Participants were enrolled in the study within 30 days of initiating treatment for their new cancer diagnosis. Individuals undergoing surgery only were enrolled within 30 days of surgery. Data were collected at baseline, two, and five-month follow-up. The study was conducted at four Siteman Cancer Center clinical centers at Washington University in St. Louis.
The institutional review board and protocol review and monitoring committee at Washington University approved this study.

4.3.1 Participants
 Eligible participants were over 18 years of age with a new primary diagnosis of brain, breast, colorectal, or lung cancer, able to read and understand English, had an email address or phone number, and were able to communicate independently. A past medical history of a different cancer type (e.g. prostate) did not exclude participants. Individuals with cancer recurrence of the four included diagnoses, aphasia, or impaired cognition inhibiting their ability to provide informed consent, as judge by their provider, were excluded.

The research team collaborated with medical, radiation, and surgical oncology providers to determine optimal methods for identifying individuals newly diagnosed. Procedures differed by disease team due to different pathways of care for the disparate disease groups. To identify potentially eligible participants we screened electronic medical record clinic lists of breast and colorectal surgeons, attended surgical and medical oncology team rounds, and attended in-person clinic visits for all disease teams. Medical team approval was provided prior to contacting patients. From March to September 2021, 228 of 271 eligible individuals were contacted to participate in the study. Participants were approached in-person during clinic visits or over the phone. Of those approached, 196 (86%) expressed initial interest and 141 (62%) consented to participate in the study (Figure 4.1). Participants provided informed consent in person (n= 88), via electronic consent (n= 27), or verbally on the phone (n= 26). For follow-up surveys participants were provided up to three reminders when they did not initially respond to or return the survey.
Figure 4.1 Study CONSORT Diagram Outlining Participant Enrollment and Retention
4.3.2 Measures

A full list of study measures is available in Appendix E. Participation was measured by the Community Participation Indicators (CPI)\textsuperscript{200} as the primary outcome. The CPI is a self-report measure of 20 items measuring participation in 3 domains: productivity, social activities, and getting out into the community.\textsuperscript{200} For each item, or area of participation, the respondent rates how often they do the activity in a typical week or month, depending on the domain. Likert scale responses document frequency of participation in days or hours per week, or times per month. Respondents rate whether the activity is important to them (yes/no) and if they are doing the activity enough, not enough, or too much.\textsuperscript{200} The CPI ratio, which measures participation in activities that are important to the individual, was calculated for the measure summary score.\textsuperscript{23} The CPI ratio is calculated by dividing the number of important activities identified as done enough or too much by the total number of activities identified as important.\textsuperscript{23} Higher ratios indicate higher participation in meaningful activities.\textsuperscript{23} The CPI was validated in a large sample of individuals with a variety of disabling conditions,\textsuperscript{23,200} but has not been used with cancer survivors. This measure was selected because using comprehensive measures of participation, such as the CPI, is essential to understand the full scope of participation restrictions experienced by survivors.\textsuperscript{45} Participants selected cancer-specific factors that supported or hindered their participation in daily life and had opportunities for open-ended responses.

The Patient-Reported Outcomes Measurement Information System\textsuperscript{136} (PROMIS)-43 profile, which measures physical function, anxiety, depression, fatigue, sleep, ability to participate in social roles and activities, and pain, was completed at all time points. Supplemental PROMIS items from satisfaction with participation in social roles and discretionary social activities, instrumental support, social isolation, and psychosocial illness impact (positive) item banks were also collected. PROMIS T-scores have a mean of 50 and standard deviation of 10;
scores within five points of the mean are considered mild impairments and within 10 points moderate impairment.\textsuperscript{201} Higher scores indicate more problems for symptoms, such as fatigue, and lower scores indicate more problems in function, such as participation.\textsuperscript{201}

Self-reported characteristics measured at baseline included: gender, race, ethnicity, highest level of education, and comorbidities as measured by the Charlson Comorbidity Index.\textsuperscript{202} Additional characteristics reported at all time points included: employment status, change in employment since cancer diagnosis or last survey, financial toxicity (single item from EORTC Quality of Life Questionnaire-C30\textsuperscript{203}) use of mobility support, and use of PT, OT, speech language pathology (SLP), or mental health support since their diagnosis. Survey data were stored in Research Electronic Data Capture (REDCap).\textsuperscript{204} Treatment and disease history and use of supportive services (e.g. OT) were extracted from the medical record.

**4.3.3 Statistical Analysis**

Baseline characteristics between disease groups and those who completed all surveys versus those lost to follow-up were compared using independent sample t-tests, one-way ANOVA, or chi-square tests, as appropriate. Descriptive statistics are presented for demographic and clinical characteristics and rehabilitation referrals. To compare change in participation, means were compared over time for the primary outcome, CPI, and secondary outcome, PROMIS ability to participate in social roles and activities subscale. To compare means between the four disease groups at each time point, one-way ANOVA was performed. Linear regression modeling was used for adjusted analyses to account for potential confounding variables (Appendix F/Online Supplement Table 1). All clinically meaningful variables were entered into the model and retained regardless of significance; exploratory variables were entered using backward selection (p<.05) to identify the most parsimonious model. Five potential outliers were
identified at baseline and two at each follow-up. Sensitivity analysis was performed and the model and coefficients were not changed in a meaningful way, so the analysis was run with the full dataset.

Mixed effect regression with random intercept was used to assess change in mean participation between the four disease groups with repeated measurement. Random intercept and slope modeling was tested, but the likelihood ratio test between this model and random intercept only model was not significant, so the simpler random intercept model was used. The model was specified as having two levels: time at level one and patient at level two. Continuous variables were grand mean centered. An initial model including time, group, and their interaction was used to examine changes over time between disease groups. Potential confounding variables were then entered into the model one at a time with time-varying covariates entered at level one and time-invariant at level two (Online Supplement). Covariates identified as clinically important were again retained regardless of significance and exploratory variables were retained when p<.05.

To identify risk factors for participation restrictions over time, mixed effect regression modeling was again used. To examine the association of individual predictors with changes in participation we started with univariate analyses where models were constructed as a function of time since baseline, group, time by group interaction, and each individual predictor. When exploratory predictors were significant they were tested in the multivariable model. The modeling strategy was similar to those previously outlined, with additional predictors.

Sample size calculation was based on the interclass correlation coefficient values for CPI and PROMIS ability to participate generated from preliminary data on these outcomes among survivors with brain, breast, colorectal, and lung cancer. The planned sample size of 120, 30
participants per group, would achieve 99% power to test group difference and 85% power to test time difference on the CPI and 73% power to test group difference, 100% power for time difference and group by time interaction using PROMIS ability to participate with a 5% significance level.

PRO findings were used to identify survivors who may benefit from rehabilitation. When PROMIS physical function, participation, or mental health domains were more than one standard deviation from the mean, referrals were suggested for PT, OT, and mental health support, respectively. OT was also suggested when the CPI score was below a designated cut point of 0.6 based on data from previous research23,205 and the team’s preliminary CPI data amongst survivors.

4.4 Results

The baseline sample included a total of 123 participants with newly diagnosed brain (n=19), breast (n=36), colorectal (n=36), and lung (32) cancer. Ninety-nine participants completed measures for all three time points (Figure 4.1). Attrition rate was 20%; 58% lost to follow-up and 42% died or transitioned to hospice. Participants were an average of 59 years old. Half had a college education or higher, 63% were female, and 86% reported White race (Table 4.1). Baseline age was significantly higher in the lung cancer group compared to brain cancer. There was a significant difference in gender between the breast cancer group, comprised of all females, and all other groups. There were no other significant differences between disease groups or those lost to follow-up versus not in baseline characteristics. Financial toxicity was significantly higher at time three for participants under 65 years old compared to those over 65.
Table 4.1 Participant Baseline Demographics

<table>
<thead>
<tr>
<th></th>
<th>Total (n= 123)</th>
<th>Brain (n= 19)</th>
<th>Breast (n= 36)</th>
<th>Colorectal (n= 36)</th>
<th>Lung (n= 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, Mean, SD (range)</td>
<td>59.0, 12.7 (21-82)</td>
<td>52.4, 14.9 (21-70)</td>
<td>59.3, 12.5 (39-77)</td>
<td>57.5, 13.0 (27-81)</td>
<td>64.4, 9.0 (45-82)</td>
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<td>Charlson comorbidity index score</td>
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<td>2.1, 0.46 (2-4)</td>
<td>2.3, 0.86 (2-6)</td>
<td>4.1, 2.4 (2-10)</td>
<td>5.1, 2.2 (2-8)</td>
</tr>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>36 (100)</td>
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<td>1 (3)</td>
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<td>High school graduate or GED</td>
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<td>Associate degree</td>
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<td>College graduate</td>
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<td>Master’s degree</td>
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<td>---------</td>
<td>----------</td>
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<td>4 (12.5)</td>
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<td></td>
</tr>
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</tr>
<tr>
<td>III</td>
<td>3 (17)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>13 (72)</td>
<td></td>
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<td>Cumulative treatment</td>
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<tr>
<td>Surgery</td>
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<td>19 (100)</td>
<td>35 (97)</td>
<td>15 (42)</td>
<td>10 (31)</td>
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<tr>
<td>Chemotherapy</td>
<td>84 (69)*</td>
<td>14 (74)*</td>
<td>14 (39)</td>
<td>31 (86)</td>
<td>25 (78)</td>
</tr>
<tr>
<td>Mean (SD) # days exposed to chemotherapy</td>
<td>120 (53)</td>
<td>112 (59)</td>
<td>108 (60)</td>
<td>126 (49)</td>
<td>122 (51)</td>
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<tr>
<td>Radiation</td>
<td>69 (57)*</td>
<td>16 (85)*</td>
<td>22 (61)</td>
<td>15 (42)</td>
<td>16 (50)</td>
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<tr>
<td>Mean (SD) total radiation dose (cGy)</td>
<td>4225 (1526)</td>
<td>5603 (633)</td>
<td>4038 (1198)</td>
<td>2806 (828)</td>
<td>4500 (1789)</td>
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<tr>
<td>Gamma knife</td>
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<td>0</td>
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<td>Hormone therapy</td>
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<td>20 (56)</td>
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<td>Mean # days exposed to</td>
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<td>Hormone therapy</td>
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<td>-----------------</td>
<td>--------</td>
<td></td>
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**Employment status**

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<tr>
<th>Employment Status</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
<th>2022</th>
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<td>Full-time</td>
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<td>2 (10)</td>
<td>12 (33)</td>
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<td>11 (34)</td>
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<td>Part-time</td>
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<td>Unemployed</td>
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<td>2 (10)</td>
<td>2 (5.5)</td>
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<td>1 (3)</td>
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<tr>
<td>Medical leave</td>
<td>13 (10)</td>
<td>6 (32)</td>
<td>0</td>
<td>6 (17)</td>
<td>1 (3)</td>
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<tr>
<td>Disability</td>
<td>11 (10)</td>
<td>3 (16)</td>
<td>1 (3)</td>
<td>2 (5)</td>
<td>5 (16)</td>
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<tr>
<td>Retired</td>
<td>42 (34)</td>
<td>6 (32)</td>
<td>15 (42)</td>
<td>9 (25)</td>
<td>12 (38)</td>
</tr>
<tr>
<td>Other</td>
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<td>0</td>
<td>2 (5.5)</td>
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**Change in employment status since cancer diagnosis**

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<tr>
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<th>2019</th>
<th>2020</th>
<th>2021</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>41 (33)</td>
<td>10 (53)</td>
<td>6 (17)</td>
<td>14 (39)</td>
<td>11 (34)</td>
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<tr>
<td>No</td>
<td>82 (67)</td>
<td>9 (47)</td>
<td>30 (83)</td>
<td>22 (61)</td>
<td>21 (66)</td>
</tr>
</tbody>
</table>

**Financial toxicity**

(Has your physical condition or medical treatment caused you financial difficulties?)

<table>
<thead>
<tr>
<th>Financial Toxicty</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
<th>2021</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>54 (44)</td>
<td>7 (37)</td>
<td>23 (64)</td>
<td>13 (36)</td>
<td>11 (34)</td>
</tr>
<tr>
<td>A little bit</td>
<td>47 (38)</td>
<td>8 (42)</td>
<td>9 (25)</td>
<td>14 (39)</td>
<td>16 (50)</td>
</tr>
<tr>
<td>Quite a bit</td>
<td>15 (12)</td>
<td>2 (10.5)</td>
<td>3 (8)</td>
<td>5 (14)</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Very much</td>
<td>7 (6)</td>
<td>2 (10.5)</td>
<td>1 (3)</td>
<td>4 (11)</td>
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</tbody>
</table>

**Mode of survey completion**

<table>
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<tr>
<th>Mode of Completion</th>
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<th>2019</th>
<th>2020</th>
<th>2021</th>
<th>2022</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online</td>
<td>93 (76)</td>
<td>17 (90)</td>
<td>32 (89)</td>
<td>26 (72)</td>
<td>18 (56)</td>
</tr>
<tr>
<td>Paper forms</td>
<td>18 (14)</td>
<td>2 (10)</td>
<td>1 (3)</td>
<td>5 (14)</td>
<td>10 (31)</td>
</tr>
<tr>
<td>In infusion</td>
<td>10 (8)</td>
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<td>2 (5)</td>
<td>5 (14)</td>
<td>3 (10)</td>
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<tr>
<td>Read to participant</td>
<td>2 (2)</td>
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<td>1 (3)</td>
<td>0</td>
<td>1 (3)</td>
</tr>
</tbody>
</table>
± Tumor grade extracted only for brain tumor group.

*Chemotherapy and radiation data unknown for one participant in the brain tumor group.

+ Time varying variables; data from last completed survey reported.

### 4.4.1 Difference in Participation by Cancer Type at Each Time Point

Average participation scores at each time point, as measured by the CPI and PROMIS, are outlined in Table 4.2. Baseline participation scores for the total sample were 0.56 on the CPI and 46.19 on the PROMIS. There were no statistically significant differences in average participation scores for individuals with different cancer types at baseline or follow-up assessments on the CPI or PROMIS (Figure 4.2a, 4.2b).

Table 4.2 Average CPI and PROMIS Participation Scores by Diagnosis at Each Time Point

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Brain</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Outcome</strong></td>
<td></td>
<td></td>
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<tr>
<td>CPI baseline</td>
<td>0.56 (0.25)</td>
<td>0.57 (0.27)</td>
<td>0.55 (0.21)</td>
<td>0.56 (0.26)</td>
<td>0.58 (0.28)</td>
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<td>CPI time 2</td>
<td>0.60 (0.25)</td>
<td>0.67 (0.20)</td>
<td>0.56 (0.23)</td>
<td>0.56 (0.28)</td>
<td>0.63 (0.27)</td>
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<td>CPI time 3</td>
<td>0.58 (0.24)</td>
<td>0.55 (0.24)</td>
<td>0.58 (0.24)</td>
<td>0.57 (0.25)</td>
<td>0.61 (0.26)</td>
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<td><strong>Secondary Outcome</strong></td>
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<tr>
<td>PROMIS ability to participate</td>
<td>46.19 (9.0)</td>
<td>46.29 (8.1)</td>
<td>45.99 (9.4)</td>
<td>44.34 (7.5)</td>
<td>48.41 (10.3)</td>
</tr>
<tr>
<td>baseline</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>PROMIS ability to participate</td>
<td>44.81 (8.0)</td>
<td>46.59 (7.2)</td>
<td>46.21 (9.1)</td>
<td>43.12 (6.1)</td>
<td>44.08 (8.8)</td>
</tr>
<tr>
<td>PROMIS ability to participate time 3</td>
<td>44.84 (8.6)</td>
<td>48.98 (9.0)</td>
<td>44.4 (9.5)</td>
<td>43.32 (7.6)</td>
<td>44.63 (8.0)</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-------------</td>
<td>-------------</td>
<td>-------------</td>
<td>-------------</td>
<td>-------------</td>
</tr>
<tr>
<td><strong>Descriptive Covariates</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PROMIS satisfaction social roles baseline</td>
<td>46.24 (11.0)</td>
<td>43.83 (8.6)</td>
<td>49.71 (11.8)</td>
<td>44.61 (9.7)</td>
<td>45.63 (12.1)</td>
</tr>
<tr>
<td>PROMIS satisfaction social roles Time 2</td>
<td>46.22 (10.3)</td>
<td>45.10 (8.8)</td>
<td>50.31 (9.9)</td>
<td>46.16 (10.6)</td>
<td>41.95 (9.6)</td>
</tr>
<tr>
<td>PROMIS satisfaction social roles Time 3</td>
<td>47.71 (11.3)</td>
<td>47.38 (11.6)</td>
<td>52.33 (10.2)</td>
<td>44.35 (11.3)</td>
<td>45.42 (11.2)</td>
</tr>
<tr>
<td>PROMIS satisfaction discretionary social activities baseline</td>
<td>46.33 (9.9)</td>
<td>47.03 (7.7)</td>
<td>46.27 (9.4)</td>
<td>45.00 (9.9)</td>
<td>47.47 (11.7)</td>
</tr>
<tr>
<td>PROMIS satisfaction discretionary social activities time 2</td>
<td>45.51 (9.7)</td>
<td>46.36 (8.8)</td>
<td>47.69 (10.1)</td>
<td>43.99 (9.1)</td>
<td>44.17 (10.4)</td>
</tr>
<tr>
<td>PROMIS satisfaction discretionary social activities time 3</td>
<td>47.14 (10.4)</td>
<td>48.49 (9.5)</td>
<td>49.60 (10.5)</td>
<td>45.57 (9.3)</td>
<td>44.60 (12.1)</td>
</tr>
</tbody>
</table>
Adjusted analyses did not yield any significant model predictors for CPI at any time point.

Significant predictors in the PROMIS baseline model ($R^2 = 0.17, p = 0.01$) included surgery ($\beta = -4.33, p = 0.03$), hormone therapy ($\beta = -9.76, p = 0.04$), and comorbidities ($\beta = -5.51, p = 0.01$) (Appendix G/Online Supplement Table 2) where participants who received the specified treatment and those with more comorbidities had lower participation scores. No significant predictors were identified in PROMIS adjusted analyses at either follow-up time point.

Figure 4.2a Change in Community Participation Indicators Score Over Time by Diagnosis Group
Figure 4.2b Change in PROMIS Ability to Participate Score Over Time by Diagnosis Group Scores below the reference line of 45 indicate mild impairments.

4.4.2 Change in Participation Over Time

The initial models, including the outcome (CPI or PROMIS) as a function of time, group, and group by time interaction, were not significant, indicating there were no differences in participation over time between individuals of different cancer types. Adjusted analyses indicated that after controlling for relevant treatment, disease, and person characteristics, physical function was a significant predictors of CPI score (Table 4.3). With every point an individual gains in PROMIS physical function, their CPI score increased by 0.005. CPI model intraclass correlation coefficient (ICC) was 0.51 indicating participants demonstrate considerable heterogeneity in CPI after accounting for confounding variables.

Adjusted analyses with PROMIS ability to participate as the outcome indicated lung cancer, receiving chemotherapy, and physical function were significant predictors, after
controlling for potential confounding variables (ICC= 0.48). Individuals with lung cancer reported higher participation over time compared to the breast cancer group (β= 5.8, p<.01), individuals receiving chemotherapy reported lower ability to participate over time (β= -3.5, p<.001), and higher physical function was again associated with higher participation (β= 0.39, p<.001).

Table 4.3 Mixed Effect Regression Model for Change in Participation Over Time

<table>
<thead>
<tr>
<th>Effect</th>
<th>Community Participation Indicators (CPI)</th>
<th>PROMIS Ability to Participate in Social Roles and Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>Estimate 0.535, Standard Error 0.053, P &lt;.001</td>
<td>Estimate 45.047, Standard Error 1.558, P &lt;.001</td>
</tr>
<tr>
<td>Time</td>
<td>Estimate 0.029, Standard Error 0.022, P 0.194</td>
<td>Estimate -0.450, Standard Error 0.683, P 0.411</td>
</tr>
<tr>
<td>Brain</td>
<td>Estimate 0.117, Standard Error 0.070, P 0.095</td>
<td>Estimate 3.090, Standard Error 2.062, P 0.136</td>
</tr>
<tr>
<td>Colorectal</td>
<td>Estimate 0.061, Standard Error 0.058, P 0.297</td>
<td>Estimate 1.199, Standard Error 1.726, P 0.488</td>
</tr>
<tr>
<td>Lung</td>
<td>Estimate 0.081, Standard Error 0.062, P 0.189</td>
<td>Estimate 5.805, Standard Error 1.824, P 0.002*</td>
</tr>
<tr>
<td>Brain*time</td>
<td>Estimate -0.038, Standard Error 0.038, P 0.319</td>
<td>Estimate 0.779, Standard Error 1.146, P 0.498</td>
</tr>
<tr>
<td>Colorectal*time</td>
<td>Estimate -0.021, Standard Error 0.030, P 0.495</td>
<td>Estimate 0.328, Standard Error 0.927, P 0.724</td>
</tr>
<tr>
<td>Lung*time</td>
<td>Estimate -0.010, Standard Error 0.032, P 0.747</td>
<td>Estimate -0.721, Standard Error 0.972, P 0.460</td>
</tr>
<tr>
<td>Surgery</td>
<td>Estimate -0.004, Standard Error 0.041, P 0.929</td>
<td>Estimate -0.333, Standard Error 1.213, P 0.784</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Estimate -0.027, Standard Error 0.032, P 0.402</td>
<td>Estimate -3.512, Standard Error 0.955, P &lt;.001*</td>
</tr>
<tr>
<td>Radiation</td>
<td>Estimate -0.035, Standard Error 0.031, P 0.264</td>
<td>Estimate 1.129, Standard Error 0.938, P 0.230</td>
</tr>
<tr>
<td>Age</td>
<td>Estimate 0.003, Standard Error 0.002, P 0.064</td>
<td>Estimate -0.040, Standard Error 0.044, P 0.371</td>
</tr>
<tr>
<td>Physical function</td>
<td>Estimate 0.005, Standard Error 0.001, P &lt;.001*</td>
<td>Estimate 0.388, Standard Error 0.043, P &lt;.001*</td>
</tr>
</tbody>
</table>
Note: Reference group= breast cancer.

CPI item-level data (Appendix H) revealed details of what survivors want to do in their daily lives. More than 90% of participants identified getting out and about, spending time/keeping in touch with family and friends, and cooking, cleaning, and looking after the home as important during the first six-months post diagnosis. Ninety percent of survivors also identified engaging in hobbies or leisure activities as important at baseline; the percent dropped to the high 80s at 2- and 5-month follow-up. Overall, only small changes were observed in the proportion of participants who identified an activity as important at baseline compared follow-up time points. The only exception was participating in civic or political activities, identified as important by 30% at baseline, 19% at time two, and 23% at time three. Only one-sixth to one-third of survivors identified participating in community clubs and organizations, participating in civic or political activities, and going to support groups or self-help meetings as important activities in the first six-months following a new cancer diagnosis.

Results also revealed activities that survivors identified as important but were not doing enough, representing participation restrictions. Participation restrictions were identified in a broad array of activities where less than half of the sample reported they felt they were doing the activity they found important enough. Examples included spending time with friends, volunteering, engaging in hobbies or leisure activities, and going to movies, sporting events, or entertainment activities. See Appendix H for additional details.

4.4.3 Risk Factors for Participation Restrictions

Based on univariate analyses, gender and race were not tested in the multilevel model for either participation outcome due to lack of statistical significance. Comorbidity and mobility support were also insignificant for CPI and social support insignificant for PROMIS. With CPI
as the outcome, testing additional covariates rendered physical function a non-statistically significant covariate. Higher fatigue and change in employment since cancer diagnosis were risk factors for lower participation (Table 4.4; ICC= 0.46). For PROMIS, lung cancer, chemotherapy, and physical function retained significance. Higher anxiety, fatigue, and change in employment since cancer diagnosis were significant predictors of lower participation (Table 4.4; ICC= 0.44).

Social support was not tested in the PROMIS model because univariate tests were not significant. Comorbidity and use of mobility support were tested as predictors of PROMIS, but they were not significant and were removed from the model.

Table 4.4 Risk Factors for Participation Restrictions Over Time

<table>
<thead>
<tr>
<th>Effect</th>
<th>Community Participation Indicators (CPI)</th>
<th>PROMIS Ability to Participate in Social Roles and Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate</td>
<td>Standard Error</td>
</tr>
<tr>
<td>Intercept</td>
<td>0.550</td>
<td>0.049</td>
</tr>
<tr>
<td>Time</td>
<td>0.030</td>
<td>0.022</td>
</tr>
<tr>
<td>Brain</td>
<td>0.116</td>
<td>0.065</td>
</tr>
<tr>
<td>Colorectal</td>
<td>0.083</td>
<td>0.055</td>
</tr>
<tr>
<td>Lung</td>
<td>0.123</td>
<td>0.058</td>
</tr>
<tr>
<td>Brain*time</td>
<td>-0.003</td>
<td>0.036</td>
</tr>
<tr>
<td>Colorectal*time</td>
<td>-0.009</td>
<td>0.030</td>
</tr>
<tr>
<td>Lung*time</td>
<td>-0.016</td>
<td>0.031</td>
</tr>
<tr>
<td>Surgery</td>
<td>-0.009</td>
<td>0.038</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>-0.009</td>
<td>0.031</td>
</tr>
<tr>
<td></td>
<td>Radiation</td>
<td>Age</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td>-0.030</td>
<td>0.001</td>
</tr>
<tr>
<td>Radiation</td>
<td>0.030</td>
<td>0.673</td>
</tr>
<tr>
<td>Physical function</td>
<td>Removed, not significant in model</td>
<td>0.236</td>
</tr>
<tr>
<td>Social support</td>
<td>Removed, not significant model</td>
<td>Univariate not significant, not tested</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Univariate not significant, not tested</td>
<td>-0.137</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.006</td>
<td>0.001</td>
</tr>
<tr>
<td>Employment change</td>
<td>-0.166</td>
<td>0.036</td>
</tr>
</tbody>
</table>

Consistent with multilevel model findings, fatigue was the factor most frequently reported by participants that made it challenging to participate. While survivors reported numerous factors that negatively impacted their participation, more than half reported cancer changed their outlook on life and resulted in a greater appreciation for the activities they do (Appendix I/Online Supplement Table 3).

**4.4.4 Rehabilitation Referrals**

The majority of participants were not referred to rehabilitation services by their medical team (Figure 4.3a). SLP received the lowest number of referrals (9%), followed by mental health (18%). One-third of those referred to PT (41%) and half referred to OT (33%) were referred for a one-time postoperative inpatient evaluation only; a few of these individuals had one additional inpatient follow-up session, but they did not engage in ongoing therapy services. PROs identified 53% of the sample may benefit from OT or PT services and 45% may benefit from mental health support (Figure 4.3b). Based on PRO findings, 133 new referrals were suggested for supportive services: 45 PT, 52 OT, and 36 mental health. Statistically significant differences (p<.05) in
referral patterns were observed where individuals with brain tumors were more likely to be referred to PT and OT by their medical team and males more likely to be referred to OT than females. Based on PROs, males and those reporting Black race were significantly less likely to indicate referrals to mental health services and retirees were less likely to be referred to OT compared to those who were unemployed or employed.

Figure 4.3a Participants Referred to Rehabilitation Services by Medical Team
4.5 Discussion

This is the first study, that we are aware of, to prospectively evaluate participation in a cohort of adult cancer survivors with various types of solid tumors. In the first six months after a new cancer diagnosis survivors report mildly impaired ability to participate in social roles and activities. Mild impairments are reported as early as within one-month of diagnosis among individuals with colorectal cancer. Average baseline CPI score for the total sample was 0.56, representing a relatively low level of participation and is similar to a sample of individuals with mild to moderate stroke (mean CPI: 0.53). Differences in participation based on cancer type were not identified at individual time points or over time, as measured by CPI or PROMIS. The lack of change may be in part attributed to nearly all participants having already initiated treatment before the baseline survey. Although specific time points or disease groups to prioritize
for intervention were not identified, findings suggest there is a need to evaluate participation in
the early phases after diagnosis.

Despite more than half the sample having PRO findings indicating they may benefit from
PT and OT, only 20% (PT) to 31% (OT) had been previously referred by their medical team.
Although not commonly studied, low referral rates to rehabilitation are a pattern within
oncology.189,206,207 Mental health services followed similar trends. Eighteen percent of the current
study sample was referred to mental health support by their medical team, which is more than
double the 7.2% of cancer survivors using services in a 2002 study.208 However, PROs indicated
45% of the sample may benefit from mental health support; 64% of these individuals had not
been referred by their medical team (Figure 3b). Our findings demonstrate low referral rates are
common for PT, OT, and mental health for survivors with brain, breast, colorectal, and lung
cancer.

One solution to address low rehabilitation referral rates is implementing a prospective
surveillance model (PSM) of care. The PSM includes evaluation from an interdisciplinary
rehabilitation team at the point of diagnosis and ongoing surveillance of needs during and
beyond cancer treatment.107 PSM care is the recommended standard for cancer rehabilitation,93
supports early identification and treatment of cancer-related disability,107 and is cost effective.209
However, the PSM is tested primarily among individuals with breast cancer and is an
underrecognized and underutilized model of care among other cancer populations.210

Patterns of participation restrictions differed based on outcome measure. For example, in
the lung cancer group, PROMIS participation scores decreased from baseline to two-month
follow-up and increased slightly at the final survey. In contrast, CPI scores increased at time two
and decreased slightly at the final survey. Differences in outcomes may be due to how
participation is conceptualized in these measures. PROMIS focuses on an individual’s ability to participate while CPI examines an individual’s desire for increased participation in valued activities.\textsuperscript{23} It is possible that despite experiencing a decrease in ability, survivors do not have a desire to change their participation. The lack of desire for change may be in part due to survivors shifting priorities when diagnosed with cancer,\textsuperscript{103} especially when their prognosis is poor. CPI ratings may also be more influenced by what survivors think is reasonable for them to accomplish given their cancer diagnosis\textsuperscript{103} while PROMIS takes a more objective approach to measurement. Discordance between PROMIS and comprehensive participation measures has been previously reported and the need to use comprehensive measures was suggested.\textsuperscript{101} Findings from the current study cannot conclude whether one measurement approach is recommended for identifying survivors in need of rehabilitation services due to the heterogeneity of means across time points and disease groups. There remains an ongoing need to identify optimal measures to screen survivors for rehabilitation needs.\textsuperscript{95}

The identification of risk factors for participation restrictions served as a method to generate hypotheses about 1) factors to investigate in more targeted studies about participation and 2) groups of survivors to prioritize for assessment and intervention. Individuals who received chemotherapy, had an employment change, or higher anxiety, fatigue, or age were at higher risk for participation restrictions. Higher physical function was associated with higher participation. Each of these factors may signify a group of individuals to target to expand rehabilitation services amongst survivors. To build towards a PSM of care where all survivors have access to rehabilitation throughout the care continuum, cancer centers may first consider rolling out this model of care among individuals who receive chemotherapy given their higher risk for participation restrictions. Findings also indicate that to comprehensively address participation, a
multidimensional and multidisciplinary approach to treatment is needed to address factors such as anxiety, fatigue, and physical function. Rehabilitation interventions effectively address fatigue and physical function amongst survivors, but there remains limited data on methods to improve participation.211,212

Surprising findings included that having lung cancer was associated with higher participation over time. High attrition in the lung cancer group may contribute to these findings; half of those lost to follow-up had stage four lung cancer, so we are missing important information about how participation may have changed in this group. Given the poor prognosis and intensive multimodal treatment approach for stage four disease it is expected the participation of many of these individuals declined. Future mixed methods studies should investigate the participation and treatment priorities of survivors with advanced disease.

This study is limited by the inclusion of only self-report measures and lack of a normative comparison for the primary outcome, CPI. Performance-based assessments of physical function and cognition were included in the initial study protocol but had to be removed from study procedures due to COVID-19 restrictions for in-person research at the time of the study. While the use of CPI among cancer survivors is novel, this also presents challenges as the assessment is not validated with the population and there are limited comparison data. Findings are also limited by lack of a pre-cancer baseline to evaluate change over time. While we enrolled survivors in the early phases after diagnosis, most had initiated treatment when the baseline measure was completed.

Future investigations should evaluate participation pre-treatment when possible to support comparisons over time. There is also a need to measure participation for longer time periods to assess how participation is impacted throughout the cancer continuum. Monitoring
participation over multiple years can identify populations of survivors with whom, and time points when, rehabilitation may need to intervene.\textsuperscript{93} Preliminary findings on risk factors for participation restrictions should be used to inform more targeted risk factor investigations to develop risk-based rehabilitation triage protocols.\textsuperscript{20,93} Determining the impact of cancer on survivors’ daily life participation will build towards interventions to enhance survivors’ participation, a field of research that is just emerging.\textsuperscript{104}

There is a need to integrate the concept of participation into cancer care to understand how survivors’ daily lives are impacted by cancer.\textsuperscript{20} Survivors experience impaired participation as early as one-month post diagnosis, but they are rarely referred to supportive services such as rehabilitation. The use of PROs to evaluate participation and other health domains is an effective method to identifying survivors who may benefit from rehabilitation services.
Chapter 5: Conclusion

5.1 Summary of Major Findings and Contribution to Rehabilitation and Participation Science

Cancer-related disability is common, yet cancer survivors are rarely referred to rehabilitation services. Barriers contributing to low rehabilitation referral rates include: 1) lack of knowledge among physicians on how to screen for rehabilitation needs, 2) low awareness among providers and patients on the benefits of rehabilitation, and 3) a lack of infrastructure to support referrals to rehabilitation. Due to barriers accessing services, survivors report unmet rehabilitation needs both during and after cancer treatment.

PROs can be used to detect impairments and generate referrals to rehabilitation. While the use of PROs in clinical care has great potential benefits, including improving survival, further study is needed to identify what PROs are valued by stakeholders and appropriate to use in clinical care. Evaluating participation, defined as doing what an individual finds important or meaningful in their daily life, should be prioritized because it is a key determinant of rehabilitation needs and has widespread benefits for health, well-being, and survival.

By measuring participation we put the concept of daily life at the forefront of clinical care and cultivate opportunities to help survivors live fulfilling and productive lives and identify individuals in need of rehabilitation. Early access to rehabilitation can lead to long-term cost savings, decrease disease burden, and mitigate disability. If we continue to deprioritize...
investigations about how survivors’ daily lives are impacted by cancer and treatment, survivors will not get connected to evidence-based rehabilitation to enhance participation and health.

The purpose of this dissertation was to advance knowledge about how participation in daily life is impacted among cancer survivors and to take a proactive and preventative approach to addressing cancer-related disability. The dissertation 1) identified what assessments of participation are used among cancer survivors, 2) characterized survivors’ perspectives of participation, 3) determined how participation changes during the first six months following a new cancer diagnosis, and 4) referred survivors to rehabilitation services based on PRO findings.

5.1.1 Assessments Used to Measure Participation

The variability in participation measures and challenges with existing assessments are commonly acknowledged in the literature.\textsuperscript{12,17,41,44} However, given the paucity of literature measuring participation amongst cancer survivors, it was necessary to first conduct a rigorous scoping review to inform our future work of prospectively evaluating participation. Two previous systematic reviews of participation measures focusing on broader populations were published in 2011 and 2013.\textsuperscript{41,44} The current scoping review, conducted in 2019, provided an opportunity to identify new measures, such as PROMIS, used to evaluate participation.

The primary aim of the scoping review was to identify what assessments of participation have been used among cancer survivors. Findings revealed a small body of literature (32 studies) investigating survivors’ participation. In these 32 studies, 20 different measures of participation were used, highlighting the lack of consistency in the field. Only four measures included subjective evaluations of participation, which are critical to comprehensively evaluating participation. Two of the four were measures for children and one (LIFE-H) contains 240 items (69 on the short form), which would likely translate to poor clinical utility of the measure.
Findings from the review did not yield strong recommendations about a participation measure that should be used with survivors.

Gaps and inconsistencies in previous participation research were also identified in the scoping review. Discordance between the study-stated purpose of a measure and the purpose of a tool when it was developed were noted. As a result, some of the measures included in the review measure concepts in addition to participation. Additionally, only one-third of studies defined participation, which is problematic when participation is not consistently defined in the literature, further contributing to measurement heterogeneity.

The scoping review informed not only our understanding of specific measurement tools but also broadened knowledge about the state of participation research among cancer survivors. Findings from the review were used to inform our investigation and selection of comprehensive measures of participation that could be used with survivors in the quantitative phase of the dissertation.

5.1.2 Cancer Survivors’ Perspectives of Participation

Participation is recognized as the ultimate goal of rehabilitation\(^1\); however, research takes a narrow approach to conceptualizing participation. Individuals embedded within rehabilitation and disability communities, such as individuals with traumatic brain injury, spinal cord injury, and stroke,\(^2\) are typically the focus of participation investigations. Focusing exclusively on individuals with ‘traditional disabilities,’ as viewed by society, leaves out a large subset of individuals living with restricted participation in daily life. Consequently, their perspectives are lacking in participation definitions, their participation experiences are not addressed, and they are not connected to rehabilitation services.
The second aim of the presented dissertation expanded the scope of research on the conceptualization of participation to a population of individuals living with widespread disability that is rarely acknowledged—cancer survivors. The presented findings are significant because they 1) confirmed core characteristics of participation identified in previous research (control, choice, competence, relationships, community engagement, and value), providing data to support the development of a more specific definition of participation beyond the ICF definition, which remains greatly needed; 2) revealed that constructs relevant to individuals embedded within disability communities were not reported by cancer survivors, raising the question of whether cancer survivors view themselves as individuals living with disabilities; and 3) highlighted that participation is identified as a top priority among cancer survivors.

The presented findings can transform our approach to disability in cancer care. First, we need to acknowledge that cancer-related disability exists and is a priority to address in clinical care. We can then progress towards an expansive view of disability beyond physical and ADL impairments to incorporate participation in daily life. Focusing on participation supports client-centered care and puts the emphasis on the priorities of cancer survivors—meaningfully living the lives they are fighting so hard to keep.

**5.1.3 Participation in Newly Diagnosed Survivors**

Daily life participation is a priority among cancer survivors, but it is rarely included in outcome assessments or addressed in clinical cancer care. When participation is measured, it is almost exclusively evaluated among survivors who have completed cancer treatment. Studies evaluating participation over time tend to have small sample sizes and/or focus on only a single disease group. The work presented in this dissertation presents a significant advancement in the field by measuring participation over time in a moderately sized cohort of adult cancer
survivors with four different cancer types: brain, breast, colorectal, and lung cancer. By measuring participation prospectively we are taking a first step towards a new standard of addressing participation in cancer care.

The baseline study sample included a total of 123 adults with newly diagnosed brain (n=19), breast (n=36), colorectal (n=36), and lung (n=32) cancer. Ninety-nine participants completed measures for all three time points (within one month of diagnosis, three months post, and six months post). PROMIS scores indicated survivors, on average, have mildly impaired ability to participate in social roles and activities in the early phases after diagnosis, specifically three and six months post-diagnosis. Additionally, survivors with colorectal cancer reported mildly impaired ability to participate within one month of diagnosis. Average baseline CPI score for the total sample was 0.56, representing a relatively low level of participation and is similar to a sample of individuals with mild to moderate stroke (mean CPI: 0.53). These findings indicate survivors experience restricted participation in the early phases after diagnosis, highlighting the importance of measuring participation from the point of diagnosis.

Changes in participation over time were not identified. The lack of change over time may be because almost all participants had initiated treatment at the time of baseline assessment. There were no statistically significant differences in participation based on diagnosis group at individual time points, as measured by CPI and PROMIS. Group differences were identified for the lung cancer group over time, with survivors with lung cancer reporting higher ability to participate over time than those with breast cancer. As an exploratory aim, risk factors for participation restrictions were identified. Because the purpose of risk factor identification was primarily to inform future research, these results are discussed in section 5.2.2.
Our results indicate that daily life participation is impacted among survivors in the early phases after a new cancer diagnosis. To support early detection of impairments and prevent long-term disability it is essential that we begin addressing survivors’ participation and rehabilitation needs starting at the point of diagnosis and throughout the entire cancer care continuum.

5.1.4 Referrals to Rehabilitation
The current study expanded on Basch’s foundational work using PROs to promote early detection and treatment of patient symptoms\textsuperscript{94,199} to a domain central to rehabilitation—participation. We determined that PROs are an effective method to identify survivors who may benefit from rehabilitation services, specifically PT, OT, and mental health support. Due to the scope of PROs used in this study, there were insufficient data to suggest referrals to speech therapy. Three-quarters of participants completed the surveys online at home, indicating PROs did not increase clinical burden for the large majority.

Referrals to PT and OT were indicated for 53% of the sample, 80% of whom had not been previously referred to PT, and 69% not previously referred to OT. Referrals to mental health support were indicated for 45% of the sample; 64% had not been previously referred by their medical team. While the literature on rehabilitation service utilization among survivors is sparse, the three studies we are aware of exploring this question have consistently demonstrated large gaps between individuals who could benefit from services (based on impairment screenings) and those who are referred.\textsuperscript{188,207,220}

While PROMIS cut points were used in our study to identify individuals who may benefit from PT and mental health support, determining when to suggest a referral to OT was more complex. The CPI, the comprehensive participation measure used in our study, does not have established cut points for therapy referral. For the purpose of OT referrals, a CPI cut point of
0.60 was identified based on a review of the available evidence\textsuperscript{23,205} and preliminary CPI data collected from the 40 survivors who participated in the qualitative portion of the study. Additionally, CPI scores were compared to PROMIS ability to participate scores when suggesting referrals, but measure discordance did sometimes exist. These challenges raise questions about what measures should be used to screen survivors for participation challenges to refer them to OT. Previous research recommends the use of comprehensive participation measures because PROMIS may lack sensitivity to identify survivors’ participation restrictions\textsuperscript{101}; however, the use of comprehensive measures comes with its own set of challenges. Comprehensive tools can be limited in their clinical utility, have difficult to interpret scores, and lack normative comparison data. While we still cannot recommend a single participation measure as a tool to triage survivors to OT, the current study suggests either CPI or PROMIS can serve as a screening tool to refer survivors for a more comprehensive OT evaluation.

5.2 Suggestions for Future Research

The findings presented in this dissertation highlight the need for future research in three primary areas: 1) participation measurement, 2) understanding the participation and disability experiences of cancer survivors, and 3) methods to improve access to comprehensive cancer rehabilitation programming.

5.2.1 Participation Measurement

The body of work presented in this dissertation provides significant contributions to participation measurement. We first identified what measures have been used to assess survivors’ participation and then used a comprehensive participation measure (CPI) to
prospectively evaluate participation over time. Despite these advances, more work is needed to expand the field of participation measurement overall and specifically within oncology.

Prior to the presented research, the CPI had not been used with cancer survivors. Thus, the CPI, and other comprehensive participation measures, are not validated for this population. Comprehensive participation measures need to be validated among cancer survivors to support rigorous investigations focusing on survivors’ participation experiences. Additionally, we need to take a participatory approach to engaging survivors in the use, refinement, and development of participation measures. In the qualitative phase of the presented dissertation, participants completed three measures of participation (PROMIS, CPI, and PM-3D4D) and shared their perspectives of and preferences for the measures. These data are in preparation for future publication and will provide another important contribution to the field.

Additional research is needed to identify what tools can be used to screen survivors for participation restrictions to triage them to OT services. Previous research among survivors suggests the PROMIS ability to participate subscale may lack sensitivity to detect impairments identified using more comprehensive participation measures, such as ACSm.\textsuperscript{101} These findings were not confirmed in the current dissertation. Both the current work and the previous study using ACSm and PROMIS did not set out to compare measure responsiveness. Thus, more focused research is needed to compare measures such as PROMIS, which has high clinical utility, to more comprehensive participation measures. In clinical care it is essential to use measures that can be quickly administered and are sensitive enough to detect impairments.

5.2.2 Survivor Participation and Disability Experiences

This dissertation presents the first study examining participation over time in a cohort of survivors newly diagnosed with solid tumors, specifically brain, breast, colorectal, and lung
cancer. While the original goal was to establish a baseline of an individual’s participation by enrolling survivors when they were newly diagnosed, identifying and enrolling survivors before they had received any treatment was not feasible. Patients needed to have a confirmed cancer diagnosis to be eligible to participate in the study, but tumor pathology is often determined only after surgical intervention. Additionally, it is common for survivors to experience a decline in their abilities leading up to a new cancer diagnosis. Thus, a pre-treatment measurement of participation still may not reflect a true baseline, making it difficult to assess change over time.

To establish a baseline participation level, one option is to ask survivors to reflect back to before they experienced symptoms related to their cancer, but this presents concerns for recall bias. Ultimately, there is a need to measure participation for longer periods of time to develop a deeper understanding of how participation is impacted throughout the cancer continuum. Monitoring participation over multiple years can distinguish populations of survivors who may benefit from rehabilitation services and identify ideal time points for intervention.\(^{93}\) Determining the impact of cancer on survivors’ daily life participation will inform the development of interventions to enhance survivors’ participation, a field of research that is just emerging.\(^{104}\)

To develop risk-based rehabilitation triage protocols for cancer survivors, we need to determine what puts an individual at increased risk for participation restrictions. Examining risk factors was an exploratory aim of the presented dissertation; these findings can be used for more targeted investigations of risk factors in future studies. Specific factors to evaluate based on study findings include treatment (specifically survivors receiving chemotherapy), age, physical function, anxiety, fatigue, and change in employment status since diagnosis.

Additional methods can also be considered to investigate different types of questions about participation. Structural equation modeling (SEM) can test hypothesized direct and indirect
relationships between biopsychosocial factors and participation. Again, preliminary risk factors identified in the presented research can inform the development of a theoretical model to test using SEM. Investigations in individuals with spinal cord injury, mobility limitations, stroke, and children and adults with physical disabilities have used SEM methods with participation, but this approach had not been used among cancer survivors. Another method to use in future research, ecological momentary assessment (EMA), investigates real-world behavior in a variety of natural contexts. EMA data are collected as individuals go about their daily lives, making it an ideal method to use to study real-world experiences such as participation. Within oncology, EMA has been used to monitor symptoms (e.g. fatigue, sleep, mood, pain, nausea), but has not been expanded to physical function, cognition, or participation.

Lastly, there is a need to better understand survivor and provider perspectives of cancer-related disability. The qualitative phase of the dissertation revealed that survivors may not view themselves as people living with disabilities. When disability is not acknowledged by survivors or providers, getting survivors connected with rehabilitation to address disability will be challenging. Future qualitative investigations can examine disability awareness, treatment approaches, and expectations about disability throughout the cancer care continuum.

5.2.3 Improving Access to Comprehensive Cancer Rehabilitation Programming

More than 100 new referrals for PT, OT, and mental health services were supported by participant PRO scores. While this is a positive step to getting survivors connected to rehabilitation services, the infrastructure does not yet exist at Siteman Cancer Center for program
sustainment. To address cancer-related disability and improve long-term health outcomes, we must develop sustainable systems to identify and refer survivors to rehabilitation services.

PROs are generally a low-cost and efficient method to screen patients for impairments without increasing clinician burden. However, simply collecting PRO data is insufficient. Electronic medical record algorithms need to be developed that link findings from PROs to real-time alerts for providers and referrals for evidence-based rehabilitation services. Measurement challenges again present a barrier to rehabilitation referrals. Rehabilitation is a multidisciplinary field including, at a minimum, the core therapy disciplines of PT, OT, SLP, and mental health support. The variety of health domains addressed across these disciplines makes it difficult to quickly and routinely screen survivors for rehabilitation needs for each discipline.

We also need to examine how supporting referrals to rehabilitation services translates to use of these services. From there, we can investigate locations of rehabilitation service use, barriers to care, and receptivity to rehabilitation. There are limited available data on survivor perceptions of rehabilitation. One study identified that about two-thirds of individuals with late-stage cancer experiencing disability were not interested in rehabilitation services. We know survivors are often unaware of their own need for and the potential benefits of rehabilitation, suggesting focused counsel about rehabilitation needs and benefits may be indicated for survivors. The development of a decision aid is one method that can help patients make a decision about whether pursuing rehabilitation services is right for them.

5.3 Summary
The presented dissertation provides several key contributions to the field of rehabilitation and participation science, outlined in Figure 5.1. These data provide evidence that the daily lives
of survivors are profoundly impacted following a new cancer diagnosis, yet referral rates to supportive care services, such as rehabilitation, remain low. We need to usher in a new era in cancer care where survivors’ disability and participation experiences are prioritized and proactively and continuously addressed throughout the care continuum.

Figure 5.1 Dissertation Summary
References


34. Martin Ginis KA, Evans MB, Mortenson WB, Noreau L. Broadening the Conceptualization of Participation of Persons With Physical Disabilities: A Configurative Review and


Appendices

Appendix A: Online Resource 1 Search Strategy

Search Strategies For:
(cancer AND measurement tools AND participation)

Ovid Medline 1946-March 2020
Date Searched: 2/24/19 ; 3/3/20
Applied Database Supplied Limits:
Number of Results:  2021; 2200

Full Search Strategy: 179 additional

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(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*).ti,ab,hw OR
((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*))

AND
(((participation) ADJ2 (measure* OR instrument* OR survey* OR assessment*)) OR
((instrument*) ADJ1 (participation*)) OR
((participation*) ADJ2 (survey*)) OR
((activit*) ADJ2 (scale*))

OR
(exp Neoplasms/ OR
(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*).ti,ab,hw OR
((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*))

AND
(exp Community Participation/ OR exp "Activities of Daily Living"/ OR exp Community Integration/ OR exp Leisure Activities/ OR exp Return to Work/ OR
(Leisure OR Shopping OR hobby OR hobbies OR self-management OR selfcare OR selfmanagement OR lifestyle* OR Housekeeping OR Housework OR
life habit OR life habits OR social life OR life style OR back to work OR return to work).ti,ab. OR

((community) ADJ1 (integrate* OR reintegrate* OR participation OR involvement*)).ti,ab. OR
((patient*) ADJ1 (participate* OR involve* OR activation OR engagement)).ti,ab. OR
((Public OR problem* OR social* OR accomplishment* OR restrict* OR general OR meaningful* OR routine* OR satisfaction* OR satisfied) ADJ1 (participate*).ti,ab. OR
((consumer*) ADJ1 (participate* OR involvement*)).ti,ab. OR
((activit*) ADJ2 (limit* OR meaningful* OR possible* OR daily)).ti,ab. OR
((participation) ADJ1 (life) ADJ1 (role*)).ti,ab. OR
((performan*) ADJ1 (limit*)).ti,ab. OR
((Public OR problem* OR social* OR accomplishment* OR restrict* OR general OR meaningful* OR routine* OR satisfaction* OR satisfied) NEAR/1 (participat*)):ti,ab OR ((consumer*) NEAR/1 (participat* OR involvement*)):ti,ab OR ((activit*) NEAR/2 (limit* OR meaningful* OR possibil* OR daily)):ti,ab OR ((participation) NEAR/1 (life) NEAR/1 (role*)):ti,ab OR ((performan*) NEAR/1 (limit*)):ti,ab OR ((functional*) NEAR/1 (deficit*)):ti,ab OR ((attend*) NEAR/1 (school OR work)):ti,ab OR ((work*) NEAR/1 (capacit* OR resumption OR abilit*)):ti,ab OR ((self) NEAR/1 (management OR care)):ti,ab OR ((home) NEAR/1 (maintain* OR maintenance*)):ti,ab) AND ('Questionnaire'/exp/mj OR 'rating scale'/exp/mj OR 'clinical assessment tool'/exp/mj))
5. [mh “community participation”] OR [mh “activities of daily living”] OR [mh “community integration”] OR [mh “leisure activities”] OR [mh “return to work”] OR (Leisure OR Shopping OR hobby OR hobbies OR self-management OR selfcare OR selfmanagement OR lifestyle* OR Housekeeping OR Housework OR “life habit” OR “life habits” OR “social life” OR “life style” OR “back to work” OR “return to work”):ti,ab OR ((community) NEAR/1 (integrate* OR reintegrate* OR participation OR involvement*)):ti,ab OR ((patient*) NEAR/1 (participat* OR involve* OR activation OR engagement)):ti,ab OR ((Public OR problem* OR social* OR accomplishment* OR restrict* OR general OR meaningful* OR routine* OR satisfaction* OR satisfied) NEAR/1 (participat*)):ti,ab OR ((consumer*) NEAR/1 (participat* OR involvement*)):ti,ab OR ((activit*) NEAR/2 (limit* OR meaningful* OR possibil* OR daily)):ti,ab OR ((participation) NEAR/1 (life) NEAR/1 (role*)):ti,ab OR ((performan*) NEAR/1 (limit*)):ti,ab OR ((functional*) NEAR/1 (deficit*)):ti,ab OR ((attend*) NEAR/1 (school OR work)):ti,ab OR ((work*) NEAR/1 (capacit* OR resumption OR abilit*)):ti,ab OR ((self) NEAR/1 (management OR care)):ti,ab OR ((home) NEAR/1 (maintain* OR maintenance*)):ti,ab

6. [mh “surveys and questionnaires”][mj] OR [mh “outcome assessment”] [mj]

7. #4 AND #5 AND #6

8. #7 OR #3

Scopus 1823-March 2020
Date Searched: 2/24/19 ; 3/3/20
Applied Database Supplied Limits:
Number of Results: 472 ; 519

Full Search Strategy: 47 additional
TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*) OR TITL-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*))
AND
TITLE-ABS(((participation) W/2 (measure* OR instrument* OR survey* OR assessment*)) OR ((instrument*) W/1 (participation*)) OR ((participation*) W/2 (survey*)) OR ((activit*) W/2 (scale*)))

PSYCInfo 1887-March 2020
Date Searched: 2/21/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 192 ; 207
Full Search Strategy: 15 additional found
(De "neoplasms" or de "benign neoplasms" or de "breast neoplasms" or de "endocrine neoplasms" or de "leukemias" or de "melanoma" or de "metastasis" or de "nervous system neoplasms" or de "terminal cancer" or
ti cancer* or ti carcinoma* or ti neoplas* or ti leukemia* or ti hodgkin* or ti nonhodgkin* or ti lymphoma* or ti neuroblastoma* or ti sarcoma* or ti malignant* or ti oncolog* or ti metastatic* or ti melanoma* or ti tumourectom* or
ab cancer* or ab carcinoma* or ab neoplas* or ab leukemia* or ab hodgkin* or ab nonhodgkin* or ab lymphoma* or ab neuroblastoma* or ab sarcoma* or ab malignant* or ab oncolog* or ab metastatic* or ab melanoma* or ab tumourectom* or
su neoplasm* or su cancer* or su carcinoma* or su neoplas* or su leukemia* or su hodgkin* or su nonhodgkin* or su lymphoma* or su neuroblastoma* or su sarcoma* or su malignant* or su oncolog* or su metastatic* or su melanoma* or su tumourectom*)
and
((ti participation) n2 (measure* or instrument* or survey* or assessment*)) or
((ti instrument*) n1 (participation*)) or
((ti participation*) n2 (survey*)) or
((ti activit*) n2 (scale*)) or
((ab participation) n2 (measure* or instrument* or survey* or assessment*)) or
((ab instrument*) n1 (participation*)) or
((ab participation*) n2 (survey*)) or
((ab activit*) n2 (scale*)))
or
(de "neoplasms" or de "benign neoplasms" or de "breast neoplasms" or de "endocrine neoplasms" or de "leukemias" or de "melanoma" or de "metastasis" or de "nervous system neoplasms" or de "terminal cancer" or
ti cancer* or ti carcinoma* or ti neoplas* or ti leukemia* or ti hodgkin* or ti nonhodgkin* or ti lymphoma* or ti neuroblastoma* or ti sarcoma* or ti malignant* or ti oncolog* or ti metastatic* or ti melanoma* or ti tumourectom* or
ab cancer* or ab carcinoma* or ab neoplas* or ab leukemia* or ab hodgkin* or ab nonhodgkin* or ab lymphoma* or ab neuroblastoma* or ab sarcoma* or ab malignant* or ab oncolog* or ab metastatic* or ab melanoma* or ab tumourectom* or
su neoplasm* or su cancer* or su carcinoma* or su neoplas* or su leukemia* or su hodgkin* or su nonhodgkin* or su lymphoma* or su neuroblastoma* or su sarcoma* or su malignant* or su oncolog* or su metastatic* or su melanoma* or su tumourectom*)
and
(de "community involvement" or de "participation" or de "client participation" or
de "daily activities" or de "leisure time" or de "activities of daily living" or
ti leisure or ti shopping or ti hobby or ti hobbies or ti self-management or ti selfcare or ti selfmanagement or ti lifestyle* or ti housekeeping or ti housework or
ti “life habit” or ti “life habits” or ti “social life” or ti “life style” or ti “back to work” or
ti “return to work” or
AB Leisure OR AB Shopping OR AB hobby OR AB hobbies OR AB self-management OR AB selfcare OR AB self-management OR AB lifestyle* OR AB Housekeeping OR AB Housework OR AB “life habit” OR AB “life habits” OR AB “social life” OR AB “life style” OR AB “back to work” OR AB “return to work” OR ((TI community) N1 (integrat* OR reintegrat* OR participation OR involvement*)) OR ((TI patient*) N1 (participat* OR involve* OR activation OR engagement)) OR ((TI Public OR TI problem* OR TI social* OR TI accomplishment* OR TI restrict* OR TI general OR TI meaningful* OR TI routine* OR TI satisfaction* OR TI satisfied) N1 (participat*)) OR ((TI consumer*) N1 (participat* OR involvement*)) OR ((TI activit*) N2 (limit* OR meaningful* OR possibil* OR daily)) OR ((TI participation) N1 (life) N1 (role*)) OR ((TI performan*) N1 (limit*)) OR ((TI functional*) N1 (deficit*)) OR ((TI attend*) N1 (school OR work)) OR ((TI work*) N1 (capacit* OR resumption OR abilit*)) OR ((TI self) N1 (management OR care)) OR ((TI home) N1 (maintain* OR maintenance*)) OR ((AB community) N1 (integrat* OR reintegrat* OR participation OR involvement*)) OR ((AB patient*) N1 (participat* OR involve* OR activation OR engagement)) OR ((AB Public OR AB problem* OR AB social* OR AB accomplishment* OR AB restrict* OR AB general OR AB meaningful* OR AB routine* OR AB satisfaction* OR AB satisfied) N1 (participat*)) OR ((AB consumer*) N1 (participat* OR involvement*)) OR ((AB activit*) N2 (limit* OR meaningful* OR possibil* OR daily)) OR ((AB participation) N1 (life) N1 (role*)) OR ((AB performan*) N1 (limit*)) OR ((AB functional*) N1 (deficit*)) OR ((AB attend*) N1 (school OR work)) OR ((AB work*) N1 (capacit* OR resumption OR abilit*)) OR ((AB self) N1 (management OR care)) OR ((AB home) N1 (maintain* OR maintenance*))) AND (MM "Questionnaires" OR MM "Surveys") OR (TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom*) AND (((TM activit) N1 (scale*)) OR ((TM participation) N2 (measure* OR instrument* OR survey* OR assessment*)) OR ((TM instrument*) N1 (participation*))) OR
((TM participation*) N2 (survey*)) OR
((TM activit*) N2 (scale*)))

PSYCtests 1910-March 2020
Date Searched: 2/21/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 9 ; 15
Full Search Strategy: 6 additional found

(PO Cancer* OR PO carcinoma* OR PO Neoplas* OR PO Leukemia* OR PO Hodgkin* OR PO nonhodgkin* OR PO lymphoma* OR PO neuroblastoma* OR PO sarcoma* OR PO malignan* OR PO oncolog* OR PO metastatic* OR PO melanoma* OR PO tumourectom*)
AND
(((TX activit) N1 (scale*)) OR (((TX participation) N2 (measure* OR instrument* OR survey* OR assessment*))) OR (((TX instrument*) N1 (participation*)) OR (((TX participation*) N2 (survey*)) OR (((TX activit*) N2 (scale*))))

Search Strategies For:
(Specific named tools AND cancer)

OVID:
Date Searched: 2/22/19
Applied Database Supplied Limits: n/a
Number of Results: 238
Full Search Strategy:

Embase:
Date searched: 2/22/19
Applied database supplied limits: n/a
Number of results: 414

Full search strategy:
'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumorectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND ('australian community participation questionnaire' OR 'craig handicap assessment and reporting technique' OR 'community integration questionnaire' OR 'functioning assessment short test' OR 'F quick disabilities of the arm, shoulder and hand' OR 'Functional status questionnaire' OR 'Hearing handicap inventory for adults' OR 'hearing handicap questionnaire' OR 'health of the nation outcome scales' OR 'ICF measure of participation and activities questionnaire' OR 'independent living skills survey self-report' OR 'impact on participation and autonomy' OR 'impact of vision impairment profile' OR 'life functioning questionnaire' OR 'living with dysarthria mayo-Portland
adaptable inventory-4’ OR ‘Multidimensional scale of independent functioning’ OR ‘new handicap scale’ OR ‘oral health impact profile instrument of home and community participation’ OR ‘perceived impact of problem profile’ OR ‘participation measure for postacute care’ OR ‘participation objective participation subjective’ OR ‘quality of life scale-Swedish version’ OR ‘rating of perceived participation questionnaire’ OR ‘re-integration to normal living index’ OR ‘medical outcomes study short form 36-item health survey’ OR ‘social role participation questionnaire’ OR ‘Walking ability questionnaire’ OR ‘world health organization disability assessment schedule II’ OR ‘World health organization quality-of-life version for older people’ OR ‘activity participation questionnaire’ OR ‘Australian therapy outcome measure’ OR ‘brief cancer impact assessment’ OR ‘community integration measure’ OR ‘household and leisure time activities questionnaire’ OR ‘London handicap scale’ OR ‘assessment of life habits’ OR ‘leisure time satisfaction’ OR ‘participation scale’ OR ‘participation objective participation subjective’ OR ‘personal and social performance scale’ OR ‘role activity performance scale’ OR ‘role functioning scale’ OR ‘social role participation questionnaire’ OR ‘work and social adjustment scale’ OR ‘activity card sort’ OR ‘clients assessment of strengths, interests and goals’ OR ‘craig handicap assessment and reporting technique’ OR ‘community integration questionnaire’ OR ‘community participation indicators’ OR ‘Frenchay activities index’ OR ‘Guernsey Community participation and leisure assessment’ OR ‘independence living skills survey’ OR ‘index of community involvement’ OR ‘katz adjustment scale’ OR ‘Keele Assessment of participation’ OR ‘late-life function and disability instrument’ OR ‘Maastricht social participation profile’ OR ‘participation assessment with recombined tools – objective’ OR ‘Instrument of home and community participation’ OR ‘participation objective participation subjective’ OR ‘social functioning scale’ OR ‘activities scale for kids – performance version’ OR ‘assessment of life habits’ OR ‘assistance to participate scale’ OR ‘child and adolescent scale of participation’ OR ‘children helping out: Responsibilities, Expectations, and supports’ OR ‘children participation questionnaire’ OR ‘childrens assessment of participation and enjoyment/preferences for activities of children’ OR ‘childrens leisure assessment scale’ OR ‘participation and environment measure for children and youth’ OR ‘participation in activities of daily living’ OR ‘participation in childhood occupations questionnaire’ OR ‘pediatric activity card sort’ OR ‘pediatric community participation questionnaire’ OR ‘pediatric interest profile’ OR ‘preschool activity card sort’ OR ‘school function assessment – participation section’ OR ‘Long Term Follow Up Study Questionnaire’ OR ‘Short Form 36 Health Survey SF-36’ OR ‘Patient-Reported Outcomes Measurement Information System’)
ti,ab

Scopus:
Date Searched: 2/22/19
Applied Database Supplied Limits: n/a
Number of Results: 309
Full Search Strategy:
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OR “independence living skills survey” OR “index of community involvement” OR “katz adjustment scale” OR “Keele Assessment of participation” OR “late-life function and disability instrument” OR “Maastricht social participation profile” OR “Participation assessment with recombined tools – objective” OR “Instrument of home and community participation” OR “participation objective participation subjective” OR “social functioning scale” OR “activities scale for kids performance version” OR “assessment of life habits” OR “assistance to participate scale” OR “child and adolescent scale of participation” OR “children helping out Responsibilities, Expectations, and supports” OR “children participation questionnaire” OR “childrens assessment of participation and enjoyment/preferences for activities of children” OR “childrens leisure assessment scale” OR “participation and environment measure for children and youth” OR “participation in activities of daily living” OR “participation in childhood occupations questionnaire” OR “pediatric activity card sort” OR “pediatric community participation questionnaire” OR “pediatric interest profile” OR “preschool activity card sort” OR “school function assessment participation section” OR “australian community participation questionnaire” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “functioning assessment short test” OR “F quick disabilities of the arm, shoulder and hand” OR “Functional status questionnaire” OR “Hearing handicap inventory for adults” OR “hearing handicap questionnaire” OR “health of the nation outcome scales” OR “ICF measure of participation and activities questionnaire” OR “independent living skills survey self-report” OR “impact on participation and autonomy” OR “impact of vision impairment profile” OR “life functioning questionnaire” OR “living with dysarthria mayo-Portland adaptability inventory-4” OR “Multidimensional scale of independent functioning” OR “new handicap scale” OR “oral health impact profile instrument of home and community participation” OR “perceived impact of problem profile” OR “participation measure for postacute care” OR “participation objective participation subjective” OR “quality of life scale-Swedish version” OR “rating of perceived participation questionnaire” OR “re-integration to normal living index” OR “medical outcomes study short form 36-item health survey” OR “social role participation questionnaire” OR “Walking ability questionnaire” OR “world health organization disability assessment schedule II” OR “World health organization quality-of-life version for older people” OR “activity participation questionnaire” OR “Australian therapy outcome measure” OR “brief cancer impact assessment” OR “community integration measure” OR “household and leisure time activities questionnaire” OR “London handicap scale” OR “assessment of life habits” OR “leisure time satisfaction” OR “participation scale” OR “participation objective participation subjective” OR “personal and social performance scale” OR “role activity performance scale” OR “role functioning scale” OR “social role participation questionnaire” OR “work and social adjustment scale” OR “Long Term Follow Up Study Questionnaire” OR “Short Form 36 Health Survey SF-36” OR “Patient-Reported Outcomes Measurement Information System”
Cochrane:
Date Searched: 2/22/19
Applied Database Supplied Limits: n/a
Number of Results:
Full Search Strategy:
1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR
malignan* OR oncolg* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw OR ( (kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab

2. (“activities scale for kids performance version” OR “assessment of life habits” OR “assistance to participate scale” OR “child and adolescent scale of participation” OR “children helping out Responsibilities Expectations and supports” OR “children participation questionnaire” OR “children’s assessment of participation and enjoyment preferences for activities of children” OR “children’s leisure assessment scale” OR “participation and environment measure for children and youth” OR “participation in activities of daily living” OR “participation in childhood occupations questionnaire” OR “pediatric activity card sort” OR “pediatric community participation questionnaire” OR “pediatric interest profile” OR “preschool activity card sort” OR “school function assessment participation section”):ti,ab

3. (“activity card sort” OR “client’s assessment of strengths, interests and goals” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “community participation indicators” OR “Frenchay activities index” OR “Guernsey Community participation and leisure assessment” OR “independence living skills survey” OR “index of community involvement” OR “katz adjustment scale” OR “Keele Assessment of participation” OR “late-life function and disability instrument” OR “Maastricht social participation profile” OR “Participation assessment with recombined tools – objective” OR “Instrument of home and community participation” OR “participation objective participation subjective” OR “social functioning scale”):ti,ab

4. (“australian community participation questionnaire” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “functioning assessment short test” OR “F quick disabilities of the arm shoulder and hand” OR “Functional status questionnaire” OR “Hearing handicap inventory for adults” OR “hearing handicap questionnaire” OR “health of the nation outcome scales” OR “ICF measure of participation and activities questionnaire” OR “independent living skills survey self report” OR “impact on participation and autonomy” OR “impact of vision impairment profile” OR “life functioning questionnaire” OR “living with dysarthria mayo Portland adaptability inventory 4” OR “Multidimensional scale of independent functioning” OR “new handicap scale” OR “oral health impact profile instrument of home and community participation” OR “perceived impact of problem profile” OR “participation measure for postacute care” OR “participation objective participation subjective” OR “quality of life scale Swedish version” OR “rating of perceived participation questionnaire” OR “re integration to normal living index” OR “medical outcomes study short form 36 item health survey” OR “social role participation questionnaire” OR “Walking ability questionnaire” OR “world health organization disability assessment schedule II” OR “World health organization quality of life version for older people” OR “activity participation questionnaire” OR “Australian therapy outcome measure” OR “brief cancer impact assessment” OR “community integration measure” OR “household and leisure time activities questionnaire” OR “London handicap scale” OR “assessment of life habits” OR “leisure time satisfaction” OR “participation scale” OR “participation objective participation subjective” OR “personal and social performance scale” OR “role activity performance scale” OR “role functioning scale” OR “social role participation questionnaire” OR “work and social adjustment scale”):ti,ab
5. (“Long Term Follow Up Study Questionnaire”):ti,ab
6. (“Short Form 36 Health Survey SF-36”):ti,ab
7. (“Patient-Reported Outcomes Measurement Information System”):ti,ab
8. #2 OR #3 OR #4 OR #5 OR #6 OR #7
9. #8 AND #1

PsycINFO:
Date Searched: 2/22/19
Applied Database Supplied Limits: n/a
Number of Results: 115
Full Search Strategy:

(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignan* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)

AND
(TI “activity card sort” OR TI “client’s assessment of strengths, interests and goals” OR TI “craig handicap assessment and reporting technique” OR TI “community integration questionnaire” OR TI “community participation indicators” OR TI “Frenchay activities index” OR TI “Guernsey Community participation and leisure assessment” OR TI “independence living skills survey” OR TI “index of community involvement” OR TI “katz adjustment scale” OR TI “Keele Assessment of participation” OR TI “late-life function and disability instrument” OR TI “Maastricht social participation profile” OR TI “Participation assessment with recombined tools – objective” OR TI “Instrument of home and community participation” OR TI “participation objective participation subjective” OR TI “social functioning scale” OR AB “activity card sort” OR AB “client’s assessment of strengths, interests and goals” OR AB “craig handicap assessment and reporting technique” OR AB “community integration questionnaire” OR AB “community participation indicators” OR AB “Frenchay activities index” OR AB “Guernsey Community participation and leisure assessment” OR AB “independence living skills survey” OR AB “index of community involvement” OR AB “katz adjustment scale” OR AB “Keele Assessment of participation” OR AB “late-life function and disability instrument” OR AB “Maastricht social participation profile” OR AB “Participation assessment with recombined tools – objective” OR AB “Instrument of home and community participation” OR AB “participation objective participation subjective” OR AB “social functioning scale” OR
IN “activity card sort” OR IN “client’s assessment of strengths, interests and goals” OR IN “craig handicap assessment and reporting technique” OR IN “community integration questionnaire” OR IN “community participation indicators” OR IN “Frenchay activities index” OR IN “Guerney Community participation and leisure assessment” OR IN “independence living skills survey” OR IN “index of community involvement” OR IN “katz adjustment scale” OR IN “Keele Assessment of participation” OR IN “late-life function and disability instrument” OR IN “Maastricht social participation profile” OR IN “Participation assessment with recombined tools – objective” OR IN “Instrument of home and community participation” OR IN “participation objective participation subjective” OR IN “social functioning scale” OR TI “activities scale for kids – performance version” OR TI “assessment of life habits” OR TI “assistance to participate scale” OR TI “child and adolescent scale of participation” OR TI “children helping out: Responsibilities Expectations and supports” OR TI “children participation questionnaire” OR TI “children’s assessment of participation and enjoyment/preferences for activities of children” OR TI “children’s leisure assessment scale” OR TI “participation and environment measure for children and youth” OR TI “participation in activities of daily living” OR TI “participation in childhood occupations questionnaire” OR TI “pediatric activity card sort” OR TI “pediatric community participation questionnaire” OR TI “pediatric interest profile” OR TI “preschool activity card sort” OR TI “school function assessment participation section” OR AB “activities scale for kids performance version” OR AB “assessment of life habits” OR AB “assistance to participate scale” OR AB “child and adolescent scale of participation” OR AB “children helping out: Responsibilities Expectations and supports” OR AB “children participation questionnaire” OR AB “children’s assessment of participation and enjoyment/preferences for activities of children” OR AB “children’s leisure assessment scale” OR AB “participation and environment measure for children and youth” OR AB “participation in activities of daily living” OR AB “participation in childhood occupations questionnaire” OR AB “pediatric activity card sort” OR AB “pediatric community participation questionnaire” OR AB “pediatric interest profile” OR AB “preschool activity card sort” OR AB “school function assessment participation section” OR TM “activities scale for kids performance version” OR TM “assessment of life habits” OR TM “assistance to participate scale” OR TM “child and adolescent scale of participation” OR TM “children helping out: Responsibilities Expectations and supports” OR TM “children participation questionnaire” OR TM “children’s assessment of participation and enjoyment/preferences for activities of children” OR TM “children’s leisure assessment scale” OR TM “participation and environment measure for children and youth” OR TM “participation in activities of daily living” OR TM “participation in childhood occupations questionnaire” OR TM “pediatric activity card sort” OR TM “pediatric community participation questionnaire” OR TM “pediatric interest profile” OR TM “preschool activity card sort” OR TM “school function assessment participation section” OR TI “australian community participation questionnaire” OR TI “craig handicap assessment and reporting technique” OR TI “community integration questionnaire” OR TI “functioning assessment short test” OR TI “F quick disabilities of the arm shoulder and hand” OR TI “Functional status questionnaire” OR TI “Hearing handicap inventory for adults” OR TI “hearing handicap questionnaire” OR TI “health of the nation outcome scales” OR TI “ICF measure of participation and activities questionnaire” OR TI “independent living skills survey self report” OR TI “impact on participation and autonomy” OR TI “impact of
vision impairment profile” OR TI “life functioning questionnaire” OR TI “living with dysarthria mayo Portland adaptability inventory 4” OR TI “Multidimensional scale of independent functioning” OR TI “new handicap scale” OR TI “oral health impact profile instrument of home and community participation” OR TI “perceived impact of problem profile” OR “participation measure for postacute care” OR TI “participation objective participation subjective” OR TI “quality of life scale Swedish version” OR TI “rating of perceived participation questionnaire” OR TI “re integration to normal living index” OR TI “medical outcomes study short form 36 item health survey” OR TI “social role participation questionnaire” OR TI “Walking ability questionnaire” OR TI “world health organization disability assessment schedule II” OR TI “World health organization quality of life version for older people” OR TI “activity participation questionnaire” OR TI “Australian therapy outcome measure” OR TI “brief cancer impact assessment” OR TI “community integration measure” OR TI “household and leisure time activities questionnaire” OR TI “London handicap scale” OR TI “assessment of life habits” OR TI “leisure time satisfaction” OR TI “participation scale” OR TI “participation objective participation subjective” OR TI “personal and social performance scale” OR TI “role activity performance scale” OR TI “role functioning scale” OR TI “social role participation questionnaire” OR TI “work and social adjustment scale” OR TI “australian community participation questionnaire” OR AB “craig handicap assessment and reporting technique” OR AB “community integration questionnaire” OR AB “functioning assessment short test” OR AB “F quick disabilities of the arm shoulder and hand” OR AB “Functional status questionnaire” OR AB “Hearing handicap inventory for adults” OR AB “hearing handicap questionnaire” OR AB “health of the nation outcome scales” OR AB “ICF measure of participation and activities questionnaire” OR AB “independent living skills survey self report” OR AB “impact on participation and autonomy” OR AB “impact of vision impairment profile” OR AB “life functioning questionnaire” OR AB “living with dysarthria mayo Portland adaptability inventory 4” OR AB “Multidimensional scale of independent functioning” OR AB “new handicap scale” OR AB “oral health impact profile instrument of home and community participation” OR AB “perceived impact of problem profile” OR “participation measure for postacute care” OR AB “participation objective participation subjective” OR AB “quality of life scale Swedish version” OR AB “rating of perceived participation questionnaire” OR AB “re integration to normal living index” OR AB “medical outcomes study short form 36 item health survey” OR AB “social role participation questionnaire” OR AB “Walking ability questionnaire” OR AB “world health organization disability assessment schedule II” OR AB “World health organization quality of life version for older people” OR AB “activity participation questionnaire” OR AB “Australian therapy outcome measure” OR AB “brief cancer impact assessment” OR AB “community integration measure” OR AB “household and leisure time activities questionnaire” OR AB “London handicap scale” OR AB “assessment of life habits” OR AB “leisure time satisfaction” OR AB “participation scale” OR AB “participation objective participation subjective” OR AB “personal and social performance scale” OR AB “role activity performance scale” OR AB “role functioning scale” OR AB “social role participation questionnaire” OR AB “work and social adjustment scale” OR TI “australian community participation questionnaire” OR SU “craig handicap assessment and reporting technique” OR SU “community integration questionnaire” OR SU “functioning assessment short test” OR SU “F quick disabilities of the arm shoulder and hand” OR SU “Functional status questionnaire” OR SU “Hearing handicap inventory for adults” OR SU “hearing handicap questionnaire” OR SU “health of the nation outcome scales” OR SU “ICF
measure of participation and activities questionnaire” OR SU “independent living skills survey self report” OR SU “impact on participation and autonomy” OR SU “impact of vision impairment profile” OR SU “life functioning questionnaire” OR SU “living with dysarthria mayo Portland adaptability inventory 4” OR SU “Multidimensional scale of independent functioning” OR SU “new handicap scale” OR SU “oral health impact profile instrument of home and community participation” OR SU “perceived impact of problem profile” OR “participation measure for postacute care” OR SU “participation objective participation subjective” OR SU “quality of life scale Swedish version” OR SU “rating of perceived participation questionnaire” OR SU “re integration to normal living index” OR SU “medical outcomes study short form 36 item health survey” OR SU “social role participation questionnaire” OR SU “Walking ability questionnaire” OR SU “world health organization disability assessment schedule II” OR SU “World health organization quality of life version for older people” OR SU “activity participation questionnaire” OR SU “Australian therapy outcome measure” OR SU “brief cancer impact assessment” OR SU “community integration measure” OR SU “household and leisure time activities questionnaire” OR SU “London handicap scale” OR SU “assessment of life habits” OR SU “leisure time satisfaction” OR SU “participation scale” OR SU “participation objective participation subjective” OR SU “personal and social performance scale” OR SU “role activity performance scale” OR SU “role functioning scale” OR SU “social role participation questionnaire” OR SU “work and social adjustment scale” OR TI “Long Term Follow Up Study Questionnaire” OR AB “Long Term Follow Up Study Questionnaire” OR SU “Long Term Follow Up Study Questionnaire” OR TM “Long Term Follow Up Study Questionnaire” OR TI “Short Form 36 Health Survey SF-36” OR AB “Short Form 36 Health Survey SF-36” OR SU “Short Form 36 Health Survey SF-36” OR TM “Short Form 36 Health Survey SF-36” OR TI “Patient-Reported Outcomes Measurement Information System” OR AB “Patient-Reported Outcomes Measurement Information System” OR SU “Patient-Reported Outcomes Measurement Information System” OR TM “Patient-Reported Outcomes Measurement Information System”

a. mentioned in Chang

Ovid:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 24 ; 26
Full Search Strategy: 2 additional found

exp Neoplasms/ OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumouresectom*).ti,ab,hw OR ((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*)).ti,ab, AND ((activity card sort).ti,ab. OR (clients assessment of strengths interests and goals).ti,ab. OR (craig handicap assessment and reporting technique).ti,ab. OR (community integration questionnaire).ti,ab. OR (community participation indicators).ti,ab. OR (Frenchay activities index).ti,ab. OR (Guernsey Community participation and leisure assessment).ti,ab. OR (independence living skills survey).ti,ab. OR (index of community involvement).ti,ab. OR (katz adjustment scale).ti,ab. OR (Keele Assessment of participation).ti,ab. OR (late life function and disability instrument).ti,ab. OR (Maastricht social participation profile).ti,ab. OR (Participation assessment with recombined tools objective).ti,ab.
OR (Instrument of home and community participation).ti,ab. OR (participation objective participation subjective).ti,ab. OR (social functioning scale).ti,ab.)

Embase:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 45; 47
Full Search Strategy: 2 additional found

'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*)):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND (‘activity card sort’ OR ‘clients assessment of strengths, interests and goals’ OR ‘craig handicap assessment and reporting technique’ OR ‘community integration questionnaire’ OR ‘community participation indicators’ OR ‘Frenchay activities index’ OR ‘Guernsey Community participation and leisure assessment’ OR ‘independence living skills survey’ OR ‘index of community involvement’ OR ‘katz adjustment scale’ OR ‘Keele Assessment of participation’ OR ‘late-life function and disability instrument’ OR ‘Maastricht social participation profile’ OR ‘Participation assessment with recombined tools – objective’ OR ‘Instrument of home and community participation’ OR ‘participation objective participation subjective’ OR ‘social functioning scale’):ti,ab

Scopus:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 50 ; 54 additional found
Full Search Strategy: 4 additional found

(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*))))) AND TITLE-ABS(“activity card sort” OR “clients assessment of strengths, interests and goals” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “community participation indicators” OR “Frenchay activities index” OR “Guernsey Community participation and leisure assessment” OR “independence living skills survey” OR “index of community involvement” OR “katz adjustment scale” OR “Keele Assessment of participation” OR “late-life function and disability instrument” OR “Maastricht social participation profile” OR “Participation assessment with recombined tools – objective” OR “Instrument of home and community participation” OR “participation objective participation subjective” OR “social functioning scale”)

Cochrane:
Date Searched: 2/24/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 2 new
Cdsr: 1
TRIALS: 3 ; 5
10. [mh neoplasms"] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab

11. (“activity card sort” OR “client’s assessment of strengths, interests and goals” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “community participation indicators” OR “Frenchay activities index” OR “Guernsey Community participation and leisure assessment” OR “independence living skills survey” OR “index of community involvement” OR “katz adjustment scale” OR “Kelee Assessment of participation” OR “late-life function and disability instrument” OR “Maastricht social participation profile” OR “Participation assessment with recombined tools – objective” OR “Instrument of home and community participation” OR “participation objective participation subjective” OR “social functioning scale”):ti,ab

CINAHL:
(MH "Cancer Patients" OR MH "Neoplasms+") OR
TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR
AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR
MW neoplasm* OR MW Cancer* OR MW carcinoma* OR MW Neoplas* OR MW Leukemia* OR MW Hodgkin* OR MW nonhodgkin* OR MW lymphoma* OR MW neuroblastoma* OR MW sarcoma* OR MW malignan* OR MW oncolog* OR MW metastatic* OR MW melanoma* OR MW tumourectom*)

AND
(TI “activity card sort” OR TI “client’s assessment of strengths, interests and goals” OR TI “craig handicap assessment and reporting technique” OR TI “community integration questionnaire” OR TI “community participation indicators” OR TI “Frenchay activities index” OR TI “Guernsey Community participation and leisure assessment” OR TI “independence living skills survey” OR TI “index of community involvement” OR TI “katz adjustment scale” OR TI “Kelee Assessment of participation” OR TI “late-life function and disability instrument” OR TI “Maastricht social participation profile” OR TI “Participation assessment with recombined tools – objective” OR TI “Instrument of home and community participation” OR TI “participation objective participation subjective” OR TI “social functioning scale” OR
AB “activity card sort” OR AB “client’s assessment of strengths, interests and goals” OR AB “craig handicap assessment and reporting technique” OR AB “community integration questionnaire” OR AB “community participation indicators” OR AB “Frenchay activities index” OR AB “Guernsey Community participation and leisure assessment” OR AB “independence living skills survey” OR AB “index of community involvement” OR AB “katz adjustment scale” OR AB “Kelee Assessment of participation” OR AB “late-life function and disability instrument” OR AB “Maastricht social participation profile” OR AB “Participation assessment with recombined tools – objective” OR AB “Instrument of home and community participation” OR AB “participation objective participation subjective” OR AB “social functioning scale” OR

[160]
IN “activity card sort” OR IN “client’s assessment of strengths, interests and goals” OR IN “craig handicap assessment and reporting technique” OR IN “community integration questionnaire” OR IN “community participation indicators” OR IN “Frenchay activities index” OR IN “Guernsey Community participation and leisure assessment” OR IN “independence living skills survey” OR IN “index of community involvement” OR IN “katz adjustment scale” OR IN “Keele Assessment of participation” OR IN “late-life function and disability instrument” OR IN “Maastricht social participation profile” OR IN “Participation assessment with recombined tools – objective” OR IN “Instrument of home and community participation” OR IN “participation objective participation subjective” OR IN “social functioning scale”)

PSYCinfo:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 9 ; 9
Full Search Strategy: no new found

(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR
TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR
AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR
SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignan* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)
AND
(TI “activity card sort” OR TI “client’s assessment of strengths, interests and goals” OR TI “craig handicap assessment and reporting technique” OR TI “community integration questionnaire” OR TI “community participation indicators” OR TI “Frenchay activities index” OR TI “Guernsey Community participation and leisure assessment” OR TI “independence living skills survey” OR TI “index of community involvement” OR TI “katz adjustment scale” OR TI “Keele Assessment of participation” OR TI “late-life function and disability instrument” OR TI “Maastricht social participation profile” OR TI “Participation assessment with recombined tools – objective” OR TI “Instrument of home and community participation” OR TI “participation objective participation subjective” OR TI “social functioning scale” OR
AB “activity card sort” OR AB “client’s assessment of strengths, interests and goals” OR AB “craig handicap assessment and reporting technique” OR AB “community integration questionnaire” OR AB “community participation indicators” OR AB “Frenchay activities index” OR AB “Guernsey Community participation and leisure assessment” OR AB “independence living skills survey” OR AB “index of community involvement” OR AB “katz adjustment scale” OR AB “Keele Assessment of participation” OR AB “late-life function and disability
b. mentioned in Chien

Ovid:
Date Searched: 2/22/19 ; 3/3/20
Number of Results: 5
Full Search Strategy: no additional found
Scopus:
Date Searched: 2/22/19 ; 3/3/20
Number of Results: 7
Full Search Strategy: 1 additional found
(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*)) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*))) AND TITLE-ABS(“activities scale for kids performance version” OR “assessment of life habits” OR “assistance to participate scale” OR “child and adolescent scale of participation” OR “children helping out Responsibilities, Expectations, and supports” OR “children participation questionnaire” OR “childrens assessment of participation and enjoyment/preferences for activities of children” OR “childrens leisure assessment scale” OR “participation and environment measure for children and youth” OR “participation in activities of daily living” OR “participation in childhood occupations questionnaire” OR
“pediatric activity card sort” OR “pediatric community participation questionnaire” OR “pediatric interest profile” OR “preschool activity card sort” OR “school function assessment participation section”)

Cochrane:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results:
cdsr: 1
TRIALS: 3
Full Search Strategy: 3 additional found

1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab

2. (“activities scale for kids performance version” OR “assessment of life habits” OR “assistance to participate scale” OR “child and adolescent scale of participation” OR “children helping out Responsibilities Expectations and supports” OR “children participation questionnaire” OR “children’s assessment of participation and enjoyment preferences for activities of children” OR “children’s leisure assessment scale” OR “participation and environment measure for children and youth” OR “participation in activities of daily living” OR “participation in childhood occupations questionnaire” OR “pediatric activity card sort” OR “pediatric community participation questionnaire” OR “pediatric interest profile” OR “preschool activity card sort” OR “school function assessment participation section”):ti,ab

3. #1 AND #2

Embase:
Date Searched: 2/22/19 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 10 ; 10
Full Search Strategy: no new found

'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND (‘activities scale for kids – performance version’ OR ‘assessment of life habits’ OR ‘assistance to participate scale’ OR ‘child and adolescent scale of participation’ OR ‘children helping out: Responsibilities, Expectations, and supports’ OR ‘children participation questionnaire’ OR ‘childrens assessment of participation and enjoyment/preferences for activities of children’ OR ‘childrens leisure assessment scale’ OR ‘participation and environment measure for children and youth’ OR ‘participation in activities of daily living’ OR ‘participation in childhood occupations questionnaire’ OR ‘pediatric activity card sort’ OR ‘pediatric community participation questionnaire’ OR ‘pediatric interest profile’ OR ‘preschool activity card sort’ OR ‘school function assessment – participation section’):ti,ab

[163]
Cinahl:
TI “activities scale for kids – performance version” OR TI “assessment of life habits” OR TI “assistance to participate scale” OR TI “child and adolescent scale of participation” OR TI “children helping out: Responsibilities, Expectations, and supports” OR TI “children participation questionnaire” OR TI “children’s assessment of participation and enjoyment/preferences for activities of children” OR TI “children’s leisure assessment scale” OR TI “participation and environment measure for children and youth” OR TI “participation in activities of daily living” OR TI “participation in childhood occupations questionnaire” OR TI “pediatric activity card sort” OR TI “pediatric community participation questionnaire” OR TI “pediatric interest profile” OR TI “preschool activity card sort” OR TI “school function assessment – participation section” OR
AB “activities scale for kids – performance version” OR AB “assessment of life habits” OR AB “assistance to participate scale” OR AB “child and adolescent scale of participation” OR AB “children helping out: Responsibilities, Expectations, and supports” OR AB “children participation questionnaire” OR AB “children’s assessment of participation and enjoyment/preferences for activities of children” OR AB “children’s leisure assessment scale” OR AB “participation and environment measure for children and youth” OR AB “participation in activities of daily living” OR AB “participation in childhood occupations questionnaire” OR AB “pediatric activity card sort” OR AB “pediatric community participation questionnaire” OR AB “pediatric interest profile” OR AB “preschool activity card sort” OR AB “school function assessment – participation section” OR
IN “activities scale for kids – performance version” OR IN “assessment of life habits” OR IN “assistance to participate scale” OR IN “child and adolescent scale of participation” OR IN “children helping out: Responsibilities, Expectations, and supports” OR IN “children participation questionnaire” OR IN “children’s assessment of participation and enjoyment/preferences for activities of children” OR IN “children’s leisure assessment scale” OR IN “participation and environment measure for children and youth” OR IN “participation in activities of daily living” OR IN “participation in childhood occupations questionnaire” OR IN “pediatric activity card sort” OR IN “pediatric community participation questionnaire” OR IN “pediatric interest profile” OR IN “preschool activity card sort” OR IN “school function assessment – participation section”
PSYCH INFO chien
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0 ; 0
Full Search Strategy: nothing found

(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR
TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR
AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR

[164]
SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignant* OR SU oncolo* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)

AND

(TI “activities scale for kids performance version” OR TI “assessment of life habits” OR TI “assistance to participate scale” OR TI “child and adolescent scale of participation” OR TI “children helping out: Responsibilities Expectations and supports” OR TI “children participation questionnaire” OR TI “children’s assessment of participation and enjoyment/preferences for activities of children” OR TI “children’s leisure assessment scale” OR TI “participation and environment measure for children and youth” OR TI “participation in activities of daily living” OR TI “participation in childhood occupations questionnaire” OR TI “pediatric activity card sort” OR TI “pediatric community participation questionnaire” OR TI “pediatric interest profile” OR TI “preschool activity card sort” OR TI “school function assessment participation section” OR

AB “activities scale for kids performance version” OR AB “assessment of life habits” OR AB “assistance to participate scale” OR AB “child and adolescent scale of participation” OR AB “children helping out: Responsibilities Expectations and supports” OR AB “children participation questionnaire” OR AB “children’s assessment of participation and enjoyment/preferences for activities of children” OR AB “children’s leisure assessment scale” OR AB “participation and environment measure for children and youth” OR AB “participation in activities of daily living” OR AB “participation in childhood occupations questionnaire” OR AB “pediatric activity card sort” OR AB “pediatric community participation questionnaire” OR AB “pediatric interest profile” OR AB “preschool activity card sort” OR AB “school function assessment participation section” OR

TM “activities scale for kids performance version” OR TM “assessment of life habits” OR TM “assistance to participate scale” OR TM “child and adolescent scale of participation” OR TM “children helping out: Responsibilities Expectations and supports” OR TM “children participation questionnaire” OR TM “children’s assessment of participation and enjoyment/preferences for activities of children” OR TM “children’s leisure assessment scale” OR TM “participation and environment measure for children and youth” OR TM “participation in activities of daily living” OR TM “participation in childhood occupations questionnaire” OR TM “pediatric activity card sort” OR TM “pediatric community participation questionnaire” OR TM “pediatric interest profile” OR TM “preschool activity card sort” OR TM “school function assessment participation section”

)**c. mentioned in Eyssen**

Embase:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 73 ; 76
Full Search Strategy: 3 additional found
'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolo* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND (*australian community participation
questionnaire” OR ‘craig handicap assessment and reporting technique” OR ‘community integration questionnaire’ OR ‘functioning assessment short test’ OR ‘F quick disabilities of the arm, shoulder and hand’ OR ‘Functional status questionnaire’ OR ‘Hearing handicap inventory for adults’ OR ‘hearing handicap questionnaire’ OR ‘health of the nation outcome scales’ OR ‘ICF measure of participation and activities questionnaire’ OR ‘independent living skills survey self-report’ OR ‘impact on participation and autonomy’ OR ‘impact of vision impairment profile’ OR ‘life functioning questionnaire’ OR ‘living with dysarthria mayo-Portland adaptability inventory-4’ OR ‘Multidimensional scale of independent functioning’ OR ‘new handicap scale’ OR ‘oral health impact profile instrument of home and community participation’ OR ‘perceived impact of problem profile’ OR ‘participation measure for postacute care’ OR ‘participation objective participation subjective’ OR ‘quality of life scale-Swedish version’ OR ‘rating of perceived participation questionnaire’ OR ‘re-integration to normal living index’ OR ‘medical outcomes study short form 36-item health survey’ OR ‘social role participation questionnaire’ OR ‘Walking ability questionnaire’ OR ‘world health organization disability assessment schedule II’ OR ‘World health organization quality-of-life version for older people’ OR ‘activity participation questionnaire’ OR ‘Australian therapy outcome measure’ OR ‘brief cancer impact assessment’ OR ‘community integration measure’ OR ‘household and leisure time activities questionnaire’ OR ‘London handicap scale’ OR ‘assessment of life habits’ OR ‘leisure time satisfaction’ OR ‘participation scale’ OR ‘participation objective participation subjective’ OR ‘personal and social performance scale’ OR ‘role activity performance scale’ OR ‘role functioning scale’ OR ‘social role participation questionnaire’ OR “work and social adjustment scale”):ti,ab

Scopus:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 67 ; 71
Full Search Strategy: 4 additional
(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*)) AND TITLE-ABS(“australian community participation questionnaire” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “functioning assessment short test” OR “F quick disabilities of the arm, shoulder and hand” OR “Functional status questionnaire” OR “Hearing handicap inventory for adults” OR “hearing handicap questionnaire” OR “health of the nation outcome scales” OR “ICF measure of participation and activities questionnaire” OR “independent living skills survey self-report” OR “impact on participation and autonomy” OR “impact of vision impairment profile” OR “life functioning questionnaire” OR “living with dysarthria mayo-Portland adaptability inventory-4” OR “Multidimensional scale of independent functioning” OR “new handicap scale” OR “oral health impact profile instrument of home and community participation” OR “perceived impact of problem profile” OR “participation measure for postacute care” OR “participation objective participation subjective” OR “quality of life scale-Swedish version” OR “rating of perceived participation questionnaire” OR “re-integration to normal living index” OR “medical outcomes study short form 36-item health survey” OR “social role participation questionnaire” OR “Walking ability questionnaire” OR “world health organization disability assessment schedule II” OR “World health organization quality-of-life version for older people” OR “activity participation questionnaire” OR “Australian therapy outcome measure”).
version for older people” OR “activity participation questionnaire” OR “Australian therapy outcome measure” OR “brief cancer impact assessment” OR “community integration measure” OR “household and leisure time activities questionnaire” OR “London handicap scale” OR “assessment of life habits” OR “leisure time satisfaction” OR “participation scale” OR “participation objective participation subjective” OR “personal and social performance scale” OR “role activity performance scale” OR “role functioning scale” OR “social role participation questionnaire” OR “work and social adjustment scale”)

Ovid:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 43 ; 45
Full Search Strategy: 2 additional found

Cochrane:
Date Searched:2/24/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results:
CDSR: 2 ; 2

[167]
Trials: 9 ; 18

Full Search Strategy: 9 additional found in TRIALS

1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab

2. (“australian community participation questionnaire” OR “craig handicap assessment and reporting technique” OR “community integration questionnaire” OR “functioning assessment short test” OR “F quick disabilities of the arm shoulder and hand” OR “Functional status questionnaire” OR “Hearing handicap inventory for adults” OR “hearing handicap questionnaire” OR “health of the nation outcome scales” OR “ICF measure of participation and activities questionnaire” OR “independent living skills survey self report” OR “impact on participation and autonomy” OR “impact of vision impairment profile” OR “life functioning questionnaire” OR “living with dysarthria mayo Portland adaptability inventory 4” OR “Multidimensional scale of independent functioning” OR “new handicap scale” OR “oral health impact profile instrument of home and community participation” OR “perceived impact of problem profile” OR “participation measure for postacute care” OR “participation objective participation subjective” OR “quality of life scale Swedish version” OR “rating of perceived participation questionnaire” OR “re integration to normal living index” OR “medical outcomes study short form 36 item health survey” OR “social role participation questionnaire” OR “Walking ability questionnaire” OR “world health organization disability assessment schedule II” OR “World health organization quality of life version for older people” OR “activity participation questionnaire” OR “Australian therapy outcome measure” OR “brief cancer impact assessment” OR “community integration measure” OR “household and leisure time activities questionnaire” OR “London handicap scale” OR “assessment of life habits” OR “leisure time satisfaction” OR “participation scale” OR “participation objective participation subjective” OR “personal and social performance scale” OR “role activity performance scale” OR “role functioning scale” OR “social role participation questionnaire” OR “work and social adjustment scale”):ti,ab

3. #1 AND #2

PsycINFO:
Date Searched: 2/24/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 9 ; 9

Full Search Strategy: nothing new retrieved
(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR [168]
AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignan* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)

AND

(TI “australian community participation questionnaire” OR TI “craig handicap assessment and reporting technique” OR TI “community integration questionnaire” OR TI “functioning assessment short test” OR TI “F quick disabilities of the arm shoulder and hand” OR TI “Functional status questionnaire” OR TI “Hearing handicap inventory for adults” OR TI “hearing handicap questionnaire” OR TI “health of the nation outcome scales” OR TI “ICF measure of participation and activities questionnaire” OR TI “independent living skills survey self report” OR TI “impact on participation and autonomy” OR TI “impact of vision impairment profile” OR TI “life functioning questionnaire” OR TI “living with dysarthria mayo Portland adaptability inventory 4” OR TI “Multidimensional scale of independent functioning” OR TI “new handicap scale” OR TI “oral health impact profile instrument of home and community participation” OR TI “perceived impact of problem profile” OR “participation measure for postacute care” OR TI “participation objective participation subjective” OR TI “quality of life scale Swedish version” OR TI “rating of perceived participation questionnaire” OR TI “re integration to normal living index” OR TI “medical outcomes study short form 36 item health survey” OR TI “social role participation questionnaire” OR TI “Walking ability questionnaire” OR TI “world health organization disability assessment schedule II” OR TI “World health organization quality of life version for older people” OR TI “activity participation questionnaire” OR TI “Australian therapy outcome measure” OR TI “brief cancer impact assessment” OR TI “community integration measure” OR TI “household and leisure time activities questionnaire” OR TI “London handicap scale” OR TI “assessment of life habits” OR TI “leisure time satisfaction” OR TI “participation scale” OR TI “participation objective participation subjective” OR TI “personal and social performance scale” OR TI “role activity performance scale” OR TI “role functioning scale” OR TI “social role participation questionnaire” OR TI “work and social adjustment scale” OR TI “australian community participation questionnaire” OR AB “craig handicap assessment and reporting technique” OR AB “community integration questionnaire” OR AB “functioning assessment short test” OR AB “F quick disabilities of the arm shoulder and hand” OR AB “Functional status questionnaire” OR AB “Hearing handicap inventory for adults” OR AB “hearing handicap questionnaire” OR AB “health of the nation outcome scales” OR AB “ICF measure of participation and activities questionnaire” OR AB “independent living skills survey self report” OR AB “impact on participation and autonomy” OR AB “impact of vision impairment profile” OR AB “life functioning questionnaire” OR AB “living with dysarthria mayo Portland adaptability inventory 4” OR AB “Multidimensional scale of independent functioning” OR AB “new handicap scale” OR AB “oral health impact profile instrument of home and community participation” OR AB “perceived impact of problem profile” OR “participation measure for postacute care” OR AB “participation objective participation subjective” OR AB “quality of life scale Swedish version” OR AB “rating of perceived participation questionnaire” OR AB “re integration to normal living index” OR AB “medical
outcomes study short form 36 item health survey” OR AB “social role participation questionnaire” OR AB “Walking ability questionnaire” OR AB “world health organization disability assessment schedule II” OR AB “World health organization quality of life version for older people” OR AB “activity participation questionnaire” OR AB “Australian therapy outcome measure” OR AB “brief cancer impact assessment” OR AB “community integration measure” OR AB “household and leisure time activities questionnaire” OR AB “London handicap scale” OR AB “assessment of life habits” OR AB “leisure time satisfaction” OR AB “participation scale” OR AB “participation objective participation subjective” OR AB “personal and social performance scale” OR AB “role activity performance scale” OR AB “role functioning scale” OR AB “social role participation questionnaire” OR AB “work and social adjustment scale” OR TI “australian community participation questionnaire” OR SU “craig handicap assessment and reporting technique” OR SU “community integration questionnaire” OR SU “functioning assessment short test” OR SU “F quick disabilities of the arm shoulder and hand” OR SU “Functional status questionnaire” OR SU “Hearing handicap inventory for adults” OR SU “hearing handicap questionnaire” OR SU “health of the nation outcome scales” OR SU “ICF measure of participation and activities questionnaire” OR SU “independent living skills survey self report” OR SU “impact on participation and autonomy” OR SU “impact of vision impairment profile” OR SU “life functioning questionnaire” OR SU “living with dysarthria mayo Portland adaptability inventory 4” OR SU “Multidimensional scale of independent functioning” OR SU “new handicap scale” OR SU “oral health impact profile instrument of home and community participation” OR SU “perceived impact of problem profile” OR “participation measure for postacute care” OR SU “participation objective participation subjective” OR SU “quality of life scale Swedish version” OR SU “rating of perceived participation questionnaire” OR SU “re integration to normal living index” OR SU “medical outcomes study short form 36 item health survey” OR SU “social role participation questionnaire” OR SU “Walking ability questionnaire” OR SU “world health organization disability assessment schedule II” OR SU “World health organization quality of life version for older people” OR SU “activity participation questionnaire” OR SU “Australian therapy outcome measure” OR SU “brief cancer impact assessment” OR SU “community integration measure” OR SU “household and leisure time activities questionnaire” OR SU “London handicap scale” OR SU “assessment of life habits” OR SU “leisure time satisfaction” OR SU “participation scale” OR SU “participation objective participation subjective” OR SU “personal and social performance scale” OR SU “role activity performance scale” OR SU “role functioning scale” OR SU “social role participation questionnaire” OR SU “work and social adjustment scale”)

d. mentioned in Ness “Limitations on…”
“Long Term Follow Up Study Questionnaire”
OVID:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0 ; 0
Full Search Strategy:
exp Neoplasms/ OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog*)
OR metastatic* OR melanoma* OR tumouresectom*).ti,ab,hw OR ((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*)).ti,ab. AND (Long Term Follow Up Study Questionnaire).ti,ab

Embase:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0
Full Search Strategy: nothing new found

'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumouresectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND (’Long Term Follow Up Study Questionnaire’):ti,ab

Scopus:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0 ; 0
Full Search Strategy: no additional found

(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumouresectom*) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*)) AND TITLE-ABS(“Long Term Follow Up Study Questionnaire”)

Cochrane:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0 ; 0
Full Search Strategy: no additional found

1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumouresectom*):ti,ab,kw OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab
2. (“Long Term Follow Up Study Questionnaire”):ti,ab
3. #1 AND #2

PsycINFO:
Date Searched: 2/22/19 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 0 ; 0
Full Search Strategy: nothing retrieved

(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR
TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI non Hodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignant* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB non Hodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignant* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU non Hodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignant* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)
AND
(TI “Long Term Follow Up Study Questionnaire” OR AB “Long Term Follow Up Study Questionnaire” OR SU “Long Term Follow Up Study Questionnaire” OR TM “Long Term Follow Up Study Questionnaire”)

e. mentioned in Ness “Physical performance”
“Short Form-36 Health Survey (SF-36)”
OVID:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 50 ; 55
Full Search Strategy: 5 additional found
exp Neoplasms/ OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR non Hodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*).ti,ab,hw OR ((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*)).ti,ab. AND (Short Form 36 Health Survey SF 36).ti,ab
Embase:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 84; 91
Full Search Strategy: 7 additional found
'neoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR non Hodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab AND (’Short Form 36 Health Survey SF-36’):ti,ab
Scopus:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 52 ; 56
Full Search Strategy: 4 additional found
(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR non Hodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignant* OR oncolog*
OR metastatic* OR melanoma* OR tumourectom*) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*)) AND TITLE-ABS("Short Form 36 Health Survey SF-36")

Cochrane:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 8 ; 14
Full Search Strategy: 6 additional found

1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw
   OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab
2. ("Short Form 36 Health Survey SF-36"):ti,ab
3. #1 AND #2

PsycINFO:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 5 ; 6
Full Search Strategy: 1 additional found

(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer"
OR TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignan* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)
AND
(TI “Short Form 36 Health Survey SF-36” OR AB “Short Form 36 Health Survey SF-36” OR SU “Short Form 36 Health Survey SF-36” OR TM “Short Form 36 Health Survey SF-36”)

f. mentioned in Promis
“Patient-Reported Outcomes Measurement Information System”
OVID:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 121 ; 170
Full Search Strategy: 49 additional found

[173]
exp Neoplasms/ OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*).ti,ab,hw OR ((kidney* OR bone* OR acral) ADJ1 (tumor* OR tumour*)).ti,ab. AND (Patient Reported Outcomes Measurement Information System).ti,ab.

Embase:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 217 ; 280
Full Search Strategy: 63 new

'Seoplasm'/exp OR 'cancer patient'/exp OR 'cancer diagnosis'/exp OR ‘cancer surgery’/exp OR ‘cancer therapy’/exp OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,de OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab
AND (‘Patient-Reported Outcomes Measurement Information System’):ti,ab

Scopus:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 143 ; 189
Full Search Strategy: 46 additional found

(TITLE-ABS-KEY(Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*)) OR TITLE-ABS((kidney* OR bone* OR acral) W/1 (tumor* OR tumour*)) AND TITLE-ABS(“Patient-Reported Outcomes Measurement Information System”)

Cochrane:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results:
Trials: 26 ; 61
Full Search Strategy: 35 additional

1. [mh neoplasms”] OR (Cancer* OR carcinoma* OR Neoplas* OR Leukemia* OR Hodgkin* OR nonhodgkin* OR lymphoma* OR neuroblastoma* OR sarcoma* OR malignan* OR oncolog* OR metastatic* OR melanoma* OR tumourectom*):ti,ab,kw OR ((kidney* OR bone* OR acral) NEAR/1 (tumor* OR tumour*)):ti,ab
2. (“Patient-Reported Outcomes Measurement Information System”):ti,ab
3. #1 AND #2

PsycINFO:
Date Searched: 2/22/19 ; 3/3/20
Applied Database Supplied Limits: n/a
Number of Results: 93; 110
Full Search Strategy: 17 new
(DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR TI Cancer* OR TI carcinoma* OR TI Neoplas* OR TI Leukemia* OR TI Hodgkin* OR TI nonhodgkin* OR TI lymphoma* OR TI neuroblastoma* OR TI sarcoma* OR TI malignan* OR TI oncolog* OR TI metastatic* OR TI melanoma* OR TI tumourectom* OR AB Cancer* OR AB carcinoma* OR AB Neoplas* OR AB Leukemia* OR AB Hodgkin* OR AB nonhodgkin* OR AB lymphoma* OR AB neuroblastoma* OR AB sarcoma* OR AB malignan* OR AB oncolog* OR AB metastatic* OR AB melanoma* OR AB tumourectom* OR SU neoplasm* OR SU Cancer* OR SU carcinoma* OR SU Neoplas* OR SU Leukemia* OR SU Hodgkin* OR SU nonhodgkin* OR SU lymphoma* OR SU neuroblastoma* OR SU sarcoma* OR SU malignan* OR SU oncolog* OR SU metastatic* OR SU melanoma* OR SU tumourectom*)

AND

Appendix B: Online Resource 2. Summary of Studies Included in Scoping Review

<table>
<thead>
<tr>
<th>First Author</th>
<th>Title</th>
<th>Year</th>
<th>n</th>
<th>Age in Years</th>
<th>Assessment Used to Measure Participation</th>
</tr>
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<tr>
<td>Berg 119</td>
<td>Late effects of childhood cancer, participation, and quality of life of adolescents</td>
<td>2009</td>
<td>25</td>
<td>14 (2.2; 10-17)</td>
<td>AACS</td>
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<tr>
<td>Davidge 106</td>
<td>Function and health status outcomes following soft tissue reconstruction for limb preservation in extremity soft tissue sarcoma</td>
<td>2010</td>
<td>247</td>
<td>Flap reconstruction: 58.2 (16.7)</td>
<td>RNL</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Primary closure: 54.0 (16.9)</td>
<td></td>
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<tr>
<td>Devoogdt 131</td>
<td>Lymphoedema Functioning, Disability and Health questionnaire (Lymph-ICF):</td>
<td>2011</td>
<td>90</td>
<td>59.8 (8.2; 42-79)</td>
<td>Lymph-ICF</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Year</td>
<td>N</td>
<td>Mean (SD) or Median (Range)</td>
<td>Scale</td>
</tr>
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</tr>
<tr>
<td>Eadie</td>
<td>Communicative participation and quality of life in head and neck cancer</td>
<td>2014</td>
<td>195</td>
<td>61.3 (12.3; 24-86)</td>
<td>CPIB of PROMIS</td>
</tr>
<tr>
<td>Fitzpatrick</td>
<td>Leisure, household activities, and health among Mexican American elders with cancer</td>
<td>2011</td>
<td>169</td>
<td>73; all 65+</td>
<td>PASE</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Year</td>
<td>Participants</td>
<td>Outcome Measure</td>
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<tr>
<td>Fleischer</td>
<td>The experience of breast cancer survivors’ participation in important activities during and after treatments</td>
<td>2017</td>
<td>8</td>
<td>41-60</td>
<td>ACSm</td>
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<tr>
<td>Fujii</td>
<td>Relationship between exercise habits and social activities of patients with gastrointestinal cancers after discharge from hospital</td>
<td>2014</td>
<td>53</td>
<td>70.9 (7.1)</td>
<td>CIQ</td>
</tr>
<tr>
<td>Hahn</td>
<td>Measuring social function in diverse cancer populations: Evaluation of measurement equivalence of the Patient Reported Outcomes Measurement Information System (PROMIS) Ability to Participate in Social Roles and Activities short form</td>
<td>2016</td>
<td>&gt;5000</td>
<td>Unclear; stated 40% &gt;65</td>
<td>PROMIS social function short form</td>
</tr>
<tr>
<td>Study Reference</td>
<td>Title</td>
<td>Year</td>
<td>Sample Size</td>
<td>Mean (SD; Min-Max)</td>
<td>Measure</td>
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<tr>
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<tr>
<td>Henry 138</td>
<td>Pilot Study of an Internet-Based Self-Management Program for Symptom Control in Patients with Early-Stage Breast Cancer</td>
<td>2018</td>
<td>50</td>
<td>58</td>
<td>PROMIS-29 profile</td>
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<tr>
<td>Kaplan 158</td>
<td>Community Integration Questionnaire for patients with brain tumor: a comparative study</td>
<td>2000</td>
<td>33</td>
<td>46.3(10.7; 18-70)</td>
<td>CIQ</td>
</tr>
<tr>
<td>Kaya 125</td>
<td>Evaluating the World Health Organization’s International Classification of Functioning, Disability and Health Framework as a Participation Model for Cancer Survivors in Turkey</td>
<td>2018</td>
<td>192</td>
<td>45.82 (11.46; 18-65)</td>
<td>IPA</td>
</tr>
<tr>
<td>Khan(^{134})</td>
<td>Multidisciplinary rehabilitation in women following breast cancer treatment: a randomized controlled trial</td>
<td>2012</td>
<td>85</td>
<td>33-80</td>
<td>PIPP</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Khan(^{135})</td>
<td>Effectiveness of integrated multidisciplinary rehabilitation in primary brain cancer survivors in an Australian community cohort: a controlled clinical trial</td>
<td>2014</td>
<td>106</td>
<td>Intervention: 53.1 (13.3; 21-77) Control: 49.6 (13.8; 28-74)</td>
<td>PIPP</td>
</tr>
<tr>
<td>Kopec(^{147})</td>
<td>Relationship between arm morbidity and patient-reported outcomes following surgery in women with node-negative breast cancer: NSABP protocol B-32</td>
<td>2013</td>
<td>744</td>
<td>78% 50+</td>
<td>DASH</td>
</tr>
</tbody>
</table>

[180]
<table>
<thead>
<tr>
<th>Lee (^{144})</th>
<th>Accuracy of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) score as an objective assessment tool for predicting return-to-work status after head and neck cancer in male survivors</th>
<th>2019</th>
<th>1206</th>
<th>44 (4.68)</th>
<th>WHODAS 2.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letellier (^{145})</td>
<td>Assessment of breast cancer disability: agreement between expert assessment and patient reports</td>
<td>2017</td>
<td>245</td>
<td>56.8 (10.6; 29-86)</td>
<td>WHODAS 2.0</td>
</tr>
<tr>
<td>Liu (^{153})</td>
<td>Correlation between functional status and quality of life after surgery in patients with primary malignant bone tumor of the lower</td>
<td>2014</td>
<td>94</td>
<td>22.84 (9.73)</td>
<td>RNL</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Year</td>
<td>Sample Size</td>
<td>Mean (SD)</td>
<td>Measure</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------------------------------------------------------</td>
<td>------</td>
<td>-------------</td>
<td>-----------</td>
<td>------------</td>
</tr>
<tr>
<td>Loh</td>
<td>The role of occupational-participation, meaningful-activity and quality-of-life of colorectal cancer survivors: findings from path-modelling</td>
<td>2020</td>
<td>113</td>
<td>64.7 (10.4; 18–75)</td>
<td>OPQ-M</td>
</tr>
<tr>
<td>Lyons</td>
<td>Changes in Activity levels of older adult cancer survivors</td>
<td>2013</td>
<td>43</td>
<td>60+</td>
<td>ACSm</td>
</tr>
<tr>
<td>Lyons</td>
<td>A Content Analysis of Functional Recovery Strategies of Breast Cancer Survivors</td>
<td>2015</td>
<td>17</td>
<td>18-59</td>
<td>WSAS</td>
</tr>
<tr>
<td>Mohammadi</td>
<td>Participation in daily life activities among</td>
<td>2017</td>
<td>30</td>
<td>8.93 (1.85; 6-12)</td>
<td>ICPA</td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Year</td>
<td>Sample Size</td>
<td>Age Range</td>
<td>Scale/Clinical Tool</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
<td>------</td>
<td>-------------</td>
<td>-----------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Nikolic</td>
<td>Social participation of women with breast cancer</td>
<td>2015</td>
<td>30</td>
<td>20-65</td>
<td>LIFE-H</td>
</tr>
<tr>
<td>Olivari-Philiponnet</td>
<td>Social participation after childhood craniopharyngioma</td>
<td>2016</td>
<td>14</td>
<td>15.5 (4.6)</td>
<td>LIFE-H (for children)</td>
</tr>
<tr>
<td>Pergolotti</td>
<td>Predicting participation in meaningful activity for older adults with cancer</td>
<td>2015</td>
<td>71</td>
<td>72; all 65+</td>
<td>MAPA; PActS</td>
</tr>
<tr>
<td>Pergolotti</td>
<td>Adaptation of the Possibilities for Activity Scale for women encountering cancer</td>
<td>2018</td>
<td>186</td>
<td>57 (13.28; 22–93)</td>
<td>PActS-W</td>
</tr>
<tr>
<td>Authors</td>
<td>Study Title</td>
<td>Year</td>
<td>Sample Size</td>
<td>Mean (SD)</td>
<td>Measure</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>------</td>
<td>-------------</td>
<td>-----------</td>
<td>---------</td>
</tr>
<tr>
<td>Sapihis</td>
<td>Participation restrictions in cancer survivors: a cross-cultural adaptation and psychometric evaluation of occupational gap questionnaire</td>
<td>2015</td>
<td>33</td>
<td>52 (9.9)</td>
<td>OGQ-M</td>
</tr>
<tr>
<td>Schreiber</td>
<td>Evaluating function and health related quality of life in patients treated for extremity soft tissue sarcoma</td>
<td>2006</td>
<td>100</td>
<td>55.17 (16.74; 18-86)</td>
<td>RNL</td>
</tr>
<tr>
<td>Sikorskii</td>
<td>PROMIS and legacy measures compared in a supportive care intervention for breast cancer patients and caregivers: Experience from a randomized trial</td>
<td>2018</td>
<td>256</td>
<td>56.44 (11.08)</td>
<td>PROMIS-29</td>
</tr>
<tr>
<td>Syrjala</td>
<td>Measuring social activities and social</td>
<td>2010</td>
<td>102</td>
<td>39.7 (8.9)</td>
<td>Social Activity Log</td>
</tr>
</tbody>
</table>
function in long-term cancer survivors who received hematopoietic stem cell transplantation

<table>
<thead>
<tr>
<th>Walsh 142</th>
<th>Pilot Use of Selected Measures from the Patient-Reported Outcomes Measurement Information System Social and Mental Health Domains with Young Adult Cancer Patients During the Transition to Survivorship Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019 13</td>
<td>22.46 (2.54; 19-27)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wilke 140</th>
<th>A Comparison of Limb Salvage Versus Amputation for Nonmetastatic Sarcomas Using Patient-reported Outcomes Measurement Information System Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019 138</td>
<td>58 (19)</td>
</tr>
</tbody>
</table>
Appendix C. Semi-Structured Interview Guide

The interview guide was modified after the first six interviews to add additional probing questions.

<<Confirm participant name, demographic information, and receive verbal consent to be audio-recorded.>>

<<Introduce self and any other team members present; XX is here to observe and also take notes on what is discussed today to make sure we capture as much of the information shared as possible.>>

Thank you for joining us today. Before we begin I just want to review some information with you. As we discussed, this interview will be audio-recorded to ensure we accurately capture the information you share with us here today. When we report the information we learn from interviews, your name will not be used and these recordings will not be shared with any individuals outside of the research team.

We are now going to turn on the audio recorders and begin our discussion.

<<Turn on 2 audio recorders or 1 audio recorder plus zoom recording.>>

Introduction

Today we are going to talk about the day to day activities that are important and meaningful to you. Having cancer can make some day to day activities difficult and we want to better understand your experiences. We want to know about the challenges, the successes, and areas of your life that have not changed because you have cancer. We want to hear about all kinds of activities that are important in your daily life like going to work, volunteering, attending medical appointments, seeing your family/friends, and leisure activities or hobbies that you do for fun.

There are no right or wrong answers to the questions we ask, we are here to learn about your experiences.

We expect the discussion to take about an hour. We’ll provide you with a break halfway through the session.

Participant Introductions

As we get started, we’ll share with each other some activities we find meaningful or important in our daily lives. This can be something you’re able to do right now or something you used to
do that is difficult for you now—either or both are fine to share.

I’ll get us started I enjoy X because…(provide at least 2 examples; make sure to touch on social activities too)

<table>
<thead>
<tr>
<th>We’re going to start off with a very broad question.</th>
<th>Provide personal example if needed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What does it mean to you to be able to fully participate in life?</strong></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for sharing that information. We recognize that the idea of participating in life is different for everybody.

Today we’re going to talk about this idea that we call participation, which is doing activities that you find important, meaningful, and/or enjoyable.

These activities tend to bring value and satisfaction to your life. They can be something you do for yourself or something you do as part of a life role, such as being a mother, son, coworker, etc.

<<Write first part of definition in zoom chat or on a whiteboard>>

We’re going to discuss how you feel your participation in life has been impacted because you have/had cancer.

Change the initial stem phrasing based on where the individual is in their cancer journey. If post-treatment: Thinking back to when you first learned you had cancer…

<table>
<thead>
<tr>
<th>Thinking about when you first learned you had cancer, how did you day to day activities change?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How did your day to day activities change throughout the time you were being treated for cancer?</strong></td>
<td>Differences experienced during radiation, chemotherapy, other treatment types?</td>
</tr>
<tr>
<td>[Since learning you have cancer,] how do you feel you are participating in life more fully than before you learned you had cancer?</td>
<td>In what way has your outlook on participation in certain activities or life roles changed?</td>
</tr>
<tr>
<td><strong>What important activities have you started doing because you have cancer, if any?</strong></td>
<td>Why did you start doing these activities—enjoyable/meaningful to you versus something you have to do?</td>
</tr>
<tr>
<td>Question</td>
<td>Answer</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>How are you participating in life less fully than before you learned you had cancer?</td>
<td>What are you doing more or less of?</td>
</tr>
<tr>
<td></td>
<td>What activities do you need help with now that you didn’t in the past?</td>
</tr>
<tr>
<td>What important activities have you stopped doing because you have cancer, if any?</td>
<td>Why did you stop doing these activities?</td>
</tr>
<tr>
<td></td>
<td>What other activities can you think of that are more challenging for you to do now than before you had cancer?</td>
</tr>
<tr>
<td></td>
<td>Think about activities during other times of the year/seasons</td>
</tr>
<tr>
<td>What activities have you been able to continue doing throughout your treatment? What motivated you to continue to do these activities?</td>
<td></td>
</tr>
<tr>
<td>How confident do you feel that you can do the things in your life that are important to you? Why?</td>
<td>Example: help from family, monetary support, etc.?</td>
</tr>
<tr>
<td></td>
<td>What limits your participation?</td>
</tr>
<tr>
<td></td>
<td>Think about an activity that’s important to you that is challenging right now. What makes doing that activity difficult?</td>
</tr>
<tr>
<td></td>
<td>Do you feel you’ve had to depend on others more to participate in the activities that are important to you since learning you have cancer? If so, tell me more about this.</td>
</tr>
<tr>
<td>Some people tell us that they stopped doing activities they felt obligated to do or they had to do, but didn’t really enjoy (e.g. attending an exercise class). What examples can you share about experiences similar to this, if any?</td>
<td></td>
</tr>
<tr>
<td>What do you want to change about your current participation in life activities?</td>
<td>Ex: do more things you want to do, be able to do activities with more people, have more energy to do the things that are important to you?</td>
</tr>
</tbody>
</table>
How do you think you could go about making changes to your current participation? If you were going to make a plan to make this change in your participation, how would you[/what would it take for you to] make that change? Will it get better with time? What can you do to change (if anything)?

Have you ever received rehabilitation services (physical or occupational therapy) to address the challenges discussed?

What additional comments or experiences would you like to share that we have not discussed yet?

<<Break, if needed>>

Now we are going to talk about three different questionnaires that are commonly used to ask people about their participation in life activities. We want to see which questionnaire you feel best represents the information you just discussed [related to participation] to help us identify which questionnaire would be best to use among people with cancer.

First I’m going to provide you with an overview of each questionnaire. Next we’ll read through a few questions together and I’ll ask for your response to a few questions. Last, we will discuss your thoughts on each questionnaire. We’ll go through each questionnaire and our interview questions one at a time.

<<Zoom: pull up assessment 1 on the screen share; phone: look at assessment together, participant will have a hard copy>>

<<Overview of assessment —provide details on basic instructions, domains measured, and response option format.>> Repeat same process for each assessment

<<After overview, researcher will read aloud 5-7 assessment questions>>

<<Assessment 1>> Feel free to refer back to the questionnaire on the screen (or hard copy) as we discuss them.

What are your initial thoughts on this questionnaire? What do you like or dislike about it?

What was easy? What was challenging or confusing

What’s missing from the questionnaires Thoughts on timeframe of questions
that’s important to understand your daily life with cancer? | Different response categories?
| Different activity categories?

What questions do you feel don’t apply to you? | What questions do you feel aren’t important for you to answer for somebody to understand your participation?

How well do you think this assessment captures your daily life participation experiences (the information we discussed during the first part of the interview)?

<<Assessment 2>>
Same questions as for assessment 1

When comparing this assessment to the assessment we just discussed, what do you like more or less about this assessment?

<<Assessment 2>>
Same questions as for assessment 1

When comparing this assessment to the two assessments we just discussed, what do you like more or less about this assessment?

Thank you so much for looking through those assessments and helping us get a better understanding of what you thought of them and what they mean to you.

Before we wrap up, is there anything that we have not talked about today that you’d like to share related to the topics discussed today?

As I mentioned earlier, we’re going to use all of the information you shared to help us choose a questionnaire to use with individuals with cancer at Siteman Cancer Center. We’re going to ask you 2 questions about your preferences related to these assessments. This is all about your perspective, so there are no right or wrong answers.

<<If on zoom: share screen with each measure and the questions on a PowerPoint slides>>
<<order of assessment presentation will be varied across participants>>

Of the 3 questionnaires we talked about today, which do you feel would best explain how you participate in meaningful activities? Please rank them from most preferred (1) to least preferred (3).

Response options:
<table>
<thead>
<tr>
<th>The Community Participation Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Participation Measure—3 Domains, 4 Dimensions</td>
</tr>
<tr>
<td>The Patient Reported Outcome Measurement Information System</td>
</tr>
</tbody>
</table>

**Think about being in a clinical setting at Siteman/the hospital sitting in the waiting room waiting for your appointment, which one would you prefer to complete in a clinical setting? Please rank them from most preferred (1) to least preferred (3).**

Same response options

**How would you feel about completing one of these questionnaires at a clinic visit with your oncologist? (before seeing the provider—waiting in waiting room or exam room)**

**What have we not talked about that you’d like to share about the questionnaires or your daily life and having cancer?**

<<Stop recording>>

<<Gift card information>>
Appendix D. Online Supplement for Cancer Survivors’ Perspectives of Participation: A Qualitative Synthesis

Methods

Participant Location

All participants were in a private location during the interview. Field notes were taken to note nuances not captured on audio recording.

Team

Team members had professional (medical oncologist, occupational therapist, researcher) and personal experiences (e.g., parent) with working with or sharing their lives with people with cancer. Due to the prevalence of cancer, it is common to have team members with personal experiences with cancer when conducting research with this population. The team-based approach to the study and ongoing reflexive discussions about data analysis and synthesis promote the trustworthiness of the data.

Participant Selection

During study enrollment procedures, three individuals shared they did not feel their life had been impacted by cancer. We explained we were interested in learning about all experiences, including those who were not impacted; two opted not to participate and one participated.

Data Collection

Throughout the data collection process, ongoing data analysis was conducted to identify emerging themes and assess saturation. After 35 interviews we determined no new themes were emerging; however, only 6 individuals with colorectal cancer had participated. To ensure themes unique to the colorectal group were not missed, additional interviews were completed for an equal sample of 10 per group.

Data Analysis

Thematic analysis is a process through which researchers synthesize participant experiences to identify collective meaning within the data.\textsuperscript{180,236} Thematic analysis and qualitative description\textsuperscript{179} were selected as analytic approaches because they are consistent with our constructivist epistemological stance, which acknowledges the role and subjectivity of the researcher in construction of meaning from the data.\textsuperscript{237} The six phases of thematic analysis\textsuperscript{236} were executed by the study team. The codebook was pilot tested by four team members on four transcripts; coding discrepancies were reviewed through discussion until consensus was reached. The codebook was updated to improve clarity of definitions and tested on one additional transcript by all team members to foster intercoder reliability prior to finalizing the codebook and coding all
transcripts. When indicated, team discussion was used to resolve coding discrepancies. Following data coding, thematic maps\textsuperscript{236} were developed to generate and refine themes.

**Quantitative Data**

Participants also completed three measures of participation online in Research Electronic Data Capture (REDCap)\textsuperscript{204,204} prior to the interview: the Community Participation Indicators (CPI),\textsuperscript{200} Participation Measure—3 Domains, 4 Dimensions (PM-3D4D),\textsuperscript{53} and participation items of the adult Patient-Reported Outcomes Measurement Information System (PROMIS)\textsuperscript{238} Participation Item Banks. These data were not reported in this publication but provide relevant context about the information survivors had prior to defining participation in the interview. Additionally, the quantitative data served as a method of triangulation in the broader qualitative study to compare participation experiences described in interviews and their congruence or incongruence with quantitative measures.

Study sample descriptive statistics were calculated using IBM SPSS Version 25.\textsuperscript{c}

**Funding**

The funders had no role in data collection, interpretation, or reporting.
## Appendix E. List of Study Measures for Quantitative Phase

<table>
<thead>
<tr>
<th>Measure</th>
<th>Measure Details (e.g. domains)</th>
<th>Time Point Collected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Participation Indicators (Primary Outcome)(^{200})</td>
<td>Productive Social Leisure</td>
<td>1-3</td>
</tr>
<tr>
<td>PROMIS-43 Profile &amp; Supplemental PROMIS items(^{136,238})</td>
<td>Ability to participate in social roles and activities (Secondary participation outcome) Physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with participation in social roles/discretionary social activities, pain interference and intensity, social support, social isolation, psychosocial illness impact (positive)</td>
<td>1-3</td>
</tr>
<tr>
<td>Charlson Comorbidity Index(^{202})</td>
<td>Self-reported comorbidities</td>
<td>1</td>
</tr>
<tr>
<td>Use of mobility aid</td>
<td>Yes/No; frequency; type of support</td>
<td>1-3</td>
</tr>
<tr>
<td>Referral to physical, occupational, speech therapy, or mental health support</td>
<td>Yes/No/Unsure</td>
<td>1-3</td>
</tr>
<tr>
<td>Financial toxicity—single item from EORTC QLQ-C30(^{203})</td>
<td>Has your physical condition or medical treatment cause you financial difficulties?</td>
<td>1-3</td>
</tr>
<tr>
<td>Employment status</td>
<td>Has your employment status changed as a result of your cancer diagnosis/since last survey?</td>
<td>1-3</td>
</tr>
</tbody>
</table>
### Appendix F/Online Supplement Table 1. Covariates in order of entry into the model

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Time Varying</th>
<th>Method of data collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Y</td>
<td>Medical record extraction</td>
</tr>
<tr>
<td>Radiation</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Baseline age</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Gender±</td>
<td>N</td>
<td>Participant report</td>
</tr>
<tr>
<td>Race±</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Comorbidity (dichotomized)±</td>
<td>N</td>
<td>Participant report Charlson Comorbidity Index</td>
</tr>
<tr>
<td>Physical function±</td>
<td>Y</td>
<td>PROMIS-43 Profile, participant report</td>
</tr>
<tr>
<td>Social support*</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Anxiety*</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Fatigue*</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Change in employment since cancer diagnosis*</td>
<td>Y</td>
<td>Participant report</td>
</tr>
<tr>
<td>Use of mobility support*</td>
<td>Y</td>
<td></td>
</tr>
</tbody>
</table>

± Indicates exploratory variables for adjusted analyses with linear regression and mixed effect regression modeling.

* Indicates covariate tested only when identifying risk factors.
Appendix G/Online Supplement Table 2. Linear Regression for Baseline PROMIS Ability to Participate

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Beta</th>
<th>Standard Error</th>
<th>Standardized Coefficient Beta</th>
<th>P</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>50.60</td>
<td>4.40</td>
<td></td>
<td>&lt;.001</td>
<td>41.87 to 59.32</td>
</tr>
<tr>
<td>Brain</td>
<td>0.93</td>
<td>2.73</td>
<td>.04</td>
<td>0.73</td>
<td>-4.49 to 6.35</td>
</tr>
<tr>
<td>Colorectal</td>
<td>-1.35</td>
<td>2.44</td>
<td>-0.07</td>
<td>0.59</td>
<td>-6.19 to 3.50</td>
</tr>
<tr>
<td>Lung</td>
<td>2.30</td>
<td>2.69</td>
<td>0.12</td>
<td>0.40</td>
<td>-3.04 to 7.63</td>
</tr>
<tr>
<td>Baseline age</td>
<td>.024</td>
<td>0.07</td>
<td>0.04</td>
<td>0.73</td>
<td>-0.11 to 0.16</td>
</tr>
<tr>
<td>Surgery</td>
<td>-4.33</td>
<td>2.01</td>
<td>-0.25</td>
<td>0.03*</td>
<td>-8.32 to -0.35</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>-3.20</td>
<td>1.83</td>
<td>-0.18</td>
<td>0.08</td>
<td>-6.83 to 0.43</td>
</tr>
<tr>
<td>Radiation</td>
<td>2.48</td>
<td>1.97</td>
<td>0.12</td>
<td>0.21</td>
<td>-1.43 to 6.38</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>-9.76</td>
<td>4.55</td>
<td>-0.21</td>
<td>0.04*</td>
<td>-18.78 to -0.72</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>-5.51</td>
<td>2.01</td>
<td>-0.31</td>
<td>0.01*</td>
<td>-9.65 to -1.36</td>
</tr>
</tbody>
</table>

*P<.05
### Appendix H. Item-Level Data from Community Participation Indicators Across Time

<table>
<thead>
<tr>
<th>Activity</th>
<th>Baseline (within 30 days of diagnosis)</th>
<th>Time 2 (3 months post diagnosis)</th>
<th>Time 3 (6 months post diagnosis)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq. (% &gt; none)</td>
<td>Imp. (%)</td>
<td>Enough (%)</td>
</tr>
<tr>
<td>Get out and about</td>
<td>93</td>
<td>96</td>
<td>53</td>
</tr>
<tr>
<td>Spend time with family</td>
<td>93</td>
<td>100</td>
<td>69</td>
</tr>
<tr>
<td>Keep in touch with family by phone or internet</td>
<td>98</td>
<td>94</td>
<td>87</td>
</tr>
<tr>
<td>Spend time with friends</td>
<td>73</td>
<td>93</td>
<td>40</td>
</tr>
<tr>
<td>Keep in touch with friends by phone or internet</td>
<td>98</td>
<td>96</td>
<td>85</td>
</tr>
<tr>
<td>Go to parties, out to dinner, or other social activities</td>
<td>59</td>
<td>81</td>
<td>43</td>
</tr>
<tr>
<td>Spend time with a significant other or</td>
<td>82</td>
<td>89</td>
<td>85</td>
</tr>
<tr>
<td>Activity</td>
<td>198</td>
<td>63</td>
<td>67</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Work for money</td>
<td>47</td>
<td>63</td>
<td>67</td>
</tr>
<tr>
<td>Cook, clean, and look after your home</td>
<td>90</td>
<td>95</td>
<td>50</td>
</tr>
<tr>
<td>Manage household bills and expenses</td>
<td>76</td>
<td>82</td>
<td>90</td>
</tr>
<tr>
<td>Look after children or provide care for a loved one</td>
<td>48</td>
<td>65</td>
<td>76</td>
</tr>
<tr>
<td>Go to classes or participate in learning activities</td>
<td>25</td>
<td>40</td>
<td>70</td>
</tr>
<tr>
<td>Volunteer</td>
<td>22</td>
<td>42</td>
<td>55</td>
</tr>
<tr>
<td>Participate in religious or spiritual activities</td>
<td>64</td>
<td>69</td>
<td>61</td>
</tr>
<tr>
<td>Go to support groups or self-help meetings</td>
<td>5</td>
<td>17</td>
<td>78</td>
</tr>
<tr>
<td>Engage in hobbies or leisure activities</td>
<td>82</td>
<td>90</td>
<td>46</td>
</tr>
<tr>
<td>Activity</td>
<td>19</td>
<td>20</td>
<td>21</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Go to movies, sporting events or entertainment events</td>
<td>41</td>
<td>69</td>
<td>40</td>
</tr>
<tr>
<td>Participate in sports or active recreation</td>
<td>75</td>
<td>87</td>
<td>36</td>
</tr>
<tr>
<td>Participate in community clubs or organizations</td>
<td>16</td>
<td>33</td>
<td>67</td>
</tr>
<tr>
<td>Participate in civic or political activities</td>
<td>19</td>
<td>30</td>
<td>75</td>
</tr>
</tbody>
</table>

Note: Imp. = Important
Appendix I/Online Supplement Table 3. Participant-Reported Factors Impacting Participation

<table>
<thead>
<tr>
<th>How cancer and treatment side effects made it difficult to participate in daily life</th>
<th>Variable</th>
<th>Time 1 n (%)</th>
<th>Time 2 n (%)</th>
<th>Time 3 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fatigue/low energy</td>
<td>75 (61)</td>
<td>85 (77)</td>
<td>77 (78)</td>
</tr>
<tr>
<td></td>
<td>Pain</td>
<td>35 (28)</td>
<td>33 (30)</td>
<td>23 (24)</td>
</tr>
<tr>
<td></td>
<td>Mobility difficulty (walking and/or moving arms)</td>
<td>28 (23)</td>
<td>27 (24)</td>
<td>26 (26)</td>
</tr>
<tr>
<td></td>
<td>Strength</td>
<td>48 (39)</td>
<td>49 (44)</td>
<td>46 (46)</td>
</tr>
<tr>
<td></td>
<td>Numbness/tingling in hands or feet</td>
<td>13 (11)</td>
<td>25 (23)</td>
<td>29 (29)</td>
</tr>
<tr>
<td></td>
<td>Breathing difficulties</td>
<td>16 (13)</td>
<td>16 (14)</td>
<td>17 (18)</td>
</tr>
<tr>
<td></td>
<td>Bathroom urgency</td>
<td>23 (19)</td>
<td>25 (23)</td>
<td>22 (23)</td>
</tr>
<tr>
<td></td>
<td>Psychosocial challenges (depression, embarrassment, etc.)</td>
<td>27 (22)</td>
<td>31 (28)</td>
<td>27 (27)</td>
</tr>
<tr>
<td></td>
<td>Large amount of time at medical appointments</td>
<td>39 (32)</td>
<td>35 (32)</td>
<td>34 (35)</td>
</tr>
<tr>
<td></td>
<td>Cancer has not made it difficult for me to participate in daily life</td>
<td>35 (28)</td>
<td>21 (19)</td>
<td>21 (22)</td>
</tr>
</tbody>
</table>

| How cancer and treatment side effects helped participate in daily life          | Motivated me to do more activities I enjoy         | 23 (19)      | 18 (16)      | 25 (26)      |
|                                                                                  | Encouraged me to try something new                 | 12 (10)      | 10 (9)       | 16 (16)      |
|                                                                                  | Changed my outlook on life; greater appreciation for the activities I do | 69 (56) | 66 (59) | 58 (59) |
|                                                                                  | Cancer has not helped me participate in daily life  | 41 (33)      | 38 (34)      | 26 (26)      |

*These categories were formed based on data collected from qualitative interviews in phase 1 of this research.