IMPROVING CARE COORDINATION FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER: BUILDING A BRDIGE BETWEEN NEEDS AND SERVICES

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ABSTRACT

Emily R. Haines: Improving Care Coordination for Adolescents and Young Adults with Cancer: Building a Bridge Between Needs and Services
(Under the direction of Sarah Birken)

Many of the 70,000 adolescents and young adults (AYAs) diagnosed with cancer each year do not receive services to address the full scope of needs they experience during and after cancer treatment. Such unmet needs result in negative outcomes for this population, including higher distress, poorer health-related quality of life, and higher physical symptom burden. Although interventions have been used to improve care coordination for AYAs (e.g., patient-reported outcome measures), limitations to their usability and usefulness have frustrated their real-world implementation and impact on AYA outcomes.

To facilitate a more systematic and patient-centered approach to coordinating care for AYAs, we developed the AYA Needs Assessment & Service Bridge (AYA NA-SB), a care coordination intervention which includes (1) a holistic needs assessment, and (2) a suite of referral pathways connecting AYAs to services and resources based on the needs they report. To optimize the usability and usefulness of AYA NA-SB, I leveraged user-centered design (UCD), an iterative process for intervention development that relies heavily on the engagement of prospective users (e.g., cancer program providers and staff and AYAs).

At the study's onset, I convened a multidisciplinary design team comprised of researchers, cancer care providers, and AYAs from whom I solicited input throughout data collection and analysis. First, I used mixed methods to examine user interactions with an initial prototype, the Cancer Needs Questionnaire-Young People (i.e., usability testing). Second, I used ethnographic contextual inquiry, including ‘guided tours’ and semi-structured interviews with prospective AYA NA-SB users, to assess characteristics of users and context which should be considered in the design and implementation of AYA NA-SB. Finally, through two prototyping workshops, the design team collaboratively redesigned the Cancer Needs Questionnaire-Young People and designed referral pathways to optimize the tool’s usability and usefulness. The product of the project, AYA NA-SB, has the potential to improve care coordination and subsequent outcomes for AYAs with cancer, an understudied and underserved population.

To William Bradley Haines. With tremendous pride, you saw me start this journey, but cancer took you from me before you could see it end. I did it, Daddy!

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LIST OF ABBREVIATIONS

AYA	adolescent and young adult
AYA NA-SB	Adolescent and Young Adult Needs Assessment & Service Bridge
CNQ-YP	Cancer Needs Questionnaire- Young People
CS	concept systems
CFIR	Consolidated Framework for Implementation Research
CT	computerized tomography
EBP	evidence-based practice
EHR	electronic health record
EORTC	European Organisation for Research and Treatment of Cancer
IV	intravenous
MRI	magnetic resonance imaging
NCCN	National Comprehensive Cancer Network
NCCH	North Carolina Cancer Hospital
NIH	National Institutes of Health
PROM	patient-reported outcome measure
TAFE	technical and further education
TIDieR	Template for Intervention Description and Replication
UCD	user-centered design
UNC	University of North Carolina

CHAPTER 1: INTRODUCTION

1.1 Background and Objectives

Many of the 70,000 adolescents and young adults (AYAs) diagnosed with cancer each year do not receive services to address the full scope of needs they experience during and after cancer treatment.[1-5] AYAs' unmet needs result in negative outcomes, including higher distress,[2,3] poorer health-related quality of life,[6] and higher physical symptom burden.[1] AYA cancer needs are *age-specific*[7,8] (i.e., different from those reported by children or older adults with cancer), *multifaceted*[3,8] (spanning across physical, psychosocial, and practical domains), *individual*[9] (varying across AYAs), and *dynamic*[10] (fluctuating as AYAs move through their cancer trajectory). Despite the complexity and scope of their needs, AYAs often do not use potentially beneficial services and resources, even when access is not an issue.[11-13] This disconnect between AYA needs and their use of existing services/resources suggests the need for a model of care coordination that (1) effectively assesses AYAs' multifaceted, age-specific, individual, and dynamic needs, and (2) uses information about those needs to connect AYAs to services and resources.

A substantial step toward this model of care coordination was taken with the development of the first multidimensional measure of unmet needs designed specifically for the AYA population: the Cancer Needs Questionnaire - Young People (CNQ-YP).[14,15] The development of the CNQ-YP and a preliminary study supporting its psychometric properties[14] represent promising steps towards improving quality of care for AYAs; however, to be a *useful* tool for care coordination, the CNQ-YP needs an accompanying process for matching AYAs to services and resources once needs are identified. In addition to its usefulness, the ability of AYA NA-SB to effectively coordinate care and reduce unmet needs depends on (1) its acceptability and perceived appropriateness to AYAs, a population with high rates of non-adherence[16,17] and low rates of participation in supportive services,[4,5] and (2) the feasibility of its implementation in cancer care programs where substantial barriers to care coordination exist (e.g., staffing and resource constraints, difficulties communicating across multiple disciplines, and "turf wars" between pediatric and medical oncologists).[18-20] For these perceptual implementation outcomes, *usability* is a key determinant.[21]

Using the CNQ-YP as a foundation, I developed the AYA Needs Assessment & Service Bridge (AYA NA-SB) to connect AYAs to needed services and resources, thus facilitating more systematic, patient-centered care coordination for AYAs diagnosed with cancer. To promote AYA NA-SB's usability and usefulness, I leveraged methods and principles from User-Centered Design (UCD). UCD is a methodological framework for intervention development and refinement that relies on the extensive and iterative engagement of prospective intervention users (e.g., AYAs; providers).[22] I accomplished these objectives through three aims:

Aim 1: **Review and refine CNQ-YP.** To identify usability and usefulness issues with the CNQ-YP in its original form, I engaged prospective AYA NA-SB users (i.e., cancer program providers and staff and AYAs) in usability testing including an online survey, cognitive interviews, and an online concept mapping exercise.

Aim 2: **Understand users and context.** I described AYA NA-SB's implementation and scale-up contexts using ethnographic methods (i.e., guided tours and semi-structured interviews) with users. Then, I identified user and contextual factors expected to affect AYA NA-SB usability and usefulness (i.e., user and contextual requirements).

Aim 3: **Generate design solutions.** Through two prototyping workshops, I collaborated with a multidisciplinary "design team" composed of researchers, AYAs, and cancer care providers to iteratively design AYA NA-SB based on feedback received during Aim 1 and 2 data collection efforts. This included designing AYA NA-SB content (i.e., the modified CNQ-YP) and AYA NA-SB delivery (e.g., who should deliver AYA NA-SB, when, where, how, and how frequently), as well as a plan for implementation.

1.2 Significance

This study's use of UCD to proactively design AYA NA-SB for implementation represents an important methodological contribution at the intersection of implementation research and UCD. Although factors at multiple levels impact implementation, less attention has been paid in implementation science to fundamental characteristics of an intervention's content or delivery which may influence its implementation; moreover, methods for ensuring that program features are compatible with user needs have not been well articulated.[23] Drawing on UCD principles and methods to develop AYA NA-SB offered preliminary insights on the extent to which incorporating UCD in intervention development and implementation can facilitate successful implementation and, subsequently, the achievement of desired intervention outcomes.

AYA NA-SB has the potential to improve care coordination at the individual level by allowing cancer care programs to tailor service delivery and resource provision to the individual needs of AYAs they serve. Additionally, AYA NA-SB addresses a critical measurement gap. In the past decade, AYA-specific programs have emerged at cancer centers across the country to better coordinate cancer care for AYAs,[18] but the impact of these programs has been largely unstudied to date.[24] In large part, the lack of evidence on AYA-specific programs is due to a lack of patient-centered metrics.[25,26] By eliciting patient-reported data on unmet needs at multiple timepoints during AYAs' treatment, AYA NA-SB will generate such patient-centered metrics to assess the effectiveness of AYA-specific programs in addressing AYAs' unmet needs as they emerge. Furthermore, AYA NA-SB will yield critical patient-reported data to inform the structure and functions of AYA-specific cancer programs.[20,27] In sum, by harnessing patient-reported data to facilitate the coordination of care for AYAs, AYA NA-SB has the potential to improve processes of care and subsequent outcomes for AYAs, an underserved and understudied population.[28]

To ensure that the product of this dissertation addresses a critical practice gap, research objectives were developed in close collaboration with key stakeholders, including AYAs and providers involved in AYA cancer care from around the country. Further, AYA NA-SB was designed with extensive input from leaders of the AYA Cancer Support Program at the University of North Carolina (UNC) Lineberger's Comprehensive Cancer Center (i.e., North Carolina Cancer Hospital), who intend to implement AYA NA-SB as part of routine care. As such, the development of the AYA NA-SB reflects not only a contribution to implementation research, through the innovative use of multidisciplinary frameworks and methods to design AYA NA-SB for implementation, but also a pragmatic solution to problems faced in "real-world" AYA cancer care practice.

1.3 Overview of Chapters

Chapter 2 summarizes the relevant literature, including extant evidence related to experiences and outcomes of AYAs with cancer, the changing landscape of AYA oncology, and the potential for patient-reported outcome measures to facilitate care coordination for this population. In Chapter 3, I describe the conceptual model for this project, which integrates frameworks from implementation science and UCD. In Chapter 4, I describe the user-centered approach I employed to develop AYA NA-SB, which consisted of three stages forming an iterative and dynamic design cycle. In Chapter 5, I present findings from this project. In Chapter 6, I discuss these findings in the context of existing literature as well as their implications for future research and practice.

CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Cancer in Adolescents and Young Adults

Cancer is the leading disease-related cause of death in adolescents and young adults (AYAs).[29] Contrary to common misconception, cancers are more common in the AYA population (i.e., individuals between the ages of 15 and 39) than in children under the age of 15.[30] Hodgkin lymphoma, melanoma, testicular cancer, female genital tract malignancies, thyroid cancer, soft-tissue sarcomas, non-Hodgkin lymphoma, leukemia, brain and spinal cord tumors, breast cancer, bone sarcomas, and nongonadal germ cell tumors account for 95% of the cancers in this age group.[30]

For AYAs, cancer survival rates are not improving as quickly as they are for children and older adults, a disparity in cancer outcomes that is widely documented.[31,32] Within this population, researchers have pointed to poor physical, psychosocial, and behavioral outcomes[33,34] These outcomes may be even worse for racial and ethnic minorities and AYAs who are uninsured.[3536] Negative outcomes in AYAs with cancer have been attributed to a range of multilevel factors. Gaps in care include low clinical trial enrollment,[37,38] poor adherence to treatment plans,[39] and a multitude of survival challenges experienced by this group.[40] Many have pointed to widespread failures of the health care system to recognize and meet the unique needs and preferences of this age group[7,41]

Despite many extant studies cataloguing the unique needs of this age group, cancer care centers in the United States have been slow to implement programs or services to meet these needs.[1] Until recently, AYAs have tended to occupy a “no-mans land” between medical oncology and pediatric oncology, [42] often reporting that existing cancer treatment programs, psychosocial programs, survivorship care are misaligned with their needs and preferences.[26,41,43] In short, models of AYA cancer care have often not been responsive to the needs of AYAs.[2,8]

Demands for improvements in cancer care for this population[44-46] have ignited an AYA oncology movement.[47] In 2012, the National Comprehensive Cancer Network released a set of guidelines for delivering cancer care to AYAs.[48] Other such guidelines and criteria for optimal AYA cancer care have been described.[46,49] Critical areas of research have been highlighted including the development of measures to assess AYAs' holistic and supportive care needs and models of care to meet these needs.[8] In the wake of the AYA oncology movement, AYA-specific cancer care programs have emerged within cancer centers across the country to address the challenge of coordinating services to meet the unique needs of AYAs.[18] The composition and functions of these programs vary greatly; however, common components include a physical space, provider expertise, coordination between pediatric and medical oncology, efforts to increase clinical trial participation, and patient and family advocacy. Although the establishment of AYA cancer programs often results in the creation of new, age-specific interventions for AYAs, much of the role of these programs tends to be in coordinating services which already exist in a given setting. Indeed, existing supportive care programs for adults can be leveraged for the AYA population, where needs overlap.[20] <u>Yet, AYA programs lack guidance for coordinating services to meet the unique needs of this population.</u>

2.2 AYA Needs

Many of the 70,000 adolescents and young adults (AYAs) diagnosed with cancer each year do not receive services to address the full scope of needs they experience during and after cancer treatment.[1-5] In addition to complex physical/medical needs (e.g., treatment-related side effects, fertility concerns),[3] AYAs' ability to cope with and manage their disease is affected by age-specific issues related to family dynamics,[50] peer engagement[8], sexuality[51], body image[52], educational and vocational needs[53], financial issues[6], and extensive information needs.[54] AYAs' unmet needs result in negative outcomes, including higher distress,[2,3] poorer health-related quality of life,[6] and higher physical symptom burden.[1]

AYA cancer needs are *age-specific*[7,8] (i.e., different from those reported by children or older adults with cancer), *multifaceted*[3,8] (spanning across physical, psychosocial, and practical domains), *individual*[9] (varying across AYAs), and *dynamic*[10] (fluctuating as AYAs move through their cancer trajectory). Certain characteristics may be associated with greater need. For example, one study found that AYAs who were older, male, of non-white race/ethnicity, or of poorer physical health status were more likely to report unmet information needs.[1] In another study, AYAs who were unemployed, less formally educated, and not in a long-term committed relationship were more likely to report unmet needs.[54]

Despite the scope and complexity of their needs, however, AYAs often do not use *services* (i.e., care provided by health or auxiliary professionals in-house or in the community) and *resources* (i.e., information, materials, facilities, funds, or anything else that helps a patient to manage their illness) – even when they face no access barriers such as cost, insurance status, or local service capacity.[4,5,11-13,55]

2.3 Care Coordination

AYAs report barriers to service and resource use including lack of awareness and skepticism about the compatibility of services and resources with their own personal needs.[13] They may also struggle to navigate a large volume of information received upon diagnosis, and multiple providers in a complex health system.[55,56] Furthermore, in the face of school, work, family, and other demands, AYAs may not have the bandwidth to research or proactively seek services and resources.[3,43] Even when they are actively experiencing unmet needs or distress, AYAs often do not broach these subjects with health care providers without prompting.[57]

These and other barriers to appropriate service and resource use for AYAs with cancer point to a need for improved care coordination for this population.[8,58,59] The Agency for Healthcare Research and

Quality defines '*care coordination'* as the deliberate organization of "patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care".[60] This includes assessing patients' needs and preferences upfront, and using this information to inform care delivery.[60] The importance of holistically coordinating care to meet AYA needs has been echoed by various clinical practice guidelines and recommendations,[26,45-47] as well as by cancer patients;[61,62] yet, care coordination in AYA cancer care remains suboptimal.[8] Cancer programs often lack effective interventions to connect AYAs with unmet needs to potentially beneficial services and resources.[8,26,43] According to Fitch's Supportive Care Needs Framework, care provided to individuals with serious illness should be "based upon, and matched with, an individual's needs within the context of his or her unique situation".[63] From this perspective, effectively caring for AYAs with cancer requires tailoring service and resource delivery to meet the unique and changing needs of each individual. <u>To bridge the disconnect between AYA needs and their use of services and resources in a way that fits within this person-centered framework, a model of care coordination is needed that (1) effectively assesses AYAs' multifaceted, age-specific, individual, and dynamic needs, and (2) uses information about those needs to connect AYAs to services and resources.</u>

2.4 Patient-Reported Outcome Measures

Patient-reported outcome measures (PROMs)- i.e., "any report coming directly from the patient about a health condition and its treatment"[64] - are increasingly recognized as exemplars of patient-centeredness and as useful care planning interventions in cancer care.[65-68] PROMs- such as distress screening scales (e.g., Symptom Distress Scale[69]), multi-symptom measures (e.g., Edmonton Symptom Assessment Scale[70]), and health-related quality of life measures (e.g., EORTC Quality of Life Questionnaire[71])- offer cancer programs tools for standardizing the assessment of patient needs, experiences, and preferences. This more systematic and formalized approach to assessment can enhance patient-provider communication and facilitate equitable care delivery, ensuring that cancer programs are responding to the multifaceted, individual, and dynamic needs of their patients.[72] Existing literature supports some of the projected benefits of PROMs, demonstrating that the use of PROMs in routine clinical practice can improve patient-clinician communication, help streamline and shorten patient visits, and facilitate more accurate symptom assessment.[73,74] These proven benefits of PROMs in terms of *care processes* should, in theory, result in improved *patient outcomes* (e.g., improved symptom burden, quality of life, experience of care). Indeed, a few studies have demonstrated such effects. For example, in one randomized controlled trial, the use of a web-based PROM for symptom monitoring improved patient quality of life, decreased emergency hospital admissions, and increased survival.[75,76]

In recognition of their potential benefits on patient outcomes, researchers[77] and consensus bodies alike (e.g., National Cancer Institute,[78] American Cancer Society, Centers for Medicare and Medicaid Services,[79] and National Institutes of Health[80]) have called for broader PROM use in cancer care practice, including the routine use of PROM information in patient-provider decision making. Furthermore, health care organizations may increasingly face quality measurement and reporting requirements which include the use of PROMs in routine care.[81] Growing interest in the use of PROMs in routine care has led to the proliferation of instruments[82] and examples of their application.

However, despite growing interest in and applications of PROMs in cancer care, their implementation[83-86] and effect on downstream patient outcomes (e.g., improved symptom burden, quality of life, experience of care)[73,87,88] has often been limited or inconsistent. In a systematic review of the impact of routine collection of PROMs in oncology, Chen et al. concluded that “despite some encouraging results, there is still a great degree of uncertainty regarding the impact of routinely collected PRO[M]s, with feedback, on patient health outcomes”.[89] These findings mirror those of a systematic review by Luckett et al., in which the effect of PROM collection on cancer patient outcomes was limited.[90] Still another systematic review by Kotronoulas et al. found mixed, often weak, evidence of PROM effectiveness in improving patient outcomes (e.g., symptom burden, quality of life, experience of care).[87] More recently, the effect of PROMs on patient outcomes has improved, as clinics leverage electronic PROM collection systems integrated with their electronic health records and deploy various implementation strategies such as clinician training and audit and feedback.[83] <u>However, barriers to PROM implementation and effectiveness remain; these barriers may be rooted in characteristics of PROMs themselves, such as their usability and usefulness in practice.</u>

2.5 Usability & Usefulness

Cancer care programs face a number of barriers to implementing PROMs such as provider-level barriers (e.g., time constraints, lack of training, attitudes towards PROMs etc.), patient-level barriers (e.g., tool length and complexity, cultural relevance and relevance to patients and cancer type, stage, and phase of the cancer journey), and organizational/structural barriers (e.g., electronic health record integration).[82,91] Lavallee et al. described the challenges associated with using PROMs in routine practice including staff and patient burden, workflow barriers, and challenges to interpreting and following up on PROM data.[72] Some of these barriers to implementation may be rooted in *usability* issues with the instruments themselves.[85] Usability, a determinant of implementation,[21] is the “extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use” where effectiveness is the accuracy and completeness with which users achieve specified goals, efficiency is the resources expended relative to that accuracy and completeness, and satisfaction includes users’ attitudes towards using the product.[92] Issues of usability include complexity, understandability (e.g., literacy demand), learnability, compatibility with context, flexibility, aesthetic, and availability of support services in a clinic.[93] Many existing PROMs demonstrate flaws along these dimensions. For example, one study found that more than half of the most commonly-used PROMs use language that is not understandable by those with low literacy rates.[94] Question clarity, including symptom recall periods, has also hindered the acceptability of PROM interventions.[95] In another study, patients reported survey length as a major barrier to their perceptions of PROM acceptability.[96] Furthermore, existing PROMs used in cancer care may lack critical content and face validity; one systematic review of PROMs designed to assess the quality of patient-centered cancer care found that none of the PROMs identified were both psychometrically rigorous and inclusive of core dimensions of patient-centeredness.[97] Similarly, another more recent systematic review of PROM use in oncology identified PROM appropriateness and relevance to patients as a major barrier to PROMs' effectiveness in enhancing patient-clinician communication.[73] Indeed, PROM development and selection does not always involve patient engagement to ensure that PROMs are measuring what matters to patients.[91,98,99]

Even in cases of successful implementation, the use and impact of PROMs may be hindered by their limited *usefulness*.[100,101] Usefulness, also a determinant of implementation, refers to the extent to which a tool generates "user-friendly data which can be acted upon by the end user in a manner that has a practical value while meeting their particular needs".[102] If PROMs demonstrate benefits in terms of care processes but not patient outcomes, this suggests gaps downstream of PROM administration and completion.[103] In other words, the mere assessment of needs is not enough to influence patient outcomes if patient information is not subsequently used. Extant PROM literature suggests a limited consideration of usefulness in PROM research and implementation. The majority of studies reviewed by Kotronoulas et al., for example, did not articulate how PROM data was used to devise or evaluate treatment plans.[87] This lack of a follow-up action after PROM collection was also a theme in another more recent review of PROM implementation in cancer care, which found that PROM data interpretation guidance was rarely offered and patient-management guidance for addressing issues identified by PROMs was only provided in 25% of studies.[104] Indeed, sensitivity to change (ability to longitudinally track progress[105]) and importance to clinical care represent two dimensions of usefulness prioritized by stakeholders.[106] Without an articulated plan for incorporating PROM data into care delivery, administering PROMs may needlessly distract from clinical encounters and burden both patients and providers; adding burden without contributing value represents an inefficient use of organizational resources and may even be considered unethical.[91,107] To be useful, PROM data must be embedded in the clinical workflow such that providers can easily access it to inform decision making, communication with patients, and multidisciplinary interaction.[77] PROM data should also be summarized in an accessible format for clinicians.[73] Otherwise, providers are unlikely to use that information in care planning. Further, PROM information typically must be paired with necessary resources such as education, referral services, and treatment plans, and must align with clinical processes such as documentation, billing, patient flow, and patient education.[77,89] Otherwise, PROMs are unlikely to improve downstream patient outcomes.

PROM properties such as usability and usefulness can significantly influence providers' attitudes towards their adoption and use.[108] Providers' acceptance of PROMs may depend on their ability to interpret and act upon PROM data.[101] Furthermore, patients may be less engaged in PROM completion if they perceive PROMs as having low usability or usefulness.[91,107] For example, if clinicians do not review PROM information with patients in a timely manner, patients may be less engaged with PROMs administered to them in the future. Finally, without an explicit connection between PROM information and the follow-up actions that information should trigger (i.e., in the absence of usefulness), the link between PROM implementation and improved patient outcomes will not be realized. In sum, the benefits of integrating PROMs into cancer care towards improving care coordination and reducing unmet needs will be limited without careful attention to issues of PROM *usability* and *usefulness*.

2.6 The Cancer Needs Questionnaire- Young People

In recent years, the proliferation of PROMs in response to calls for their use in research and practice has resulted in a multitude of tools to choose from.[82] However, although PROM use in cancer care is increasing,[109] until recently, measures specific to AYAs were lacking. For example, many multidimensional *needs assessment* PROMs have been developed for cancer patients and their family members; one systematic review identified 24 instruments[110] and another identified 15; none addressed the unique needs of AYAs, specifically.[67] This is problematic given the range of age-specific needs reported by this population.

In 2012, to address this gap, Clinton-Mcharg et al. developed the first multidimensional PROM assessing unmet needs of AYAs with cancer: the Cancer Needs Questionnaire- Young People (CNQ-YP) (see **Appendix A**).[14] The development of the CNQ-YP and a preliminary study supporting its psychometric properties[14] represent promising steps towards implementing a patient-centered approach to assessing and addressing the needs of AYAs with cancer. However, the CNQ-YP, like many PROMs, has several key shortcomings with respect to its usability and usefulness. First, its length and complexity may limit the feasibility of its ongoing administration in real-world practice environments which are subject to resource and staffing shortages and competing priorities. Second, it was developed and has only been used in Australia, raising concerns about its appropriateness for an American cancer care context. Third, only younger AYAs (i.e., adolescents) were involved in the CNQ-YP's development; as such, its acceptability and applicability to older AYAs remains to be seen.[14] Perhaps the biggest limitation of the CNQ-YP is its limited usefulness for care coordination: the tool lacks a subsequent process for connecting AYAs to services and resources once needs are identified.

Thus, in this study, we adapted the CNQ-YP for implementation in the AYA cancer program at the North Carolina Cancer Hospital (NCCH), to promote its usability and usefulness for coordinating care for AYAs. This resulted in the AYA Needs Assessment & Service Bridge (AYA NA-SB), a holistic needs assessment paired with a suite of explicit referral pathways for connecting AYAs to services and resources based on the needs they report.

CHAPTER 3: CONCEPTUAL MODEL

3.1 Implementing EBPs in Context

Proctor et al.'s popular conceptual model of implementation research demonstrates the relationship between an evidence-based practice (EBP), its implementation, and associated outcomes (i.e., implementation outcomes, service outcomes, and patient outcomes).[111] In terms of implementation outcomes, Lyon et al., distinguished between perceptual and behavioral implementation outcomes.[21] Perceptual implementation outcomes include *feasibility* (e.g., extent to which users believe that AYA NA-SB can be successfully used in cancer programs), *acceptability* (e.g., perception of whether AYA-NA-SB is agreeable, palatable, or satisfactory to users), and *appropriateness* (e.g., perception of AYA-NA-SB's fit, relevance, or compatibility with the context in which it will be used). In theory,[21] these perceptual implementation outcomes, which are anchored to the perspective of users, influence behavioral implementation outcomes (e.g., fidelity, reach, sustainment).

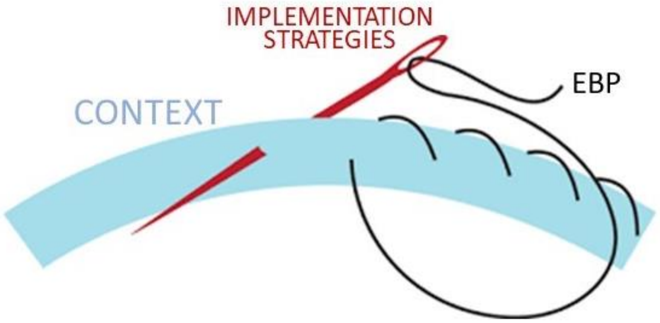
Less emphasized in Proctor's model is the inextricable role of context (i.e., the "set[s] of characteristics and circumstances that consist of active and unique factors, within which the implementation is embedded"[112]). EBP implementation is often challenged by poor fit between EBPs and their implementation contexts.[113] Use of an *EBP* (i.e., intervention with proven efficacy and effectiveness[114]) in a context for which it is not well-suited can compromise its effectiveness and burden users (e.g., patients, providers, healthcare organizations) with elaborate strategies intended to force implementation. However, EBPs are seldom designed to address the nuances of multiple, varying, complex, and changing practice contexts.[113] To accommodate nuanced contexts, EBP developers may produce increasingly complex EBPs,[115] resulting in EBPs "that are ultimately too expensive, impractical, or even impossible to construct within real-world constraints".[23] Despite consistent recognition that there is no implementation without some adaptation, few methods exist to inform systematic EBP adaptation.[116]

Implementation scientists have identified various EBP characteristics that influence implementation[117]; such evidence may inform efforts to adapt EBPs to improve implementation. However, the relationship between EBP characteristics and implementation outcomes varies across EBPs and contexts,[117] and the same EBP may demonstrate varying degrees of effectiveness in achieving the desired patient outcomes across different contexts.[118] All of this suggests that an EBP's implementation and effectiveness are inextricably linked to *context*. Methods for considering the dynamic interplay between EBP and context have not been well articulated.[116]

To address discordance between EBPs and contexts, implementation scientists often turn to *implementation strategies* – i.e., "methods or techniques used to enhance the adoption, implementation, and sustainability" of EBPs.[119,120] However, a "more is better" approach to deploying implementation strategies to compensate for poor EBP-context fit may burden EBP users. Moreover, implementation strategies have shown only modest effect sizes.[121] These findings may be in part due to an insufficient consideration of key determinants, such as contextual appropriateness, when selecting or designing implementation strategies.[122] To this end, implementation scientists have called for methods for tailoring implementation strategies to EBPs and contexts.[122,123]

Rather than deploying cumbersome EBPs or implementation strategies to improve EBP-context fit, implementation scientists should seek to harmonize EBPs, contexts, and strategies (i.e., design each with respect to the other two). An analogy (**Figure 1**) helps illustrate this harmonization: in embroidery, decisions about fabric, needle, or thread are interdependent. For example, a lightweight fabric and thin thread demand a smaller needle; using a large needle may damage lightweight fabric and thin thread. Likewise, too-thin thread may break if used with a thick needle or heavy fabric. Depending on thread count, fabric may require stabilizer or alteration before embroidering. Similarly, an *EBP* (i.e., the thread), *context* (i.e., the fabric), and *implementation strategies* (i.e., the needle) should be harmonized to minimize user burden and optimize implementation. In **Figure 1**, the **black thread** represents an **EBP** and the **blue fabric** represents **context**. Just as an embroiderer must first understand the fabric with which they are working, researchers and practitioners must obtain a nuanced understanding of context before selecting and adapting EBPs and implementation strategies[117,124-126]. The **red needle** represents the **implementation strategies** deployed to facilitate implementation. Just as the thread cannot weave itself into the fabric, an EBP is unlikely to embed itself into highly complex health care contexts, even if EBP usability and contextual appropriateness are high. In sum, embroidering requires harmony among **thread**, **fabric**, and **needle**. Analogously, the successful implementation and sustainment of EBPs requires alignment among **EBP**, **context**, and **implementation strategies**.

Figure 1. Harmonizing EBP, context, and implementation strategies



There is a critical need for the development of "relational, and dynamic approaches to theorising the complex interplay between the characteristics of interventions, the activities of implementers, and the properties of variable broader contexts"[127]. Indeed, advancing methods for harmonizing EBPs, contexts, and implementation strategies has been articulated as a priority for implementation research[117,128]. In this study, we sought to achieve this harmonization among AYA NA-SB, context, and implementation through the use of User-Centered Design (UCD).

3.2 User-Centered Design

UCD is an iterative and highly stakeholder-engaged process for creating products or innovations which are directly responsive to their intended users and users' contexts.[129] Primary goals of UCD are improving EBP *usability* (ease with which it can be successfully used[92]) and *usefulness* (extent to which it does what it is intended to do[130]). Usability and usefulness are theorized as proximal determinants of perceptual implementation outcomes (i.e., acceptability, feasibility, and appropriateness; e.g., usability promotes acceptability) through which they should also influence distal behavioral implementation outcomes (e.g., penetration, reach, sustainment; e.g., acceptability promotes reach)[21]. In this light, UCD may increase the extent to which interventions meet the goals and needs of users, thus facilitating their achievement of target service and patient outcomes.[131]

Most UCD definitions and frameworks share a common set of principles that can contribute to harmonizing EBPs, contexts, and implementation strategies: (1) refining innovations based on user input to optimize usability and usefulness;[132] (i.e., *review and refine prototypes*) (2) engaging prospective users to achieve a nuanced understanding of context (i.e., *understand users and context*), and (3) a multidisciplinary design team collaborating to *generate design solutions*. Together, these domains comprise an iterative cycle in which an EBP's design and implementation strategies can be refined until optimized for a given context.[22] Within each of these domains, UCD offers myriad methods[132] and strategies[133] for harmonizing EBPs, contexts, and implementation strategies (summarized in **Table 1)**. Although some of UCD's discrete methods and principles resemble those traditionally used in implementation science (e.g., stakeholder engagement), UCD is unique in its offering of an extensive suite of methods that may be leveraged to refine EBPs, contexts, and implementation strategies.

Table 1. Applications of UCD in implementation science

Construct	Definition	What UCD offers
Evidence-based practice *(the thread)*	Interventions with demonstrated efficacy and effectiveness including programs, actions, processes, policies, and guidelines[114]	• Selecting EBPs that are appropriate for users and their context (e.g., by leveraging UCD measures of usability such as *the System Usability Scale*[134]) • Redesigning EBPs to better fit users and their context (e.g., conducting *usability test* or *heuristic evaluation* to identify an EBP's design limitations)
Context *(the fabric)*	Set of characteristics and circumstances that consist of active and unique factors, within which the implementation is embedded including: • Inner (i.e., intra-organizational) context[135] • Outer (i.e., extra-organizational) context[135]	• Assessing context (e.g., conducting *ethnography* or developing *user experience models*) • Preparing context to promote receptivity to EBP (e.g., using *workflow mapping* to modify workflow to accommodate EBP implementation)
Implementation strategies *(the needle)*	Methods or techniques used to enhance the adoption, implementation and sustainability of an EBP[119]	• Anticipating needed implementation strategies based on context assessment (e.g., conducting *design workshops* to identify areas where fit between EBP and context is low and problem-solve accordingly) • Selecting strategies that are appropriate given EBP and context (e.g., using the *Cognitive Walkthrough for Implementation Strategies*[136] to assess strategy usability) • Tailoring/designing strategies for EBP and context (e.g., by conducting iterative *co-creation sessions* with users)

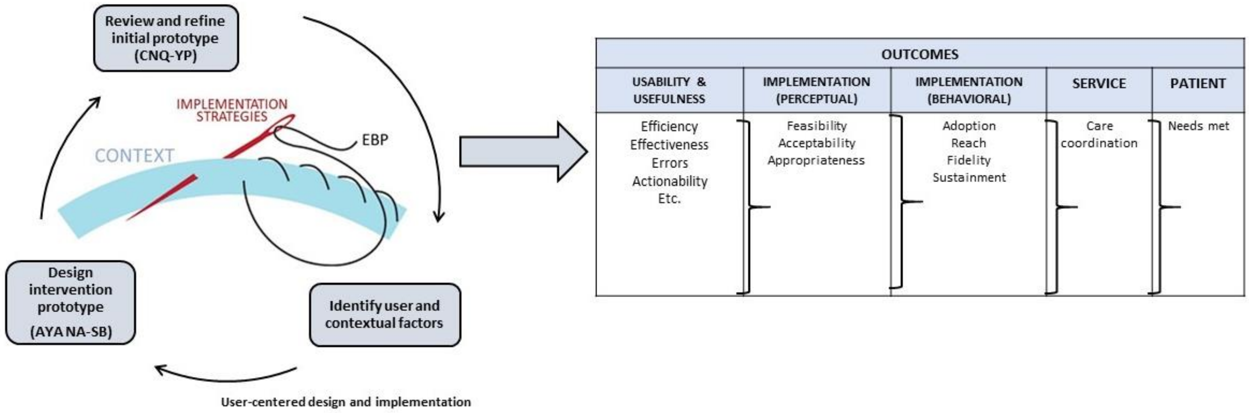
UCD flips the typical top-down approach to EBP design and implementation,[137] and instead relies on "action-oriented rapid prototyping of user-driven insights"[138]. As a result, UCD may increase stakeholder buy-in, generate pragmatic solutions, and facilitate rapid real-world practice improvement. Evidence suggests that UCD might be useful for developing EBPs which are more "implementable".[23] However, UCD's full potential for advancing the field of implementation science has not yet been realized [139,140]. In addition to its upstream utility for considering implementation during initial EBP development, UCD has other potential downstream uses in implementation science including: (a) optimizing an *EBP's* design to improve implementation outcomes (e.g., streamlining an EBP to improve feasibility), (b) preparing *context* to promote receptivity toward EBPs (e.g., redesigning workflows to accommodate EBP implementation), and (c) selecting or designing *implementation strategies* to be more attentive to EBP and context (e.g., deploying strategies that increase the contextual appropriateness of an EBP) —in effect, harmonizing EBP, context, and implementation strategies, advancing key goals of implementation science.

3.3 This Study's Conceptual Model

This conceptual model for this study integrates a UCD framework[22] into Proctor et al.'s conceptual model for implementation research[111] to illustrate more granularly the mediators between intervention (i.e., AYA NA-SB) and patient outcomes of interest (i.e., reduction in AYAs' unmet needs). Specifically, I used the embroidery analogy described above to embed context into Proctor's model and highlight the inextricable interplay among EBP, context, and implementation. Additionally, I positioned usability and usefulness as target outcomes of the UCD process, and determinants of implementation.[21]

Per this study's integrated conceptual model (**Figure 2)**, leveraging UCD should help to harmonize AYA NA-SB, its implementation context, and its implementation; this, in turn, should promote AYA NA-SB's usability and usefulness and, subsequently, implementation. In short, incorporating UCD to design AYA NA-SB *for implementation in context* should facilitate the intervention's achievement of key implementation, service, and patient outcomes.[141]

Figure 2. User-centered design and implementation



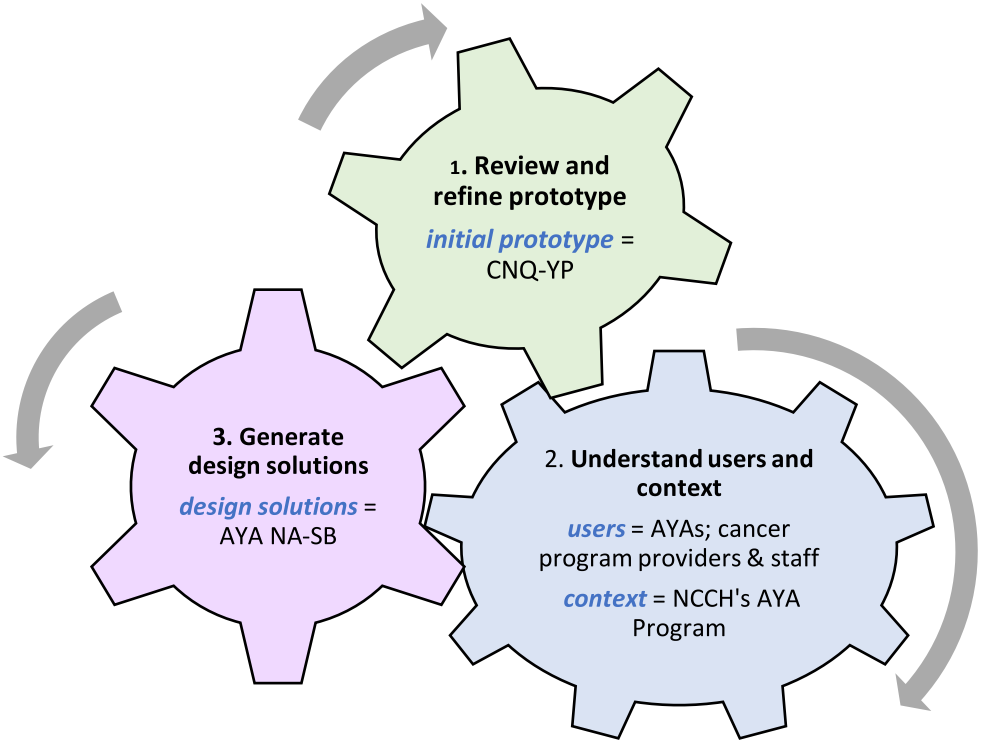
OUTCOMES				
USABILITY & USEFULNESS	IMPLEMENTATION (PERCEPTUAL)	IMPLEMENTATION (BEHAVIORAL)	SERVICE	PATIENT
Efficiency Effectiveness Errors Actionability Etc.	Feasibility Acceptability Appropriateness	Adoption Reach Fidelity Sustainment	Care coordination	Needs met

CHAPTER 4: METHODOLOGY

4.1 Overview

Leveraging the CNQ-YP as a starting point, I sought to develop AYA NA-SB and a plan for its implementation using principles and methods from UCD. Because I had a prototype already (the CNQ-YP), I approached the UCD process as outlined in **Figure 3**. Data collection methods, timeline, and users engaged for each of these stages are summarized in **Table 2** and **Figure 4**. All procedures were approved by the University of North Carolina's Institutional Review Board (19-0255).

Figure 3. UCD process



Stage 1: Review and refine prototypes

I used mixed methods to examine user interactions with the CNQ-YP in its current form (i.e., *usability testing*). Usability testing activities included (1) an online survey assessing AYAs' needs and preferences for a PROM using the CNQ-YP as a prototype for them to react to, (2) cognitive interviews with AYAs to obtain more in-depth qualitative data on the usability of the CNQ-YP, and (3) concept mapping[142] exercises focused on usefulness, in which AYA program providers and staff grouped PROM-identified AYA needs based on follow-up actions they should trigger.

Stage 2: Understand users and context

I used *ethnographic contextual inquiry*, including 'guided tours' and semi-structured interviews with prospective users (i.e., AYAs and AYA program providers and staff), to assess characteristics of users and context which should be considered in the design and implementation of AYA NA-SB.

Stage 3: Generate design solutions

At the study's onset, I convened a multidisciplinary *design team* comprised of researchers, cancer care providers, and AYAs from whom I solicited input throughout data collection and analysis. Through two *prototyping workshops*, the design team collaboratively redesigned the CNQ-YP with usability in mind and redesigned care processes to facilitate the tool's implementation and usefulness in routine care. These workshops resulted in an AYA NA-SB prototype and a preliminary plan for its implementation.

Table 2. Data collection summary

UCD Aim	Method	Deliverable
Review and refine prototype	Usability Testing • AYA Survey • Cognitive interviews with AYAs • Concept mapping with providers/staff	Evidence of the usability and usefulness of the CNQ-YP
Understand users and context	Ethnography • Guided tours with AYAs and providers/staff from NCCH • Semi-structured interviews with providers/staff from outside of NCCH	User and contextual requirements for AYA NA-SB's design and implementation
Generate design solutions	Design Team Workshops • Workshop #1 • Workshop #2	AYA NA-SB prototypes and anticipated implementation strategies needed
RESULT		A usable and useful PROM linked to available services and resources + implementation guidance

Figure 4. Data collection timeline and users engaged

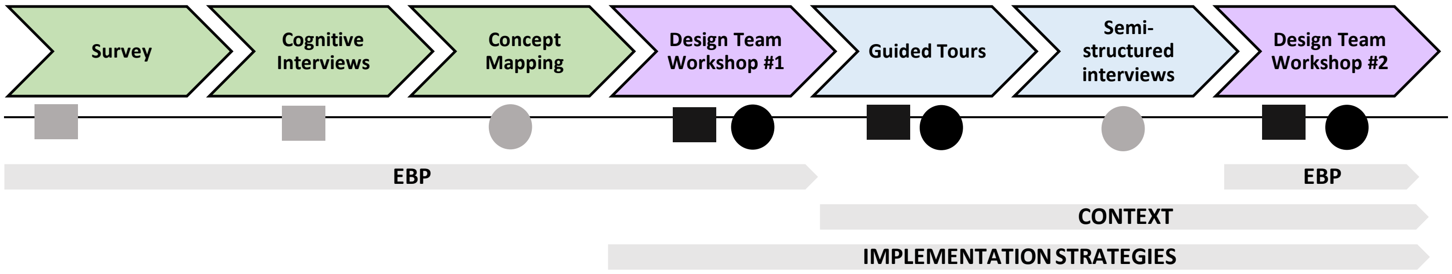


Figure 4 legend

▨ External young adults
■ NCCH young adults
○ External providers
● NCCH providers

🟩 **UCD STEP 1:** Review and refine EBP prototype

🟦 **UCD STEP 2:** Identify user and contextual requirements

🟪 **UCD STEP 3:** Design EBP and implementation strategy prototypes

Figure 4 demonstrates the iterative engagement of both NCCH and external users to harmonize, EBP, context, and implementation strategies. External users were engaged in the review and refinement of the CNQ-YP to avoid over-tailoring EBP to one unique context (i.e., to promote generalizability). Because guided tours would inform preparation of the implementation context (i.e., NCCH), NCCH users were engaged. Semi-structured interviews with external providers were then conducted to explore differences across contexts (i.e., to inform future scale-up in other cancer programs). The design team was comprised of NCCH users to allow for in-person collaboration to produce design solutions highly applicable to NCCH.

4.2 Stage 1: Review and Refine Prototypes

Overview

I conducted three rounds of *usability testing* to examine user interactions with the CNQ-YP: (1) an online survey assessing AYAs' needs and preferences for a needs assessment using the CNQ-YP as a prototype for them to react to; (2) cognitive interviews[143] with AYAs to triangulate survey data with in-depth evidence of their perceptions of the CNQ-YP's usability and usefulness; and (3) concept mapping[142] exercises focused on usefulness, in which AYA program providers mapped CNQ-YP-identified needs onto services/resources to address the needs.

AYA survey

I surveyed AYAs to assess the usability and usefulness of the Australia-developed CNQ-YP among AYAs in an American cancer care context. By administering the CNQ-YP and probing respondent reactions, I sought to identify missing content and streamline redundant or low-priority content and identify any other issues with the CNQ-YP's usability and usefulness. I considered an online survey an appropriate data source to meet these objectives because a broad and diverse sample of AYAs could be engaged, increasing the likelihood of AYA NA-SB's eventual generalizability.[144]

Sample. My target sample size for the survey was between 50 and 100 AYAs. Individuals were included in the survey sample if they met two inclusion criteria. First, they had to be between the ages of 18 and 39 at the time of survey completion. Individuals ages 15-17 years of age were not included; however, only this younger group of AYAs were engaged in initial CNQ-YP development so I expected their perspectives to have already been captured to some extent. The second inclusion criterion for the survey was a cancer diagnosis at some point prior to survey administration. I did not specify at which phase respondents should be in their cancer journey, as I was interested in responses of both cancer survivors and those actively in treatment.

Recruitment. To ensure that I recruited diverse AYAs from across the country (including variation across race, ethnicity, age, geographic region, setting of care, etc.), I used several approaches to obtain my survey sample:

- First, I employed a two-stage purposive sampling approach to recruit AYAs in which I identified five AYA cancer programs which vary along characteristics identified by Ferrari et al. as key areas of variation among AYA programs: location (e.g., state), type of institution (e.g., academic medical center; community-based cancer care program), model of care (e.g., pediatric oncology-based vs. adult oncology-based), and funding source (e.g., in-house, foundation, philanthropic, etc.).[27] Within each of these programs, clinical partners at NCCH identified key contacts through their existing professional network. Once identified, I emailed key contacts a brief description of the project and our requests for recruitment support. I followed up with key contacts who did not respond to initial emails using Dillman's approach for maximizing survey response rates which includes initial contact, then follow-up with non-responding key contacts at one, three, and seven weeks.[145] Next, key contacts facilitated the recruitment of AYAs at their respective institutions, using recruitment materials (i.e., email language describing the project + survey link) I provided them with. After their initial response, I sent email reminders to key contacts at two-week intervals, prompting them to redistribute the survey link to AYAs.
- Second, I recruited AYAs using social media, an approach that has proven viable for this population.[146] I tweeted the survey link five times over the course of five weeks. I also leveraged AYA cancer programs, networks, advocacy groups and individual advocates on Twitter (i.e., Stupid Cancer; Critical Mass, Teen Cancer America, and the AYA Cancer Societal Movement), asking these individuals and organizations to "retweet" survey information to their followers. For example, Teen Cancer America, an organization which partners with

hospitals throughout the United States to develop specialized facilities and services for teens and young adults with cancer, played an integral role in recruitment, disseminating the survey link through all of their social media channels, as well as through their national advisory boards comprised of AYAs. Additionally, I enhanced the visibility of Twitter posts by connecting to the recruitment Tweets multiple hashtags used commonly by the AYA cancer Twitter community (e.g., #ayacancer; #youngadultcancer; #cancersurvivor; #ayacsm).

- Finally, AYA design team representatives helped to disseminate the survey link to their networks (e.g., through listservs and groups pages for cancer support and advocacy groups such as First Descents and Cancer Dudes).

Instrument. I collaborated with the AYA NA-SB design team to develop a survey instrument with three sections (see **Appendix B)**. The first section included study information and consent and items collecting demographic and clinical information (i.e., age, gender, clinical characteristics, social support, educational/vocational status, health insurance status). The second section prompted AYAs to complete the CNQ-YP in its original form. The third section included items assessing respondents' perception of the CNQ-YP. To assess general attitudes towards the PROM, I used items from three validated Likert-type measures of feasibility, acceptability, and appropriateness.[147] I assessed usefulness (i.e., actionability) through two Likert-type items asking (1) the extent to which respondents thought the CNQ-YP accurately captured their needs, and (2) the likelihood that they would use services or resources offered to them based on indicated needs. These items were developed specifically for this project. For each of these measures, I qualitatively probed respondents on usability and usefulness issues driving their concerns with the PROM's feasibility, acceptability, or appropriateness.

Before broader dissemination, the tool was reviewed by clinical partners at NCCH and piloted by five AYA members of the study's design team (composition described in later section) to resolve any issues with wording, format, content, etc. I asked AYA representatives to take notes as they reviewed the survey independently, capturing any issues or concerns they encountered with the survey instrument. They then emailed that feedback to me and I synthesized this information and revised the survey instrument accordingly. Although a few minor changes were made to demographic questions (i.e., making the sex/gender item more inclusive) and item formatting (i.e., providing more explicit instructions for check all that apply items) in response to feedback from piloting, no changes were made to CNQ-YP content at this stage, as I wanted respondents to react to the PROM in its original form.

Procedure. I administered the survey through a secure online platform, Qualtrics (Provo, UT). Based on piloting of the survey instrument, I expected the 53-item survey to take approximately 30 minutes to complete.

Analysis. I exported survey data from Qualtrics and analyzed it using StataMP 15. I used descriptive statistics for respondents' demographics, needs reported on the CNQ-YP tool, and perspectives of the CNQ-YP tool's feasibility, acceptability, appropriateness, and actionability. For feasibility, acceptability, appropriateness, and actionability, I calculated an index score for each respondent by calculating an unweighted average score of items corresponding to each construct. I used template analysis[148] to synthesize responses to free-text items. Template analysis is a group of approaches for thematically analyzing and organizing textual data. In this approach, the researcher produces a 'template' (i.e., list of codes) which represent themes present in the data. Often, some codes are defined a priori in an initial template; a priori codes are supplemented and modified as the researcher interprets data. Template analysis often includes hierarchical coding, in which codes are clustered together under higher-order codes. For survey analysis, excerpts from free-text items were coded as usability or usefulness issues. Within each of these higher-order codes, I synthesized excerpts to identify emergent themes regarding the CNQ-YP's usability and usefulness.

Finally, I conducted bivariate regression analyses to examine (1) the relationship between demographic items and number of needs reported as "high" or "very high" on the CNQ-YP, and (2) the relationship between number of needs reported as "high" or "very high" and feasibility, acceptability, appropriateness, and actionability ratings. The purpose of these regression analyses was to identify patient characteristics which may influence level of need or receptivity to PROMs; this information would be useful in later discussions about potential barriers to implementing AYA NA-SB. For bivariate analyses of categorical independent variables, the most common responses were selected as referent groups.

Cognitive interviews

I conducted cognitive interviews with AYAs to supplement survey data on AYAs' perception of the CNQ-YP's usability and usefulness. The primary objective of these interviews was to explore in more depth any issues identified by survey respondents and to identify any remaining wording or comprehension issues with CNQ-YP items. Cognitive interviews are widely used in survey or questionnaire development to ensure respondents interpret and understand items as intended by developers.[149] They are particularly useful for developing surveys for diverse populations.[150]

To answer survey items, respondents must (1) understand the question (i.e., *interpretation*), (2) recall information pertinent to the question (i.e., *memory retrieval*), (3) decide on the relevance of information recalled (i.e., *judgment formation*), and (4) translate that information into an answer in the format provided by the interviewer (i.e., *response editing*).[143] One cognitive interviewing technique is asking participants to "think aloud", or verbalize their thoughts, as they walk through these four tasks of survey response. This approach can identify usability issues such as confusion or error in interpretation of items, difficulty recalling information needed to respond to items, or potential sources of bias in a set of items (e.g., content subject to social desirability bias).[150] Cognitive interviews can also help design or revise items that are usable across respondent subgroups; for example, they might be used to examine whether items are interpreted similarly across cultures.[151]

Sample. From among the AYA survey sample, I purposively recruited individuals between the ages of 18 and 39 with a current or past diagnosis of cancer. Consistent with cognitive interview methodology,[143] the target sample size was small (i.e., n=5-10); however, I prioritized demographic variation when sampling to promote the refined CNQ-YP's relevance to diverse AYAs. In cognitive interviewing, analytical objectives are qualitative, not quantitative. The goal is not to achieve sample sizes large enough for statistical analysis but, rather, to engage a variety of participants.[149]

Recruitment. At the end of the AYA online survey, respondents were asked whether they would be willing to participate in a future phone interview. If so, they were prompted to provide their email address to be contacted by a member of the study team. Using basic demographic information from the survey (i.e., geographic location, sex, age), I selected and recruited via email cognitive interview participants using the Dillman method,[145] described above. Once these individuals were contacted, email address information was deleted from the AYA survey dataset, to ensure that respondent data was not stored in conjunction with identifiable data. Through concurrent recruitment and data collection, I continued to recruit AYAs for cognitive interviews until thematic saturation was reached, i.e., when subsequent interviews did not generate new data regarding the CNQ-YP's usability or usefulness.

Instrument. With input from the design team, I developed the cognitive interview guide to encourage participants to "think aloud" as they read and reflected on the CNQ-YP itemset and probe them to comment on topics such as item content and wording, response options, format, length, comprehensiveness, repetitiveness, etc. (**Appendix C**). AYA design team representatives reviewed the instrument prior to conducting the first cognitive interview.

Procedure. I conducted cognitive interviews using the video-conferencing platform, Zoom; they were audio-recorded, and lasted one hour. I navigated the CNQ-YP through the Zoom screen-share function, walking the participants through the tool while soliciting their input on each section and item.

At the end of each CNQ-YP section, I summarized key takeaways with interviewees for the purposes of member checking.[152]

Analysis. Immediately following each cognitive interview, I used interview recordings to review and expand on interview notes. I then coded cognitive interview notes by section of the CNQ-YP. Although cognitive interviews are sometimes transcribed for analysis, it is often sufficient to analyze recordings or written notes, rather than transcriptions.[149] Given that the goal of cognitive interviews is often to generate item-level user feedback on a tool or instrument, it is also common practice in cognitive interview analysis to code data by section or item of that tool or instrument.[149] Within each CNQ-YP section, I coded excerpts as (1) usability/usefulness criticism, (2) usability/usefulness praise, and (3) recommendations for improvement. Themes within each of these domains were then summarized in a table organizing usability and usefulness input by CNQ-YP section for presentation to the design team during our first workshop, described in detail, below (**Section 4.4**).

Concept mapping

To promote the CNQ-YP's usefulness in practice, I engaged cancer care program providers and staff in an online concept mapping exercise. Through concept mapping, stakeholders are engaged in various activities to conceptualize constructs and relationships of interest,[153] Concept mapping is useful for triangulating across diverse stakeholder groups and is similar to "card sorting", a method frequently used in UCD.[132,154,155]

Concept mapping has been used in intervention development,[156,157] including the development of measures[158,159] and patient-reported outcome instruments.[160,161] It provides "(a) a solid method for establishing content validity, (b) [data to] facilitate researcher decision-making, (c) insight into target population perspectives that are integrated a priori, and (d) a foundation for analytical and interpretative choices".[159]

Because it engages stakeholders to create visualizations of constructs of interest, concept mapping represents a user-centered method for interpreting user data and making design decisions.[162] For example, Onken et al. engaged individuals with serious mental illness in concept mapping to generate clusters of community services and supports; these clusters were then interpreted by study participants to conceptualize and prioritize services and supports based on their most salient needs.[163] Similarly, the primary objective of concept mapping for this study was to generate data to aid the design team in connecting PROM-identified needs with the follow-up actions those needs should trigger. Ultimately, this would help organize our PROM based on follow-up actions needs should trigger, optimizing its usefulness for service and resource provision for AYAs.

Sample. Concept mapping participants included cancer program providers (e.g., oncologists, nurses, and social workers) and staff (e.g., program managers and administrators), prospective AYA NA-SB users who were expected to have the most knowledge about service and resource delivery for this population. These user groups were expected to provide key insights to ensure AYA NA-SB usefulness (i.e., that patient-reported data collected is explicitly tied to care delivery such that needs inform services and resources provided to AYAs). Although AYA feedback would be important in confirming concept mapping results during subsequent design team workshops, AYAs were not engaged in concept mapping because of extant literature pointing to their low awareness or knowledge of services and resources available to address their cancer needs.[13]

Recruitment. Recruitment through the key contacts established during AYA survey recruitment was intended to achieve the minimum sample size of n=15 needed for concept mapping analyses.[153] I emailed recruitment information to each of these key contacts, asking them to share the information with their colleagues. I also did a web-search to identify additional contacts from 20 AYA programs around the country; recruitment information was sent via email to each of these contacts, requesting that they participate in the concept mapping exercise and share the information with other AYA providers at their institution. Finally, recruitment information was disseminated through Twitter.

Data collection. In concept mapping, the first step often involves group brainstorming to generate a list of statements or items based on a focus statement or question of interest; participants then sort and rate these items, or a subset of them.[142] For this project, items were generated prior to the onset of concept mapping (i.e., during usability testing). After modifying the CNQ-YP according to feedback from the AYA surveys and cognitive interviews and with input from the design team, I pre-loaded the resulting list of AYA needs into an online secure platform called Concept Systems (CS) Global Max©. **Appendix D** includes this list of needs. Participants then completed two concept mapping exercises in CS Global Max©.

First, participants *sorted* an electronic deck of cards, each containing one AYA need, into like categories (i.e., “follow-up domains”). Although concept mapping studies often take an unstructured approach to sorting (e.g., instructing participants to sort items into categories which “make sense to you”), I offered a more specific focus statement to concept mapping participants in this study. In this study, the goal of concept mapping was to group needs into follow-up domains. Thus, it was necessary to provide more structure around the sorting exercise to prompt participants to conceptualize constructs in terms of service and resource provision. Specifically, I invited participants to sort AYA needs into groups “which they believe could be addressed by the same follow-up action”. For example, needs related to depression and anxiety might be grouped together as potentially addressable by referral to a mental health professional. After grouping needs into follow-domains, participants were asked to label each of the follow-up domains.

Second, participants *rated* AYA cancer needs on Likert-type response scales (from one to five) in terms of their *importance* (i.e., severity of consequences if that need goes unmet) and *actionability* (i.e., likelihood that need can be met through a service or resource), key pragmatic properties for measures and instruments.[164] Because AYA NA-SB is intended to facilitate service or resource delivery, it was particularly important to hone in on needs potentially amenable to services and resources.

Administration. Participants accessed the web-based concept mapping exercise through emailed links to the project in CS Global Max©. I expected the exercise to take approximately 30 minutes to complete.

Analysis. CS Global Max© software was used for a three-stage analysis of concept mapping data. First, the software places the data in a symmetric similarity matrix comprised of 0s and 1s denoting whether or not participants grouped pairs of needs in the same follow-up domain. Matrices for AYA needs were then summed within and across participants, resulting in a single overall matrix for the sample. Second, the overall matrix was analyzed using multidimensional scaling to create a two-dimensional visual representation of the distance between AYA needs (points on the map). Proximal needs (points) were more frequently grouped in the same follow-up domain than distal ones. The software then used hierarchical cluster analysis to characterize how participants grouped needs, creating as many potential cluster solutions as there were needs. Cluster solutions group points on the point map based on proximity into non-overlapping clusters; each cluster solution contains a different number of clusters. In concept mapping, selecting the most useful cluster solution, or number of clusters, represents a critical piece of analysis. There is no singular way to do this, however, the analyst typically facilitates discussion among a subset of participants, or a group of relevant stakeholders, who select the cluster solution that is most useful for the purposes of the project.[153] Because it is not feasible to present all cluster solutions to stakeholders, this process requires discretion on the part of the analyst in determining which cluster solutions make sense to present to stakeholders, given the goals of the project. The CS Global Max© software also created "go-zone graphs" by calculating descriptive statistics for the importance and actionability ratings and plotting them for each need. Using the mean score for each need, the resulting scatterplot featured four quadrants displaying the relative importance and actionability of needs; the quadrants were formed based on the overall mean for importance and actionability ratings across all needs.

Cluster solutions and go-zone graphs were reviewed by the design team during the first design team workshop (described in **Section 4.4**) to inform modifications to the CNQ-YP to enhance the tool's usability and usefulness. I selected a small subset of cluster solutions to present to the design team. For a set of fewer than one hundred statements, Kane & Trochim recommend starting by looking at cluster solutions ranging from three to 20 clusters.[153] Starting with the 20-cluster solution, I examined how the grouping of needs changed as the number of clusters decreased. Through this process, I selected five cluster solutions in which the grouping of needs made the most sense in terms of service or resource provision; I presented these five cluster solutions to the design team.

4.3 Stage 2: Understand Users and Context

Once usability testing of the CNQ-YP was complete, I used *ethnographic contextual inquiry*, including guided tours and interviews, to gather detailed information about prospective users and contexts to inform the tool's transformation into our next prototype, AYA NA-SB. The UCD process commonly incorporates *contextual inquiry* to gather detailed data on users and context. Contextual inquiry is a "field data-gathering technique that studies a few carefully selected individuals in depth to arrive at a fuller understanding of the work practice across all [users]".[165] The core premise of contextual inquiry is observing users in their own context and asking them questions about their attitudes, actions, and experiences. Specifically, contextual inquiry may be used to elicit data on user characteristics (e.g., knowledge, skills, experience, goals), tasks (i.e., activities undertaken to achieve a goal), and environment (technical, e.g., physical, social and organizational).[166]

In this study, I took an ethnographic approach to *contextual inquiry*. Ethnography, or research conducted in everyday settings, can provide rich data on health care experiences and interactions.[167,168] Ethnographic research focuses less on the quantification of individuals' words and actions and more on deriving meaning from these words and actions.[169] Such methods are applicable to the UCD process because they allow a more nuanced understanding of users and context than traditional questionnaires, including insights on user behaviors, attitudes, needs, and preferences.[129,132,170] Specifically, I conducted a focused ethnography, which differs from traditional ethnography because it is time-limited and topic-specific.[171]

Despite its potential value for contextualizing healthcare experiences, ethnography remains underused in health services research. In a 10-year review of the use qualitative methods in published health services and management research, Weiner et al. found that only four of 3,637 studies used ethnographic methods.[172] Nonetheless, some have recognized the important role that ethnography can play in the co-creation of health care interventions,[173] and also in implementation research.[174] For example, ethnographic methods can facilitate the in-depth study of organizational and contextual processes influencing implementation and sustainment,[175] particularly the non-rational (i.e., difficult to quantify e.g., emotional, collective) dimensions of healthcare interactions which other qualitative methods might not capture.[176] Finally, ethnography can illuminate the difference between what people say and what people do.[177]

Guided tours

To describe users and context, I first conducted "guided tours" with prospective AYA NA-SB users at NCCH, an ethnographic method in which study participant leads researcher through their environment, commenting on their thoughts and experiences as they go.[178] This method offers "details and motivations that are implicit to peoples' work because they have become habitual, who the users really are, how they work, and insight into the context of the usage situation."[144]

Sample. Understanding user and contextual factors necessitated the engagement of multiple user groups, particularly since providers and patients have reported differing perceptions of AYAs' prioritized needs.[179,180] To capture the perspective of those who would be responsible for implementing

AYA NA-SB in the future, I conducted guided tours with NCCH providers and staff including an AYA oncologist and an AYA social worker and program manager (n=2).

To capture the patient perspective, I conducted guided tours with AYAs receiving outpatient or inpatient care at NCCH (n=8). Although NCCH's AYA program serves individuals ages 15 to 39, I recruited only individuals between 18 and 39 years of age. However, AYAs were purposively sampled to included individuals receiving care in both pediatric and adult oncology departments. Since both departments serve AYAs, it is important that AYA NA-SB accommodate contextual factors which may vary between them (e.g., staffing). AYAs were also purposively sampled such that they varied along gender, race/ethnicity, and clinical characteristics.

Recruitment. The providers with whom guided tours were conducted were my clinical partners at NCCH and also members of the study's design team. As such, their involvement spanned the entire project. They also helped to facilitate the recruitment of AYAs for guided tours. First, I provided a list of eligibility criteria to them and a one-page document summarizing the study and what participation would entail. During visits with AYA patients, clinical partners offered AYAs this recruitment flyer. Clinical partners then connected me via email or text message to AYAs interested in participating. I then responded to these individuals with additional information about the project and their potential role. I followed up with non-responders using the Dillman method, described in a previous section (**Section 4.2**). Once AYAs indicated their willingness to participate, I moved forward with scheduling a time to meet with them during an upcoming appointment.

Instrument. Guided tours require flexibility and an unstructured approach to interviewing, such that the study participant is in control.[178,181] However, with input from the design team, I developed a repository of potential questions in advance based on four domains of Maguire et al.'s typology of user and contextual factors to consider in UCD: (1) user group characteristics (e.g., "what is your role in caring for AYAs with cancer?"), (2) user tasks (e.g., "walk me through what a typical appointment looks like for you”), (3) physical and technical environment (e.g., “where do you currently seek information about resources and services available for AYAs?”), and (4) organizational environment (e.g., “does your institution support the establishment of systems or processes specifically for AYAs?”).[132] Maguire et al.’s framework is sufficiently broad to capture the experience of various user types (e.g., AYAs and providers); however; a separate list of example questions were developed for AYA and provider guided tour participants. This typology and example questions can be found in **Appendix E.**

Procedure. During guided tours with providers, I shadowed each for 4 hours, as they completed clinical, administrative and other duties, asking them questions about their tasks and thoughts as we went.

During AYA outpatient guided tours, I met AYAs in the lobby of NCCH 15 minutes before their appointment time to walk them through the consent form and answer any questions they had before giving consent to participate. I then followed AYAs and accompanying family members for the duration of their outpatient appointments, asking them questions as they interacted with their environment and health care professionals while also taking care not to interject too often. During AYA inpatient guided tours, I visited AYAs in their rooms. After receiving their informed consent, I proceeded to spend the next one to three hours with them, observing their surroundings and interactions, and asking them about their daily tasks and experiences while receiving inpatient care. All AYA participants received a $50 Amazon gift card as a modest token of appreciation for their time.

Guided tours were audio-recorded with consent of participants and anyone accompanying them, including providers and hospital staff present for any length of time. To respect the privacy of non-consenting individuals, the recording device was only turned on during more private interactions. For example, when walking through busy hallways or areas with other patients and families around, the recording device would be turned off. I took extensive field notes, capturing conversations with AYA participants as well as conversations amongst AYAs and their treatment staff or other parties present. Also documented in field notes were nonverbal cues and features of the physical environment.

Important to ethnography and contextual inquiry is the researcher's triangulation across multiple data sources.[182] Thus, during guided tours, I collected documents (e.g., informational materials in patient waiting rooms) and took photographs of physical spaces in NCCH to supplement data from field notes and recordings. All photographs and documents were uploaded and amended to field notes.

Analysis. Immediately following each guided tour, I reviewed recordings from that tour to elaborate extensively on field notes. Because these tours often spanned the course of several hours, it was not feasible to transcribe each of them. In fact, transcription is not always appropriate for ethnographic activities such as observation because key nonverbal information is lost when data is extracted solely from transcripts. In ethnography, data collection and analysis are recursive[183] and field notes are expanded post-data collection through inscription (i.e., retrospectively recording events from memory), additional data sources (e.g., photographs), and returning to participants for additional information. "The point of field notes is eventually to have written down all the information that you think may be relevant to your research".[182] Thus, it is standard practice in ethnography to code field notes, rather than transcribing detailed encounters occurring during participant observation.[184-186]

Data from guided tours and subsequent semi-structured interviews were analyzed using a template analysis approach based on *a priori* themes (i.e., Maguire's constructs) but allowing for emergent themes (see **Section 4.2** for a description of template analysis).[148] See the codebook for ethnography analyses in **Appendix E**; the broadly applicable domains and constructs of Maguire's framework allowed me to use the same codebook for both AYA and provider guided tours as well as for semi-structured interviews. In ethnography, "solo coding" is not uncommon, as one researcher works intimately and recursively with the data.[187,188] However, to ensure interpretive convergence, a colleague with extensive experience conducting qualitative research and I independently abstracted excerpts from one set of guided tour field notes to calibrate our coding schema. We then met to discuss any discrepancies in our coding. Once all discrepancies were resolved, I proceeded to code the remaining guided tour field notes and semi-structured interview transcriptions. This double coding of a subset of the data, followed by individual coding of the remaining data, represents a commonly-used approach in the qualitative literature,[189] and a useful means of ensuring codebook quality.[190] For each Maguire domain, I synthesized user and contextual factors and created a "translation table"[191], which translates factors into their implications for designing an intervention and its implementation. This translation table was reviewed by the design team during our second workshop (described in **Section 4.4**).

Interviews

To ensure AYA NA-SB's applicability outside of NCCH, I also conducted semi-structured interviews with external (i.e., non-NCCH) users to inform future scale-up and sustainability.[192] The primary objective of these interviews was to review the user and contextual factors identified by NCCH users during guided tours, and to identify any areas of divergence or additional factors to consider across diverse health systems. Because the goal of these interviews was to identify differences between NCCH and other institutions, priming participants with user and contextual information about NCCH was considered appropriate. Such information was critical in identifying areas in which AYA NA-SB would require flexibility in delivery to accommodate differences across users and contexts.

Sample. I conducted interviews with users outside of NCCH (n=5), specifically, the key AYA program contacts who helped facilitate AYA survey and concept mapping recruitment (described above, in **Section 4.2**). These individuals included program managers, nurses, and patient navigators serving primarily AYA patients.

Interview guide. With input from the design team, I developed a semi-structured interview guide based on Maguire's typology [132] and guided tour findings (**Appendix F**). Topics addressed included AYA program structure, functions, funding and staffing; processes and tools used for identifying AYA patients, assessing and addressing AYAs' needs, and documenting information about AYAs' needs; and perspectives on AYA NA-SB content and delivery.

Data collection. I conducted one-hour semi-structured telephone interviews. At the end of each interview, I summarized major takeaways for the purposes of member checking. [152] I audio-recorded and transcribed interviews verbatim.

Data analysis. I analyzed interview data alongside data from guided tours, using the template analysis approach[148] described above, in **Section 4.3**. I summarized points of variation between NCCH and interviewees' institutions for presentation to the design team during the second workshop. Where interviewees discussed tools and other interventions their institution had employed to assess and address AYAs' needs, I summarized this information in an additional table for presentation to the design team during the second workshop.

4.4 Stage 3: Generate Design Solutions

Overview

A key UCD principle is the collaboration of a multidisciplinary design team to create intervention prototypes.[132] At each phase of the project, AYA NA-SB prototypes were presented to the design team and, based on their interactions with prototypes, iterative improvements made to AYA NA-SB content and delivery. Design team members offered key insights to inform data collection (e.g., review of instruments), data analysis (e.g., selection of concept mapping cluster map; prioritization of user and contextual requirements), and, ultimately, AYA NA-SB and implementation strategy design. Further, design team members proved critical to the recruitment of users for usability testing and ethnographic data collection. The design team in this study represents an iterative approach to user engagement, with the same group of users reviewing prototypes at multiple time points; this type of iteration may be a key moderator in the relationship between stakeholder engagement and improved design.[193]

Sample. At the onset of the project, I convened a design team consisting of academic researchers in cancer care delivery and implementation science, individuals with expertise in UCD, and prospective AYA NA-SB users. User groups included clinical partners at NCCH, and five AYA representatives nominated by clinical partners. These AYAs were primarily individuals who had previously expressed interest in research or advocacy activities related to AYA cancer and would thus be more likely to consider the ongoing participation that joining the design team would entail.

Recruitment. To recruit young adult representatives for the design team, clinical partners connected young adult representatives to me via email. I provided them with project materials including a project summary, a breakdown of their expected role and time commitment, and a brief summary of UCD. I then met with each young adult interested in participating to discuss the project and develop rapport, followed by meeting with all young adult representatives to build group rapport. I offered young adult representatives a one-time $150 incentive for participation.

Design Team Workshop #1

Overview. After the survey, cognitive interviews, and concept mapping, I convened the AYA NA-SB design team for a workshop in which we selected the most interpretable concept mapping cluster map and considered eliminating from the CNQ-YP needs that were, relative to others, less important and actionable. The elimination, addition, or refinement of CNQ-YP items was further informed by usability and usefulness data from the AYA survey and cognitive interviews. Once the design team generated a list of high-priority needs grouped by follow-up domains, they collaboratively identified services and resources at NCCH which corresponded to each follow-up domain. The goal of the meeting was to redesign a PROM for use in AYA NA-SB in which priority needs were grouped based on services and/or resources available at NCCH that could address those needs.

Sample. Attendees of Design Team Workshop #1 included me (expertise in implementation science and UCD), AS (AYA oncologist), LL (AYA program director and social worker), a palliative care fellow, and AYA design team representatives (n=3).

Materials. Design team participants were each given a packet of information including (1) a meeting agenda, (2) a project overview, (3) the original CNQ-YP, and (4) usability testing results (see **Appendix G**). Additionally, I developed index cards representing each item up for discussion (i.e., those rated as low importance-low actionability during concept mapping, or those for which other salient issues were identified during usability testing). On the front of these index cards was the item itself; on the back, I included results from usability testing with respect to that item. Specifically, results depicted on the index cards included (1) each item's average importance and actionability ratings from concept mapping, (2) each item's average rating on the AYA survey from one (no need) to five (very high need), and (3) select takeaways from cognitive interviews related to that item's usability or usefulness. I also developed index cards representing needs to consider amending to the itemset. I elicited these potential additional needs from qualitative data from the AYA survey and cognitive interviews. Attendees were also given "cluster comparison worksheets" (**Appendix G**) which visually depicted, by cluster, the differences between various cluster solutions generated from concept mapping data.

Procedure. Design Team Workshop #1 was held on January 29, 2020 from 12:00pm to 4:00pm. Lunch was provided. First, I gave a brief presentation outlining goals for the project, goals for the workshop, and a summary of project activities and results to date (i.e., usability testing results). Second, we used usability testing results to refine the CNQ-YP itemset, eliminating, revising, and adding items based on user feedback. To facilitate this conversation, we discussed each index card in the two decks representing items up for discussion and potential additional items, respectively. Points of discussion included usability testing results with respect to each item and potential overlap with other items in the itemset. After a brief discussion about each item, workshop attendees then voted on that item through open (versus private) voting. Red stickers were used to vote on an item's elimination; green stickers were used to vote to keep an item; yellow stickers were used to vote on a major revision or indecision about an item. Votes were then tallied to arrive at a decision about that particular item; where voting was split (i.e., greater than two design team members in opposition), we discussed further until the design team reached consensus.

Once changes were made to the itemset, we turned our focus towards grouping items into appropriate follow-up domains. First, to inform our discussion, I gave a brief overview of services and resources available at NCCH, identified through an environmental scan of NCCH's website, in-clinic brochures, and other relevant documents. We then reviewed various cluster solutions generated from concept mapping results. Attendees recorded on their "cluster comparison worksheets" their preferences regarding cluster breakdowns. They were also asked to highlight any items which seemed out of place in a given cluster. Then, through collaborative discussion, we selected the most interpretable cluster map (i.e., the one with the highest face validity). We then moved items between clusters, as needed. Finally, we labeled each cluster according to the service/resource/follow-up action that needs in that cluster should trigger. Labeling was informed by labels ascribed to clusters by concept mapping participants, which are distilled by the CS GlobalMax software during analysis. Labeling was also informed by a list of services and resources at NCCH, generated through the aforementioned environmental scan.

Finally, we discussed response options, format, and sequencing of the PROM. This discussion was informed by summaries of user feedback on these issues. After a brief discussion of the upcoming Design Team Workshop #2 and brainstorming of necessary attendees, we concluded the meeting.

Analysis. Detailed notes were taken during Design Team Workshop #1 to capture all discussion points leading to decisions on AYA NA-SB content; the meeting was also recorded for further elaboration on meeting notes. After the workshop, I drafted the revised PROM based on items eliminated or added to the CNQ-YP as well as item revisions discussed. In this draft, needs were grouped by follow-up domain. This revised PROM also reflected changes made to item formatting, sequencing, and response options. I sent this refined PROM via email to all members of the design team to solicit additional feedback on the itemset and its division into follow-up domains.

Design Team Workshop #2

Overview. After soliciting user and contextual data through guided tours and interviews, I convened the design team for a second workshop during which I presented them the ethnography findings in juxtaposition with the PROM content produced during the first design team workshop. This juxtaposition allowed design team members to anticipate context modifications and needed implementation strategies *with respect to* the redesigned tool itself. For example, the content of the tool might necessitate its administration by providers with certain areas of expertise (e.g., social workers); staffing and workflow patterns may need modification to facilitate this administration by social workers. Through popular UCD methods, 'storyboarding' (i.e., "sequences of images which show the relationship between user actions or inputs and system"[132]), 'personas' (i.e., using caricatures of key user groups to convey users' needs to the design team), and 'scenarios of use' (i.e., using specific examples of how users, context, and AYA NA-SB might interact),[132] we collaboratively specified who will deliver the needs assessment, when, how often, and the materials and procedure that will be used to do so. Additionally, we used this workshop to co-design the bridge between identified needs and care delivery—in other words, making explicit the referral pathways connecting PROM-identified needs and follow-up actions they should trigger. Finally, this workshop was used to plan for AYA NA-SB implementation.

Sample. Attendees of Design Team Workshop #2 included me, AS (AYA oncologist), LL (AYA program director and social worker), and the same AYA design team representatives who attended Design Team Workshop #1 (n=3). Because designing AYA NA-SB referral pathways was an objective of this meeting, I also included various providers involved in AYA care at NCCH (n=6) including (1) a pediatric oncology nurse practitioner, (2) a pediatric palliative care social worker, (3) a nurse navigator, (4) a pediatric palliative care physician, (5) a chaplain, and (6) a second AYA social worker. The purpose of including these individuals was to capture the perspectives of the range of provider groups that might interface with AYA NA-SB in practice and also to build buy-in for future AYA NA-SB implementation at NCCH, potentially strengthening referral pathways.

Materials. I gave design team participants a packet of information including (1) a meeting agenda, (2) a project overview, (3) the revised PROM developed through Design Team Workshop #1, and (4) ethnography results (see **Appendix H**). Ethnography results included translation tables from provider and AYA guided tours (i.e., user and contextual factors translated into their implications for AYA NA-SB delivery), a synopsis of how data from semi-structured interviews with external users converged and diverged from ethnography data collected at NCCH, and a table displaying case examples of how other institutions were delivering similar interventions (elicited from semi-structured interviews). Other materials included a storyboard of AYA NA-SB delivery, personas, and scenarios of use (see **Appendix H**), all of which were generated based on ethnography findings. Four personas were crafted to represent four user types: (1) an AYA receiving care in pediatric oncology, (2) an AYA with frequent inpatient stays, (3) an AYA receiving maintenance treatment with appointments occurring less frequently, and (4) an AYA with a prognosis of less than one year. Scenarios of use reflected various appointment types and were presented using a flowchart of patients' appointments. For example, one scenario included labs, treatment, and a clinical appointment; another included just treatment; a third included just a clinical appointment.

Procedure. Design Team Workshop #2 was held on February 26, 2020 from 12:00pm to 4:00pm. Lunch was provided. First, I gave a brief presentation outlining goals for the project, goals for the workshop, and a summary of project activities and results to date (i.e., Design Team Workshop #1 and ethnography). Second, we revisited the needs assessment revised through Design Team Workshop #1 to discuss some outstanding issues related to needs assessment content (e.g., the response scale).

After discussing the needs assessment, I reviewed the ethnography translation tables, giving the design team the opportunity to vet my translation of user and contextual factors into user and contextual requirements. I then engaged design team members through storyboarding, scenarios of use, and personas to inform the collaborative specification of AYA NA-SB delivery, including who should deliver the PROM, through what mode, and when and how often the PROM should be administered. These specific dimensions of delivery were derived from the Template for Intervention Description and Replication (TIDieR) checklist.[194] To facilitate this discussion, I divided AYA NA-SB delivery into six segments: (1) AYA receives and completes needs assessment, (2) AYA "turns in" needs assessment, (3) data is documented, (4) data is interpreted to identify appropriate services/resources, (5) service/resource providers are notified, and (6) services and resources are provided. I then walked workshop attendees through each segment, priming them with user and contextual requirements relevant to that segment, as well as any other pertinent data. Together, we specified each segment of delivery, discussing both a pilot scenario as well as future broader implementation. The selected specification options were then vetted in terms of personas and scenarios of use generated from ethnographic data. The goal of this vetting process was to ensure that the specification of AYA NA-SB delivery was appropriate across the various user types depicted by personas (e.g., pediatric vs. adult patient) and across potential scenarios of use (e.g., different appointment types).

During the second design team workshop, we also discussed the future implementation of AYA NA-SB, anticipating barriers and facilitators to implementation and brainstorming strategies to optimize AYA NA-SB implementation. This discussion was informed by a list of barriers and facilitators that I gleaned from usability testing and ethnographic data. We used PollEverywhere to rank this list of barriers from most to least salient. We then discussed the three barriers ranked as the most salient in terms of the mechanisms driving those barriers as well as potential strategies to address them.

Analysis. I took detailed notes during Design Team Workshop #2 to capture all discussion points leading to decisions on AYA NA-SB delivery and implementation; the meeting was also recorded for further elaboration on meeting notes. I synthesized and analyzed notes inductively to document the results of design team prototyping and generate guidance for AYA NA-SB delivery and implementation.

CHAPTER 5: FINDINGS

5.1 Design Team Composition

Young adult representatives included a racially and ethnically diverse group three women and two men. They represented different diagnoses and different timepoints in their cancer trajectory, with one in active treatment, one in maintenance treatment, and the others in the survivorship phase. In addition to their lived experience with cancer, young adult representatives brought various other areas of content expertise to the project, including training in instructional design and mental health service delivery.

5.2 AYA Survey

Participants

A total of 99 AYAs completed the online survey, with n=70 meeting the eligibility criteria and the threshold for response completeness (i.e., made it to the CNQ-YP section of the survey). Although my recruitment approaches did not allow for the calculation of a response rate, the broad dissemination of the survey link through various channels increases the likelihood that I reached a diverse national audience as intended. Based on analytics provided by Twitter, the 5 tweets disseminated by the study team received 13,088 views. This does not include views of Tweets disseminated by other stakeholders (e.g., Teen Cancer America) through their own social media channels. Key contacts also proved vital to recruitment. These AYA providers disseminated the survey link through social media, patient advisory boards, email listservs, newsletters, and word-of-mouth. AYA design team representatives also disseminated the survey link to their networks (e.g., online cancer support groups and email listservs for

AYA programs). Qualtrics analytics indicated that most survey respondents (81%) accessed the survey through social media versus 19%, who accessed the survey through another means.

Survey respondents, summarized in **Table 3**, were 79% female and 21% male. N=2 respondents reported being transgender. Respondents ranged in age from 18 to 30, with a mean age of 24. In terms of race/ethnicity, they identified as Non-Hispanic White (70%), Hispanic (14%), Non-Hispanic Asian or Pacific Islander (4%), Non-Hispanic American Indian or Alaska Native (3%), Non-Hispanic Black (1%), and other/unknown (7%). They represented 18 types of cancer, with Hodgkin Lymphoma (n=14, 21%), leukemia (n=11; 16%), and sarcoma (n=9; 13%) being the most common. 1% of respondents were stage 0 at diagnosis; 34% were stage I/II; 31% were staged III/IV; the rest (32%) reported that they were not staged or stage unknown. 27% reported being in active treatment at the time of survey completion but, for most respondents (71%), a year or more had passed since their initial cancer diagnosis.

Survey respondents reported a diversity of living situations: 12% reported living alone, 43% with parent(s), 28% with spouse or partner, and 18% with roommates. N=4 respondents reported having children. AYAs varied in terms of educational level, with 3% reporting less than high school education, 38% reporting some college or an associate degree, 22% reporting college graduation, and 24% reporting educational training beyond an undergraduate degree. They represented a range of insurance sources, both public and private; parents' insurance, however, was the most commonly reported source of insurance (37%), followed by employer/school insurance (27%). Of note, 5% reported being uninsured.

Table 3. AYA survey summary statistics

Sex and gender identity	
Female	55 (78.6%)
Male	15 (21.4%)
Transgender	2 (2.9%)
Age	
Mean (SD)	24.24 (3.96)
Race	
Hispanic (all races)	10 (14.3%)
Non-Hispanic American Indian/ Alaska Native	3 (4.3%)
Non-Hispanic Asian or Pacific Islander	2 (2.9%)
Non-Hispanic Black	1 (1.4%)
Non-Hispanic White	49 (70.0%)
Other	5 (7.1%)
Cancer type	
Non-Hodgkin lymphoma	5 (7.1%)
Hodgkin lymphoma	15 (21.4%)
Leukemia	11 (15.7%)
Sarcoma	9 (12.9%)
Cervical	1 (1.4%)
Other female reproductive	3 (4.3%)
Male reproductive	1 (1.4%)
Thyroid	5 (7.1%)
Brain	5 (7.1%)
Melanoma	2 (2.9%)
Colorectal	1 (1.4%)
Breast	4 (5.7%)
Other	8 (11.4%)
Stage at diagnosis	
0	1 (1.4%)
I/II	24 (34.3%)
III/IV	22 (31.4%)
Unknown/ unstaged	23 (32.9%)
Time since diagnosis	
< 3 months	3 (4.3%)
3-6 months	9 (12.9%)
7-12 months	8 (11.4%)
>12 months	50 (71.4%)
In active treatment?	

no	51 (72.9%)
yes	19 (27.1%)
Cohabitants	
Parent(s)	29 (42.7%)
Spouse	12 (17.7%)
Non-spouse partner	7 (10.3%)
Child/children	4 (5.9%)
Roommate(s) (not parent, spouse, or child)	12 (17.7%)
Lives alone	8 (11.8%)
Education level	
< high school	2 (2.9%)
Completed high school	9 (13.2%)
Some college/ vocational training	23 (33.8%)
Associate degree	3 (4.4%)
College graduate	15 (22.1%)
Graduate degree or some post-graduate education	16 (23.5%)
Insurance source	
Self-pay	4 (5.9%)
No insurance	3 (4.4%)
Employer/ school	18 (26.5%)
Spouse's employer/ school	2 (2.9%)
Parent	25 (36.8%)
Medicare	3 (4.4%)
Medicaid	8 (11.8%)
Military/ TRICARE	8 (11.8%)
other	5 (7.3%)
	N=70

Descriptive statistics

Needs. AYA survey respondents reported many and diverse needs on the CNQ-YP section of the survey. **Figure 5** displays the distribution of the number of needs rated as "high" or "very high". Number of needs rated as "high" or "very high" ranged from 0 to 54, with an average of 24 needs. **Figures 6-10** display the average rating of needs by CNQ-YP section.

Figure 5. Number of needs reported as "high" or "very high"

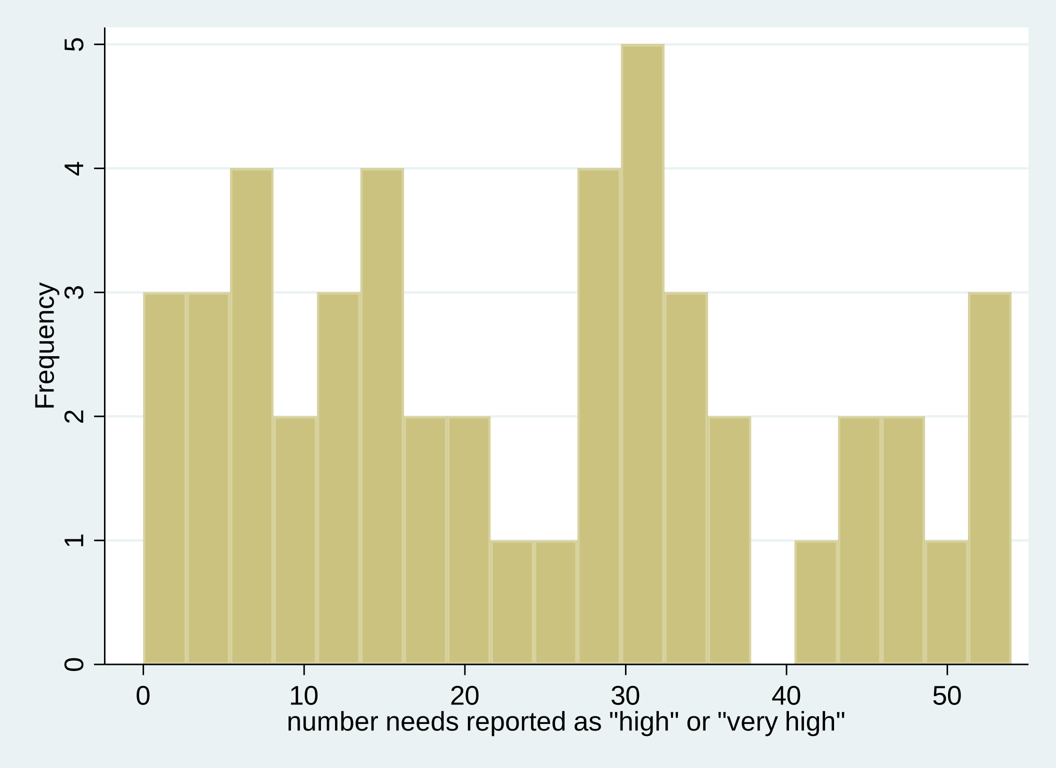


Figure 6. Average rating of needs: treatment environment & care section

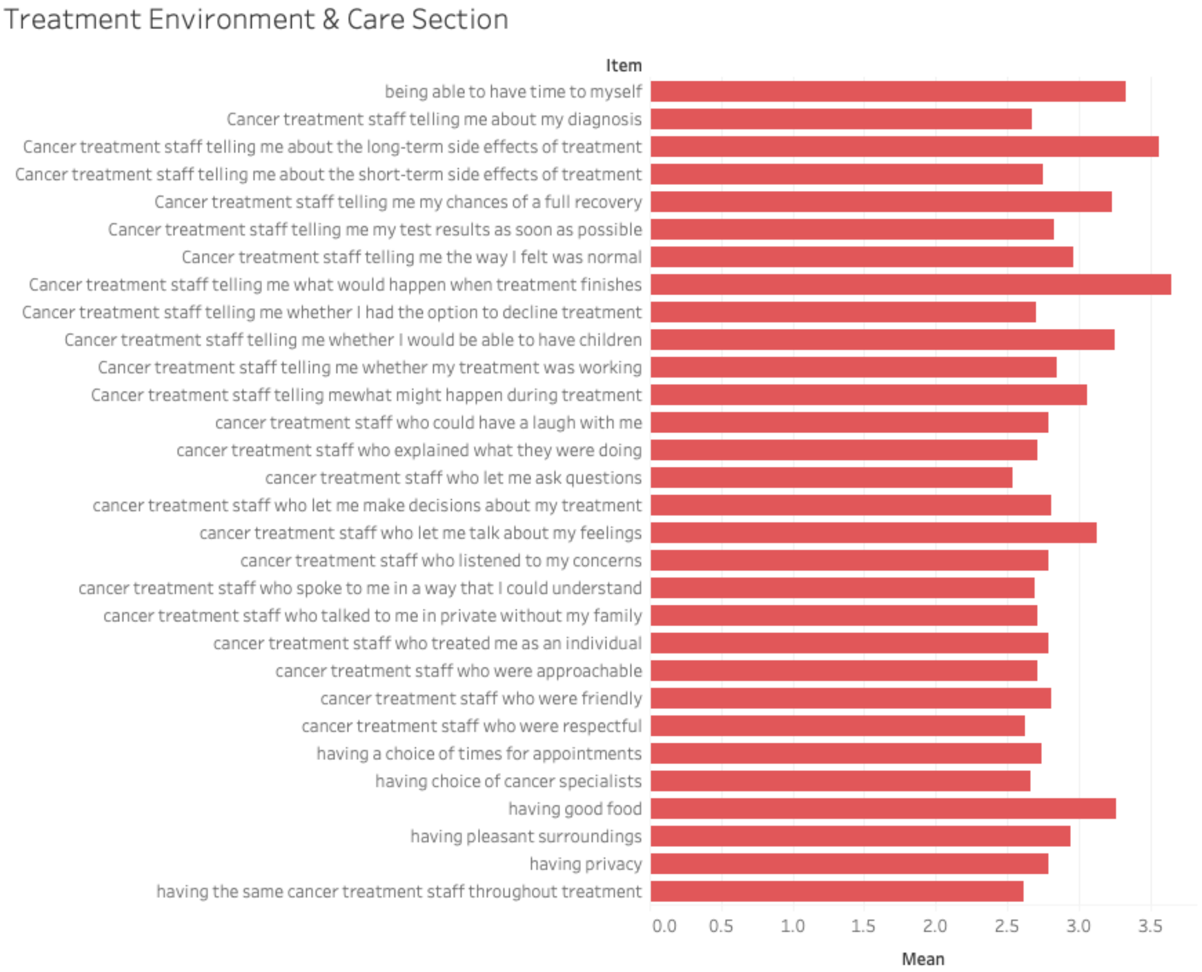


Figure 7. Average rating of needs: education section

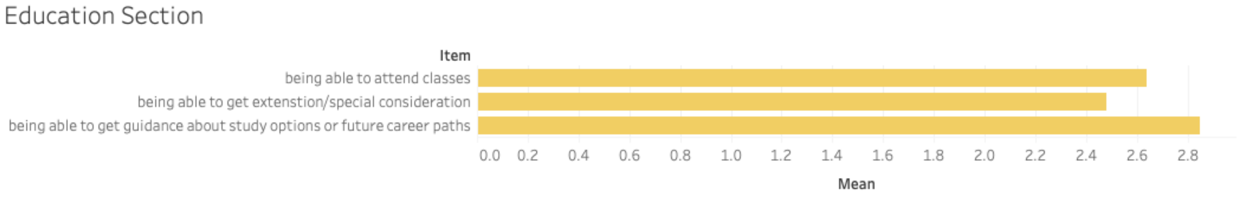


Figure 8. Average rating of needs: work section

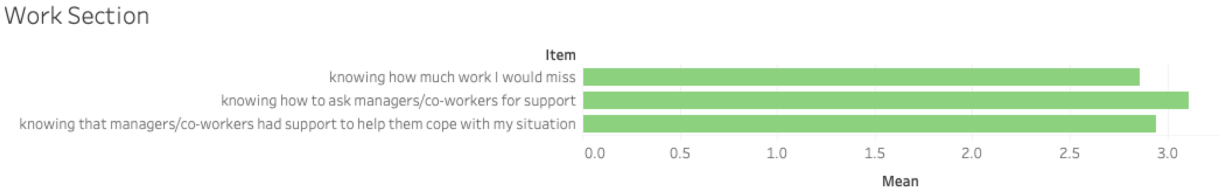


Figure 9. Average rating of needs: feelings & relationships section

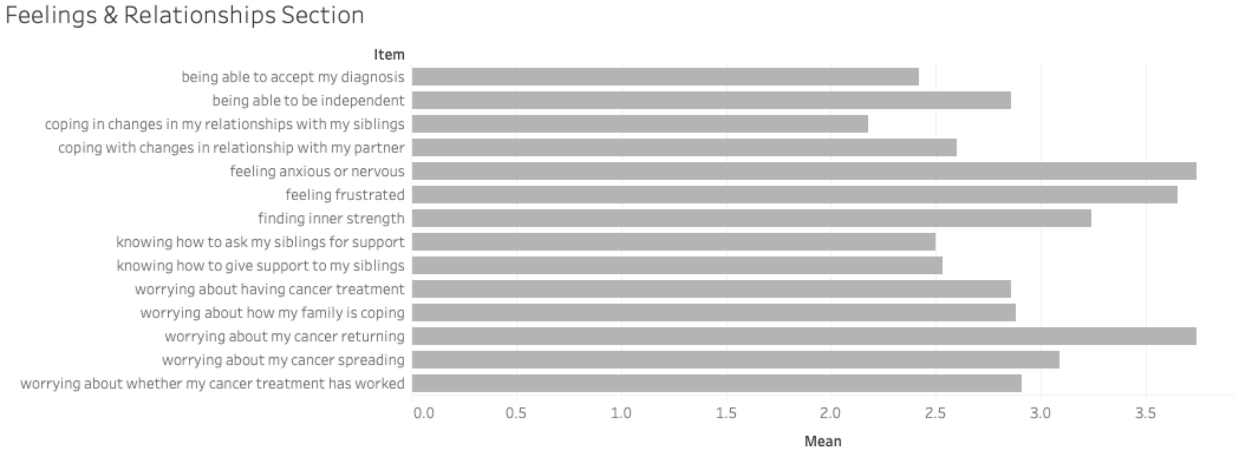
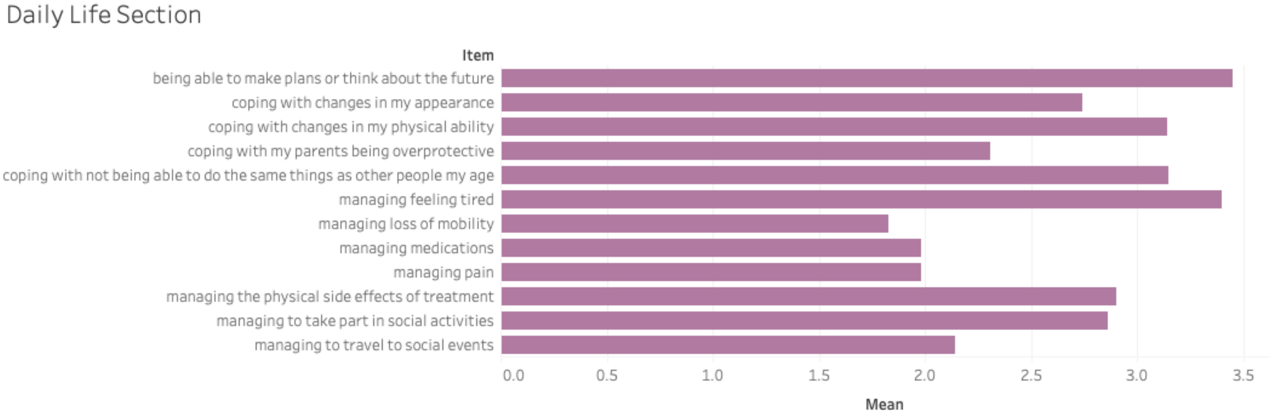


Figure 10. Average rating of needs: daily life section

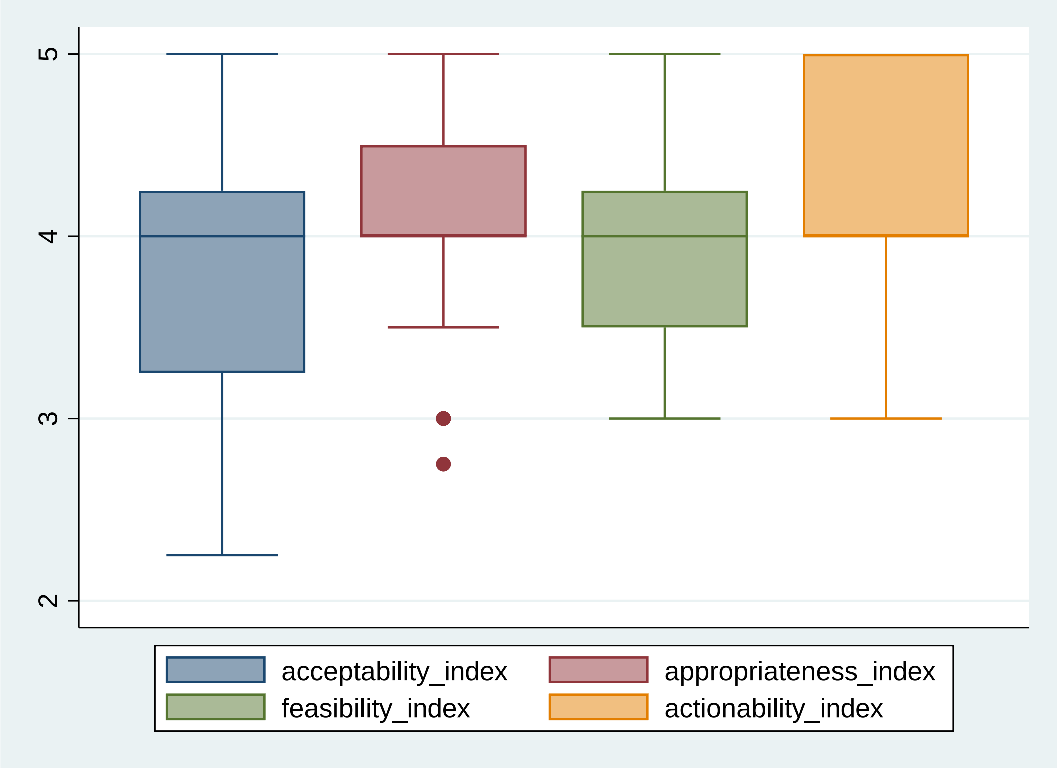


Evaluation of CNQ-YP. On average, respondents scored CNQ-YP's acceptability at 3.8 out of 5, its appropriateness at 4.1, its feasibility at 4.0, and its actionability at 4.3 (i.e., where 1=strongly disagree; 5=strongly agree). **Table 4** depicts these mean index scores as well as mean scores for the individual items comprising each measure. **Figure 11** displays index scores on box and whisker plots.

Table 4. Evaluation of CNQ-YP

Measure	Statistics
Acceptability	
The CNQ-YP meets my approval	4.0 (0.7)
The CNQ-YP is appealing to me	3.8 (0.9)
I like the CNQ-YP	3.7 (0.9)
I welcome the CNQ-YP	3.8 (0.8)
Index	3.8 (0.7)
Appropriateness	
The CNQ-YP seems fitting as a needs assessment tool for adolescents and young adults with cancer	3.9 (0.9)
The CNQ-YP seems like a suitable tool for my doctor to administer to me as part of my cancer care	4.1 (0.6)
The CNQ-YP seems applicable to adolescent and young adult cancer care	4.2 (0.6)
The CNQ-YP seems like a good match for adolescents and young adults	4.1 (0.6)
Index	4.1 (0.6)
Feasibility	
The CNQ-YP seems like something my doctor could administer to all of their patients	4.0 (0.8)
The CNQ-YP seems possible for me to complete as part of my care	4.1 (0.6)
The CNQ-YP seems doable	4.1 (0.6)
The CNQ-YP seems easy to use	3.9 (0.9)
Index	4.0 (0.6)
Actionability	
My doctors would gain a good understanding of my needs from reviewing my answers to this survey	4.2 (0.7)
I would consider using services/resources offered by my doctor if they matched them to the needs I identified in this survey	4.4 (0.6)
Index	4.3 (0.6)

Figure 11. Evaluation of the CNQ-YP



When asked whether they believed that anything was missing from the CNQ-YP, 40% percent of respondents reported "yes", listing a number of gaps with the current itemset. For example, respondents wanted more content related to financial needs, sexual health, mental health, social needs, physical activity, and in-hospital space and activities specifically for AYAs. A few respondents wanted the tool to solicit need for specific specialists such as nutritionists or physical therapists. Several respondents wanted additional free-response opportunities to report more specific and individualized information about the needs they were experiencing.

Respondents were also asked whether anything was in the CNQ-YP that should not be. Although most (97%) responded "no", a few noted that the response scales were cumbersome and recommended streamlining the item response format.

Bivariate statistics

Through bivariate analyses, I assessed the relationship between demographic and patient characteristics and number of needs rated as "high" or "very high" (i.e., greater need; see **Table 5**). In terms of cancer type, having breast cancer was associated with having fewer needs. Being uninsured was also associated with having greater need. These relationships were statistically significant at the α=.05 level. Having non-Hodgkin lymphoma and being Black were also associated with having greater need but these relationships were only statistically significant at the α=.10 level.

I also examined the relationship between number of needs and ratings of the CNQ-YP's feasibility, acceptability, appropriateness, and actionability (see **Table 6**). Reporting greater need was associated with higher ratings of the CNQ-YP's actionability; this relationship was statistically significant at the α=.05 level.

Table 5. Bivariate relationship between demographic/patient characteristics and number of needs reported as "high" or "very high"

Demographic & Patient Characteristics		**y= # of needs reported as "high" or "very high"** *correlation coefficient (standard error) reported*
Sex		
	(ref: female)	
	male	-2.7778 (5.920)
Age		0.2186 (0.595)
Time since diagnosis		
	(ref: >12 months)	
	<3 months	24.72 (16.20)
	3-6 months	-0.85 (6.66)
	7-12 months	2.84 (6.31)
Active treatment?		
	(ref: no)	
	yes	-6.96 (5.0)

Cancer type		
	(ref: Hodgkin Lymphoma)	
	Non-Hodgkin lymphoma	18.78 (10.8)*
	Leukemia	-8.24 (9.04)
	Sarcoma	-8.73 (8.17)
	Cervical	18.56 (17.08)
	Other female reproductive	-2.44 (12.67)
	Male reproductive	3.56 (17.08)
	Thyroid	-7.69 (9.74)
	Brain	-11.19 (9.74)
	Melanoma	-6.44 (17.08)
	Colorectal	0.56 (17.08)
	Breast	-21.44 (9.74)***
	Other	-6.94 (8.54)
Cancer stage		
	(ref: I/II)	
	0	-20.82 (16.26)
	III/IV	2.74 (5.5)
	Unknown/unstaged	6.32 (5.7)
Race/ethnicity		
	(ref: Non-Hispanic White)	
	Hispanic (all races)	1.03 (6.57)
	Non-Hispanic American Indian/Alaska Native	-2.89 (11.5)
	Non-Hispanic Asian or Pacific Islander	19.61 (16.02)
	Non-Hispanic Black	30.61 (16.02)*
	Other/Unknown	-3.89 (8.36)
Cohabitants		
	(ref: Parent(s))	
	Spouse	3.86 (6.09)
	Non-spouse partner	-6.05 (8.12)
	Roommate(s)	1.45 (6.79)
	Lives alone	7.20 (8.89)
Education		
	(ref: Some college/vocational training)	
	<high school	-7.38 (12.39)
	Completed high school	5.12 (9.23)
	Associate degree	-3.88 (10.4)
	College graduate	-1.11 (6.17)
	Graduate degree or some post-graduate education	3.33 (6.66)

Insurance		
	(ref: Parent)	
	Self-pay	-3.11 (9.79)
	No insurance	27.06 (11.71)***
	Employer/school	3.02 (5.72)
	Spouse's employer/school	14.06 (11.71)
	Medicare	13.22 (9.79)
	Medicaid	4.56 (8.68)
	Military/TRICARE	2.56 (9.79)

*Statistically significant at the α=.10 level (p<.10)
***Statistically significant at the α=.05 level (p<.05)

Table 6. Relationship between number of needs and evaluation of CNQ-YP

	y= acceptability index	**y= appropriate-ness index**	**y= feasibility index**	**y= actionability index**
	Correlation coefficient (standard error) reported			
# of needs reported as "high" or "very high"	0.004 (0.007)	0.003 (0.006)	0.007 (0.006)	0.013*** (0.006)
Constant	3.694 *** (0.211)	3.993*** (0.181)	3.826*** (0.182)	3.913*** (0.168)
Observations	41	40	38	40
R-squared	0.010	0.005	0.036	0.126

***Statistically significant at the α=.05 level (p<.05)

5.3 Cognitive Interviews

Participants

Cognitive interviews were conducted with n=5 AYAs in treatment or survivorship, including 4 females and 1 male. Interviewees represented 4 different states including California, Georgia, Michigan, and Indiana.

Table 7 summarizes the usability and usefulness concerns reported by cognitive interview participants, and changes made to the CNQ-YP in response to those concerns. All changes made were vetted by the design team during the first design team workshop.

Table 7. Suggestions for CNQ-YP refinement from cognitive interviews

Category	Theme	Changes made
Response format	Confusion surrounding “no need” response option including both no need, and need already met	Changed the name of the “no need” response option to “no need/need met”
	Item S1 and S2 (“since my cancer diagnosis I have enrolled at/had problems enrolling at”) response option “TAFE”(i.e., “technical and further education”) not understood	Removed response option “TAFE” from S1 and S2
	For items S1 and S2 (“since my cancer diagnosis I have enrolled at/had problems enrolling at”), AYAs wanted a response option related to internships	Added response option for S1 and S2: “internship (paid or unpaid)”
	In Items S3 and S4 (“since my cancer diagnoses I have been employed/ have had problems finding work”) response option “part-time/casual”, AYAs didn’t like the term “casual”	Removed the word “casual” so response option just reads “part-time”
	For Items S3 and S4 (“since my cancer diagnoses I have been employed/ have had problems finding work”), AYAs wanted a response option for trade school/apprenticeship	Added response option for S3 and S4: “trade school or apprenticeship”
Question format	Throughout the CNQ-YP the questions are broken up into different rows. For example, “I had the following need”, “before treatment”, “cancer treatment staff telling me”, and “about my diagnosis” are on separate lines. AYAs found this confusing.	All question wording consolidated onto one line.
Lookback periods	In general, AYAs found the multiple lookback periods (e.g., “before treatment”, “during treatment”, “after treatment”, etc.) confusing. Although they emphasized that needs do change depending on how far along you are in your treatment trajectory, these lookback periods were not considered helpful for informing current service provision	All needs items were anchored to needs currently being experienced (i.e., at the time of assessment completion). Redundancies stemming from the multiple lookback periods were removed.
Treatment Environment and Care section	Item 2 (“cancer treatment staff telling me what might happen during treatment”) interpreted the same as Item 4 (“about the short-term side effects of treatment”)	Removed Item 2
	Item 3 (“cancer treatment staff telling me whether I have the option to decline treatment”) perceived as less relevant/important	Removed Item 3
	AYAs did not like Item 6 (“cancer treatment staff telling me my chances of a full recovery”) because it is unclear what is meant by “full recovery”	Removed Item 6
	Section lacks item about sexual health	Added item assessing whether treatment staff provided information about sexual health
	Item 9 (“cancer treatment staff telling me whether my treatment was working”) is too narrow	Changed item to “how my treatment is working”
	Item 12 (“being able to have time to myself”) perceived as unimportant	Removed Item 12

	Item 14 (“cancer treatment staff telling me what I could do to stay healthy”) perceived as too vague; interpreted as putting the onus on AYAs to prevent secondary cancers which may be out of their control	Changed Item 14 to “cancer treatment staff giving me information about nutrition and exercise”
	Item 16 (“having cancer treatment staff who listened to my concerns”) and Item 24 (“having cancer treatment staff who let me talk about my feelings”) perceived as redundant	Collapsed items 16 and 24 into “listened to my concerns and let me talk about my feelings”
	Item 19 (“having cancer treatment staff who were approachable”) and Item 20 (“having cancer treatment staff who were friendly”) perceived as redundant	Collapsed Items 19 and 20 into “having cancer treatment staff who were friendly and approachable”
	Item 22 (“having cancer treatment staff who explained what they were doing”) does not capture the importance of explaining *before* doing; redundant with Item 23 (“having cancer treatment staff who spoke to me in a way that I could understand”)	Collapsed Items 22 and 23 into “having cancer treatment staff who explained what they were doing before they did it, in a way that I could understand”
Education section	Items 34-36 had the question stem “I had the following needs when studying”. AYAs interpreted this as actively studying for a test.	Changed the question stem for Items 34-36 to “I had the following needs while enrolled at school”
	Section is missing an item related to financial aid or loan repayment	Added item “being able to get guidance about financial aid or loan repayment options”
Work section	Item 39 (“knowing that managers/co-workers had support to help them cope with my situation”) not perceived as important	Removed Item 39
	Section lacks item about health insurance, which is a major need with respect to employment	Added item “worrying about my health insurance coverage”
Information and Activities section	AYAs did not understand/like Item 43 “finding information that was specifically designed for me”	Removed Item 43
Feelings and Relationships section	Item 45 (“feeling frustrated”) not perceived as important relative to other psychosocial concerns	Removed Item 45
	Item 45 (“feeling anxious or nervous”) doesn’t fully capture the feeling of fear which is pervasive during treatment	Changed item 45 to “feeling anxious or scared”
	Section lacking item about depression	Added item “feeling depressed”
	Item 48 (“worrying about my cancer returning”) does not capture pervasive fear surrounding secondary cancers	Changed Item 48 to “worrying about my cancer returning or secondary cancers”
	Item 50 (“worrying about having cancer treatment”) too vague	Removed Item 50
	Section only includes items assessing changes in relationship with partner and siblings; not inclusive of all the important relationships that may be affected by cancer	Added items assessing changes in relationship with parent/s and changes in relationships with friend/s
Daily Life section	Item 63 (“coping with my parent/s being overprotective”) not relevant for many AYAs	Changed Item 63 to “coping with my parent/s and/or partner being overprotective”

	Section has item about physical side effects of treatment (Item 66) but none about the emotional side effects of treatment	Added item “managing emotional side effects of treatment”
	Item 67 (“feeling tired”) does not capture fatigue, which AYAs felt was more severe than tiredness	Changed Item 67 to “feeling tired/fatigued”
	AYAs did not understand or like Item 70 (“managing to travel to social event”)	Removed Item 70

Response format

In general, cognitive interview participants liked the CNQ-YP’s 5-option response scale, displayed in **Table 8**, and did not have trouble distinguishing among the response options. One said, *“the five options is always kind of what is done on surveys so I think it’s not intimidating.”* One noted that the survey, at its current length, would be less burdensome with fewer response options. Several AYAs noted that assigning number values (e.g., 0-4) to each of the response options would make the response format even clearer. One AYA talked about how this would mimic other questions asked by their physicians (e.g., what is your pain level?). When asked if they felt the response option table should be displayed on every page of the survey, most responded that it was sufficient just to include it at the beginning of the assessment. One noted that, if the survey was administered electronically, it might be helpful to have an information box, so that hovering over the response options would make the response option key appear.

Interviewees reported some confusion surrounding the “No Need” response option, which groups needs that were *met* with needs that were *not experienced*. Most recommended splitting the response option into two, or relabeling it to improve clarity (e.g., “No Need/Needs Met”). One noted that, “*for what this tool is trying to be, it’s fine to lump them*” but the language should be adjusted to clarify. Otherwise, they felt that the response options would be misinterpreted, and respondents would rate a need that had already been met based on the level of need experienced before the need was met.

Table 8. CNQ-YP response format

No Need	All my needs were met for this issue <u>or</u> this was not a problem for me.
Low Need	I needed a low amount of help with this problem but was not able to get it.
Moderate Need	I needed a moderate amount of help with this problem but was not able to get it.
High Need	I needed a high amount of help with this problem but was not able to get it.
Very High Need	I needed a very high amount of help with this problem but was not able to get it.

<u>Item format</u>

In the original CNQ-YP, items are broken up into different rows based on common roots. For example, in Item 1, “I had the following needs…”, “before treatment”, “cancer treatment staff telling me”, and “about my diagnosis” are on separate lines (see **Table 9**). AYAs found this confusing, and several noted that they would have preferred the questions to be kept intact and presented on the same row (e.g., “cancer treatment staff telling me about my diagnosis”).

Table 9. CNQ-YP question format

<table>
<tr><th colspan="7">I had the following needs…</th></tr>
<tr><th colspan="7">BEFORE TREATMENT</th></tr>
<tr><th colspan="2">Cancer treatment staff telling me:</th><th>No Need</th><th>Low Need</th><th>Moderate Need</th><th>High Need</th><th>Very High Need</th></tr>
<tr><td>1</td><td>about my diagnosis</td><td>○</td><td>○</td><td>○</td><td>○</td><td>○</td></tr>
</table>

<u>Lookback periods</u>

The CNQ-YP features several different lookback periods which generated confusion among some interviewees. They recommended streamlining the transitions among lookback periods or making the lookback period instructions more visually detectable (e.g., by highlighting or centering the text). Some AYAs emphasized that their needs have changed a lot as they moved through their treatment trajectory, denoting the importance of assessing needs longitudinally. Ultimately, though, after I reiterated the intent of the tool (i.e., to facilitate service and resource provision to meet needs in real time), interviewees felt that these lookback periods were unnecessary. For this reason, we opted to anchor all items to current needs (i.e., needs present at the time of assessment completion), or needs present within a shorter lookback period. This issue would be discussed in detail during the first design team workshop (see **Section 5.5**).

"Treatment Environment and Care" section

In general, AYAs liked the items related to information provision. One said, *"there's a lot of things they don't talk to you about and you kind of find out on your own… it's a lot."* One wanted to revise the question root "cancer treatment staff telling me" to "cancer treatment staff talking to me about", to reflect a more bidirectional discussion.

AYAs noted instances in which items in this section were ambiguous. For example, in reference to Item 6 ("cancer treatment staff telling me my chances of a full recovery"), one AYA said the term, "full recovery," was ambiguous. They said, *"a full recovery could mean no side effects; a full recovery could mean no evidence of disease."* Another said, *"I don't think you fully ever recover from something like cancer."* When asked about framing this question around "prognosis" instead, one said that was a "*jargon-y term*", often conflated with "diagnosis". Another AYA recommended using the language "*my chances of having a normal life after cancer*". One AYA wanted Item 29 ("being able to have pleasant surroundings") to be more granular, for example, by asking about the availability of entertainment (e.g., books, movies, videogames, etc.). In some cases, AYAs noted an item's ambiguity, but still thought the question was important. For example, for Item 11 ("cancer treatment staff telling me the way I felt was normal"), several AYAs talked about how this could be referring to physical or emotional concerns. "*It's a little bit confusing if it is referring to side effects, or the emotional side of treatment, or both*." However, they still thought it was an important question to ask.

For other items, AYAs seemed to interpret them in a way that was redundant with other items in the assessment. For example, Item 2 (“cancer treatment staff telling me what might happen during treatment”) was interpreted by most as asking about side effects, making it repetitive with Items 4 and 5, which ask about short-term and long-term side effects. There was much discussion about Items 18 (“having cancer treatment staff who were respectful”), 19 (“having cancer treatment staff who were approachable”), and 20 (“having cancer treatment staff who were friendly”). In general, AYAs felt these items were different, and important, but most noted that they could be combined into one or two questions. Other items that they felt could be combined included Item 22 (“cancer treatment staff who explained what they were doing it”) and Item 23 (“cancer treatment staff who explained what they were doing”). Additionally, they felt Item 16 (“cancer treatment staff who listened to my concerns”) and Item 23 (“cancer treatment staff who let me talk about my feelings”) were similar and could be collapsed.

AYAs also pointed to questions that were too narrow in scope. For example, in reference to Item 9 (“cancer treatment staff telling me whether my treatment was working”), one interviewee said, “*I think I wanted more of a qualitive assessment of how my treatment was working.”* Just being told whether or not treatment was working was insufficient. For Item 30 (“being able to have good food” at the cancer treatment center), several AYAs suggested that this item ask more specifically about nausea-friendly food or availability of food that meets dietary restrictions (e.g., cultural dietary restrictions). One AYA recommended revising Item 7 (“what would happen when treatment finished”) so that it asks more specifically about whether one has the resources they need to transition from treatment to post-treatment. For Item 15 (“what to do if I noticed a particular side-effect”), one AYA thought the term, “side-effect” was too narrow; they recommended rewording it to “*what to do if I noticed anything out of the ordinary*”. One AYA said that Item 27 (“cancer treatment staff talked to me in private, without my family”) was too narrow because it only referenced family, and did not discuss privacy from others (e.g., partners and friends) who may be present.

AYAs also flagged select items as less important or applicable. For example, although one interviewee liked Item 12 (“being able to have time to myself”), most perceived it as unimportant relative to other items. *“As a cancer patient, you have a lot of time to yourself.”* For them, feeling isolated was a bigger problem; one AYA said a better question would ask about “being able to spend time with other people.” They did, however, note that this item may be more relevant during inpatient stays. Additionally, Item 3 (“whether I had the option to decline treatment”) was described as *“a little weird”.* Describing this item, one AYA said, *“I don’t think it really comes up.”*

Finally, AYAs pointed to information missing from this section. Several AYAs noted that this section was lacking information about sexual health. *“It talks a lot about fertility, which is important, but it doesn’t talk at all about sexual health”.* They also noted that there was nothing in this section about nutrition.

“Education” section

AYAs felt that the response options for Items S1 (“since my cancer diagnosis, I have had problems enrolling at”) and S2 (“since my cancer diagnosis, I have attended”) were comprehensive. All AYAs agreed that the response option “TAFE” (i.e., “technical and further education”) should be eliminated, as it is not applicable in the United States. For S1 (“since my cancer diagnosis, I have had problems enrolling at”), one AYA questioned what kind of problems the assessment was referring to. They suggested the item mention specific problems such as accessing accommodations/disability services, finding school difficult, or being too immunocompromised to attend.

For the question root of Items 34-36 (“when studying”), AYAs did not like the term “when studying”. *“For me studying is studying, like, when I’m studying for a test.”* They recommended revising it to “*when I’m enrolled at school*”. One AYA said that Item 34 (“being able to attend classes”) was too vague. In reference to Item 35 (“being able to get extensions/special considerations”), one AYA noted that this item may be particularly important for “*normal-passing*” AYAs, who may have more trouble getting accommodations. *"They take your needs more seriously if you're bald,"* she said. Looking at Item 36 ("being able to get guidance about study options or future career paths"), one AYA wanted a standalone item asking about guidance on future career paths, since they felt this was important enough to warrant its own item.

In terms of missing content in this section, one AYA recommended a question about being able to receive medication at school as needed. One AYA noted that getting doctors' notes for school was a major hassle, so an item assessing whether doctors provided the needed paperwork to have school absences excused could be important. This AYA also recommended an item related to navigating financial aid or loan deferment. Another AYA recommended being more specific about information on disability options available.

"Work" section

For Items S3 ("since my cancer diagnosis, I have had problems finding work") and S4 ("since my cancer diagnosis, I have been employed"), several AYAs wanted a response option for paid or unpaid internships. They did not like the term "casual" work, a response option to Item S4 in the original CNQ-YP.

For Item S3 ("since my cancer diagnosis, I have had problems finding work"), one AYA asked, *"what are they asking for when they are talking about problems?"* One AYA wanted "if needed" added at the end of Item 38 ("how to ask managers/co-workers for support"). One AYA questioned Item 39 ("knowing that managers/coworkers had support to help them cope with my situation") as currently written. *"Where I was working, they don't really sit down and talk to you about things that are happening."* However, this AYA's employer did provide resources; thus, they recommended hinging the question more on the provision of resources rather than support. Another AYA said about this item, *"I guess that would be dependent on how many people worked there, how close you were, what the* *culture was like."* Based on previous job experiences, they said *"I don't think that would be an important question to include,"* although in their current tighter-knit job, they said the item may be more relevant.

Several AYAs mentioned the need for an item related to health insurance, since this is a major consideration associated with employment for AYAs with cancer. *"For me, [health insurance coverage] has been an important part of me taking certain jobs and I know that I closely monitor my benefits."* One AYA mentioned adding an item addressing the issue of *"how I would tell my employer, or do I have to tell my employer?"*

"Information and Activities" section

AYAs unanimously disliked Item 43 ("finding information that was specifically designed for me"). One said, *"this question gives me no information".* Another asked if the item was asking about information specifically designed *"for me in general? or for my diagnosis?"* Others did not understand what type of information the item was referring to.

When asked about overlap between Items 40 ("being able to spend time with people my own age") and 41 ("being able to talk to people my age who had been through a similar experience"), AYAs said these items should be kept separate because they are sufficiently different and both important. For Item 42 ("being able to have leisure spaces and activities"), one AYA recommended revising "leisure spaces and activities", to "*a safe place to hang out*". For Item 44 ("finding information that described relaxation techniques"), a couple of AYAs mentioned the need for parenthetical examples (e.g., meditation, yoga, etc.).

In this section, AYAs noted the need for items assessing the availability of information about therapy and other psychosocial support for anxiety, depression, post-traumatic stress disorder, isolation, etc. One AYA said, *"the number one thing I wanted to find was a community of people and that took me five years to find it by just typing random google searches… I thought I was alone."*

“Feelings and Relationships” section

Several AYAs noted that the questions in this section didn’t make sense with the question root “I had the following needs”. Similarly, the response scale was not considered as applicable to items in this section. AYAs suggested a response scale that does not center around need-level for these items. For example, one recommended changing the response scale for Items 45-51 to “always, often, sometimes, never”.

One AYA wanted Item 46 (“feeling anxious or nervous”) revised to “feeling anxious or scared”, because the fear of disease spread or recurrence is so ubiquitous. For Items 45 and 46, several AYAs noted that other mental health concerns beyond frustration, anxiety, and nervousness should be captured here, including depression and post-traumatic stress disorder.

For Item 48 (“worrying about my cancer spreading”), one AYA noted that, because of her specific cancer diagnosis, she did not have concerns about her cancer returning; she did, however, worry about secondary cancers and recommended adding “or secondary cancers” to this item. AYAs felt that Item 50 (“worrying about having cancer treatment”) was ambiguous. Although some liked Item 52 (“finding inner strength”), one noted that this question *“triggers that kind of combative language, like, oh the fight against cancer, I think that simplifies cancer treatment in a way that’s unhelpful”.* One AYA recommended changing Item 53 (“being able to accept my diagnosis”) to “*being able to accept and cope with my diagnosis*”.

Several AYAs wanted Item S5 and Items 55-58 to capture additional relationships. In addition to relationships with partners and siblings, they wanted items assessing relationships with parents/guardians. *“Parental relationships are the other thing that changes a ton for AYAs”.* Several AYAs also wanted changes in relationships with friends to be captured in this section. *“I think that’s a big part of it, too… People’s friend circles get a lot smaller”*. One noted that Item 56 (“coping with changes in my relationships with my sibling/s”) should also be inclusive of stepsiblings. They also questioned why

Item 57 ("knowing how to ask my sibling/s for support") and 58 ("knowing how to give support to my sibling/s") were only asked with respect to siblings, and not with respect to relationships with partners. One AYA noted that their partner was their primary caregiver and thus, these questions would be important to ask with respect to that relationship. Another AYA noted that, although they did not currently have a partner, the question about changes in relationships with partners (Item 55) would still be important to them. *"Even single people without siblings struggle with navigating relationships during and after cancer treatment, things like, hooking up with a wig and a port."* Thus, they recommended removing the skip pattern which only makes this item applicable to those who answered in Item S5 that they have a partner.

<u>"Daily Life" section</u>

For Items 60 ("coping with changes in my physical ability") and 61 ("coping with changes in my appearance"), one AYA wanted parenthetical examples of these changes. For example, Item 61 might list examples such as weight loss and hair loss. One AYA wanted to revise Item 63 ("coping with my parent/s being overprotective") to "*coping with my parents and/or partner being overprotective*". For Item 67 ("managing feeling tired"), several AYAs mentioned that it would be helpful to use the word "fatigue" in this item, noting that *"everybody can be tired, but fatigue is a whole 'nother level*." For Item 69 ("being able to take part in social activities"), one AYA recommended expanding this item to ask, not just if they were able to take part in social activities, but also whether they were able to enjoy them. AYAs were confused about Item 70 ("being able to travel to social events"). One wondered whether the item was talking about *"being able to drive myself there? You can always take Uber somewhere."*

5.4 Concept Mapping

<u>Participants</u>

A total of 26 AYA program providers/staff, summarized in **Table 10**, participated in the concept mapping exercises, exceeding the recommended sample size for concept mapping (>15).[142] Concept mapping participants were from 13 different states including California, Illinois, North Carolina, Texas and Utah. They represented several different institution types including hospital-based cancer programs (n=15) and community cancer centers (n=3). Many of their programs were housed within pediatric cancer programs (n=14), teaching hospital cancer programs (n=13), and National Cancer Institute-designated comprehensive cancer centers (n=19). Most (92%) reported that their cancer care program provides care specifically to adolescents and young adults. Within their institutions, seven respondents were social workers; three were oncologists; three were oncology nurse navigators; one was a nurse practitioner; one was a patient navigator; one was a health educator. Most (62%) reported being in these roles for less than five years; 19% reported being in these roles for between five and 10 years; the remainder (19%) reported being in these roles for greater than 10 years.

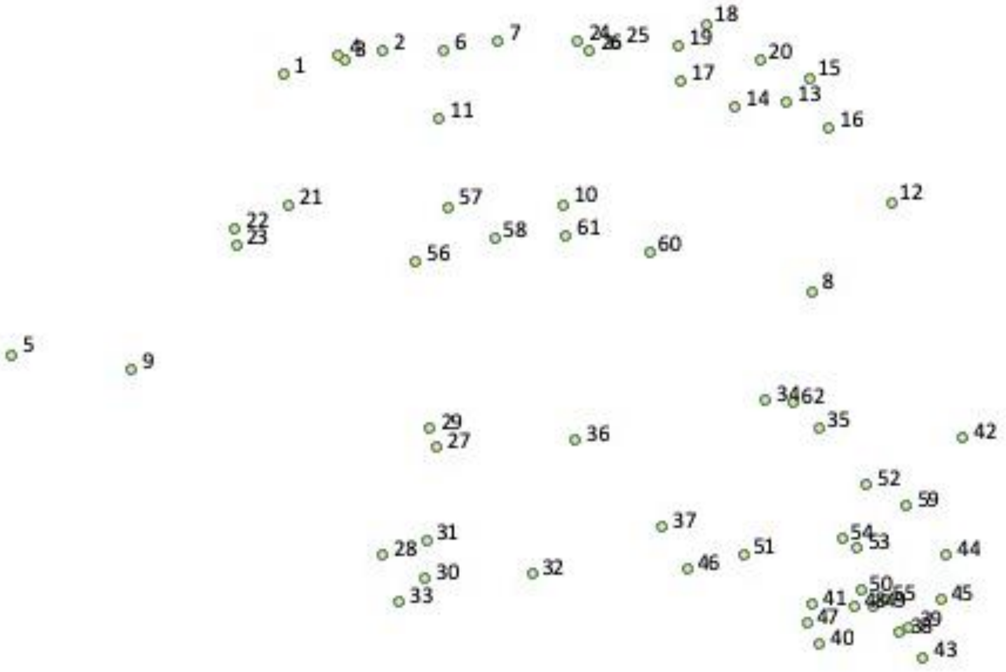
Table 10. Concept mapping summary statistics

Location	
California	5
Florida	2
Illinois	3
Indiana	1
Michigan	1
Missouri	1
New York	1
North Carolina	2
Ohio	2
South Carolina	1
Tennessee	2
Texas	4
Utah	1
Cancer Program Type	
NCI-designated comprehensive cancer center	19
Teaching hospital cancer program	13
Veterans Affairs cancer program	0
Pediatric cancer program	14
Community cancer center	3
Hospital-based cancer program	15
Private oncology practice	0
Freestanding cancer center program	1
Role	
Oncologist	3
Physician (non-oncology)	1
Physician assistant	0
Nurse practitioner	1
Oncology nurse navigator	3
Nurse	1
Child life specialist	0
Dietician	0
Patient navigator	1
Social worker	7
Health educator	1
Other	8
Years in role	
Less than 5	16
Between 5 and 10	5
Between 10 and 20	2
Greater than 20	3
Does your cancer program provide care specifically to adolescents and young adults?	
Yes	24
No	2
	N=26

Sorting

Participants sorted and rated a set of 62 AYA needs (**Appendix D**). The point map in **Figure 12** displays the relationship and proximity of needs to one another. Each point on the map represents one AYA need. Those closer in proximity to each other were sorted together more often by concept mapping participants than those farther apart. The stress value for this point map was 0.2474, demonstrating goodness of fit. The lower the stress value, the better the fit between the map and the input matrix. In a review of 38 concept mapping studies, stress values ranged from 0.155 to 0.352, with an average of 0.285.[142] CS GlobalMax produced many different cluster solutions, ranging from two to 61 follow-up domain clusters. Based on my own review of all cluster solutions, I presented 5 different cluster solutions to the design team during our first workshop with 8, 10, 12, 14, and 16 clusters. The design team walked through the differences between each cluster solution and then collaboratively selected the one with the highest face validity (i.e., in which needs were best grouped according to service or resource that could address them). The results of this process are described in **Section 5.5**.

Figure 12. Concept mapping point map



<u>Rating</u>

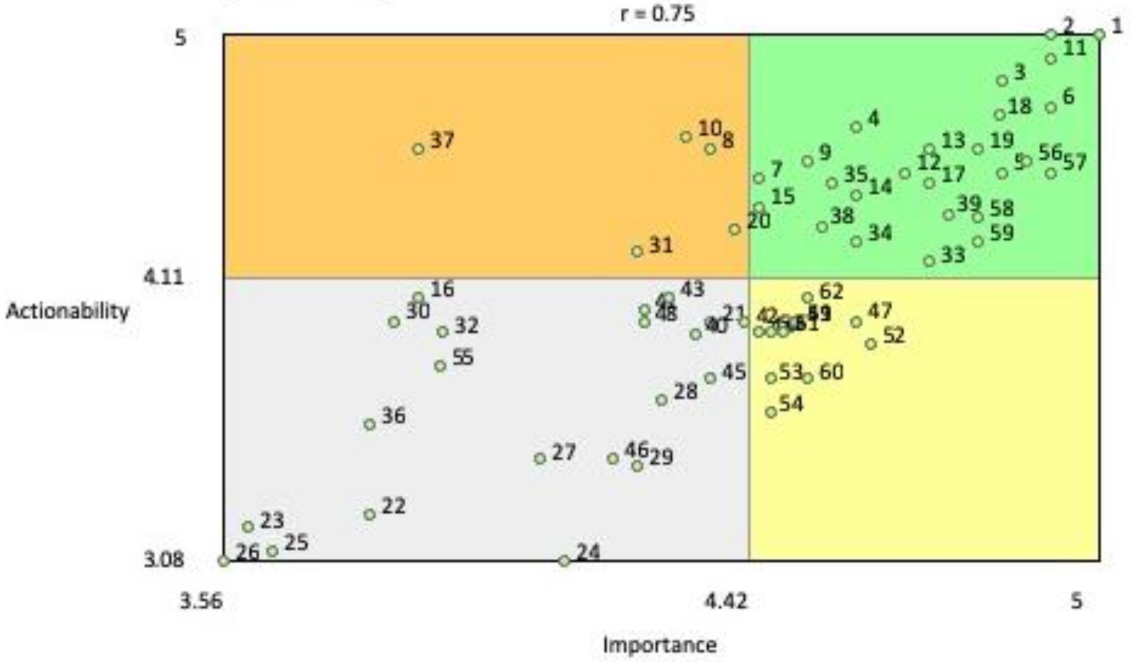
Overall, the mean ratings for needs were relatively high for both importance (4.42) and actionability (4.11) (i.e., 1=low importance/actionability; 5=high importance/actionability). **Table X** summarizes the average rating of each need's importance and actionability. **Figure 13** displays the average importance and actionability ratings among concept mapping participants. In this graph, the overall mean ratings for importance and actionability across all needs form the four quadrants; each need falls with respect to its overall mean rating for importance and actionability. Needs regarded as most important and actionable included "cancer treatment staff telling me about my diagnosis," "cancer treatment staff telling me about the short-term side effects of treatment", and "cancer treatment staff telling me what to do if I noticed a particular side effect". Conversely, needs regarded as least important and actionable included "being able to have a choice of appointment times," "being able to have the same cancer treatment staff throughout treatment," and "being able to have good food". Some needs were rated high on the importance scale, but low on the actionability scale, including "coping with not being able to do the same things as other people my age," "coping with changes in my appearance," and "managing feeling tired/fatigued." Other needs were rated high on the actionability scale and low on the importance scale such as "finding information that described relaxation techniques (e.g., yoga, meditation)".

Table 11. Concept mapping participants' average rating of each need's importance and actionability

#	Statement	Importance	Actionability
1	Cancer treatment staff telling me about my diagnosis	5	5
2	Cancer treatment staff telling me about the short-term side effects of	4.92	5
3	Cancer treatment staff telling me about the long-term side effects of	4.84	4.8333
4	Cancer treatment staff telling me what will happen when treatment	4.6	4.6667
5	Cancer treatment staff telling me whether I will be able to have children	4.84	4.5
6	Cancer treatment staff telling me about how my treatment is working	4.92	4.7391
7	Cancer treatment staff telling me my test results as soon as possible	4.44	4.4783
8	Cancer treatment staff telling me the way I feel is normal	4.36	4.5833
9	Cancer treatment staff giving me information about sexual health	4.52	4.5417
10	Cancer treatment staff giving me information about nutrition and	4.32	4.625
11	Cancer treatment staff telling me what to do if I noticed a particular side	4.92	4.9167
12	Having cancer treatment staff who listened to my concerns and let me	4.68	4.5
13	Having cancer treatment staff who treated me as an individual	4.72	4.5833
14	Having cancer treatment staff who were respectable	4.6	4.4167
15	Having cancer treatment staff who were approachable and friendly	4.44	4.375
16	Having cancer treatment staff who could have a laugh with me	3.88	4.0435
17	Having cancer treatment staff who explained what they are doing in a	4.72	4.4583
18	Having cancer treatment staff who let me ask questions	4.8333	4.7083
19	Having cancer treatment staff who let me make decisions about my	4.8	4.5833
20	Having cancer treatment staff who talked to me in private, without my	4.4	4.2917
21	Being able to have privacy	4.36	3.9583
22	Being able to have pleasant surroundings	3.8	3.25
23	Being able to have good food	3.6	3.2083
24	Being able to have a choice of cancer care specialists	4.12	3.0833
25	Being able to have the same cancer treatment staff throughout	3.64	3.125
26	Being able to have a choice of times for appointments	3.56	3.0833
27	Being able to attend classes (if enrolled in school)	4.08	3.4583
28	Being able to get extensions/special consideration (if enrolled in school)	4.28	3.6667

29	Knowing how much work I would miss	4.24	3.4348
30	Being able to get guidance about study options or future career paths	3.84	3.9583
31	Being able to get guidance about financial aid or loan repayment	4.24	4.2083
32	Knowing how to ask managers/coworkers for support	3.92	3.9167
33	Worrying about my health insurance coverage	4.72	4.1739
34	Being able to spend time with people my own age	4.6	4.25
35	Being able to talk to people my own age who had been through a	4.56	4.4583
36	Being able to have leisure spaces and activities	3.8	3.5833
37	Finding information that described relaxation techniques (e.g., yoga,	3.88	4.5833
38	Feeling anxious or scared	4.5417	4.3043
39	Feeling depressed	4.75	4.3478
40	Worrying about my cancer spreading	4.3333	3.913
41	Worrying about my cancer returning or secondary cancers	4.25	4
42	Worrying about whether my cancer treatment has worked	4.4167	3.9565
43	Worrying about how my family is coping	4.2917	4.0435
44	Finding inner strength	4.44	3.9167
45	Being able to accept my diagnosis	4.36	3.75
46	Being able to be independent	4.2	3.4583
47	Coping with changes in my relationship to my partner	4.6	3.9583
48	Coping with changes in my relationship to my sibling/s	4.25	3.9583
49	Coping with changes in my relationship to my parent/s	4.5	3.9583
50	Coping with changes in my relationship to my friend/s	4.4583	3.9167
51	Being able to make plans or think about the future	4.5	3.9583
52	Coping with changes in my physical ability	4.625	3.875
53	Coping with changes in my appearance	4.4583	3.75
54	Coping with not being able to do the same things as other people my	4.4583	3.625
55	Coping with my parent/s and/or partner being overprotective	3.9167	3.7917
56	Managing pain	4.88	4.5417
57	Managing my medications	4.92	4.5
58	Managing physical side effects of treatment	4.8	4.3333
59	Managing emotional side effects of treatment	4.8	4.25
60	Managing feeling tired/fatigued	4.52	3.75
61	Managing loss of mobility	4.48	3.9167
62	Managing to take part in social activities	4.52	4.0417

Figure 13. Concept mapping go-zone graph



5.5 Design Team Workshop #1

During the first workshop, the AYA NA-SB design team collaboratively refined the CNQ-YP itemset, selected the most interpretable cluster map and labeled each cluster according to the service or resource it corresponded to, and made decisions about the needs assessment's response options, format, and sequencing.

Itemset refinement

Table 12 displays the items under consideration for elimination during Design Team Workshop #1, as well as design team member decisions about their elimination. Based on design team voting, 15 items were removed from the CNQ-YP itemset. For example, the design team voted to eliminate items assessing whether patients perceived their treatment staff as "approachable" or "friendly" based on concept mapping participants' low ratings of these items' actionability in terms of service or resource provision. Design team members also voted to eliminate other items because they were already captured by other items. For example, "*coping with my parent/s and/or partner being overprotective*" was eliminated because it was already captured by broader items about coping with changes in relationships with family members and partners. 12 CNQ-YP items were revised; these revisions and the rationale for making them are also described in **Table 12**.

Table 12. Items under consideration for elimination

Item	Decision	Rationale
Being able to have a choice of times for appointments	Eliminate	Low importance (a choice of appointment times is typically "a given")
Being able to have the same cancer treatment staff throughout treatment	Eliminate	Low actionability
Being able to have a choice of cancer care specialists	Eliminate	Low actionability
Knowing how much work I would miss	Eliminate	All work-related items into one item "*Navigating my work life while going through cancer treatment*" to avoid being unnecessarily specific.
Being able to have leisure spaces and activities	Eliminate	Low actionability in terms of leisure "spaces". "Activities" covered by other items.
Knowing how to ask managers/coworkers for support	Revise	All work-related items collapsed into one item: "*Navigating my work life while going through cancer treatment*" to avoid being unnecessarily specific
Being able to get guidance about study options or future career paths	Revise	All school-related items collapsed into one item: "*Navigating my school life while going through cancer treatment*" to avoid being unnecessarily specific
Coping with my parent/s and/or partner being overprotective	Eliminate	Captured by other items: "*Coping with changes in my relationships with my family members*" and "*Coping with changes in my dating or romantic life*". Additionally, users said this was an issue to solved or navigated and not "coped" with.
Being able to be independent	Revise	Revised to "*Feeling independent*" to capture psychosocial implications. Physical independence captured by other items.
Having cancer treatment staff who treated me as an individual	Revise	Revised to "*Having cancer treatment staff who respected me as an individual, not just a cancer patient*" to capture a more specific and relevant concern.

Item	Decision	Rationale
Having cancer treatment staff who talked to me in private without my family	Revise	Revised to "*Having cancer treatment staff who offered to talk to me in private without my family*" to leave room for patient choice.
Having cancer treatment staff who could have a laugh with me	Eliminate	Low actionability
Being able to have pleasant surroundings at the cancer treatment center	Eliminate	Low actionability
Being able to have good food at the cancer treatment center	Eliminate	Low actionability
Being able to attend classes (while enrolled in school)	Eliminate	All school-related items collapsed into one item: "*Navigating my school life while going through cancer treatment*" to avoid being unnecessarily specific.
Being able to get extensions/special considerations (while enrolled in school)	Eliminate	All school-related items collapsed into one item: "*Navigating my school life while going through cancer treatment*" to avoid being unnecessarily specific.
Worrying about whether my treatment is working	Revise	Revised to "*Cancer treatment staff giving me honest and timely information about the status of my cancer treatment*" to more broadly capture transparent and timely communication during treatment. Additionally, users noted that whether treatment is working is not binary.
Being able to have privacy at the cancer treatment center	Eliminate	Low actionability
Finding inner strength*	Eliminate	Evokes the "fight against cancer" narrative (i.e., "toxic positivity", which is not palatable to many AYAs
Having cancer treatment staff who were respectful*	Eliminate	Low actionability; addressed by other items about cancer care team
Having cancer treatment staff who were approachable and friendly*	Eliminate	Low actionability
Having cancer treatment staff who listened to my concerns*	Revise	Revised to "*Having cancer treatment staff who asked about my concerns about treatment*" because AYAs often don't broach their concerns with their providers ("you don't know what you don't know")
Having cancer treatment staff who let me ask questions*	Revise	Revised to "*Having cancer treatment staff who encouraged me to ask questions*" to make more patient-centered

Item	Decision	Rationale
Having cancer treatment staff who let me make decisions about my treatment*	Revise	Revised to "*Having cancer treatment staff who engaged me in decision-making about treatment and respected my decisions*" to reflect the process, rather than the outcome. Additionally, provider users noted that it's not always possible to relinquish total control of decision-making.
Finding information that described relaxation techniques*	Revise	Revised to "*Finding information on alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.)"* to make more inclusive of other modalities.
Being able to accept my diagnosis*	Revise	Revised to "*Having what I need to cope with my diagnosis*" to make more actionable.
Cancer treatment staff telling me whether I would be able to have children*	Revise	Broke this item into multiple items about fertility to be more comprehensive and less presumptuous regarding AYAs' desire to have children: *"Receiving information and counseling about risk for infertility and fertility preservation options"* *"Receiving information on treating infertility and other options for having children (i.e., artificial insemination, in vitro fertilization, surrogacy, adoption, etc.)"* *"Receiving information on the genetic inheritability of my cancer"*

* *These items were raised by design team members during Design Team Workshop #1 as additional items to consider for elimination or revision*

Table 13 displays the potential additional items I raised for consideration during Design Team Workshop #1, as well as design team members' decisions about whether to include them. Based on design team voting, 12 items were added to the itemset including items related to sexual health, financial needs, sexual and reproductive health, and health behaviors.

Table 13. Potential additional items

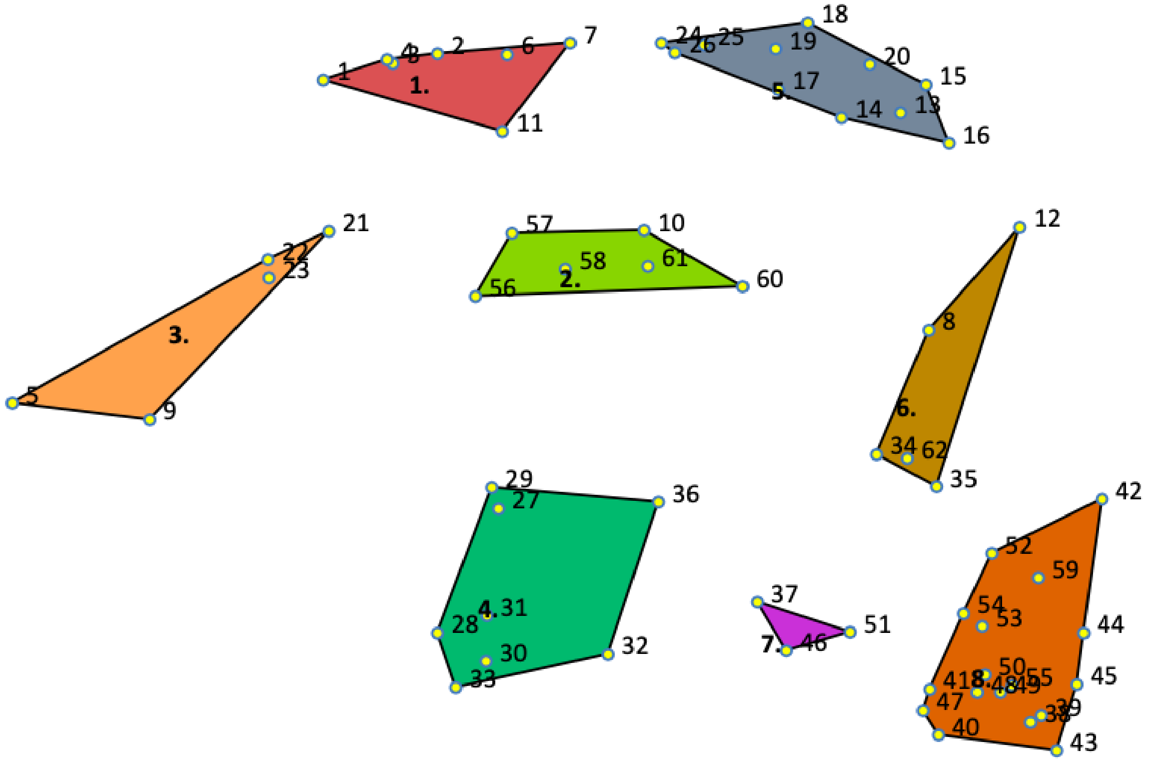
Item	Decision	Wording
Sexual health	Add	*Cancer treatment staff giving me information about sexuality and intimacy during cancer treatment*
Worrying about health insurance coverage	Add	*Worrying about my health insurance (e.g., access/eligibility, coverage, cost)*
Physical therapy	Don't add	N/A
Being able to get guidance about financial aid or loan repayment	Add	*Getting guidance about scholarships or loan repayment options*
Other financial needs	Add	*Paying my bills* *Having childcare during my cancer care appointments* *Having stable housing*
Transportation	Add	*Getting to and from my cancer care appointments*
Coping with changes in my relationships with friends	Add	*Coping with changes in my relationships with friends*
If and how to tell my employer I have cancer	Don't add	All work-related items collapsed into one item: *Navigating my work life while going through cancer treatment*
Sleeping*	Add	*Sleeping well*
Spiritual needs*	Add	*Having spiritual support or faith-based resources*
Alcohol and drug use *	Add	*Cancer treatment staff giving me information about drug and alcohol use during cancer treatment* *Having the resources I need to quit smoking*

** These items were raised by design team members during Design Team Workshop #1 as additional topics or items to consider adding to the itemset*

Cluster map selection and labeling

Based on my own review of all cluster solutions, I presented 5 different cluster solutions to the design team with 8, 10, 12, 14, and 16 clusters. We walked through the differences between each cluster solution and then collaboratively selected the one with the highest face validity (i.e., in which needs were best grouped according to service or resource that could address them). Ultimately, we selected the 8-cluster solution (see **Figure 14**). Based on design team discussion, several changes were made to the cluster map. We broke cluster 4 into two follow-up domains: one related to work and education, and another related to finances and logistics. Additionally, we moved a few items between clusters such that they fell in a more appropriate follow-up domain. Those changes are summarized in **Table 14**.

Figure 14. Selected cluster map



Cluster		Need
1		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
2		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
3		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
4		
	27	Being able to attend classes (if enrolled in school)
	28	Being able to get extensions/special consideration (if enrolled in school)
	29	Knowing how much work I would miss
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	32	Knowing how to ask managers/coworkers for support
	33	Worrying about my health insurance coverage
	36	Being able to have leisure spaces and activities
5		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	17	Having cancer treatment staff who explained what they are doing in a way I could understand
	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	20	Having cancer treatment staff who talked to me in private, without my family
	24	Being able to have a choice of cancer care specialists
	25	Being able to have the same cancer treatment staff throughout treatment
	26	Being able to have a choice of times for appointments
6		
	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
7		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
8		
	38	Feeling anxious or scared
	39	Feeling depressed
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	42	Worrying about whether my cancer treatment has worked

🟥	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	55	Coping with my parent/s and/or partner being overprotective
	59	Managing emotional side effects of treatment

Table 14. Items moved between clusters

Item	Original Cluster	New Cluster	Notes
10	2	7	Item 10 was moved to a non-adjacent cluster, which was unusual. However, the design team felt that Item 10, which addresses nutrition and exercise, best fit with other items about health behaviors and wellness (cluster 7) rather than with items about physical health (cluster 2) because cluster 2 is focused more on needs addressable by the primary cancer care team.
12	6	5	Item 12 is positioned on the outer edge of cluster 6, directly adjacent to cluster 5.
46	7	8	Item 46 is positioned directly adjacent to cluster 8.
51	7	8	Item 51 is positioned directly adjacent to cluster 8.

CS GlobalMax© generates labels for clusters based on participants' labeling. Using these labels as a starting point, we collaboratively re-labeled each cluster based on the follow-up action (i.e., service or resource) that needs in that cluster should trigger. This resulted in nine follow-up domains: (1) Information (cluster 1), (2) Cancer Care Team (clusters 5), (3) Physical Health (cluster 2), (4) Emotional Health (cluster 8), (5) Sexual & Reproductive Health (cluster 3), (6) Health Behaviors & Wellness (cluster 7), (7) Work & Education (cluster 4), (8) Peer Support & Programming (cluster 6), and (9) Finances & Everyday Needs (cluster 4). The nine follow-up domains and items falling within each are listed in **Table 15**.

Table 15. Refined items by follow-up domain

Information		
1	Cancer treatment staff telling me about my diagnosis	Cluster 1
2	Cancer treatment staff telling me about the short-term side effects of treatment	
3	Cancer treatment staff telling me about the long-term side effects of treatment	
4	Cancer treatment staff telling me what will happen when treatment finishes	
5	Cancer treatment staff giving me honest and timely information about the status of my cancer treatment	
6	Cancer treatment staff telling me my test results as soon as possible	
7	Cancer treatment staff telling me what to do if I noticed a particular side effect	
Cancer Care Team		
8	Having cancer treatment staff who respected me as an individual, not just a cancer patient	Cluster 5
9	Having cancer treatment staff who offered to talk to me in private, without my family	
10	Having cancer treatment staff who explained what they are doing in a way I could understand	
11	Having cancer treatment staff who encouraged me to ask questions	
12	Having cancer treatment staff who engaged me in decision-making about my treatment and respected my decisions	
13	Having cancer treatment staff who asked about my concerns about treatment	
Physical Health		
14	Managing pain	Cluster 2
15	Managing my medications	
16	Managing physical side effects of treatment	
17	Managing feeling tired/ fatigued	
18	Managing loss of mobility	
Emotional Health		
19	Feeling anxious or scared	Cluster 8
20	Feeling depressed	
21	Having what I need to cope with my diagnosis	
22	Worrying about my cancer spreading	
23	Worrying about my cancer returning or secondary cancers	
24	Worrying about how my family is coping	
25	Coping with changes in my dating or romantic life	
26	Coping with changes in my relationships with my family members	
27	Coping with changes in my relationships with friends	
28	Feeling independent	
29	Coping with changes in my physical ability	
30	Coping with changes in my appearance	
31	Coping with not being able to do the same things as other people my age	
32	Managing the emotional side effects of treatment	
33	Being able to make plans or think about the future	
Sexual & Reproductive Health		
34	Receiving information and counseling about risk for infertility and fertility preservation options	Cluster 3
35	Receiving information on treating infertility and other options for having children (i.e., artificial insemination, in vitro fertilization, surrogacy, adoption, etc.)	

36	Receiving information on the genetic inheritability of my cancer	
37	Cancer treatment staff giving me information about sexuality and intimacy during cancer treatment	
	Health Behaviors & Wellness	
38	Cancer treatment staff giving me information about nutrition and exercise	Cluster 7
39	Sleeping well	
40	Having the resources I need to quit smoking	
41	Cancer treatment staff giving me information about drug and alcohol use during cancer treatment	
42	Having spiritual support or faith-based resources	
43	Finding information on alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.)	
	Work & Education	
44	Navigating my school life while going through cancer treatment	Cluster 4
45	Navigating my work life while going through cancer treatment	
	Peer Support & Programming	
46	Being able to spend time with people my own age	Cluster 6
47	Being able to talk to people my own age who have been through a similar experience	
48	Managing to take part in social activities	
	Finances & Everyday needs	
49	Paying my bills	Cluster 4
50	Getting guidance about scholarships or loan repayment options	
51	Worrying about my health insurance (e.g., access/eligibility, coverage, cost)	
52	Getting to and from my cancer care appointments	
53	Having childcare during my cancer care appointments	
54	Having stable housing	

Response options

The design team approved the revision of the “no need” response option to “no need/need met”, as suggested by cognitive interview participants. The design team also discussed whether to use the same response scale throughout the entire instrument. Although users expressed some concerns about the applicability of the response scale to all items, the design team saw value in remaining consistent throughout the tool, noting that multiple response scales could be cumbersome for users. However, we opted to table the discussion about the response scale until the design team had had the opportunity to review the revised itemset after the meeting.

Lookback periods

The original CNQ-YP features similar items with different lookback periods (e.g., “since my diagnosis”, “in the last month”); survey and cognitive interview participants felt these multiple reference periods were confusing and redundant given the tool's goal of addressing current needs through service provision. Thus, the design team opted to anchor all items to current needs, or needs within a shorter lookback period (e.g., "in the past month"), and eliminate redundant content stemming from the original CNQ-YP's multiple periods of reference. Several considerations were raised during this discussion.

First, design team members noted that the lookback period may depend upon the frequency with which the needs assessment is administered. For example, if the tool were to be administered every three months, design team members wondered whether a lookback period of three months would be appropriate. They definitely felt that administering the needs assessment every month would be too often. In general, providers preferred the idea of tying needs assessment administrations to specific time intervals (e.g., administering it every three months), as opposed to anchoring administration timing to certain events (e.g., change in treatment or disease status). They felt that this would be more seamless from a workflow perspective. We discussed the importance of administering the tool at diagnosis, at the end of treatment, and somewhere in between. One provider said, *"I definitely think those bookends are important, right when treatment starts and ends. And definitely in the middle. But I think it's so variable what 'in the middle' looks like for people. It could be years."*

Design team members also noted that, in determining the lookback period for the needs assessment, we should consider how frequently AYAs are coming through NCCH. For an AYA with four-week treatment cycles, one month would be the longest they would go without seeing a provider. In this sense, design team members felt that a one-month lookback period would be appropriate. One AYA said, *"If you're in treatment, a month is going to capture your time in treatment. If you're out of treatment and you haven't experienced something over the last month, it's probably not a pressing issue… it will capture a full cycle, or close to it."* One provider suggested framing the lookback period as "*in the last month or so*" so that it is *"not so concrete as to stress people out.*"

Ultimately, the design team made the tentative decision to use a one-month lookback period for all items. We planned to revisit this discussion once decisions about administration timing were made.

Item format

In the original CNQ-YP, questions are broken up into different rows based on common roots. For example, in Item 1, “I had the following needs”, “before treatment”, “cancer treatment staff telling me”, and “about my diagnosis” are on separate lines. Based on feedback received during cognitive interviews, the design team opted to collapse item wording such that each item was displayed on one line of the needs assessment tool. Because we made many revisions to CNQ-YP wording and grouping, the original item formatting no longer made sense (i.e., groups of items no longer shared the same root).

Sequencing

The design team opted to abandon the original CNQ-YP’s sequencing in favor of ordering items based on follow-up domains.

Other discussion

During the workshop, the question was posed: do we still want to include items assessing needs for which NCCH does not have services or resources to address? The decision was made to err on the side of inclusion and include items for which services and resources might not be available. Although the primary purpose of AYA NA-SB is to respond to needs in real time, clinical design team representatives also expressed interest in using the tool for program development (i.e., to inform institutional changes). They noted that capturing needs for which services and resources do not exist could be helpful in identifying areas where resources need to be built in or community providers need to be identified to bolster support available through NCCH.

Another point of discussion was the potential for tailoring the needs assessment based on where respondents are in their disease trajectory. For example, some items may be relevant for

AYAs in the earlier phases of treatment than for AYAs transitioning into survivorship. This discussion was tabled for a later date.

AYA NA-SB administration was also discussed in the context of the tool's length. AYA representatives noted that the length of the survey would be "*less irritating*" and "*less intimidating*" were the assessment to be administered electronically (e.g., through a Smart Phone application). This would allow for flexibility in terms of when AYAs could complete the assessment and, depending on the platform, could facilitate the easy documentation and use of data on the back end.

5.6 Guided Tours

I first conducted guided tours with clinical partners at NCCH (i.e., providers; n=2), LL (social worker/AYA program director) and AS (oncologist/medical director of AYA program), for a total of 10 hours across three days. I then conducted guided tours with AYAs (n=8). Guided tours generated many insights on the NCCH context, which were critical to informing AYA NA-SB design and implementation planning. These user and contextual factors were analyzed based on Maguire et al.'s framework of user and contextual factors that influence an intervention's usability and usefulness in practice.[132] They are reported below, along with their implications for AYA NA-SB, by domain of the Consolidated Framework for Implementation Research (CFIR) including: (1) outer context, (2) inner context, (3) individuals, (4) process, and (5) intervention. I applied this framework retrospectively to anchor user and contextual factors to AYA NA-SB implementation. The implications of guided tour findings, summarized in **Table 16**, were considered by the design team in designing and planning to implement AYA NA-SB (Section 5.8).

Table 16. Implications of ethnography findings for AYA NA-SB

Construct	Summary of user/contextual factors	Implications for AYA NA-SB
Outer context		
Patient characteristics	• At NCCH, around 150 individuals ages 15-30 are diagnosed each year	
Location	• Many AYAs do not live locally • Proximity to hospital is a major factor influencing AYAs' use of services and resources	• Transportation represents an important for AYA NA-SB to address. • To the extent possible, AYA NA-SB should be flexible to the diverse locations of AYAs.
Technology	• AYAs are tech-savvy and use a broad range of technologies to manage their cancer	• Electronic delivery of AYA NA-SB should be considered.
Inner context		
Structure	• NCCH's AYA program is relatively new (est. 2015) and currently undergoing expansion	• The expansion of NCCH's AYA program represents an opportunity for the implementation of AYA NA-SB.
Staffing	• LL and AS work closely with non-AYA-specific providers and staff across disease groups from both pediatric and adult oncology, including oncologists, nurse practitioners, physician assistants, and other oncology providers. • NCCH's model of cancer care hinges on the provision of multidisciplinary services and resources to support patients.	• AYA NA-SB delivery should leverage AYA-specific staff where possible • AYA NA-SB should facilitate the communication and sharing of information across providers from pediatric and adult oncology and across disease groups. • Clear referral pathways should be established with other providers to facilitate the provision of services from across departments and disciplines.
Leadership	• NCCH's AYA program falls partially under the umbrella of the Comprehensive Cancer Support Program.	• AYA NA-SB should leverage Comprehensive Cancer Support Program resources, where applicable
Physical space	• NCCH is positioned within a sprawling medical campus; AYAs' appointments are held in disparate locations across the medical campus.	• AYA NA-SB delivery should accommodate the variety of locations where AYAs have appointments. • The centralized layout of pediatric oncology may

Construct	Summary of user/contextual factors	Implications for AYA NA-SB
	- For AYAs receiving care in pediatric oncology, registration, labs, clinical appointments, and infusions occur in one centralized location on the first floor (the Pediatric Oncology Clinic). - NCCH is in the process of building an AYA-specific infusion center.	facilitate the communication and information sharing that AYA NA-SB will require. - For AYAs receiving infusion treatments, the addition of an AYA-specific infusion space represents an opportunity for AYA NA-SB service and resource provision, as AYAs will be concentrated in one central location.
Culture	- NCCH has a culture of collaboration and improvement but provider buy-in is an important prerequisite of any change initiative.	- The collaborative, improvement-oriented culture of NCCH bodes well for AYA NA-SB implementation. Building buy-in among providers will be critical to implementation.
Reference materials	- AYAs did not find brochures and other non-tailored resources very helpful.	- The provision of reference materials through AYA NA-SB should be highly tailored to the unique needs reported by each AYA.
	Individuals	
Program director/ social worker	- LL divides her time among (1) administrative tasks, (2) research-related tasks, and (3) clinical tasks. - An additional AYA social worker was recently hired to help offload some of LL's clinical tasks.	- The hiring AYA-specific social worker represents an increase in staffing hours that might allocated towards AYA NA-SB.
Oncologist	- AS's time is split between research (75%) and clinical (25%). Although this is a larger research focus than most of his colleagues have, most of them do have some time carved out for nonclinical tasks	- Oncology providers, particularly those doing research or other nonclinical tasks, may not have the time to delivery AYA NA-SB.
Organizational knowledge	- Social workers have a robust knowledge of services and resources available at NCCH.	- Social workers may be particularly fit to facilitate the care coordination required by AYA NA-SB.
Knowledge and beliefs about the intervention	- LL and AS are accustomed to assessing AYAs' needs as part of routine care.	- LL and AS possess the fundamental knowledge and skills required to

Construct	Summary of user/contextual factors	Implications for AYA NA-SB
		engage in a more formalized needs assessment process.
Experience with PROMs	• Providers had some experience administering PROMs. • Some AYAs have experience completing surveys. However, all AYAs were amenable to completing surveys as part of their cancer care.	• Providers' experience administering PROMs will facilitate their ability to administer AYA NA-SB. • Completing a PROM as part of their cancer care is acceptable to AYAs
	Process	
AYA Tasks		
Diagnosis	• After receiving a cancer diagnosis, AYAs are often in shock or in high distress, and may not know what their service needs are yet.	• AYA NA-SB should not be administered immediately upon diagnosis.
Treatment schedules	• AYAs experience appointment fatigue during cancer treatment • AYAs struggle to balance their treatment schedules with competing priorities such as work, school, and raising children.	• AYA NA-SB should be minimally burdensome to AYAs. • To the extent possible, services rendered should be embedded in existing treatment appointments, while patients are already in the hospital.
Outpatient appointments	• During outpatient visits, AYAs' task load can be extensive. • Appointments entail some combinations of segments including transportation, parking, registration, labs, imaging, treatment, clinical	• AYA NA-SB should accommodate the range of appointment types that AYAs have. • To the extent possible, AYA NA-SB should incur no additional time burden to AYAs' already long and exhausting appointments.
Inpatient stays	• Many AYAs have an inpatient stay at some point while they're undergoing treatment • AYAs staying inpatient have lot of "deadtime"	• Capturing the needs of inpatient AYAs is important. • There is ample opportunity for AYA NA-SB administration for AYAs staying inpatient.
End-of-life care	• For some AYAs, cancer is more than just a temporary hurdle.	• AYA NA-SB content and delivery should be sensitive to those whose cancer is terminal.
Caregivers' tasks	• AYAs rely heavily on their loved ones to navigate cancer care.	• AYA NA-SB content should reflect the importance of changes that these

Construct	Summary of user/contextual factors	Implications for AYA NA-SB
		relationships undergo after a cancer diagnosis.
Provider tasks		
Identifying AYAs	- There is currently no systematic way for new AYA patients to be identified.	- As such, AYA NA-SB should include a process or strategies for identifying new AYA patients (e.g., strengthening referral networks to expand reach).
Assessing AYAs' needs	- For non-medical concerns, AYAs rely on the AYA social workers more than their oncology providers. Social workers are currently conducting needs assessments, although informally/conversationally	- AYA NA-SB should leverage social workers' existing workflow and expertise in the domain of needs assessment.
Documenting and communicating AYAs' needs	- Providers use EPIC to document and communicate about patient information. - Providers also communicate via phone, email, pager and in-person. - AYAs are active users of MyChart.	- If possible, AYA NA-SB should interface with EPIC in order to capitalize on existing systems. - AYA NA-SB could also leverage existing communication channels (e.g., EMR messaging, pager, phone, etc.) - AYA NA-SB could interface with MyChart.
Providing services and resources to meet AYAs' needs	- AYAs report a number of barriers to service and resource use; some of these barriers (e.g., service capacity) may not be addressable by AYA NA-SB.	- Flexibility should be built into AYA NA-SB service provision to address downstream barriers to service use . For example, multiple services might be offered for a given need such that an AYA can select the option that is most feasible and appealing to them.
Intervention		
Goals for intervention		
Intervention outcomes	- Providers wanted AYA NA-SB to fit seamlessly with existing workflows. They hoped it would formalize documentation and communication channels. - AYAs wanted the needs they report in AYA NA-SB to be followed up on in a timely manner.	- To the extent possible, AYA NA-SB should leverage and strengthen existing provider workflow, communication channels, and documentation practices. - Needs reported on AYA NA-SB should trigger

Construct	Summary of user/contextual factors	Implications for AYA NA-SB
		timely referral to appropriate services or other follow-up actions.
Needs assessment content	• AYAs reported many and diverse needs, but financial concerns were the most commonly discussed.	• In addition to capturing psychosocial concerns, peer support, transportation, and side effect management, it is particularly important that AYA NA-SB capture financial needs which are pervasive among AYAs.
Timing	• Providers and AYAs wanted AYA NA-SB to account for the dynamic nature of needs as AYAs move through treatment. • After receiving a cancer diagnosis, AYAs are often in shock or in high distress, and may not know what their service needs are yet. • AYAs appointments are long and exhausting.	• AYA NA-SB should be administered at multiple timepoints throughout cancer including diagnosis, during treatment, at the end of treatment, and at some interval in survivorship. • AYA NA-SB should not be administered immediately upon diagnosis when AYAs might not have a grasp of what they need yet. • In the clinic, AYA NA-SB should be administered during times when AYAs' wait times so as not to lengthen AYAs' already long appointments.
Format	• AYAs did not express a strong preference in terms of paper versus electronic delivery of AYA NA-SB.	• AYA NA-SB could be administered through a paper or electronic format.
Benefits of intervention	• AYAs and providers expressed numerous potential benefits of AYA NA-SB	• AYA NA-SB potentially has high acceptability among prospective users.
Costs of intervention	• Providers expressed some potential costs of AYA NA-SB including staffing time, workflow disruptions, and provider buy-in. • For AYAs, downstream barriers to service and resource exist (e.g., strict eligibility requirements, service capacity and timeliness)	• Staffing time, workflow disruptions, and provider buy-in represent potential barriers to implementation. • Additional strategies may be needed to address downstream barriers to AYAs' use of services and resources.

Outer context

Patient characteristics. At NCCH, around 150 individuals ages 15-30 are diagnosed each year. About one third of these patients are treated in pediatric oncology and the remainder in adult oncology. I conducted guided tours with AYAs (n=8), described in **Table 17.** AYAs were diverse with respect to clinical and demographic characteristics. Three were male and five were female. Four identified as non-Hispanic White, two as non-Hispanic Black, one as Asian, and one as Hispanic. They ranged in age from 18 to 34, with a mean age of 23. They represented seven different diagnoses including non-Hodgkin, Hodgkin, and Burkitt's Lymphoma, osteosarcoma, liver cancer, testicular cancer, and Chronic Myeloid Leukemia. They also represented varying points on their cancer trajectory with two diagnosed in the past three months, two diagnosed between three and six months ago, one diagnosed between seven and 12 months ago, and three diagnosed more than 12 moths ago. Two lived with parent(s); five lived with their spouse or partner; one lived alone. One had a child.

Table 17. AYA guided tour participants

Sex and gender identity	
Female	5
Male	3
Age	
Mean (SD)	23.4 (5.0)
Race	
Hispanic (all races)	1
Non-Hispanic Black	2
Asian	1
Non-Hispanic White	4
Cancer type	
Non-Hodgkin Lymphoma	1
Hodgkin's Lymphoma	1
Osteosarcoma	2
Chronic Myeloid Leukemia	1
Burkitt's Lymphoma	1
Testicular cancer	1
Liver cancer	1
Time since diagnosis	
< 3 months	2
3-6 months	2
7-12 months	1
>12 months	3
Cohabitants	
Parent(s)	2
Spouse	2
Non-spouse partner	3
Child/children	1
Lives alone	1
Other	
	N=8

Location. Many NCCH patients do not live locally. Several AYA guided tour participants lived in other North Carolina cities and had to drive multiple hours for appointments at NCCH. As such, AYAs cited location as a barrier to service use. One AYA, who lived several hours from NCCH, discussed this issue in terms of her psychosocial needs. *"I had a few phone call sessions with [the social worker] but it's not like I live in Chapel Hill so it's not easy for me to have an appointment with her all the time. So, I need to find somebody in my area… but then it's really hard to find someone in* *my area that is what I'm looking for without the resources to help me navigate it… I want someone who is familiar with young adult cancer patients and that's not necessarily an easy find."* Relatedly, transportation proved another barrier to AYAs' use of services and resources. One AYA's wife talked about the toll that cancer had taken on her and her husband's mental health, and how much they needed *"someone to talk to."* However, she said she would struggle to make it to regular outpatient therapy appointments because she did not have a ride. Instead, she wanted access to services housed in NCCH so that she could access these services while accompanying her husband to his daily radiation appointments.

I visited with one AYA during an inpatient stay. He and his family lived on the North Carolina coast, about a 4-hour drive from NCCH. After each chemotherapy session, he was admitted inpatient for observation until the chemotherapy levels in his blood fell to an acceptable level. His parents or partner typically dropped him off for inpatient stays. However, his parents were older, so he often did the driving. He would have liked to drive himself but said it's cheaper to be dropped off because parking at NCCH costs $10 per day. *"When you're here for a week plus, that adds up."* He was finally cleared to be discharged while I was with him. However, he had to wait several hours for his family members to drive there from the coast. When asked what kind of needs he had while receiving inpatient care, he said that the number one thing that has been on his mind was financial help. He could not work because of his treatment regimen and was struggling to shoulder the costs of hospital bills, transportation, etc. He had not been connected to a financial navigator but had talked to the social worker about different financial assistance options, such as a program that provides gas cards for transportation to and from the hospital.

Another AYA moved back home from Scotland to live near her family, so that they could help to support her during treatment. Proximity to the hospital became a driving factor in her life decisions, ultimately altering the course of her career. Another AYA made a similar move, quitting her job as a flight attendant in DC so that she could be closer to family, and to her providers in North Carolina.

IMPLICATIONS FOR AYA NA-SB. Given that many AYAs do not live locally, transportation represents an important need for AYA NA-SB to address. Additionally, proximity to hospital is a major factor influencing AYAs' use of services and resources. When connecting AYAs to services and resources, access should be an important consideration. To the extent possible, AYA NA-SB should be flexible to the diverse locations of AYAs, for example, by offering external referrals convenient to AYAs' place of residence or services that can be delivered remotely.

Technology. Unsurprisingly, AYAs were tech-savvy, and used their mobile phones and other technologies to seek information and manage other aspects of their illness. Leading into our guided tours, several preferred to communicate with me via text versus via email. Most had their mobile phones out frequently during guided tours, using them to communicate with friends and family, access needed information, or bade time while waiting at various points throughout their appointments. The wife of one AYA said that she used her phone to record notes about upcoming appointment times and questions she had for the providers. To keep track of his appointment schedule, one AYA relied primarily on text and call reminders from NCCH, saying they would call *"like 5 times"* before appointments. Interestingly, these automated reminders asked about transportation. This AYA noted that they also received emails about upcoming appointments. Prior to being diagnosed with cancer, they said they seldom used email. However, they had become much more *"email-active"* because of all the emails they receive related to their cancer care. When asked if they opened emailed appointment reminders, several AYA guided tour participants said yes.

IMPLICATIONS FOR AYA NA-SB. Given that AYAs are tech-savvy and use a broad range of technologies to manage their cancer, electronic delivery of AYA NA-SB should be considered. For example, AYA NA-SB could be embedded in emailed appointment reminders or delivered through a mobile application.

Inner context

Structure. NCCH is a public, National Cancer Institute (NCI)-designated Comprehensive Cancer Center located in central North Carolina, in a relatively metropolitan area. NCCH's AYA program was established in 2015 with funding from a local nonprofit organization, the BeLoud Sophie Foundation. This funding was initially allocated towards hiring one fulltime employee (a social worker/program director) to provide AYA-specific care at NCCH. Since 2015, the program has evolved, hiring new AYA-specific staff members and expanding program activities and reach.

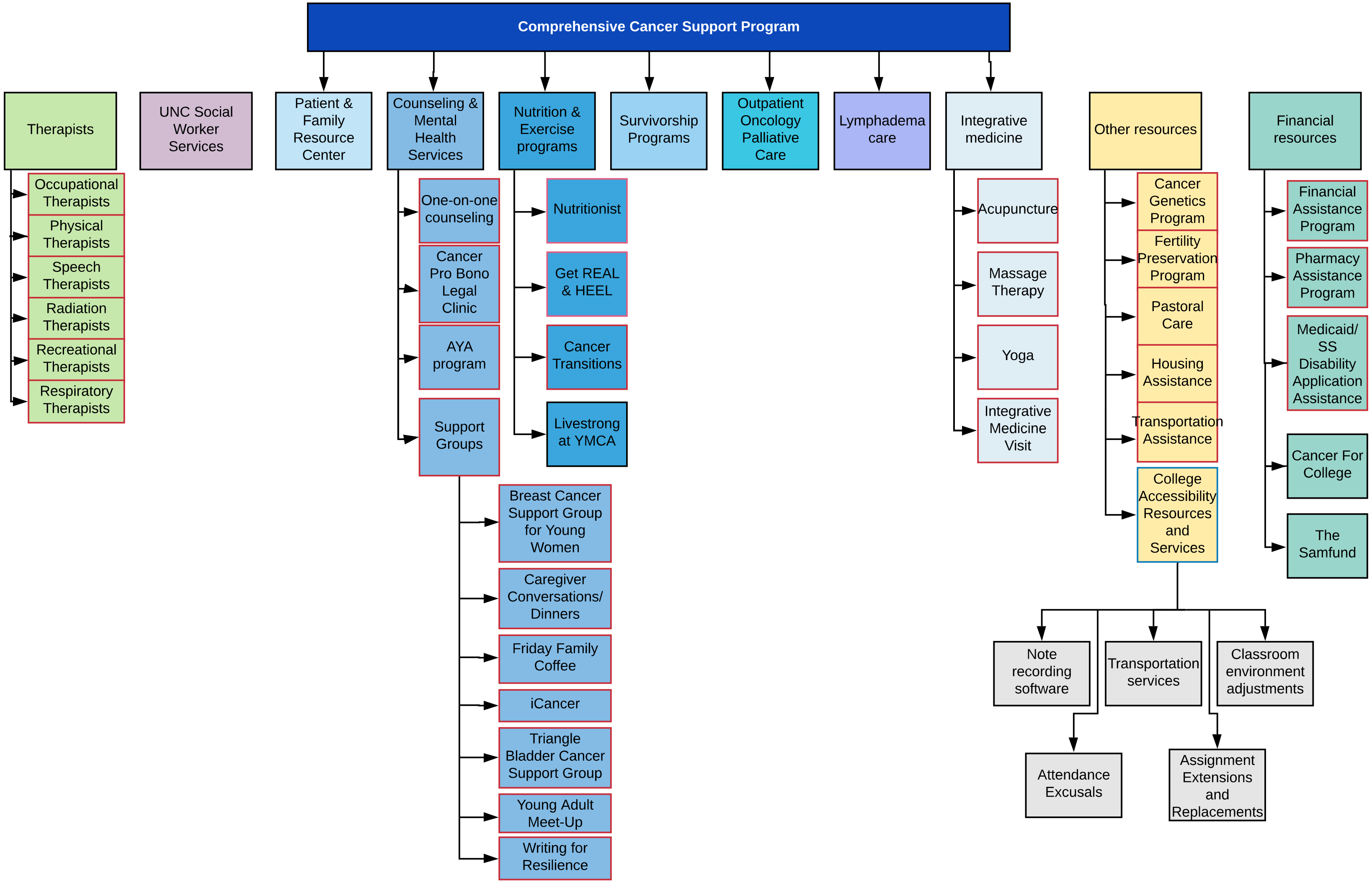
> IMPLICATIONS FOR AYA NA-SB. NCCH's AYA program is relatively new; it is currently undergoing expansion, representing an opportunity for the implementation of interventions like AYA NA-SB.

Staffing. NCCH's AYA program is led by clinical partners and guided tour participants: LL (program director, social worker) and AS (program medical director, pediatric oncologist). AS sees both pediatric and AYA patients; LL exclusively sees AYA patients. An additional AYA-specific social worker was hired recently to help offload some of LL's clinical duties.

LL and AS reported working closely with non-AYA-specific providers and staff across disease groups from both pediatric and adult oncology, including oncologists, nurse practitioners, physician assistants, and other oncology providers. In adult oncology, there are 15 oncologists. There is a psychiatry physician assistant who LL said can visit patients *"on the fly",* at her request. There are patient navigators who help with logistics like setting up appointments and scans. There are five outpatient social workers who can help with financial and other logistics; however, you have to ask to see them, and typically would only see them if *"something is wrong."* There is one dietician serving all of NCCH. There are also a number of fellows available through psycho-oncology. In pediatric oncology, there are 13 pediatric oncologists and six fellows who see an average of six to eight patients in a given day. There are two outpatient social workers. There are child life specialists and teachers. There are also nurse practitioners, common extenders, nurses, nurse navigators, volunteers, and research staff. The two AYA social workers and a psychologist *"tag team"* AYA psychosocial concerns. The psychologist typically takes patients with preexisting mental health concerns, but his caseload is not constrained to just AYA patients.

NCCH's model of cancer care hinges on the provision of multidisciplinary services and resources to support patients. **Figure 15** displays the services and resources available to NCCH patients. In this figure, NCCH resources are outlined in red; external resources are outlined in black. LL has forged relationships across pediatric and adult oncology, and across disease groups. This relationship-building has given her the ability to advocate for her patients and *"push back against the status quo."* LL questioned whether someone without these relationships would be able to do the job of care coordination as easily. She described cross-departmental relationships as critical to coordinating care.

Figure 15. Services and resources available to NCCH patients



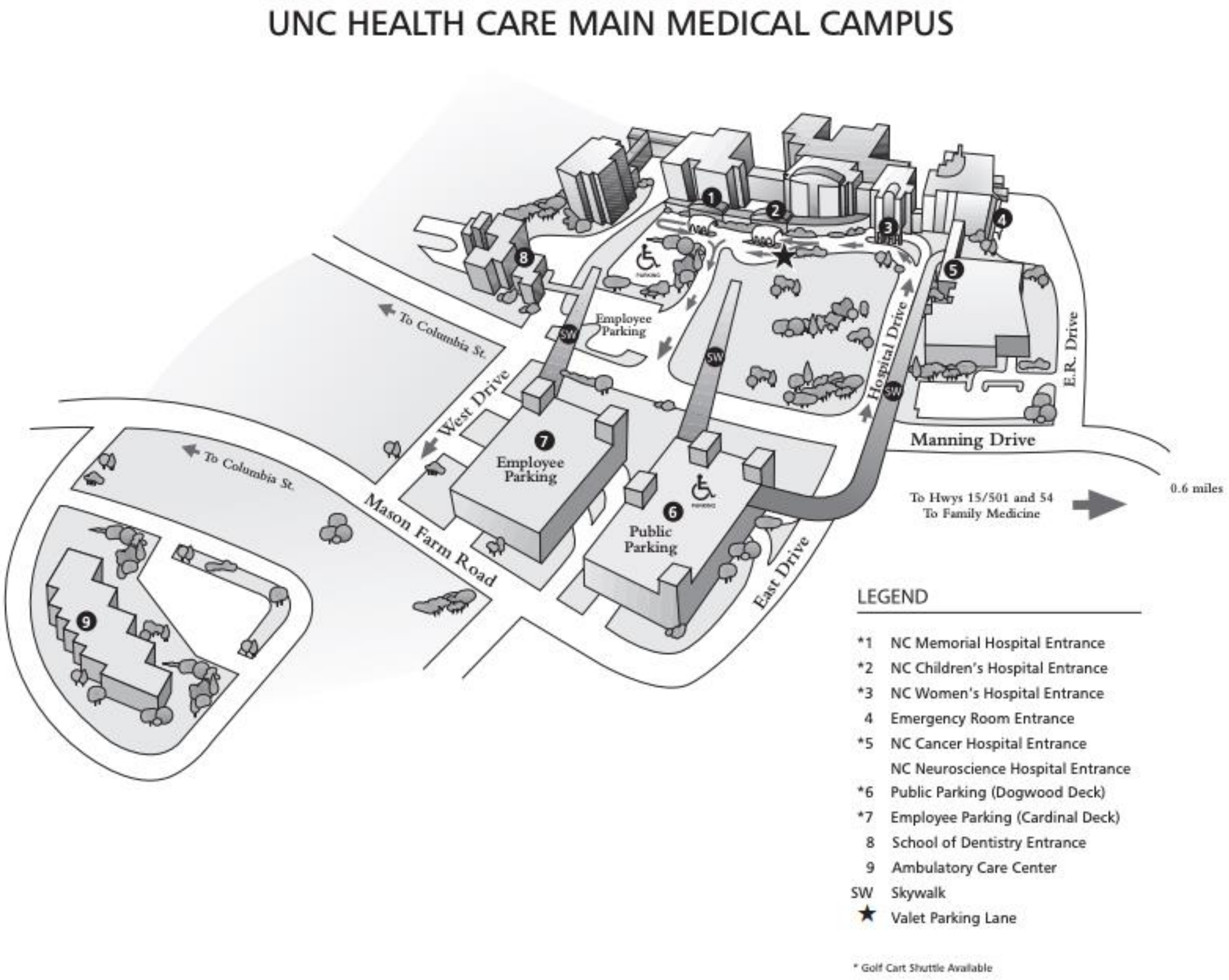
IMPLICATIONS FOR AYA NA-SB. AYA NA-SB delivery should leverage AYA-specific staff where possible as these individuals' time is already allocated towards providing care to AYAs. AYA NA-SB should facilitate the communication and sharing of information across providers from pediatric and adult oncology and across disease groups. Clear referral pathways should be established with other providers to facilitate the provision of services from across departments and disciplines.

Leadership. LL works under the Division Head of General Adult Psychiatry; her position falls within NCCH's Comprehensive Cancer Support Program. AS works under the Division Chief of Pediatric Oncology who works under the Chair of Pediatrics.

IMPLICATIONS FOR AYA NA-SB. AYA NA-SB should leverage Comprehensive Cancer Support Program resources, where applicable, to build leadership buy-in.

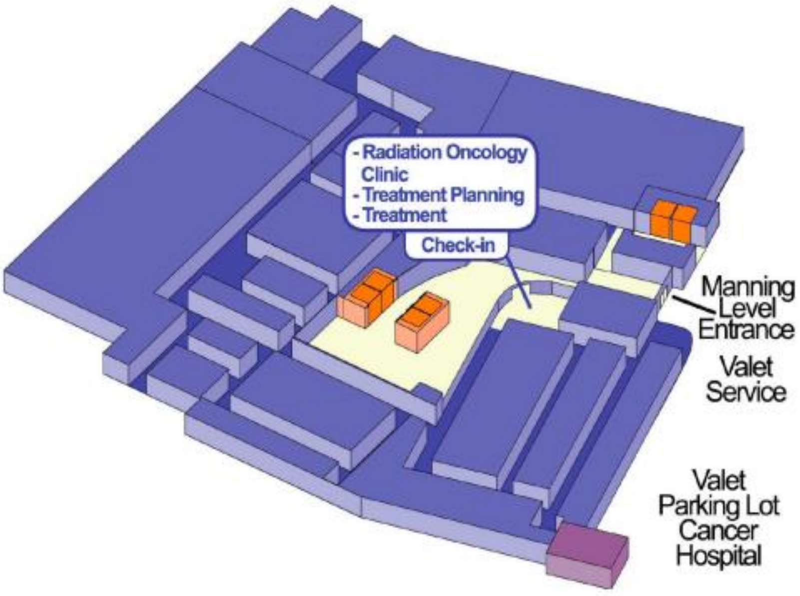
Physical space. NCCH is positioned in University of North Carolina (UNC) Health Care's Main Medical Campus (see **Figure 16**), adjacent to the Emergency Room and across a courtyard from the main hospital, children's hospital, and women's hospital. In reference to navigating the sprawling medical campus, one AYA said, *"it's big, but once you get the hang of it, it's not that bad."* To access the 315,000 square-foot cancer hospital, patients, some of whom have driven hours to get there, pay to park in a deck across the street, and follow a pedestrian skybridge to the hospital's ground-level entrance.

Figure 16. UNC Health Care main medical campus



NCCH has seven floors. Radiology and Radiation Oncology, Imaging, and a Lab Draw Station, are located on two basement floors (**Figure 17, 18**). The ground-level floor includes a lobby, patient admitting, the Patient and Family Resource Center, a conference center, food service, a retail pharmacy, and a gift shop (see **Figure 19**). Mammography and the Pediatric Oncology Clinic are located on the first floor (**Figure 20**). Outpatient Multidisciplinary and Surgical Oncology Clinics are located on the second floor (**Figure 21**). The infusion center for adult oncology is located on the third floor (**Figure 22**). The fourth floor contains 50 inpatient beds (**Figure 23**). Although patient appointments vary, a typical appointment for AYAs currently in treatment in adult oncology included checking in at the ground-floor registration desk, going downstairs for labs, going up to the first or second floor for a clinic appointment, and then going up to the third floor for an infusion. Patients receiving radiation would go directly to the basement level for their radiation appointments. Young adults with obstetric-gynecologic cancers, however, receive much of their clinical care in the Women's Hospital. The social worker, LL, noted that physical space becomes a major barrier for providing AYA services to these patients.

Figure 17. NCCH basement floor (Level M)



- The lowest level of the N.C. Cancer Hospital is called **LEVEL M**.
- The Valet Parking Lot for the N.C. Cancer Hospital is on this level.
- The Manning Level contains all the radiation oncology clinics and treatment rooms.

Figure 18. NCCH basement floor (Level B)

- **LEVEL B** of the N.C. Cancer Hospital is between the Manning Level and the Ground Level.
- Level B connects to an outdoor courtyard and labyrinth for meditation.
- The Lab Draw Station for bloodwork, Radiology and x-ray services are on Level B.

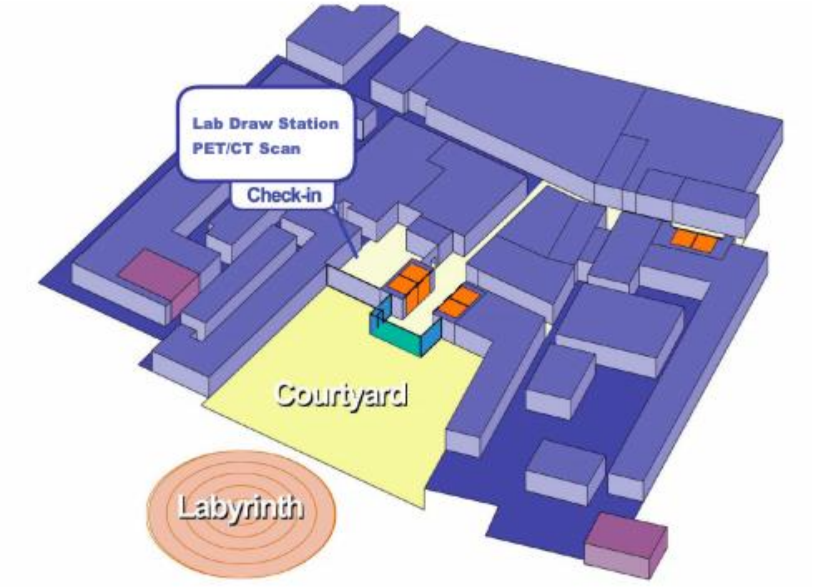


Figure 19. NCCH ground floor level

Figure 20. NCCH first floor

- The Mammography **LEVEL 1** Center and the Pediatric Hematology/ Oncology Clinic are both on Level 1 of the N.C. Cancer Hospital.
- All pediatric inpatient rooms are located in the N.C. Children's Hospital.

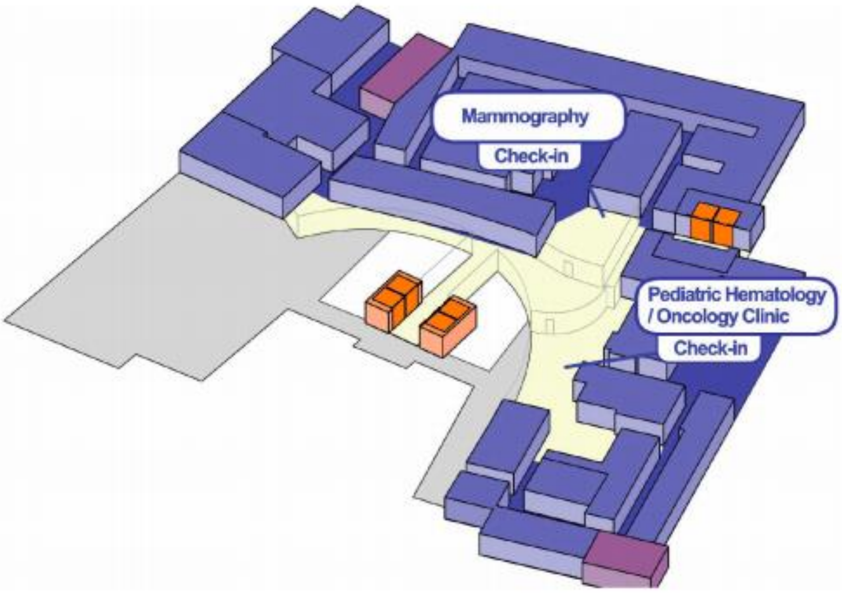


Figure 21. NCCH second floor

- The following Adult Oncology Clinics are on **LEVEL 2**:
  - Surgical Oncology,
  - Multidisciplinary Oncology
  - Hematology/Oncology
  - Bone Marrow Transplant.
- Comprehensive Cancer Support Program Counseling and Genetic Counseling are also on this level.

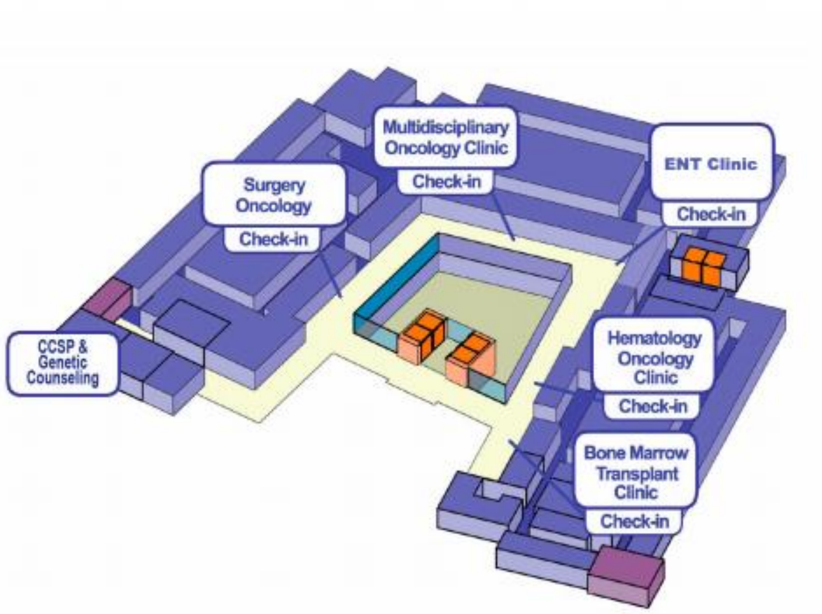
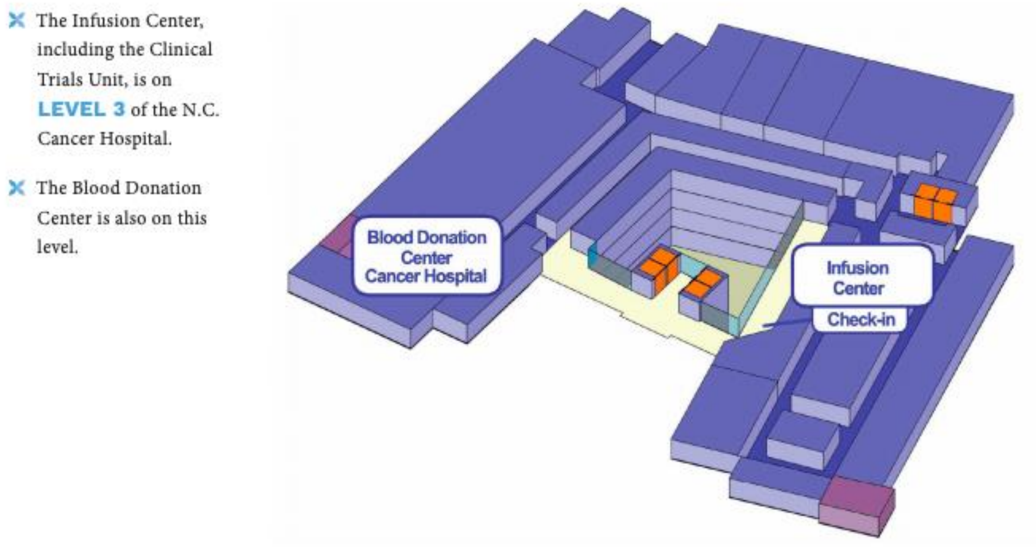
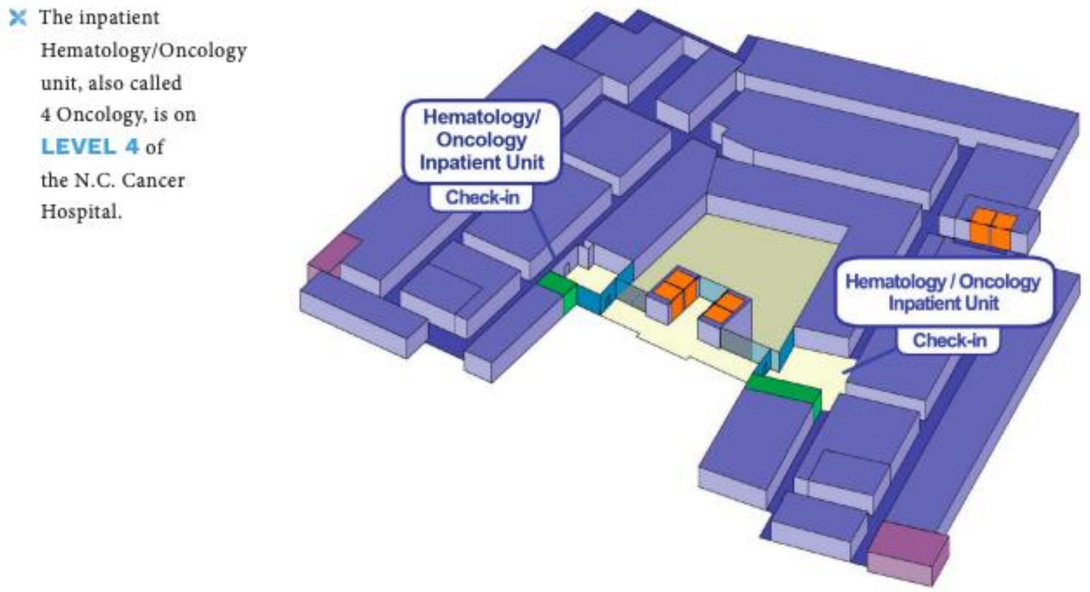


Figure 22. NCCH third floor



- The Infusion Center, including the Clinical Trials Unit, is on **LEVEL 3** of the N.C. Cancer Hospital.
- The Blood Donation Center is also on this level.

Figure 23. NCCH fourth floor



- The inpatient Hematology/Oncology unit, also called 4 Oncology, is on **LEVEL 4** of the N.C. Cancer Hospital.

The Patient and Family Resource Center, located on the ground floor of NCCH, offers education, support and comfort services, patient assistance, and referrals to both internal and external resources. Its Education Center offers a lending library of books, pamphlets, and audiovisual resources to help patients and families learn about their disease. Its image boutique offers a variety of head coverings to those going through chemotherapy.

For AYAs receiving care in pediatric oncology, registration, labs, clinical appointments, and infusions occur in one centralized location on the first floor (the Pediatric Oncology Clinic). There is even a procedure space in pediatric oncology where anesthesiology can be brought in. The pediatric oncology suite opens to a large waiting room, equipped with an interactive touch board on the floor. In the waiting room, there is a registration desk and a play area. The aesthetic is colorful and cheery. The waiting room leads back to a physician workspace with desktop computers lining the exterior walls and a conference table positioned in the middle. Physicians and other staff bustled around the workspace, talking to each other. The oncologist, AS, noted that, in the pediatric clinic, working in such close proximity to the other providers facilitates communication among them. Because the physical space is so centralized, it allows for more in-passing informal communication. AS said that he often asks other providers for advice when he runs into them around the pediatric oncology suite. Past the physicians' workspace, the hallway splits. On the right, there are about 10 exam rooms, each with their own animal theme; a nursing station lines the wall opposite of the exam rooms. On the left, the hallway leads past a kitchen and playroom into an open-concept infusion room. On one side of the infusion room, there is a long nursing station and a couple of small rooms reserved for labs and procedures. On the other side, 14 infusion chairs line the windowed walls. The pediatric infusion space is bright and colorful, with ample natural light and artwork. Each infusion chair has a television. Families, providers and volunteers moved around the communal space, engaging in amicable conversation.

During guided tours, the importance of physical space became apparent. One AYA guided tour participant, who had just finished four three-week chemotherapy cycles and begun one month of near-daily radiation therapy, spoke to this. When describing the difference between her experience with chemotherapy versus radiation, she talked at length about physical space. She was receiving care in pediatric oncology; when I accompanied her there for a clinical appointment, it was clear that she was comfortable and familiar with the space and the providers there. After her clinical appointment, we visited the infusion room, where she greeted and chatted with staff and other patients and family members. For example, she stopped to talk to the mother of a child receiving an infusion, with whom she shared information about treatment side effects. Later, I accompanied her to her radiation appointment. We took the elevator down to NCCH's basement floor to enter the Radiation Oncology suite. She swiped an ID badge to indicate her arrival and we followed a dimly lit hallway to a women's dressing room. She put her belongings in a locker, donned a hospital gown, and met me in the waiting room directly adjacent to the lockers. We were the only occupants of the small waiting room. Within 10 minutes, a radiation therapist arrived to take her back. She was gone for approximately 10 more minutes, during which she said she was *"tied down to the radiation machine",* with little to no conversation occurring. She went on to describe her radiation appointments as *"cold and mechanical"* and the radiation oncology suite as *"dark and depressing"*, a stark contrast from the bright and social pediatric infusion space. *"I barely say two words to anyone"* during the radiation appointments, she said. Because of the difference in physical space and atmosphere, she said that radiation has been far more demoralizing for her than chemotherapy.

The adult infusion center has 57 infusion spaces. Some of the spaces are set in an open-concept layout, separated only by curtains. Others are set in private rooms with sliding glass doors. One AYA described the adult infusion center as a "*cold factory*" that is always "*just packed*". After his first infusion, him and his wife bought noise-cancelling headphones, because the adult infusion center can be very noisy. They said that they were consistently the youngest people in the room "*by three decades*." In recognition of the importance of physical space, the AYA program at NCCH is in the process of designing and implementing an infusion space specifically for AYAs. The social worker, LL, noted that this will streamline AYA programming tremendously; by having all AYAs in one centralized location, she will be able to connect with and provide services to AYAs more easily. She added that the new infusion space will also facilitate peer-to-peer connection.

The private inpatient rooms at NCCH are spacious, with a bed in the middle of the room, and a seating area with two chairs and a table against the window. A modestly sized television is mounted to the wall and can be turned to face the bed or the sitting area. Underneath the television, there is a desk and computer for nursing staff to use. There is a mini refrigerator in the closet and a private bathroom by the door. A large whiteboard hangs on the wall with names of the patients' care team, lab results, a "to-do" list, precautions, and skin concerns. A field at the bottom of the whiteboard says "goals/needs/questions". For one guided tour participant, this field had his methotrexate (chemotherapy) level. He did not recall the space being used to notate any other goals, needs, or questions during his frequent inpatient stays.

> IMPLICATIONS FOR AYA NA-SB. Given that AYAs receive care in disparate locations throughout UNC's Medical Campus, AYA NA-SB delivery should accommodate the variety of locations where AYAs have appointments. The centralized layout of pediatric oncology may facilitate the communication and information sharing that AYA NA-SB will require more so than the more scattered layout of adult oncology. For AYAs receiving infusion treatments, the addition of an AYA-specific infusion space represents an opportunity for AYA NA-SB service and resource provision, as AYAs will be concentrated in one central location.

Culture. Providers described the culture in pediatric oncology as highly collaborative. They described this collaboration as critical given that *"pediatric oncology (and probably oncology in general) can generate a lot of tension and stress".* A group-oriented culture, in which providers freely solicit each other's advice, helped to ease some of that tension.

Providers also said there is a culture of continuous improvement at NCCH. However, the extent to which staff buy in to a new initiative or change is contingent upon how dramatically it impacts current workflow as well as staff members' perception of the initiative's merits. I asked AS what it takes to get his leadership and colleagues on board with new research or quality improvement initiatives. He provided a recent example of a survivorship initiative he spearheaded. First, AS pulled together a stakeholder panel including his supervisor (the Director of Pediatric Oncology), a nurse with robust survivorship research experience, and several oncologists with large panels of survivors. Together, they reviewed and refined his protocol. Finally, he presented the protocol to a larger group including nursing management and all oncologists. The goal of this meeting was to solicit input on the protocol but also to build buy-in and provide education on the intervention being implemented as part of the initiative.

IMPLICATIONS FOR AYA NA-SB. The collaborative, improvement-oriented culture of NCCH will likely support the multidisciplinary cooperation needed for AYA NA-SB implementation and delivery. However, building buy-in among providers will be critical to implementation.

Reference materials. "After-Visit Summaries" are printed and given to families after each visit. They include information about medications, possible side effects, and upcoming appointments. LL noted that, although she sometimes prints out additional resources for patients and families, it is typically not very helpful for them to receive a *"pile of non-tailored resources".* When asked if she often leaves appointments with paperwork or printed resources one AYA said, *"not really at all."* Another AYA said*, "for the cancer, they gave me a book on the different types of treatments and what kind of treatment I was going to have and stuff like that so that was helpful.. that's about it."* One AYA's wife sought resources in NCCH's Patient and Family Resource Center. Specifically, she leveraged the *"wall of brochures"* to learn more about young adult cancer, talking to children about a parent's cancer, and what happens after radiation. Brochures are also staged throughout NCCH clinic waiting rooms (see **Figure 24**), although AYA guided tour participants said they rarely looked at them. NCCH's AYA program is in the process of revamping their website and using it to house resources for patients and families.

Figure 24. NCCH brochures

IMPLICATIONS FOR AYA NA-SB. Printed resources could be provided with the After-Visit Summaries given to AYAs at the end of each appointment. However, the provision of non-tailored reference materials may not be helpful for AYA; as such, the provision of resources through AYA NA-SB should be highly tailored to the unique needs reported by each AYA.

<u>Individuals</u>

Program director/social worker. LL, who has been at NCCH for 4 years, divided her time among (1) administrative tasks, (2) research-related tasks, and (3) clinical tasks. Her administrative and program development tasks included identifying gaps in care and spearheading quality improvement projects, advocating for the AYA program at the hospital-level, program branding, and hiring new staff. Over the course of this project, LL hired another social worker to help assume some of her AYA clinical duties so she could devote more time to advancing program goals. As far as clinical tasks, LL shifted between adult and pediatric oncology and between outpatient and inpatient patients. LL noted that, while most providers at NCCH have *"homes"* (i.e., departments, disease groups, or physical locations where all of their work is done), she did not. Because of the scattered locations of her patients, LL said she is *"always on the move"* and rarely at her desk. She added that other providers and staff do not always understand this and expect her to be immediately available in their physical location.

> IMPLICATIONS FOR AYA NA-SB. The hiring of another AYA-specific social worker represents an increase in staffing hours that might allocated towards AYA NA-SB.

Oncologist. AS's time is split between research (75%) and clinical (25%). He noted that, although this is a larger research focus than most of his colleagues have, most of them do have some time carved out for nonclinical tasks (e.g., education, administrative tasks, advocacy). For four weeks out the year (in 1-week blocks), AS worked in the inpatient unit. Additionally, for four weeks out of the year (in 1-week blocks), AS was on consultation for other providers in the community.

> IMPLICATIONS FOR AYA NA-SB. Oncology providers, particularly those doing research or other nonclinical tasks, may not have the time to deliver AYA NA-SB.

Organizational knowledge. LL and AS both demonstrated extensive knowledge about NCCH. LL was knowledgeable about patient flow and the workflow of various provider groups. She had an idea of the bigger picture of how those workflows culminate in patient care. AS easily cited information about NCCH including the leadership structure, the number of oncologists, fellows, and other types of providers employed in pediatric oncology, and the number of AYAs served including breakdowns by pediatric versus adult, tumor type, etc.

Although social workers demonstrated robust knowledge on the psychosocial services and resources available at NCCH, this was not always the case for other providers whose focus was more constrained to medical concerns. For example, one AYA, who was also a pediatric oncology provider, noted that he had never referred patients to NCCH's Patient and Family Resource Center because he was not sure what resources the program offered. *"I'll be honest, I guess I don't know what exactly is down there. And I don't know how much of it is directed at pediatric support."*

> IMPLICATIONS FOR AYA NA-SB. Given that they have a robust knowledge of the services and resources available at NCCH, social workers may be particularly well-positioned to facilitate the care coordination required by AYA NA-SB.

Knowledge and beliefs about intervention. Providers demonstrated deep knowledge and experience with assessing AYAs' needs informally (i.e., without using a formalized tool). Observing AS and LL interact with patients and families, it was clear that they had a high level of comfort and skill with engaging with patients about their medical, psychosocial, and practical needs. Both had a robust base of knowledge on AYA guidelines, research, and programming.

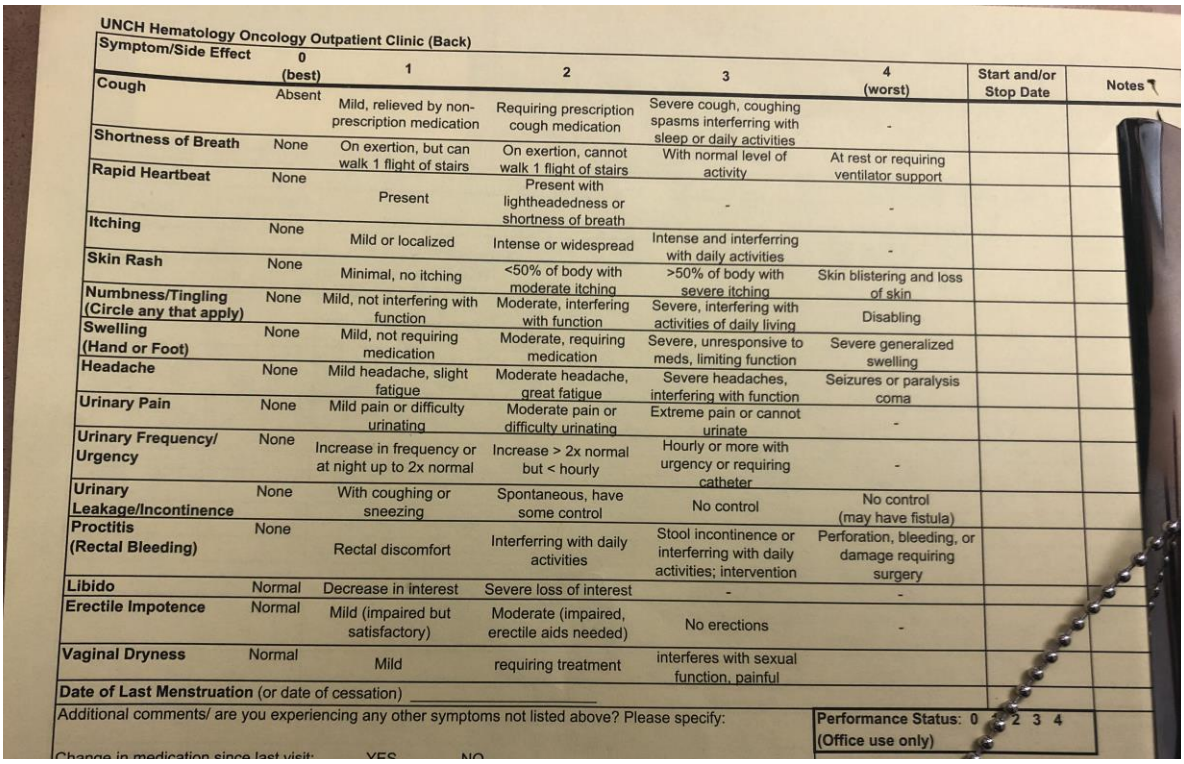
> IMPLICATIONS FOR AYA NA-SB. LL and AS are accustomed to assessing AYAs' needs as part of routine care. As such, they possess the fundamental knowledge and skills required to engage in a more formalized needs assessment process.

Experience with PROMs. A critical component of AYA NA-SB is the administration of a patient-reported outcome measure (PROM); thus, we asked providers and AYAs about their experience administering or completing PROMs. Providers demonstrated some experience administering PROMs. LL talked about the Distress Thermometer, which is currently being rolled out in adult oncology at NCCH. The tool is administered during patients' first follow-up visit after their initial visit. Front desk staff give patients a piece of paper containing the tool upon signing in at the registration desk. Someone then enters this information in EPIC, the electronic health record (EHR) used by NCCH. Although LL does not administer the Distress Thermometer, she has received some referrals through Distress Thermometer screening. A Distress Thermometer score of four to seven triggers a referral to the Patient and Family Resource Center; if it's an AYA, LL will be called. She noted, however, that this is not a major source of referrals. The Distress Thermometer has not been implemented in pediatric oncology. However, AS reported that he routinely administers the PHQ-9 and GAD-7, popular depression and anxiety screening tools, to pediatric patients.

Overall, AYAs had little experience completing surveys or questionnaires, but were amenable to the idea of it. One AYA had recently completed a survey as part of another research study she was participating in. A couple of AYAs recalled completing patient satisfaction questionnaires after certain visits or procedures. One said, "*now the hospital is trying to do a lot of surveys…I guess they're starting to listen people*". When I asked her if she was overburdened by surveys, she replied, "*it's not too many surveys, 'cause before it was a point where it was no surveys... I would rather for them to ask me what it is I need and what's going on versus them not asking and just making the assumption of 'this is what people need'*". She added that surveys are critical to her work as a customer service representative. "*I don't mind a survey…to come from a place where surveys do matter… it doesn't bother me*". One AYA said he received mailed and emailed surveys, but never completed them.

One AYA receiving care in the Multidisciplinary Oncology Clinic said that he completes a survey assessing his symptoms during every visit with his oncologist or nurse practitioner. The survey includes just over 30 items, in which respondents are asked to rate the severity of symptoms/side effects from 0 ("best") to 4 ("worst") (see **Figure 25**). The majority of the symptoms addressed in this questionnaire are physical; however, there are a couple of items assessing anxiety and depression. The survey is administered via paper in the clinic exam room, after the nurse assesses vitals, but before the oncology provider comes in. It is attached to a clipboard which the nurse hands to the patient and it takes approximately two minutes to complete. When the nurse practitioner arrived in the room during our guided tour, she used the completed survey as a reference point for her conversation with the AYA, asking him questions about the symptoms he reported. This AYA said he was not sure what, if anything, was done with the survey after that (e.g., if the information was documented somewhere) and speculated that the survey "*may be unique to the Multidisciplinary Clinic*" because he had not been asked to complete it during appointments with other providers (e.g., his clinical pharmacist in the Surgical Oncology Clinic). In general, he did not mind completing the survey and said "*it wouldn't be necessarily a hard thing to just slide another survey underneath that symptom reporting thing on the same clipboard and just have them fill all of it out all at once... I would do that*".

Figure 25. NCCH symptom report form (side B)



UNCH Hematology Oncology Outpatient Clinic (Back)

Symptom/Side Effect	0 (best)	1	2	3	4 (worst)	Start and/or Stop Date	Notes
Cough	Absent	Mild, relieved by non-prescription medication	Requiring prescription cough medication	Severe cough, coughing spasms interfering with sleep or daily activities	-		
Shortness of Breath	None	On exertion, but can walk 1 flight of stairs	On exertion, cannot walk 1 flight of stairs	With normal level of activity	At rest or requiring ventilator support		
Rapid Heartbeat	None	Present	Present with lightheadedness or shortness of breath	-	-		
Itching	None	Mild or localized	Intense or widespread	Intense and interferring with daily activities	-		
Skin Rash	None	Minimal, no itching	<50% of body with moderate itching	>50% of body with severe itching	Skin blistering and loss of skin		
Numbness/Tingling (Circle any that apply)	None	Mild, not interfering with function	Moderate, interfering with function	Severe, interfering with activities of daily living	Disabling		
Swelling (Hand or Foot)	None	Mild, not requiring medication	Moderate, requiring medication	Severe, unresponsive to meds, limiting function	Severe generalized swelling		
Headache	None	Mild headache, slight fatigue	Moderate headache, great fatigue	Severe headaches, interfering with function	Seizures or paralysis coma		
Urinary Pain	None	Mild pain or difficulty urinating	Moderate pain or difficulty urinating	Extreme pain or cannot urinate	-		
Urinary Frequency/ Urgency	None	Increase in frequency or at night up to 2x normal	Increase > 2x normal but < hourly	Hourly or more with urgency or requiring catheter	-		
Urinary Leakage/Incontinence	None	With coughing or sneezing	Spontaneous, have some control	No control	No control (may have fistula)		
Proctitis (Rectal Bleeding)	None	Rectal discomfort	Interferring with daily activities	Stool incontinence or interferring with daily activities; intervention	Perforation, bleeding, or damage requiring surgery		
Libido	Normal	Decrease in interest	Severe loss of interest	-	-		
Erectile Impotence	Normal	Mild (impaired but satisfactory)	Moderate (impaired, erectile aids needed)	No erections	-		
Vaginal Dryness	Normal	Mild	requiring treatment	interferes with sexual function, painful			

Date of Last Menstruation (or date of cessation) ___________________

Additional comments/ are you experiencing any other symptoms not listed above? Please specify:

Performance Status: 0 1 2 3 4
(Office use only)

Change in medication since last visit: YES NO

IMPLICATIONS FOR AYA NA-SB. Providers had some experience administering PROMs, which will facilitate their ability to administer AYA NA-SB. Although some AYAs had experience completing surveys as part of their cancer care, many do not. However, all AYAs were amenable to it.

Process

AYA tasks

Diagnosis. The lives of AYA guided tour participants were changed dramatically by their cancer diagnosis. "*It's hard to handle, hard to live with,*" the wife of one guided tour participant said. One AYA had had the phrase, "the thing is…", tattooed in delicate cursive on her left wrist to commemorate the date she was diagnosed. *"It's a big life changing event and I feel like it should be acknowledged. so, I went and got this tattoo because it's actually the title of a poem I've found helpful and comforting these past two years."* Another AYA recalled being completely shocked when she was diagnosed, saying that she barely remembers a thing from the weeks after she got the news. However, she quickly took on a *"let's do this mentality",* looking ahead to treatment as *"just a* *thing, just a shitty thing."* Another AYA echoed this sentiment, saying *"this is just a small portion of my life"*.

IMPLICATIONS FOR AYA NA-SB. Because of the shock rendered by a cancer diagnosis, AYA NA-SB should not be administered immediately upon diagnosis.

Treatment schedules. Patients are generally in active treatment for between six months and one year, barring no recurrence. Some diagnoses, like osteosarcoma, require lengthy treatment schedules. One guided tour participant with osteosarcoma had an 11-week chemotherapy schedule, followed by surgery, followed by another round of chemotherapy. For other diagnoses, treatment schedules are shorter. For example, one AYA described his treatment schedule as "*hard and fast*" because it would only last 80 days from start to finish. During active treatment, patients are typically coming in for appointments between weekly and monthly. Some, however, come in more frequently. One AYA guided tour participant, for example, came in everyday Monday through Friday for radiation appointments. Others come less frequently. For example, one AYA guided tour participant receiving maintenance chemotherapy for Chronic Myeloid Leukemia only came in for appointments once every three months.

After receiving a cancer diagnosis, AYAs found themselves responsible for a range of tasks related to managing their treatment and disease including seeking information, managing complex appointment schedules, managing medications and side effects, and navigating relationships with family and friends, among others. This task load was exhausting for AYAs. One AYA said she was *"pretty burnt out of the back-and-forth driving, the constant appointments."* Another AYA echoed her appointment fatigue: *"it's the same thing every day, and weekends I get off, and then repeat the cycle".*

Treatment side effects represented a major interference in AYAs' regular role and activities. One said, *"when I'm done with these 5 days of chemo, I generally am so wiped out that I can't even safely drive a car… I basically can't do anything around the house... I can't do anything"*. Another AYA's wife talked about navigating the physical effects of cancer while raising a 2-year old son. *"It's* *just my husband's worried that he's gonna be too sick to, like, enjoy things, like his birthday 'cause our son's birthday is coming up, and Christmas was difficult because he was too sick to drive… it's just hard."* For some AYAs, the physical effects of cancer are more permanent. One 19-year-old AYA guided tour participant, an aspiring pediatrician with a love of dance, lost her leg to osteosarcoma. More than a year later, she was still adjusting to her prosthetic leg and learning how to do things like climb stairs and dance again. Her mother told me, "*she has suffered so much… I just thank God that she can still walk*."

AYAs managed their illness in the context of a variety of other obligations including work, school, and raising children, among others. The work of being a cancer patient required AYAs to put their lives on hold. One AYA talked about how much work she had missed while undergoing treatment for Hodgkin's Lymphoma: "*if I didn't have FMLA, I probably would have been fired by now*." One AYA, who couldn't work, said, *"I went from working 60 plus hours a week to nothing. I have nothing to do. It's driving me crazy."* For other AYAs, competing priorities represented a barrier to service use. For example, one AYA was working fulltime while undergoing maintenance treatment for Chronic Myeloid Leukemia. She routinely exhausted her sick days and vacation days. Although her job was relatively accommodating, she did not think she could take off additional time for programming beyond regular appointments (e.g., counseling, peer support programs, etc.). Another AYA's wife faced a similar predicament. While her husband was staying inpatient, she would attend weekly caregiver support group meetings in NCCH's Patient and Family Resource Center. She really liked this group, however, it was held at an "*odd time of day*", so she could only go when her husband was staying inpatient at NCCH. She wished that they held the support group at multiple different times so she could attend more regularly.

> IMPLICATIONS FOR AYA NA-SB. Service provision through AYA NA-SB should reflect AYAs' appointment fatigue while undergoing treatment and competing priorities such as work, school, and raising children. To the extent possible, services rendered should be embedded in existing treatment appointments, while patients are already in the hospital.

<u>*Outpatient appointments.*</u> During outpatient visits, AYAs' task load was extensive. For some, these appointments lasted almost all day. One AYA arrived at the hospital for his 6:30am registration time and did not leave until after 2:00pm. AYA guided tour participants came to appointments equipped with snacks, entertainment, and other supplies; one AYA's wife said she had learned to never show up "*emptyhanded*". Appointments entailed some combinations of segments including transportation, parking, registration, labs, imaging, treatment, clinical appointments, and scheduling. **Figure 26** summarizes the flow of patients through their appointments. During each of these appointment segments, AYAs faced waiting times that ranged from 5 minutes to more than 2 hours. One AYA and his wife found the waiting time during appointments to be *"the hardest part of all of this",* describing the waiting as "*anxiety-provoking*".

1. *Getting there*: Although some AYAs were local, others travelled for hours to get to their appointments. For some, family or friends would drive and drop them off. Others drove themselves to their appointments. One AYA and his wife took the Medicaid Chatham Country Transit bus to daily radiation appointments because their car was in disrepair; this incurred an extra four hours roundtrip to their already long appointment days. Another AYA and her boyfriend, neither of whom could drive, got rides to the hospital from a free Uber service. One AYA said they she typically arrives a few minutes early to appointments because she often is not sure, based on her appointment reminders, where exactly she is supposed to be. Another AYA said that, although he did not necessarily have control over his appointment times, he preferred early appointments because the doctors wouldn't yet have fallen behind and thus, the waiting times would be shorter.
2. *Parking:* The hospital parking deck costs $1.50 per hour. AYAs and families paid to park in deck and walked across a skybridge to NCCH. There are shuttles running frequently from the parking deck to NCCH. For patients receiving frequent treatments, special parking privileges may be given. For example, one guided tour participant undergoing daily radiation therapy

received a parking permit for a small parking lot adjoining NCCH. Valet parking is also available.

3. *Registration:* For appointments in Radiation Oncology, Pediatric Oncology or Gynecologic Oncology, AYAs go directly to the clinic to register. All other adult oncology patients check in on the ground floor. Registration appointments are 30 minutes prior to appointment time and may be as early as 6:30am. If AYAs have more than one appointment in a day, they need only register before their first appointment. After checking in at the registration desk, where AYAs are given a numbered ticket, there may or may not be a short waiting time before they are called back to one of the 11 registration stations. *"Normally, waiting to register is not that bad,"* one AYA said. The registration waiting area was particularly busy on the day of our guided tour; we waited for 15 minutes. A large screen hanging above the registration desk indicates patients' ticket numbers and designates a station number for them to proceed to when their number is called. Once in the registration station cubicle, registration center staff scan AYAs' license and insurance card and provide them with a bracelet that will be scanned during subsequent steps of their appointment (e.g., for lab appointments). AYAs sign any necessary forms and may pay their copay at this time. If patients are receiving treatment on the weekend, they bypass registration and go directly to the location of their treatment appointment.

   At registration, adult oncology patients receive a 1-page document ("a patient passport"), which they hand off to providers at each segment of their appointment. On the front of this form, there is a step-by-step summary of their appointment itinerary. On the back, there is information about moving through the hospital visit (see **Figure 27**).

4. *Labs/Imaging:* Many visits include labs, which typically occur prior to clinical appointments. Some clinics (e.g., pediatric oncology, bone marrow transplant) have their own designated room where labs are done. In these clinics, after checking in at the clinic's front desk, AYAs waited in the clinic waiting room for their name to be called. Once called by a nurse, AYAs

went back to the lab room and had their vitals taken and blood drawn, a process that took about 5 minutes. Afterwards, they returned to the waiting room to wait for the next segment of their appointment. For other disease groups, labs are done in the Lab Drawing Station on the 2nd basement level of NCCH. After checking in at the front desk of the Lab Drawing Station, AYAs waited in a large waiting room for about 20 minutes before they were called back; however, this wait can be as long as an hour and a half, leading one AYA to question *"what their system is, if they have one."* Once they were called back, labs took approximately 5 to 10 minutes.

Patients may also have imaging scheduled during their appointments. Imaging equipment is scattered throughout UNC's medical campus. For example, the magnetic resonance imaging (MRI) machine is located on the ground floor of the children's hospital and the computerized tomography (CT) machine is located in the basement of the women's hospital. Thus, depending on the scans they are receiving, patients may have to walk all over the medical campus to various locations. Scans may also be scheduled in locations outside of UNC's main medical campus. For example, one AYA guided tour participant had a CT scheduled at UNC Hospital's Hillsborough location (about 20 minutes away), before her clinical appointment in NCCH. One AYA described her most recent scans, saying that it took all day because there was a period of waiting prior to each scan.

5. *Treatment:* Visits may include treatment (i.e., infusion or radiation). For radiation appointments, AYAs proceeded directly to radiation oncology, located in the basement-floor of NCCH. AYAs swiped an ID badge to enter the radiation oncology suite. They put their belongings in a locker and changed into a hospital gown in gender-separated dressing rooms. They waited in a small waiting room for between 0 and 15 minutes and then were taken back by a radiation therapist. Radiation took approximately 10 minutes. Infusions, however, can take between 1 and 8 hours and require, at least for adult oncology, more waiting time. One AYA said, *"I'm there for like 4 hours, killing time".* In pediatric oncology,

infusions occur in the pediatric oncology clinic infusion room. In adult oncology, infusions occur in the third-floor adult infusion center. There, AYAs said the wait for an infusion chair ranges from 15 minutes to almost 2 hours, although everything moves more quickly on the weekends.

6. *Clinic appointment:* Many visits included a clinical appointment with an oncologist, nurse practitioner, or physician's assistant. The wait for these appointments can be long, particularly in adult oncology, depending on how behind a provider is that day. For example, in a guided tour with one AYA, we waited for nearly two hours in the clinic waiting room. From the clinic waiting rooms, nurses called AYAs back to assess their vitals and then took them into an exam room where they waited for their provider. AYAs may also have to wait for a while once in the exam room. Once their provider arrives, visits were mostly focused on medical concerns (e.g., physical symptoms and side effects), but sometimes included some discussion of psychosocial or other concerns. During this time, AYAs might raise any questions or concerns they have. AYAs said that these visits can be as quick as five minutes. As one AYA put it, *"it's just a lot of waiting for a little bit of progress."* Another AYA echoed this sentiment, describing how her conversations with her provider typically went: *"How you doing? You doing good? Ok, bye."*

   In addition to their appointments with oncology providers, AYAs may have appointments with other providers across UNC's medical campus. For example, I accompanied one AYA to her appointment with an infectious disease doctor who, after a transplant, was working with her cancer doctors to manage the various aspects of her health. I accompanied another AYA to her appointment with the prosthetics doctor. She had lost her leg to osteosarcoma and met with him every six months to adjust her prosthetic leg.

7. *Scheduling.* After their clinical appointment is complete, AYAs worked with a Linberger scheduler to schedule their next visit(s). At this time, an After Visit Summary was often printed and given to AYAs. For adult oncology clinics, scheduling took place at the clinic front

desk or check-out stations, on their way out. The pediatric oncology suite had separate scheduling cubicles.

Figure 26. Patient flow through appointments

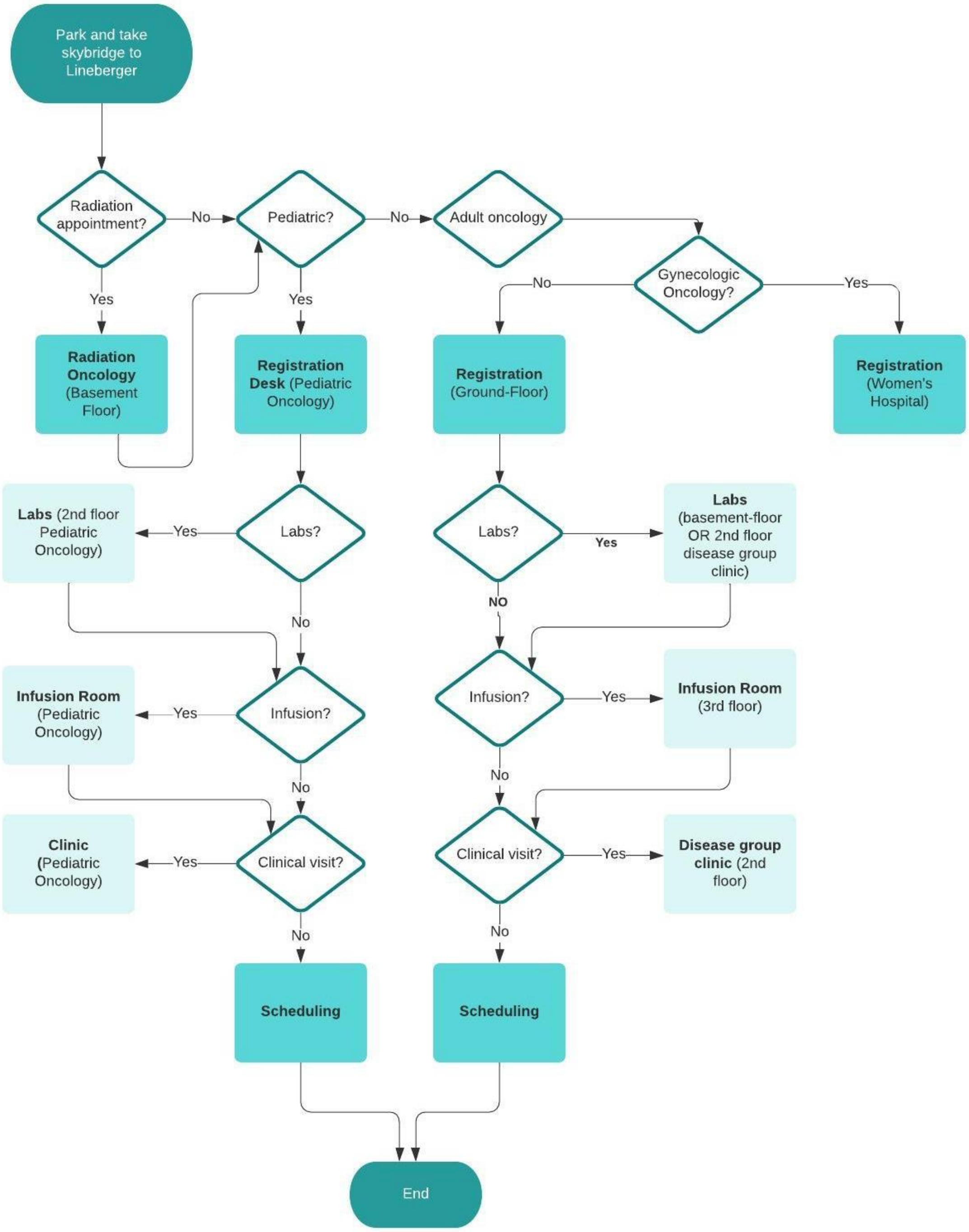
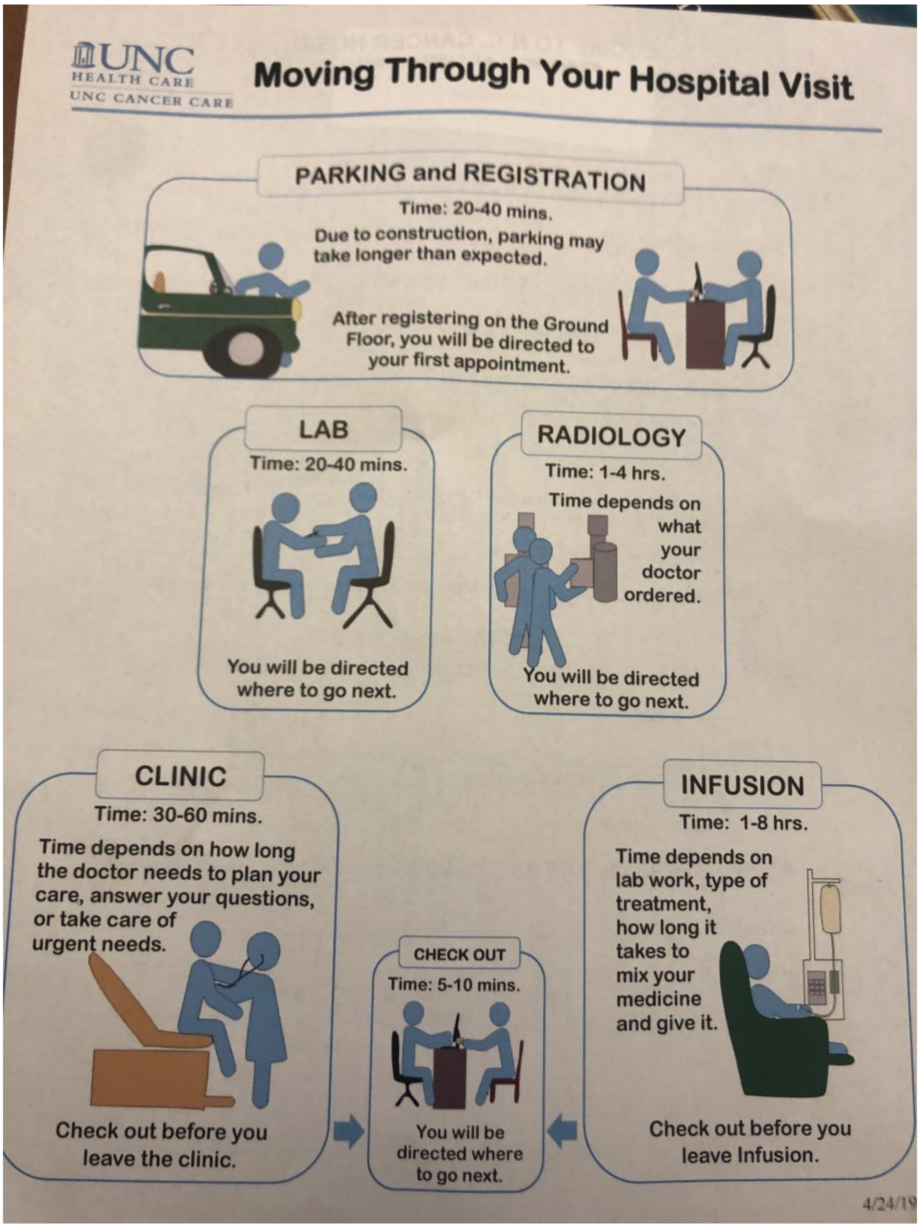


Figure 27. NCCH patient passport



UNC HEALTH CARE
UNC CANCER CARE

Moving Through Your Hospital Visit

PARKING and REGISTRATION
Time: 20-40 mins.
Due to construction, parking may take longer than expected.
After registering on the Ground Floor, you will be directed to your first appointment.

LAB
Time: 20-40 mins.
You will be directed where to go next.

RADIOLOGY
Time: 1-4 hrs.
Time depends on what your doctor ordered.
You will be directed where to go next.

CLINIC
Time: 30-60 mins.
Time depends on how long the doctor needs to plan your care, answer your questions, or take care of urgent needs.
Check out before you leave the clinic.

CHECK OUT
Time: 5-10 mins.
You will be directed where to go next.

INFUSION
Time: 1-8 hrs.
Time depends on lab work, type of treatment, how long it takes to mix your medicine and give it.
Check out before you leave Infusion.

4/24/19

IMPLICATIONS FOR AYA NA-SB. AYA NA-SB should accommodate the range of appointment types that AYAs have. Additionally, to the extent possible, AYA NA-SB should incur no additional time burden to AYAs' already long and exhausting appointments.

Inpatient stays. Many AYAs have at least one inpatient stay during their course of treatment. One guided tour participant was required to stay inpatient after every chemotherapy infusion, resulting in frequent inpatient stays. Another guided tour participant had spent a total of nearly 12 months staying inpatient. During inpatient stays, AYAs had a different set of tasks to attend to.

Guided tour participants spoke to the boredom and "*killing time*" associated with inpatients stays. One, for example, spoke about his daily routine during frequent inpatient visits. An early riser, he was typically already awake when the nurse arrived to do labs at 6:00am. Then, he laid in bed until around 8:00am. At some point during the morning, the doctors on rotation would visit his room. He said he rarely saw his primary oncologist while staying inpatient; the inpatient team rotated continuously. *"They never tell me much,"* he said, just whether or not he could be discharged; for him, inpatient stays were just a waiting game until the levels of chemotherapy in his blood fall to a threshold at which it was safe for him to leave the hospital. He received IV fluids and medications throughout the day to flush the chemotherapy from his system. Nurses came in and out throughout the day to take his vitals and change out intravenous (IV) bags. He ordered food when hungry but said he *"struggles to eat in the hospital"* even though the food *"isn't that bad."* Chicken noodle soup was his *"go-to nausea-friendly meal". "Time gets kind of weird in the hospital"*, so he tried to stay busy with video games, music, podcasts, adult coloring books. Since his parents and girlfriend did not live in town, they usually stayed all day when they did visit. Earlier in his treatment trajectory, they visited more often during his inpatient stays. He would leave the room sometimes to go to the Family Resources Room on the inpatient floor, which has a computer, board games, books, and informational pamphlets for patients and family members. He visited this room more often during his last inpatient stay; this time, he had *"more or less kept to himself."* He said that he felt *"a little stir crazy sometimes but [he tries] to just take a deep breath and maintain a positive attitude. The doctors wouldn't keep [him] here if they didn't have to. This is just a small portion of [his] life, something to get through, and hopefully come out healthy on the other side."*

> IMPLICATIONS FOR AYA NA-SB. Many AYAs have an inpatient stay at some point while they're undergoing treatment; thus, capturing the needs of inpatient AYAs is important. AYAs staying inpatient have lot of "deadtime", providing ample opportunity for AYA NA-SB administration.

End-of-life care. For some AYAs, however, cancer represented more than just a temporary hurdle. I met with another 22-year old AYA and her boyfriend. In the waiting room, she opened up to me about their relationship, a recent falling out with her family, and their plans for the future. They were getting on a Greyhound bus the following morning to start a new life together in Oklahoma. Although she was still struggling with the decision to leave her family behind, they were both excited for the adventure and confident in their ability to support each other through the move and through her illness. Shortly after we were taken back to the exam room, her oncologist came in and sat across from her. She said that, initially, they had planned to treat her tumors with chemotherapy until they had shrunk enough to operate on. However, although the tumors had indeed shrunk, they were still inoperable. The oncologist said, gently but matter-of-factly, that her cancer was incurable. She likely had less than a year to live.

> IMPLICATIONS FOR AYA NA-SB. AYA NA-SB content and delivery should be sensitive to those whose cancer is terminal.

Caregivers' tasks. Guided tours also shed light on the roles and tasks of AYAs' family members and partners. Family members and partners of guided tour participants drove them to appointments, helped them process and keep track of information, entertained them during waiting times, and offered them moral support. One dad of a guided tour participant waited outside with her dog for the entire length of her appointment. The wife of another guided tour participant stayed on a pull-out couch with him every night during his inpatient stays. Family members even communicated with me prior to guided tours to make arrangements on their loved one's behalf. One AYA warned me that his treatment had affected his vocal cords so he might not be able to communicate easily; fortunately, he said, his wife would be there to talk for him. When I commented on how much was on her plate, his wife said simply, *"I'm his wife."* Another AYA's wife came to all of his appointments equipped with a list of questions for the doctors. One AYA's mom made tamales for her doctors and brought them to nearly every appointment. AYAs' loved ones regularly took days off work to accompany AYAs to appointments and spoke passionately about the care AYAs were receiving.

> IMPLICATIONS FOR AYA NA-SB. AYAs rely heavily on their loved ones to navigate cancer care. AYA NA-SB content should reflect the importance of changes that these relationships undergo after a cancer diagnosis.

Providers' tasks.

Identifying AYA patients. There was no singular or formalized process for LL to identify AYAs to visit. For initial referrals for outpatient AYAs, oncologists or other providers would contact LL via email, phone, or EPIC message. For inpatient AYAs, a nurse often notified LL through those same channels. LL said that her relationship-building across disease groups has been essential to this referral process. One pediatric oncology provider said that AYA patients are often referred to LL or the psychologist. However, he noted, "*I don't know if it happens automatically for every single one, but if there's a clear need identified, we will often refer them to [LL or the psychologist]*."

When a patient LL had seen before is in the hospital (inpatient or outpatient), they would show up in LL's EPIC screen. She would click on notes from their previous visit, and would check in with them if (1) she had not seen them in a while, (2) they or their parents had contacted her, (3) their other providers had let her know they may benefit from speaking to her, or (4) just because. For example, while I was with her, a nurse practitioner called LL to say that one of the AYA patients was looking great, and she should come see her during her outpatient appointment that day. Also during my time with her, LL was texting with the mother of a newly-diagnosed AYA who wanted LL to come by during a clinical appointment that day and speak with the AYA and her family about coping with the diagnosis.

> IMPLICATIONS FOR AYA NA-SB. There is currently no systematic way for new AYA patients to be identified. As such, AYA NA-SB should include a process or strategies for identifying new AYA patients (e.g., strengthening referral networks to expand reach).

Assessing AYAs' needs. During our guided tour, LL approached AYAs during various segments of their appointments to assess their needs. Sometimes, these appointments were made in advance. LL said that appointments made with her are typically by families who live locally and have more resources. For these appointments, LL usually meets with the families in NCCH's Patient and Family Resource Center. Typically, however, LL would seek out patients during their appointments for impromptu visits. She did not think AYAs would come to her because it would be just *"one more thing".* She saw logistical barriers as the primary thing keeping patients from engaging more proactively with her or with other supportive services available at NCCH. AYAs echoed the impromptu nature of social workers' visits. One AYA, describing her relationship with an AYA social worker, said, *"she pops in here and there. Or she'll email me and ask if I need anything or if I'm OK, or if I've found any more programs to help with like paying rent and stuff like that… I don't schedule appointments with her. I guess its one of those things where, if I need something, I'll just email her and ask."* Another AYA said that the AYA social worker would often come by the infusion space for "*quick, informal check-ins*". Similarly, one AYA and her boyfriend said that the social worker would stop by and see them during nearly every appointment.

When she approached AYAs during our guided tours, I watched LL seamlessly initiate and engage them in meaningful conversation. Her demeanor was informal and approachable as she asked them what is going on with their treatment, or where they are in the course of things. She then asked, in a very organic and conversational manner, a series of questions to assess their needs. *"How are you feeling?" "Have you been sleeping well?" "How is school going?" "How's your family handling everything?" "How are you handling everything emotionally?"* Based on their responses to these questions, LL offered services and resources to support them. Some of these services and resources were housed in NCCH, while others were external. For example, she followed up with one patient about their Make a Wish Foundation submission. She spoke to another AYA about a free rock-climbing trip through a nonprofit organization, First Descents. She helped another apply for financial assistance from a local nonprofit. After offering services and resources, LL discussed next steps with AYAs. For example, one AYA we saw was nearing the end of his chemotherapy regimen. LL discussed this transition with him, telling him about NCCH's Survivorship Clinic. During these conversations with AYAs, LL also checked in with family members to ensure that their needs were being met. Watching these interchanges, I was reminded that the goal of AYA NA-SB is to systematize these conversations between LL and AYAs.

During outpatient appointments, AS said he currently engages in an informal needs assessment process. For AS, Fridays are clinical days, although he said the clinical work always spills over into other days depending on patients' emergent issues. He has nine patient slots available but sees about six patients on an average clinical day. The slots are 45 minutes to an hour in duration but, for the patients we saw during our guided tour, appointments were much shorter. On Thursday nights, AS said he typically reviews information on patients he is seeing the following day. He reviews and prints notes from previous visits, jotting down handwritten notes to remind himself of things to address during the upcoming visit. AS thought that this type of preparation work was pretty typical of oncologists in his department. On Friday, AS can see in EPIC when a patient has arrived, and when they are ready for him. He said he looks in EPIC to see if anything stands out about their vitals. He then retrieves their patient folder and goes to find the patient; they may be in the waiting room, infusion space, playroom, etc. He leads them to the exam rooms and follows them into the room of their choice. During these visits, although he said he largely focuses clinic visits on patients' medical needs (e.g., symptomology, medication management, treatment details, etc.), AS also asked about things going on at home (i.e., social concerns), mood, and other psychosocial concerns. Particularly during the initial visit after diagnosis, AS says he assesses the patient's situation at home.

AS reported that, in general, patients don't tend to ask him about their psychosocial concerns. Interestingly, though, AYAs reported feeling like it was their responsibility to initiate conversations with their oncology providers about their needs, particularly nonmedical needs. I asked one AYA if she recalled being asked about her nonmedical needs. She responded, *"not really, I* *have had talks with [my oncologist] about that, but that's been me saying hey, I'd like to talk to somebody about this, and she'll be like, oh OK, I know where those resources are, let me connect you."* Another AYA responded to this question: *"No… that would be good for them to ask, 'besides this, what else do you need?'… I'm sure if you mention what you need, they'll figure out how to get it to you. They're not going read your mind."* In reference to asking patients about nonmedical needs, one AYA guided tour participant, who was also a pediatric oncology fellow, said, *"I think it happens both ways though, either we will dig it up by asking or patients will volunteer that they have a concern*". He said that he frequently addresses non-medical concerns during patient visits, particularly right after diagnosis. "*We'll talk about anything that could potentially have any effect on their care… we will talk about psychosocial stuff…if we identify a psychosocial or financial hardship need from talking, we have social workers at our disposal."* During guided tours, however, nurse practitioners seemed to broach the subject of non-medical concerns more frequently than oncologists. For example, a nurse practitioner in the Multidisciplinary Oncology clinic addressed topics ranging from side effects, to fertility, to psychosocial concerns with a guided tour participant and his wife. Another AYA guided tour participant, who was struggling to keep up with her schoolwork due to "*chemo brain*", told me that her nurse practitioner, after eliciting the AYA's concerns about school, had helped her to initiate the process of applying for disability support services.

> IMPLICATIONS FOR AYA NA-SB. In addressing their non-medical concerns, AYAs rely on the AYA social workers more than their oncology providers. Social workers are currently conducting needs assessments, although informally/conversationally; AYA NA-SB should leverage their existing workflow and expertise in this domain.

Documenting and communicating AYAs' needs. Both AS and LL reporting using EPIC to document and communicate patient information, including EPIC messaging with other providers. They said that all patient information is recorded in EPIC, primarily as provider notes. *"Any little bit of data that I got from my history and exam, I'll put in my note. Almost anything that we either* *gather or intervene on will likely have even a very brief note put into EPIC."* These notes include fields for history of illness, social history, and family history. Oncology providers and auxiliary providers separately document notes from their visits with patients. For example, social workers and Child Life Specialists would record their own unique note for a given patient. To view information, providers must open notes one at a time. Based on their timestamp, providers can identify notes recorded during the same appointment. For providers, notes in EPIC seemed to be a major source of information. Prior to all patient visits, AS printed out patient information for his own use, with handwritten notes about what to address during an upcoming visit. LL also used notes in EPIC to jog her memory about patients' histories and concerns before visiting with them.

Providers relied on other technologies to communicate patient information. One AYA, who is also a pediatric oncology fellow, said that provider communication was "*a healthy mix of emails, EPIC, and phone."* LL used her laptop and iPhone at work. Since she is rarely at her desk, LL said she has all calls and emails forwarded to her iPhone. She does not, however, access EPIC on her iPhone; for this, she used her laptop. Providers also called and texted each other to coordinate care. For example, during our guided tour, AS texted LL because his patient wanted to see her. He noted that LL is very responsive through text. AS used desktop computers and office phones available in the physicians' workspace in the pediatric oncology clinic. He also communicated via pager, which a pediatric oncology fellow noted was the fastest way to communicate.

Additionally, LL and AS echoed that there is frequent in-person communication among NCCH providers. AS described several ways through which providers in pediatric oncology communicate. First, there is informal consultation among providers (i.e., "input-seeking") which occurs almost daily. The centralized layout of the pediatric oncology clinic facilitates in-person communication, but this input-seeking may also occur via phone. For example, during our guided tour, AS called a nurse manager after meeting with a patient. He asked the nurse manager to check in on the patient who had seemed "*a bit down*" and whose visit had raised some concerns about his home situation. Second, there are "interest groups" for each tumor type in pediatric oncology, composed of two oncologists and one nurse practitioner. They are available to meet within a day or two of diagnosis, or after any change in status, to conduct a more formal review of the patient's case and achieve consensus on treatment plan. Finally, weekly tumor boards are held, rotating in focus between solid and liquid tumor. These meetings are attended by surgeons, radiation oncologists, radiologists, geneticists, and others. Providers can present a patient's case and proposed treatment plan for input. Patients are only presented to the tumor board if there are questions or complexities surrounding the course of treatment.

Providers also described various ways through which they communicate with patients. LL and the other AYA social worker emailed and texted with patients and their families. Although LL used to give most or all patients her cellphone number, she has slowed down on that due to her limited bandwidth to respond. AYAs said they communicated with their providers through text, email, and MyChart messaging. MyChart is an online, mobile-enabled portal through which patients can view their health information, manage their appointments, communicate with their providers, and request prescription refills. Although one AYA said he did not use MyChart, most said they use it regularly to manage their tasks as a patient. One AYA saw a specialist at UNC every three months, but her primary oncologist was in Wilmington, where she lived. Because MyChart pulled her information from both hospitals into one place, she found the platform extremely useful for reviewing lab results and upcoming appointment reminders and keeping track of billing information. She also appreciated *"handy reminders"* offered through MyChart, such as flu shot and other preventative care reminders. Another AYA used MyChart to track her appointments, ask her provider questions, and refill prescriptions. Another AYA said, *"I constantly look at the MyChart thing,"* and his wife emphasized that they are "*very active on MyChart*." One AYA, during our guided tour, declined a printed copy of his After-Visit Summary, saying that he would just view it on MyChart.

IMPLICATIONS FOR AYA NA-SB. Providers use EPIC to document and communicate about patient information. If possible, AYA NA-SB should interface with EPIC in order to capitalize on existing systems. Providers also communicate via phone, email, pager and in-person; AYA NA-SB could also leverage these existing communication channels. AYAs are active users of MyChart; as such, AYA NA-SB could interface with MyChart.

Providing services and resources to meet AYAs' needs. When needs emerged, AYAs sought help in various ways; in general, they reported relying most heavily on social workers. *"We have had quite a few talks together,"* one AYA said about the AYA social worker, who was helping connect him with a program that finances Christmas gifts. Because this AYA was unable to work during treatment, such resources were critical to him. The social worker was also helping him to expedite the process of filing for disability and Medicaid, a process which he had been told can take up to six months to complete, at which point he hopes to be cured. Another AYA's wife benefitted from seeing the AYA social worker. She was helping her apply for a program that provides support for car repairs. Similarly, a social worker set another AYA up with a program that helped reimburse patients for their medical bills.

In addition to social workers, AYAs sought help from psychologists, psychiatrists, and nurse navigators. For example, a social worker connected one AYA's boyfriend to a psychologist at NCCH, so that he would have someone to talk to separately. One AYA said that he texts his nurse navigator to ask, *"what's going on with such and such."* He added that the nurse navigator is pretty responsive, and usually has an answer for him, although it is not always the answer he wants.

AYAs also noted that services and resources can be difficult to navigate or may not be delivered in a timely manner. One AYA was uninsured prior to being diagnosed. He had a lump on his neck for more than two months before going to the doctor. His wife talked about the process of applying for Medicaid after he was diagnosed. She was grateful for NCCH social workers who help facilitate this process. However, she said:

> *It's just the initial getting a person that is the issue. When we were in inpatient with him, it took four days for a person to come up and talk to us and then it took another week and a half and we never got information until we came down here one day and he checked in and they were like 'oh you have Medicaid, you're good to go'. And he doesn't actually have a card, he never got a notification that he got Medicaid, we just know he has it now… it's just*

> *very discouraging. They're supposed to help but it just seems like it'd be easier if we just did it ourselves.*

In some cases, clinician demand outstripped supply. For example, one AYA said, *"I had a visit with one of the psychiatrists here actually this week. I've been trying to get in, I think, since I was first diagnosed, so it's taken a long time to get in. They're very busy."*

The perceived applicability of services represented another barrier to AYA use of services and resources. One AYA said that, soon after diagnosis, she went to NCCH's Patient and Family Resource Center to find AYA-specific resources. They referred her to First Descents, a program that organizes trips for young cancer patients. However, she opted not to go because she believed trip attendees would be much younger than she was. Other AYAs echoed such concerns about services/resources not being applicable to them or their specific needs. For example, one AYA with a relatively rare diagnosis said that, although she was able to find plenty of general information on her cancer type, it was difficult to find information that felt tailored to her. One AYA said that she had not used certain peer support programs because she was "*socially awkward*" and "*a crier*". Although she desired to meet others her age going through a similar experience, she feared that it would be uncomfortable for her.

Eligibility requirements represented another barrier to AYA use of resources. One AYA talked at length about the challenges she has faced in finding financial support programs that she qualifies for. *"I know the thing that I've really struggled with that other people probably have is the financial benefits. It's not only hard to find resources but it's especially hard to find resources that kind of fit this really weird category I'm in where it's like, I have a full time job; I don't meet most of the guidelines; I'm at a weird age where I'm in between a lot of the benefits that are out there; I'm too old for a lot of the teen and pediatric stuff but I don't really meet a lot of the criteria for some of the other things that are out there… because I am able to work, I'm on private health insurance through my job. And then, on top of that, my diagnosis is pretty rare. There's not a whole lot of benefits out there for [my cancer type]."* A similar predicament was echoed by another AYA who, because he had

Medicaid insurance, was not eligible the Pharmacy Assistance Program, a NCCH program that provides financial support for patients' prescriptions. Similarly, his wife said, *"he was going to apply for social security/disability, but we never went through with that because he was able to start working part-time again, and he worked part-time, then he can't get disability."* Eligibility constraints beyond financial requirements were reported. For example, one AYA said she did not qualify for a financial support program because she was taking oral chemotherapy; eligibility for the program required receiving infusion treatments.

> IMPLICATIONS FOR AYA NA-SB. AYAs report a number of barriers to service and resource use. Although some of these barriers (e.g., service capacity) may not be addressable by AYA NA-SB, flexibility should be built into AYA NA-SB service provision to accommodate for these barriers. For example, multiple services might be offered for a given need such that an AYA can select the option that is most feasible and appealing to them.

Intervention

Goals for intervention.

Intervention outcomes. Providers articulated the goal of AYA NA-SB as *"formalizing something that is already being done more informally."* They wanted the intervention to facilitate better documentation in the electronic health record (EHR) surrounding patient needs so that providers could use that information as a resource. Currently, they said that *"things get lost in the medical record."* They saw a needs assessment as a way of getting information about the patient to everyone on the care team so that everyone would be on the same page, allowing for better patient care. LL said that it's important to *"build better communication processes around needs assessment, so that needs information is being communicated to people caring for the patient."* Ideally, providers wanted AYA NA-SB to fit "*seamlessly*" into their existing workflow. Were AYA NA-SB to interface with EPIC, NCCH's EHR, it would help to accomplish this seamless integration because provider and patient information are *"already there."* Then, AYAs' needs information could be *"pulled into a note or whatever and transmitted to other providers."*

Importantly, AYAs wanted needs data collected through a PROM to actually drive service provision. One AYA said that a needs assessment would be a valuable tool as long as *"it's actually used to meet my needs."* When asked what would make a needs assessment worthwhile, another AYA said, *"I guess if the survey allowed us to express what type of needs we needed or express what's really actually going on with us. And then if we actually see results from the survey within a timely manner…like, if I put in the survey that I want to have therapy services and stuff like that and I turn the survey back in, I guess within like a month or two, I would expect somebody to reach out to me and be like 'hey we seen that you need this type of services, here are some options that are available to you'."* AYA guided tour participants agreed that they would indeed use services and resources offered to them based on their responses to a needs assessment tool.

> IMPLICATIONS FOR AYA NA-SB. To the extent possible, AYA NA-SB should leverage and strengthen existing provider workflow, communication channels, and documentation practices. Needs reported on AYA NA-SB should trigger timely referral to appropriate services or other follow-up actions.

Needs assessment content. In terms of needs assessment content, financial support was the most commonly reported need among guided tour participants. One AYA and his wife who were relying on food stamps, gas cards, and family support said, "*we are just living in debt right now."* AYAs also the wanted the tool to capture needs related to transportation (e.g., gas cards, discounted Uber/Lyft rates, parking vouchers), therapy, and peer-to-peer connection. One AYA suffering from myriad side effects from radiation said he wanted "*just help management with the side effects. I knew they said I would get a sore throat, but I have an ulcer in my throat, the side of my tongue has sores on it, the radiation's affected my skin, the way you can see there's just weak spots in my skin. If I had a way to get help for the side effects, that'd be peachy".* His wife added*, "he had almost no side effects when he was doing chemo, so we thought everything was gonna be smooth. And then he's hit this wall. And 'sorrys' don't exactly fix throat ulcers".* AYAs also wanted opportunities built into the assessment for them to elaborate on their own unique concerns. To this end, one AYA suggested that standard survey questions should be supplemented with free-response questions. *"If you're trying to find resources to help people and stuff like that, the best way to do it would be like asking the question and allowing them to respond. That would be good for us 'cause some of the stuff that people are probably asking on the survey is probably not relevant to what's going on to that particular person so you have to give them room to leave a comment so you can get other ideas."*

> IMPLICATIONS FOR AYA NA-SB. In addition to capturing psychosocial concerns, peer support, transportation, and side effect management, it is particularly important that AYA NA-SB capture financial needs which are pervasive among AYAs. AYA NA-SB should also include a free-response opportunity for AYAs to list needs outside of those covered by the tool.

Timing. With respect to needs assessment timing, providers and AYAs emphasized the importance of folding the assessment into existing patient flow so that it would not add additional time to visits. They consistently pointed to the time period during infusion as an ideal opportunity. AYAs thought this would be a good time to complete a needs assessment because *"you're just sitting there for hours."* One noted more specifically that the best time would be right after the nurse takes their vitals, when they were first sitting down in the infusion chairs. AYAs not receiving infusion therapies noted other times when a needs assessment could be folded in without incurring additional time or burden. One AYA guided tour identified two time points during clinical appointments that typically require some waiting time: (1) in the clinic waiting room, after any labs are done, but before being called back to the exam room by a nurse, or (2) in the exam room, after the nurse takes vitals, before the AYAs oncology provider enters the room. The latter time point was echoed by another AYA. *"That would be perfect because most of the time, well, all of my appointments that I've had with the cancer doctor, they have either been 30 minutes to an hour behind, so it'd be perfect for that. I haven't had an appointment with them that I've been on time for. They're never really on time."* For inpatient stays, AYAs noted that needs assessment timing wouldn't really matter, since *"you're just sitting around"* for much of the day anyway. One AYA, in the context of inpatients stays, said, "*cancer patients have an abundance of time.*" As one AYA put it, though, "*in the population you're capturing, we have very different experiences... I don't know if there's something we all have in common then, in terms of the place you would pick to [administer AYA NA-SB]".*

As far timing in the disease trajectory, one AYA noted that one month after diagnosis would be ideal. They said that, initially, you have not yet grasped the gravity of everything but, by the time you are one month out, you have *"a better idea of what is happening".* This AYA said that their needs had been relatively constant throughout the course of treatment; they did not think their responses to a needs assessment would be that different right after diagnosis versus in the middle of treatment, versus later in treatment. A few AYAs echoed this; one said, *"every cycle has been pretty much the same."* One AYA, however, talked about the dynamic nature of his needs with respect to managing side effects. *"[My needs have] changed somewhat, because like right now I can't really eat. I went from being able to eat anything I wanted to everything tastes like cardboard and I can't really open my mouth to eat a lot."* In this light, providers emphasized the need to administer a needs assessment at multiple time points. The oncologist, AS, for example, recommended administering it once at admission/diagnosis, once around three to fourth months later, and again at the end of active treatment. He noted that the needs assessment may also need to be administered annually in survivorship. The social worker, LL, agreed with these general intervals, noting that needs tend to be distinct at diagnosis, during treatment, and in survivorship. One AYA agreed with these general intervals but noted that his treatment schedule was especially short (80 days), so these time general time intervals might need to be compressed in his case.

> IMPLICATIONS FOR AYA NA-SB. AYA NA-SB should be administered at multiple timepoints throughout cancer treatment to capture the changing needs of AYAs, including diagnosis, during treatment, at the end of treatment, and at some interval in survivorship. It should not be administered immediately upon diagnosis when AYAs might not have a grasp of what

they need yet. In the clinic, AYA NA-SB should be administered during times when AYAs' wait times so as not to lengthen AYAs' already long appointments.

Format. In terms of administration, AYAs tended to favor technology but most did not have a strong preference. *"People our age are so used to tech."* One said that, although he wouldn't mind completing a paper survey, he would probably opt to complete it via iPhone or iPad if that were an option. Another said that she might be faster on paper but didn't have a strong preference as far as format. Another AYA said, "*I just feel like nobody's gonna be into paper. Maybe if it was like a paper survey where the person was right there and you were able to turn it in at that moment kinda thing, but if it came in, like, the mail or something, I would probably never look at it because I don't read my mail".* One AYA said that, were the survey emailed to him with appointment reminders, he "*could easily do it."* AYAs said they would prefer to complete the survey independently rather than have a clinician present while they complete the assessment. AYAs also wanted the needs assessment to be brief. *"The most a survey should be, if it's going to be electronic or paper, it should probably be like 5 or 10 minutes, just kind of ask straight-to-the-point questions."*

IMPLICATIONS FOR AYA NA-SB. AYAs did not express a strong preference in terms of paper versus electronic delivery of AYA NA-SB. The needs assessment should be brief, allowing AYAs to complete it in less than 10 minutes.

Benefits of intervention. AYAs expressed largely positive attitudes towards the potential value of AYA NA-SB. One AYA could not think of any downsides of having to complete a needs assessment. They saw *"a lot of positives that would come from it and not a lot of negatives."* Another said, that *"benefits, depending on the resources you get connected to, could be pretty high."*

Providers also pointed to several important potential benefits of AYA NA-SB. LL said, *"you don't know what you don't know"* and saw AYA NA-SB as a means of making sure that nobody's needs were missed. Providers noted that formalizing processes around care coordination could ensure that *"things aren't falling through the cracks"*. She added that:

> *'We have a lot of resources [at NCCH] but they can be difficult to access. You have to open the door for them', something that AYA NA-SB could accomplish. An AYA guided tour participant echoed this sentiment. 'One potential benefit is that, I think I would even include myself in this, a lot of patients probably don't know what resources they even have access to and they don't know to ask. They don't know what they don't know. So, something that somebody else sees as a potential trigger and offers them something will, I think, help connect people to more stuff that they might not have otherwise known existed. Even I probably don't know all the stuff that I would have had access to if I needed anything.'*

LL also noted that formalizing the needs assessment process would allow other providers and staff to do it, making it more sustainable than her maintaining sole responsibility for identifying needs and coordinating care. Finally, AS and LL agreed that AYA NA-SB could serve as a valuable source of patient information for providers.

IMPLICATIONS FOR AYA NA-SB. AYAs and providers expressed numerous potential benefits of AYA NA-SB, suggesting that the intervention has high potential acceptability among prospective users.

Costs of intervention. Potential costs of AYA NA-SB cited by providers included increase in staffing hours, disruptions to workflow, and potential duplicativeness with existing processes. As far as staffing hours, LL said that administering a needs assessment would not necessarily incur additional burden for her; since it's something she is already doing informally, it would just be *"a matter of formalizing the process."* LL cited another challenge associated with AYA NA-SB related to leadership buy-in. Because it is difficult to measure the financial gains associated with AYA programming, she thought it could be difficult to justify additional resources needed to implement and sustain AYA NA-SB. An AYA guided tour participant, who is also a pediatric oncology fellow, added that provider buy-in could also be a challenge. He noted that provider awareness of the intervention was an important first step. "*Providers have more and more things to keep track of,"* so If AYA NA-SB added to provider workflow, this could negatively impact buy-in, particularly if the additional burden incurred was not reimbursable. Additionally, providers pointed to patients' time as another potential cost. However, AS noted that AYAs are a *"captive audience"* during various appointment waiting times. *"If you fold it into where they currently are, it wouldn't be super* *burdensome for them."* AYAs echoed this sentiment; one said, *"I mean, as long as the survey is kind of happening during your routine of your appointment, and it's not an additional thing added on, I think the costs are pretty low."* Another AYA said, *"time doesn't necessarily seem to be a barrier, because there seem to be a lot of gaps in time where you're just sitting and waiting".* This AYA also said, *"paperwork burden is always a concern with surveys… as long as it was appropriately efficient, short, I don't think that would be a big deal".*

One AYA brought up a concern related to the use of services and resources once needs are identified through AYA NA-SB:

> *There is an element of adding more appointments to our to-do list, even if it's something that's supposed to be helpful, it's another thing. I think that's a potential cost, too, if linking people with services means it just adds to their plate in a state where they're already overwhelmed. Sure, I probably should go see a psychiatrist one time through this to talk about how it's going but it's just another thing. I'm tired of driving here to check in for appointments, sitting in waiting rooms. You could end up hooking people up with things that just adds stuff to their to-do list, even if it's helpful.*

IMPLICATIONS FOR AYA NA-SB. AYAs and providers expressed some potential costs of AYA NA-SB. Staffing time, workflow disruptions, and provider buy-in represent potential barriers to implementation. For AYAs, downstream barriers to service and resource exist; additional strategies may be needed to address these barriers.

5.7 Semi-Structured Interviews (Comparison Between NCCH and Other Contexts)

Semi-structured interviews were conducted with key provider contacts from around the country. These individuals (n=5) represented four healthcare systems in California, Ohio, South Carolina and one advocacy and consulting organization (i.e., Teen Cancer America). Providers were program managers and nurse navigators, dividing their time between clinical and program development tasks. Interview results are presented below by CFIR domain (i.e., intervention; outer setting; inner setting; individuals; process). The points of contextual divergence between NCCH and other cancer programs that interviewees described are summarized in **Table 18**. These differences represent areas in which AYA NA-SB may require flexibility or adaptation to accommodate differences across contexts.

Outer context

Patient population. NCCH's AYA program is housed within the Comprehensive Cancer Support Program and serves patients across adult and pediatric oncology. However, other AYA programs may be housed within either adult oncology or pediatric oncology. For example, one provider reported that her AYA program was *"adult-based and does not see pediatrics 'proper' [but] AYAs ages 15 through 40 are seen within the health system under the direction of the AYA medical director."* Another provider, on the other hand, reported that her program *"lives under the children's hospital side, but serves patients in both adult and pediatric oncology."* She described adult and pediatric oncology as "*fiscally separated but physically connected*" in her institution. Some AYA programs are constrained to pediatric oncology, with little interface with adult oncology. One provider said, "*we only serve patients at our pediatric site; we will get community referrals from adult institutions when an adult-aged patient has a pediatric cancer. They will get often referred for care here. We do take care of patients older than 21 with a pediatric illness."* Some AYA programs based in pediatric oncology may serve even younger patients. For example, one provider's program included patients as young as 13. "*A lot of programs start at 15. We start at 13, just making the assumption that a lot of our 12 and 13-year olds are of reproductive capacity, so we kind of just bring them into the fold with the AYA programming concept."* Some programs may start out by serving a smaller age range, and expand that age range as the program grows. One provider, who consulted with AYA programs from around the country, said:

> *I think the programs are blooming from both [pediatric and adult oncology] and what we're really trying to do is make sure that they bloom together versus from one side or the other because, if you make a peds AYA program without including your adult people or vice versa, then getting the buy-in to support your efforts and to work together becomes more challenging.*

IMPLICATIONS FOR AYA NA-SB. The population reached by AYA NA-SB may vary by institution.

Cosmopolitanism. One provider noted that structures and functions of AYA programs depend largely on their external network, or how they are positioned within their larger institutional network. "*Are you a hospital within a hospital? Are you a hospital who has a community partner hospital? Are you a freestanding children's hospital? Are you an adult cancer hospital? How are you working with people in your area? That also determines a lot. The geography of the institution is part of it.*"

> IMPLICATIONS FOR AYA NA-SB. The geography of an institution dictates the structure and functions of an AYA program. The referral networks established for AYA NA-SB may depend on these external relationships. For example, AYA programs with satellite locations may need to consider whether AYAs receiving care in these satellite locations will be reached.

Inner context

Structure. Institutions varied in their model of AYA care. One provider, who consulted with hospitals from around the country considering establishing AYA programs, said, *"I think we see different things around the country and that they're definitely are models where the AYA service is a consultation service. And then, there are other programs where they really try to have an AYA-based program and dedicated staff."* She said that AYA program establishment is often a "*phased project*", in which the structure and reach of a program expand overtime.

> IMPLICATIONS FOR AYA NA-SB. The development of AYA programs often occurs in a phased fashion. In this context, the implementation of AYA NA-SB may also occur in a phased fashion (e.g., initially delivered only to a certain disease or age group).

Staffing. Given staffing and resource constraints faced by many institutions, providers noted the potential time and personnel burden associated with delivering NA-SB and following up on needs reported as a potential challenge to implementation. AYA-specific staffing varied across institutions. "*Sometimes they don't have any dedicated staff members and they're just kind of piecing together with whatever they can have*." However, speaking to what makes for a successful AYA program, one provider said, *"I think what we've learned is that there has to be some dedicated AYA staff. Because it's really hard to move these programs forward if you don't have positions where time is bought out to really focus on them*." For some programs, AYA-specific staffing evolves over time. “*It’s definitely gradual and sometimes it can be that they’re starting with one dedicated staff member.”* One provider felt that program managers may be the most important staff members of AYA programs because “*they’re the ones who are really helping to push these programs forward.*” Program managers were social workers, nurse practitioners, navigators, or registered nurses; they were typically supported by program medical directors from either adult or pediatric oncology, or both. Other AYA-specific staff included nurses, nurse navigators, Child Life Specialists, and other providers. AYA-specific staff were typically supported by shared staffing and resources across adult and pediatric oncology (e.g., social work, palliative care, nutrition, counseling, etc.).

> IMPLICATIONS FOR AYA NA-SB. The availability of AYA-specific staff varies by institution. Programs without dedicated AYA staff may face additional challenges in implementing AYA NA-SB.

Funding. AYA programs varied in the extent to which their funding came from inside the health system. Many programs, like NCCH, relied on foundation or grant funding. Others, however, were largely health system-supported with some auxiliary funding from local or national nonprofit organizations. Some providers reported that AYA-specific staff positions were initially grant-funded but have since transitioned into being internally funded positions.

> IMPLICATIONS FOR AYA NA-SB. Particularly for programs seeking internal funding for AYA programming, AYA NA-SB could provide valuable patient-reported data to justify new or continued support of AYA programs.

Physical space. Another difference among AYA programs was the availability of designated spaces for AYAs. Some AYA programs, like NCCH, did not currently have dedicated space for AYA-specific programming. In contrast, other AYA programs had AYA-specific infusion spaces, exam rooms, waiting rooms, lounges, or inpatient centers. One provider’s AYA program even had a dedicated outpatient AYA clinic 2.5 days per week. Other programs had done the best they could with limited space. “*In the infusion space, they tried to create an AYA room. It’s been a bit of a* *disaster. There's not a big enough physical footprint to make it really functional, but there is an AYA room. Granted, only like two patients can be in it at a time."*

IMPLICATIONS FOR AYA NA-SB. AYA programs with designated spaces for AYAs (e.g., AYA-specific infusion rooms) could use these spaces for AYA NA-SB administration or service provision since they represent central locations where AYAs may be congregated. However, privacy is an important consideration.

Functions. In general, AYA programs were designed to provide age-appropriate care to AYAs with cancer. Their specific functions, however, varied. One provider said that her AYA program *"provides clinical/medical care to AYAs throughout treatment and into survivorship, with a focus on providing age appropriate support, services, resources, opportunities for AYA's and their caregivers/team."* The AYA team in this program were involved in treatment team communication immediately upon diagnosis, attending interdisciplinary team meetings for new AYA patients. Another provider described the functions of her program similarly:

> *We work with all of the doctors and all of the nurses; we come in and we do assessments and we provide referrals to resources. And I do some level of care coordination for these patients. When I say that, I mean I convene a meeting where we run a list of the patients coming through the clinic that week and who are currently hospitalized just to make sure everybody's on the same page about what their care needs are and whose doing what. And that's an interdisciplinary meeting where we pull in social workers, clinical therapists, nutritionists, physical therapy, and the team nurses and the physician. Not everybody comes to every meeting but it's an opportunity for us to talk through where everybody is in their care, if there's any concerns raised, we address them.*

IMPLICATIONS FOR AYA NA-SB. AYA programs are largely functioning as care coordination hubs for AYAs but face challenges to coordinating care for this population; as such, there is a need for tools like AYA NA-SB to guide these care coordination efforts.

Implementation climate. Provider buy-in was mentioned by several interviewees as a potential barrier to implementation. One provider noted that implementation could be relatively seamless at her institution so long as there was sufficient buy-in among members of the AYA team. Providers noted several ways in which their programs had worked to increase buy-in from other providers. Describing their implementation of distress screening tool, one provider said:

> *We spent a lot of time on process mapping things. We created our process as a psychosocial team. And that was awesome. That's what pulled in buy-in. I think it has done a good job of giving our team a sense to get to work together, because we were fairly siloed. That was part of what was identified as something that we wanted to work on. So, this is a nice project to bring us all to the table. Personally, I can speak to how its changed professional interventions and professional relationships in a positive way. As opposed to just the AYA team process mapping it for other people.*

Now in their second month of implementation, this provider's team continued to meet weekly to iron out implementation issues and tweak their process. Another provider pointed to the importance of education in building provider buy-in and changing the culture around AYA care. "*I think there's still a lot of education that has to happen. I think that's part of the phased and growing process until people truly understand what you're doing and how you can add value to the patient experience as well as to the work that they're already doing, rather than often seeing it as a threat in some way. That's going to help, too."* Another provider, echoing this sentiment, said, "*this takes time because it is about culture change*." Another provider emphasized the importance of involving providers beyond just the core AYA team in implementation planning.

> IMPLICATIONS FOR AYA NA-SB. AYA NA-SB implementation will require buy-in from providers beyond just the AYA team. Building this buy-in often requires some degree of culture change with respect to the perceived value-add of AYA-specific care.

Leadership engagement. Leadership buy-in was also flagged by providers as a potential implementation challenge. One provider emphasized the importance of establishing a clear plan prior to proposing the intervention to leadership. "*You're going to get a lot of questions about the who and the how. The more you can lay that out and create that plan and show the value of having the metrics for their patients, then they'll be more apt to use it. The more you can map that out for them, the more likely they'll go and implement it and adapt it for their institution*."

> IMPLICATIONS FOR AYA NA-SB. AYA NA-SB implementation will require the articulation of a clear plan for implementation and a compelling case for the value of the intervention.

Individual characteristics

Related experience. While AYA care at NCCH was primarily delivered by two AYA social workers, other programs had nurses, Child Life Specialists, nurse navigators, or other providers who do this work. A common element of those delivering care to AYAs was an expertise on this population. At NCCH, AYA social workers did the work of AYA needs assessment and thus, were proposed during provider interviews as central to AYA NA-SB delivery. However, for some institutions, this would not be the case. One provider said, "*in our program, it would be the AYA Life specialist to lead this, gather and then update the medical team promptly with results.*" For another provider's AYA program, the AYA navigator was doing the work of needs assessment.

Determining who follows up on needs reported on an assessment was also mentioned as an implementation challenge. Providers listed a number of characteristics that this individual should have. When asked about the qualifications needed to follow-up on a needs assessment, one provider said, "*the biggest thing is well-integrated into the team and is aware of who they are referring to. Clear referral pathways make it open to more people who could administer it.*"

Assessment expertise was another qualification deemed important for the individual delivering AYA NA-SB. *"They have to have good enough assessment skills to know when there's discordance between the numbers circled on the distress screen and what the person is talking about. To know, that maybe they're telling me their overall score is 4, but then they're talking about this box in a way that they probably should see clinical therapy. You have to have that level of thought flexibility to know when to elevate a concern."*

Providers also pointed to training in counseling as an important characteristic of the individual delivering AYA NA-SB, particularly for the follow-up piece. "*A social worker, in my mind, is just a perfect fit for that kind of discussion, especially if they have background and training in counseling. Because, they might have an opportunity to even do a little bit of a therapeutic discussion if there's something that comes up right then and there, that they're skilled and trained to handle versus maybe an NA, who basically collects the form and puts it in a box and now is waiting for* *someone to be aware of it. They can kind of deal with it right then and there and maybe close that loop, or get things generated right away because they know what to do with it."* Another provider said, "*what's helpful is having someone who is skilled in having difficult conversations, or uncomfortable conversations and normalizing them.*"

Providers also mentioned rapport with AYAs as an important characteristic of the individual delivering AYA NA-SB. One provider talked about the importance of having a trusting relationship in place when assessing AYAs' needs. Another provider noted that AYAs desire consistency in psychosocial care and a point-person to take their concerns to. To the extent that AYA NA-SB delivery could be consistent, this provider felt that AYAs would be more receptive to the intervention and honest in their responses to needs assessment questions.

> IMPLICATIONS FOR AYA NA-SB. The individual who delivers and follows up on AYA NA-SB should have established relationships with providers to whom referrals will be made, assessment expertise, training in counseling, and rapport with AYAs. Although this may be social workers at NCCH, it varies among other institutions (e.g., child life specialists, nurse navigators).

Attitudes towards AYA NA-SB. Overall, providers liked the revised needs assessment which resulted from Design Team Workshop #1, but they offered some critiques. One provider found the needs assessment "*a bit lengthy*" and "*too academic in verbiage*". They felt that AYAs might lose interest and be noncompliant with a long survey, particularly if it was administered at multiple time points. This provider also recommended streamlining the response scales, for example, by reducing the five response options to three (e.g., low need, moderate need, high need). One provider questioned whether the tool's intent was to identify patient needs or determine whether patient needs are being fulfilled. She felt the that the question phrasing, in combination with the response scale wording, made the tool's intent unclear and recommended revising such that the items and response scale were more aligned.

One provider, who consulted with AYA programs around the country, spoke to broader provider receptivity to an intervention like AYA NA-SB.

> *There are so many people that if you could just hand them something and say 'hey, here's an idea we have and we thought might be helpful', so many of them would just eat that up. Because it would give them something to focus on, and a structure, and I think that's what they're all trying to do and right now everyone is sort of reinventing the wheel in a lot of ways. People are so wanting information and ideas to move their program forward.*

AYA receptivity was not considered a major challenge, although providers offered a few strategies for engaging them in the process. "*We just normalize it and are careful with our scripting, making sure they understand this is something we ask everyone to complete, and its just so we can understand how to take care of you in the way that you'd like to be taken care of.*"

IMPLICATIONS FOR AYA NA-SB. Providers expressed largely positive attitudes towards AYA NA-SB, suggesting that they are receptive to its implementation.

Process

Identifying AYA patients. Speaking to the challenges of implementing a formalized needs assessment process, one provider noted that identifying new AYA patients represents a major hurdle. At her institution, like at NCCH, the AYA program relied on referrals from disease group providers. As such, not every AYA that came through the door was referred to the AYA program. One said, "*I'm not seeing every AYA. We probably have 1800 clients active in our system. And there's one nurse navigator*." Referral networks varied across programs. One provider said that social work, nurse practitioners, and nurse coordinators represented major sources of referrals for her program. For another program, internal referrals came from navigators, registered nurses, social workers, and oncology providers. One AYA provider reported that the most common issue leading to an AYA program referral were concerns about fertility. The provider noted that fertility issues "*get people in the door*", allowing her program to then follow up on other AYA needs and offer AYA-specific programming accordingly. Another provider said:

> *'At the pediatric hospital, [reaching AYAs] is much easier for us to do because they have a clinic that meets monthly, an AYA clinic, so all the clients are lined up for us; we know that they're game; we get in there. The adult side is very different because everything is disease*

> *specific. So, their survivorship clinics are all over the place, and they might have 1 AYA in three weeks… they're not kind of all conjugated together. That becomes much more a challenge and we're still trying to figure that out.' This provider said that her AYA program was having more success generating referrals from satellite locations; 'it feels like, the social workers have a little less of a case load so we're getting more referrals from that aspect'.*

No providers reported a singular way in the EMR to identify new AYA patients. For example, one provider said:

> *We don't have official referral within our EMR. It's a combination of me stalking the patient list to make sure that I haven't missed anyone. But communication is really tight in our team so anytime there's a new patient who comes through the door, there's an email generated that talks about newly diagnosed patient, age, diagnosis, any pertinent information. So that's kind of the trigger point.*

This provider's institution only had 45 new AYA diagnoses per year, making it possible for them to reach all AYA patients this way.

Providers reported different strategies for strengthening referral pathways. One provider's AYA program opted for a phased scale-up approach. Their AYA program started out covering just a few disease groups (i.e., leukemia, lymphoma, sarcoma) and has since expanded to include all disease groups. She noted that, as program manager, she had spent a lot of time building relationships with disease group providers and establishing AYA champions throughout the hospital to facilitate AYA referrals. Another provider's AYA team often sat in on tumor boards in her health system:

> *We'll kind of talk about, 'these are our services. Are there any needs? Has anyone talked about fertility yet?', those types of things. What started happening was they just started giving us referrals. I think, initially, it was a really good place to start because they really didn't know what was this program and who are these people. She described taking on an advocacy role during these meetings,' helping physicians do the right thing'.*

IMPLICATIONS FOR AYA NA-SB. There is currently no systematic way for new AYA patients to be identified. As such, AYA NA-SB should include a process or strategies for identifying new AYA patients (e.g., strengthening referral networks to expand reach).

Assessing AYAs' needs. Some AYA programs were assessing AYAs' needs informally/conversationally (i.e., without using a standardized tool). This informal needs assessment process was sometimes done through a pre-scheduled appointment. Often, though, like at NCCH, AYA providers make impromptu visits to AYAs while they are in the hospital, stopping by to check in with them in the clinic, during infusions, during inpatient stays, etc. "*We follow them wherever they go,"* one provider said. Describing her visits with AYA patients, one provider said, *"it's more impromptu. We try to touch every patient at least once when they're inpatient. We're not in every visit all the time, but we do have a high level of touch. I would say one of us sees a patient practically every time they're in clinic".* Another provider said, "*it's very free-flowing".* In making these visits, providers emphasized the importance identifying times that did not disrupt or prolong AYAs' clinical appointments.

Some programs were working towards assessing needs using a standardized tool. For example, one provider had developed a needs assessment tool based on National Comprehensive Cancer Network (NCCN) guidelines and piloted it with a small sample of 10 AYA patients. Another provider said, "*when I started, it was much more conversational, and I still think a large part of it is conversational, but we are definitely moving towards a more systematic approach*." Her program was in the early stages of implementing a needs assessment/distress screening tool:

> *The distress thermometer is a paper assessment. We'll go in and kind of introduce the concept and we give them time to fill it out and then we, either myself or [the child life specialist], usually me, will sit down and sort of review it with them as a conversation. So, sort of like, 'I see you checked the box about changes in your romantic relationships. Can you tell me a little bit more about that?' Things like that, just to get more depth.*

This provider noted that AYAs had been hugely receptive to completing the screening tool. Explaining their receptivity, she said, "*I think the fact that it's not something we send home with them- it's something they get that real-time feedback. 'I fill this paper out. Then his person comes and talks to me about it. And then we make a plan. All in the same session'. That's been helpful for them in seeing it's not just another piece of paper. They put a concern out there and we are acting upon it".*

Another provider's program had recently implemented a tool for assessing needs:

> *We have a care consultation model that is pretty much based on the NCCN distress screening tool that [the social worker will] go in and kind of talk to clients about when she first meets them, whether it's in person, or remotely. We give them a paper consultation sheet, and this*

> *is front and back, and ask them to fill it out. And then the social worker will wait [in the room while AYA completes form] and then sit down and talk about, 'ok I see that you indicated this, what's going on there'.*

This provider described the care consultation model document as a "*living document*", saying, "*it's not an event, it's a process*". The social worker would keep going back to a patient to work on the document, focusing on the most pressing concerns during any given visit. Another provider recommended a similar approach to needs assessment, in which assessment content depended on content addressed in previous assessments. In other words, the full range of needs would not be assessed during every administration but, rather, a subset of pressing concerns. *"I feel like it should be more often just maybe not all parts of it- I think depending on what you learn from your first or second time."*

> IMPLICATIONS FOR AYA NA-SB. Some providers' programs were in the early phases of implementing a more formalized needs assessment process. Success in their institutions suggests that AYA NA-SB is feasible to implement.

Documenting and communication AYAs' needs. Another challenge to implementation noted was sorting out how the needs assessment would interface with the EHR and working with software vendors to make the necessary changes. One provider said, "*our system is so back-logged with EMR requests, that if we waited, it would probably be a year before they could build it, unfortunately, so we've just plodded ahead."*

Across the board, information about AYAs' needs was documented in notes in the EHR by whichever provider had the interaction with the AYA. These EHR notes were routed to other providers, or a page sent for pressing concerns. Otherwise, the AYA team followed up with other providers about AYAs' needs via email, phone, or in-person communications. One provider described a "*multidisciplinary team-based approach to AYA care*" in which "*needs are addressed in real time*". Within this institution, interdisciplinary team meetings were held for new AYA patients to share information and coordinate care. Similarly, another provider described a weekly, multidisciplinary "*AYA psychosocial round"* where all current inpatient AYAs and AYAs coming in for outpatient appointments in the upcoming week were discussed. During these meetings, AYAs' needs and appropriate follow-up actions were discussed.

One provider, whose program was in the process of implementing a distress screener, said that screening results and follow-up actions were documented retrospectively in the EHR. "*We use EPIC. We created dot phrases to make it consistent in terms of, this is a tool that was administered, this is the score, these are the concerns, and then this triggered XYZ referrals. And then, if you receive a referral, we have a dot phrase there so its auditable as a trail- a closed loop that can be traced through the EMR*." Similarly, another provider (and program director) said that their program's social worker would "*scan the document into our EMR because it's not an electronic document at this point in time."* At the end of the day, the social worker would send this provider for her review:

> *I'll kind of review it and then we'll discuss like, is there anything else we think we should add in there, is that enough, anyone we should let know? And then she'll do a nice follow-up with their care team if she feels there's anything that's necessary.*

IMPLICATIONS FOR AYA NA-SB. Providers use the EHR to document and communicate about patient information. If possible, AYA NA-SB should interface with the EHR to capitalize on existing systems. However, working with software vendors to make the necessary changes represents a challenge to implementation.

Providing services and resources. One provider noted institutional service capacity as a potential barrier to implementation. "*I think it's building the infrastructure within your organization to support the needs."* Thus, she emphasized the importance of identifying gaps in service capacity prior to implementing a needs assessment tool and building up services to fill existing gaps. ***"****And that's one thing we sat down before we launched the tool. We went through all of these and said 'ok, so if they stay yes to financial distress, what do you do with that'. It's unethical to ask a question that you cannot answer or point them to a service*." To this end, One provider described conducting an environmental scan of services and resources available at her institution across pediatric and adult oncology:

> *One of the things we built is a Supportive Services Guide, which basically said who are the social workers in [pediatric oncology] and on the adult side. What are their names? What floors should they cover? What diseases do they manage? How do I contact one if I need one? What are the head nurses names in both areas? So, we could do cross-linkage of services and get a good feel for what we had on both sides of the organization. And that was very helpful and helped us to get acquainted with folks that we may not have even known existed. And other things like supportive integrative medicine- all of those other aspects that can really enrich their experience and help them.*

IMPLICATIONS FOR AYA NA-SB. Institutional service capacity represents a potential barrier to AYA NA-SB implementation. A thorough understanding of existing services and resources should be gathered prior to implementation.

Intervention

Goals for intervention.

Timing. One challenge to implementing AYA NA-SB identified by providers was related to timing of needs assessment administration. They noted that, given variation among AYAs and the unpredictability of clinical workflow, getting the needs assessment to AYAs at the opportune times would be really challenging. Furthermore, treatment trajectories vary tremendously, making it difficult to time re-assessment.

Providers emphasized the importance of not administering AYA NA-SB too soon after diagnosis. One provider recommended meeting with the patient as soon after diagnosis as possible but cautioned, *"the problem is trying to get in with that initial discussion when the client and their family is just so completely obliterated emotionally by hearing that they have cancer. We have found that that has not necessarily been that productive. Like, you're trying to with them, they can't barely hear you, it's just very emotional."* One provider recommended a month or two after diagnosis as the first administration time point. Another recommended the third visit after diagnosis; she added that the assessment should also be administered during the third visit after relapse. Another provider felt that, ideally, needs should be assessed within 2 weeks of diagnosis but noted that this may not always be logistically feasible.

In terms of frequency of AYA NA-SB administration, providers suggested administering the needs assessment relatively frequently. *"The treatment journey changes so frequently and the* *different factors that come up along the ways. So, I think checking in periodically, we'll miss less."* However, in pinpointing a specific interval for screening needs, providers noted the challenge of accommodating different treatment trajectories. "*Who knows what the middle of treatment is. For someone like a non-Hodgkin's, the middle of treatment might be two months. For someone else, the middle of treatment could be six months*." One provider's program was aiming for quarterly re-screening of needs. Another provider, whose institution was in the process of implementing a distress screening tool said that they are re-screening based on the level of distress at initial screening. For patients whose initial distress screening score was "low", they were re-screening at 6 months; those with a "medium" distress score were re-screened at three months; a "high" distress score triggered a re-screening at one month. They were keeping track of this timing in an Excel spreadsheet, which was feasible in part because of their small patient case load (i.e., 45 AYA diagnoses per year). Eventually, they wanted to build these re-screening rules into the EHR so that patients due for re-screening would be flagged for easy identification. One provider noted the importance of following up on needs reported in a timely manner. "*If you wait too long, they have forgotten what the reported on the assessment*".

Providers also discussed administering the tool during the survivorship phase. One articulated the importance of assessing needs in survivorship because, after treatment ends, AYAs no longer have providers readily available to help them with their needs. "*What clients are telling us is that, after they ring that bell, the bottom falls out. They don't know what to do. They're going back to school or they're going back to work if they're able, and they're like, 'I don't have the skills for this. I'm just starting to process this trauma I went through. I'm a different person'. With very little support*." One provider noted that the assessment may require shortening for AYA survivors, as many of the items may only be relevant during treatment.

Providers agreed that AYA NA-SB should be administered during times when patients are already waiting in the clinic. One said that this was how she currently determined times to visit with patients; she always aimed to meet with them while they were waiting. She noted that clinical flow can change quickly, though, making it challenging to identify these periods of waiting time. More specifically, providers agreed with several time points for AYA NA-SB delivery: (1) during infusion, (2) in the clinic waiting room, and (3) in the exam room prior to the oncology provider coming in. One provider noted, however, that infusion spaces at many institutions may lack privacy. *"I have done one follow-up in the infusion space for that very reason, of not wanting to hold up their whole appointment. It's just harder because our infusion space has no privacy, and some of the things that get raised are private."* Providers emphasized the importance of screening the needs of inpatient AYAs, not just those coming in for outpatient appointments. In regard to administering a tool to an AYA staying inpatient, providers felt there was ample opportunity, saying, "*there's tons of deadtime in the hospital*."

> IMPLICATIONS FOR AYA NA-SB. AYA NA-SB should be administered at multiple timepoints throughout cancer treatment to capture the changing needs of AYAs, including diagnosis, during treatment, at the end of treatment, and at some interval in survivorship. It should not be administered immediately upon diagnosis when AYAs might not have a grasp of what they need yet. In the clinic, AYA NA-SB should be administered during times when AYAs' wait times so as not to lengthen AYAs' already long appointments.

Format. Overall, providers did not express a strong preference about paper versus electronic delivery of AYA NA-SB. One said, *"I personally don't [have a preference]. I think whatever's going to be easiest and helps you get the information you need, as easily as possible*." Another provider said, *"I think, if it's not while they're sitting there, then technology is something to consider. But if there just like right there in the space [i.e., clinic], then I don't know if it really makes a difference*." However, one provider, who developed and piloted a needs assessment in-house, reported that participants in her pilot study favored paper over electronic assessment completion. They were sent a survey link in advance and given the option to complete it electronically either before or during their clinical appointment; 9 out of 10, however, opted to complete it on paper, in the clinic. This suggests that AYAs may be less amenable to administration outside of the clinic setting. Another provider said, "*Some locations may not have option to implement electronically so paper options should be available for all institutions if widespread*." One provider described her institution's implementation of a distress screening tool:

> *For us, the paper is working. We are still considering this a pilot so that's why we haven't gone that next step. Personally, I like the paper. It's a concrete thing I can do with a patient. My AYAs aren't checking their emails. They have a really low rate of saying that they use the MyChart access through EPIC to check their chart. So many of us get bombarded with digital things all day long, that it's not really helpful. It would be helpful from a documentation standpoint, for sure, because right now we scan that paper back into the EMR, and it lives in a different tab of the EMR, where its findable but it's not integrated like a flow sheet, which would be great, because then you could track it really easily side-by-side. There are benefits from a documentation and tracking standpoint, but I don't know what patient response to that would be. I think that might be our next phase of things.*

> IMPLICATIONS FOR AYA NA-SB. Although providers did not express a strong preference for AYA NA-SB format, they recommended considering electronic delivery if AYA NA-SB were to be delivered outside of the clinic. In the clinic, they noted several advantages of paper.

Benefits of intervention. Providers saw AYA NA-SB as an opportunity for AYA programs around the country. One provider said, *"I think its invaluable."* She noted that, even if AYAs didn't have pressing needs at the time of assessment administration, merely completing the survey could be hugely informative to them in terms of pointing out resources and services that are available to them should needs arise. Another provider echoed this sentiment, describing the benefits of a distress screening tool her program was in the process of implementing:

> *It's been incredibly useful as a conversation starter and it's also been really clarifying for the patients as to what they can talk to our team about. It helps them see 'oh, so like when you say you're here to support the intersectionality between my life as a teenager, or young adult, and my cancer, that's what you mean'. It's really been really helpful in clarifying that for them. And then also, again, giving them permission to talk about things. It sort of like normalizes 'oh, OK, so this body image thing I've been dealing with, it's not so strange that I can't talk to them about it.'*

One provider noted that AYAs may be more inclined to indicate concerns on a needs assessment, than to broach these conversations with their providers, unprompted. Another provider said that her program's distress screening tool "*helps us to align ourselves with what's important to [AYAs] pretty quickly."* Similarly, another provider said, *"I think it has taught us to be thorough. As* *humans, we all have areas and things we're more comfortable discussing than others….by standardizing the types of questions we're asking, it legitimizes all of these discussions."*

An intervention like AYA NA-SB was also seen as a way to make sure no patients fell through the cracks. *"It's a good reminder to address those non-urgent needs of the patient, that are still needs. It's a concrete way of making sure that you're closing the loops with every patient, not just your highest needs ones. It's sometimes easiest for those highest-drama, sickest patients to get a disproportionate amount of time at the expense of the care of other people who do have needs, they may just not be as vocal about them, or they may not appear as urgent or tragic. So that's another benefit, I think, for the team."* Similarly, another provider reported described the usefulness of a standardized tool in identifying issues among patients who seem like they are coping well or have no issues. One provider felt that, by identifying issues upfront that may have otherwise been missed, a needs assessment could help move from a reactive to a more proactive space. "*A lot of time, we always feel like we're running around putting out fires."*

A needs assessment intervention was also regarded as a means of justifying an AYA-specific program to other health system providers and leadership:

> *I think there can be a lot of benefit in saying, we are assessing the needs, and these are the needs that have been uncovered by our AYA team. These were not questions that other members of the health care team are asking. So, if people are like 'why do we need AYA-specific care? what's so unique about that?', it gives you data. It can give concrete numbers data to the psychosocial support work that's being done. That's a huge benefit. That's sort of as a justifying your role to administration or whatever. Also, for the actual providers, in real time, to see what's important and to see what's covered by the AYA team. If I uncover an issue and I take that to the doc, then they're able to do a better job of caring for the patient. It's also that individual patient-level feedback to the provider team that helps describe the reason we care about having an AYA team at your site.*

One provider felt that AYA NA-SB could offer a uniform approach for assessing needs across AYA programs. She felt that this could generate national-level data to advance AYA cancer practice. *"The need is there. I think everyone is searching for something like this. And everyone's kind of doing it in different ways. So, if we had a universal one that everyone was using, I think that would be fantastic. Especially, to show some data on the national level."*

IMPLICATIONS FOR AYA NA-SB. Providers expressed numerous potential benefits of AYA NA-SB, suggesting that the intervention has high acceptability among prospective users.

Table 18. Contextual differences identified in semi-structured interviews

Contextual feature of AYA Program	UNC	Variation
Structure	Under the umbrella of NCCH's Comprehensive Cancer Support Program which is directed by the Vice-Chair of General Hospital Psychiatry. There is not currently a designated space for AYA care. However, an AYA infusion space is in development.	• Some AYA programs have designated AYA spaces (e.g., infusion centers, inpatient centers), but some do not. • Some AYA programs are housed within pediatric oncology; some are housed within adult oncology. The extent to which there is interface between pediatric and adult oncology varies.
Staffing	Medical director; program director/social worker; social worker Patients rely on social workers for non-medical needs, saying that their oncology providers rarely ask them about non-medical concerns.	• Core members of the AYA care team vary across institutions. As such, who assesses and addresses AYAs' needs varies. A common element of those who do the work of AYA needs assessment is an expertise on the AYA population.
Funding	Foundation + grant funding	• Some AYA programs are largely health system supported, while others rely on foundation grants and other external funding.
Functions	Coordinating across disease groups and across pediatric and adult oncology to provide age appropriate services and resources to AYAs	• Some AYA programs are modeled as consultations services while others function more as part of the primary treatment team.
How are new AYA patients identified?	AYA social workers rely on referrals from disease group providers.	• In general, AYA programs rely on referrals from disease group providers. However, the reach of programs vary, with some AYA programs reaching every AYA patient and some only reaching a subset for whom referrals were initiated.
When and where does AYA needs assessment take place?	Although sometimes AYA social workers schedule appointments with AYAs, they often just "pop in" while AYAs are in the hospital for appointments	• AYA programs vary in the extent to which AYA visits are scheduled versus impromptu.
Are any standardized tools or questionnaires	AYA needs are assessed informally/conversationally by the AYA social workers	• Some AYA programs are working towards implementing distress screening/needs assessment tools

Contextual feature of AYA Program	UNC	Variation
used to assess needs?		
How do providers document AYAs' needs?	Information about patient needs is stored as notes in the EHR; each provider records their own separate note for each interaction with a patient.	• Same
How do providers communicate about AYAs' needs?	Providers communicate about AYAs' needs via phone, text, email, EHR messaging, and in-person.	• Same

5.8 Design Team Workshop #2

In preparation for the second design team workshop, the research team distilled the most pertinent implications of ethnography data to create a translation table, which translates user and contextual factors into requirements for NA-SB delivery (see **Table 19**).

Table 19. Ethnography translation table

Domain	User/contextual factor identified through ethnography	Requirement for AYA NA-SB delivery
User characteristics	AYAs desire a tool that is used to address their needs in a timely manner	AYA NA-SB follow-up actions should be delivered in a timely manner
	Needs change as AYAs move through their treatment trajectory. Time points when needs are particularly distinct include (1) after diagnosis, (2) end of treatment, and (3) somewhere in between	AYA NA-SB should be administered at multiple timepoints, including after diagnosis, during treatment, and at the end of treatment
	AYAs feel overwhelmed immediately following diagnosis and may not know what they need yet	AYA NA-SB should not be administered immediately upon diagnosis
User tasks	AYAs at NCCH rely heavily on social workers to address their nonmedical needs	AYA NA-SB should be delivered by those who are currently doing the work of AYA needs assessment and those who have relationships with providers to whom referrals will be triggered (i.e., social workers at NCCH)
	oncologists are primarily focused on medical concerns during patient visits	
	NCCH has two social workers dedicated to AYA patient care; AYA social workers are already doing the work of needs assessment, although informally/conversationally; AYA social workers have robust knowledge of services and resources available to	

Domain	User/contextual factor identified through ethnography	Requirement for AYA NA-SB delivery
	AYAs and established relationships with providers across clinics	
	NCCH has nurse navigators for each disease group; nurse navigators often see patients at the beginning and end of their visits	
	At other institutions, nurses, nurse navigators, child life specialists, and others may do the work of needs assessment	
	Appointments vary among AYAs, including some combination of the following: (1) labs, (2) imaging, (3) treatment, (4) clinical appointment. Clinical appointments typically occur monthly.	AYA NA-SB delivery should be flexible to the various types of appointments AYAs have (i.e., labs/imaging/treatment/clinical appointment). Monthly clinical appointments may be the common thread.
	AYA tasks are very different during outpatient visits versus inpatient stays	AYA NA-SB delivery should accommodate both inpatient and outpatient AYAs
	Users expressed the importance of not extending AYAs' already long and exhausting appointments.	AYA NA-SB administration should occur during appointment waiting times
	AYA social workers identify new AYA patients through disease group referrals; since the referral process is not systematic, not all AYAs are reached	A process for identifying new AYA patients should be built into AYA NA-SB delivery
Technical & physical environment	Adult oncology appointments are scattered across NCCH	AYA NA-SB administration should account for disparate physical locations
	NCCH is building an AYA-specific infusion space	AYA NA-SB could leverage the new AYA space for needs assessment administration and/or service provision; however, privacy should be considered
	AYAs prefer technology, but are not averse to paper format	If possible, AYAs should have the option to complete AYA NA-SB electronically
	AYAs are active users of MyChart	AYA NA-SB could interface with MyChart
	Providers use EPIC for patient information documentation and communication across providers	If possible, AYA NA-SB should interface with EPIC
		AYA NA-SB should facilitate communication and the sharing of

Domain	User/contextual factor identified through ethnography	Requirement for AYA NA-SB delivery
Organizational Environment	AYA providers collaborate with providers across adult and pediatric oncology, and across disease groups.	information across pediatric and adult oncology, and across disease groups
		Clear referral pathways should be established to facilitate follow-up on reported needs
	the extent to which staff buy in to a new initiative or change is contingent upon how dramatically it impacts current workflow as well as staff members' perception of the initiative's merits.	AYA NA-SB development and implementation planning should involve key stakeholders who will interface with the intervention in practice
	NCCH's AYA program falls within the Comprehensive Cancer Support Program, which has a catalogue of resources for patients and families	AYA NA-SB should leverage Comprehensive Cancer Support Program resources where applicable
	Leadership buy-in often hinges on measurable impacts	AYA NA-SB data should be documented somewhere to allow for the evaluation of its impact, and its use to inform program changes
	NCCH's AYA program is growing and expanding in scope	

During the second workshop, the AYA NA-SB design team reviewed user and contextual requirements and collaboratively specified AYA NA-SB delivery (**Figure 28**). The final AYA NA-SB prototype can be found in **Appendix I**.

When should AYA NA-SB be delivered?

Given the diversity in AYAs' illness and treatment trajectories and the unstandardized approach to AYA care at many institutions, it was determined that some degree of clinical judgment will be necessary for identifying the appropriate timepoints to administer AYA NA-SB, at least initially. In the future, systems can be built to facilitate a more standardized approach to needs assessment timing.

First administration. Based on ethnography data, I proposed that AYA NA-SB should not be administered immediately upon diagnosis, because AYAs are overwhelmed and do not yet know what they need. During the workshop, one AYA pushed back on this, noting that he had already been diagnosed and undergone surgery by the time he met with his oncology provider for the first time. Thus, during this first visit, he already had a list of questions and needs. Waiting to administer the needs assessment could result in these initial needs being missed. Fertility concerns were mentioned as an example of a particularly time-sensitive need that could be missed in the time period immediately after diagnosis. However, providers noted that administering AYA NA-SB during the first visit could potentially result in many "*false positives*". Furthermore, there may not be the workforce capacity to respond to these false positives. Other arguments against administering AYA NA-SB during the first visit included concerns about overwhelming AYAs and concerns about fitting the assessment into the hectic logistics of the first visit.

Ultimately, design team workshop attendees determined that AYA NA-SB should be administered within one month of diagnosis. However, this would not necessarily be the first contact with the AYA team. For example, information about the services the AYA team can provide and contact information might be provided to AYAs immediately upon diagnosis, with a heads-up that more extensive conversation will follow.

Frequency. Design team workshop attendees expressed differing views regarding the frequency with which AYA NA-SB should be administered. One AYA recommended 1-month intervals to get a "*continuous snapshot of needs as they develop*." However, another AYA said that completing a needs assessment monthly would be "*really annoying*". One suggestion was to increase the interval as AYAs progress through treatment, extending the space between assessments from, for example, one month to three months to six months. Another suggestion was to determine the timing of reassessment based on the severity of needs indicated in previous screens. However, for these two options, concerns were raised about the feasibility of tracking this. Another recommendation was to administer subsets of the needs assessment during reassessments, or allow AYAs to update their previous assessment rather than having to complete it again. These options were considered more feasible were the assessment to be administered electronically. Another suggestion was to tie reassessment to change in clinical status. However, providers expressed concerns about being able to identify and track these time points. As such, providers favored anchoring frequency to a given time period, rather than something like clinical changes which vary from person to person. To this end, one design team member recommended tying timing to typical treatment cycles. For example, many chemotherapy regimens operate on 3-week cycles; he suggested administering AYA NA-SB every cycle, or every other cycle. However, given the variation among treatment protocols and schedules, this option was passed on.

Ultimately, design team workshop attendees determined that pilot testing would be used to determine the frequency of AYA NA-SB administration. Specifically, pilot testing will include two arms. In one arm, AYA NA-SB will be administered monthly; in the second arm, it will be administered every three months. Feedback from AYA and provider pilot participants will inform the ultimate determination of needs assessment frequency. Since AYAs typically have monthly appointments with their oncology provider(s), the design team discussed tying assessment administration to those monthly appointments.

Who should deliver AYA NA-SB?

AYA NA-SB drop-off and pick-up. We initially discussed the option of having the needs assessment offered to AYAs during registration. However, there were concerns about relying on staff working at the registration desks to identify eligible patients; providers felt that this would require a significant workflow and culture change. The second option we discussed involved AYA social workers dropping off the needs assessment with AYAs, giving them 10 minutes to complete it, and then coming back for an immediate follow-up discussion. Since social workers know where people are in treatment as well as where they are in the clinic, this was considered a viable option. However, from a workflow perspective, there were concerns about the feasibility of this approach. Not only would timing this interchange during complicated visit schedules be challenging, but it would also be time-intensive for AYA social workers. Ultimately, we decided that AYA social worker time should be reserved for following up on needs identified in the assessment.

Tentatively, we determined that nurse navigators might be the best equipped to drop off the assessment with AYAs and pick it up once complete. Each disease group has one or more nurse navigators who often see patients at the beginning and end of their appointments, providing the perfect opportunity for dropping off and picking up a needs assessment. However, at NCCH, there are no nurse navigators in pediatric oncology; thus, a different approach would be needed in the pediatric oncology clinic.

Interpretation of data. Regarding who would interpret needs assessment data and identify appropriate services and resources triggered, we discussed several approaches. We determined that, so long as referral pathways were explicitly laid out, AYA expertise was not a necessary qualification of the individual interpreting AYA NA-SB data. Thus, nurse navigators were identified as appropriate arbiters of this task. Nurse navigators are currently doing the work of care coordination and are deeply embedded in patients' care teams; as such, assuming this task would be not be hugely disruptive to their workflow.

Documentation of data. Ultimately, we determined that whoever is interpreting the data would document needs identified and referrals made in the EMR. Thus, if a nurse navigator is the one triaging services based on needs assessment responses, they would be the one to record this information in notes in the EMR. Service and resource providers will also document follow-up actions made to address reported needs.

Service and resource providers. For follow-up domains 1 (information), 2 (cancer care team), and 3 (physical health), an AYAs' oncology providers were identified as the appropriate points of contact. Workshop attendees felt that the close proximity of nurse navigators' workspaces to oncology providers' workspaces would facilitate this communication. For follow-up domains 4 (emotional health), 6 (health behaviors & wellness), 7 (work & education), and 8 (peer support & programming), AYA social workers were identified as the appropriate points of contact. Follow-up domain 5 (sexual & reproductive health) was split in terms of point of contact. Concerns related to sexuality would be directed to AYA social workers; concerns related to reproductive health would be directed to NCCH's Fertility Preservation Coordinator. For follow-up domain 9 (finances & everyday needs), outpatient social workers were identified as the appropriate points of contact.

Where should AYA NA-SB be delivered?

In general, design team workshop attendees felt that the needs assessment should be "dropped off" with patients at the beginning of their clinical visit, allowing flexibility for them to complete the assessment as they had waiting time. In terms of where this takes place, design team members thought that some degree of variation should be tolerated. "*It's going to have to be a flexible deploymen*t" to accommodate diversity in AYAs' treatment and appointment schedules. Thus, the design team determined that nurse navigators would drop off and pick up needs assessments in the locations consistent with their current workflow, which vary by disease group and by patient.

How should AYA NA-SB be delivered?

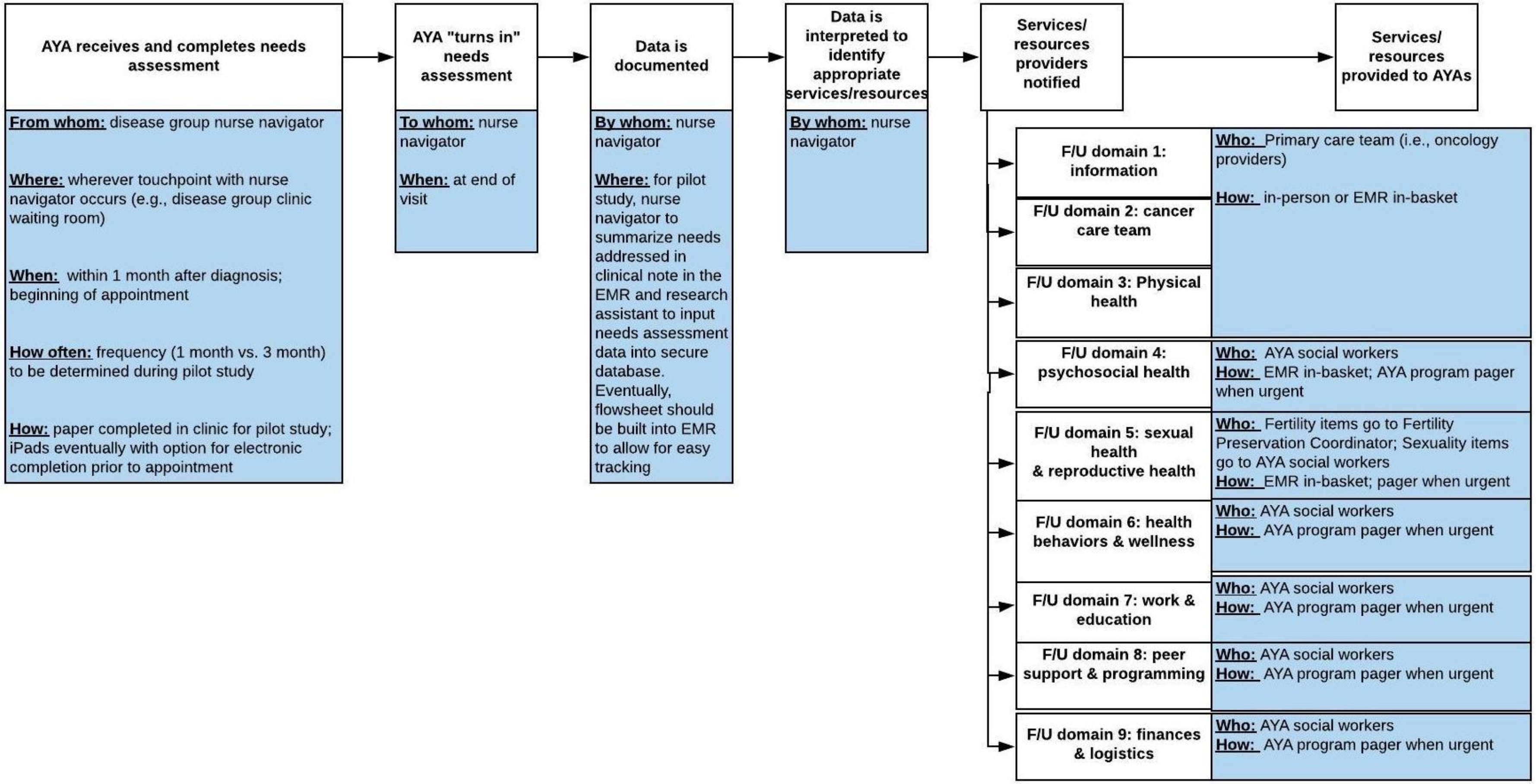
Mode. Many of the workshop attendees liked the idea of offering AYAs the choice to complete the needs assessment electronically prior to appointments, for example, through MyChart or a mobile application. Workshop attendees also liked the idea of having AYAs complete the needs assessment on an iPad, in the clinic. For pilot testing, however, paper was deemed most feasible.

Documentation of data. Workshop attendees expressed the importance of documenting needs assessment data to inform program changes. Eventually, design team workshop attendees agreed that the needs assessment should be built as a flowsheet into the EHR, to allow for easy tracking and running of reports. However, working with software vendors to build such changes into the EHR can take more than six months. Thus, we opted to use pilot testing as an opportunity to clearly outline changes that should be made in the EHR.

For pilot testing, however, we determined that needs assessment data would be uploaded by research staff into a separate, secure database. Then, nurse navigators would only be responsible for recording as notes in the EHR details about needs identified and follow-up actions taken. This decision was based on concerns about nurse navigators having to upload or scan needs assessments into the EHR. This task was considered overly burdensome and minimally helpful given that you cannot query or run reports on scanned documents in the EHR.

Notification of service/resource providers. Workshop attendees determined that the nurse navigators would notify service and resource providers through EHR messaging, or by pager for urgent concerns.

Figure 28. AYA NA-SB delivery



AYA receives and completes needs assessment

From whom: disease group nurse navigator

Where: wherever touchpoint with nurse navigator occurs (e.g., disease group clinic waiting room)

When: within 1 month after diagnosis; beginning of appointment

How often: frequency (1 month vs. 3 month) to be determined during pilot study

How: paper completed in clinic for pilot study; iPads eventually with option for electronic completion prior to appointment

AYA "turns in" needs assessment

To whom: nurse navigator

When: at end of visit

Data is documented

By whom: nurse navigator

Where: for pilot study, nurse navigator to summarize needs addressed in clinical note in the EMR and research assistant to input needs assessment data into secure database. Eventually, flowsheet should be built into EMR to allow for easy tracking

Data is interpreted to identify appropriate services/resources

By whom: nurse navigator

Services/ resources providers notified

Services/ resources provided to AYAs

F/U domain 1: information **F/U domain 2: cancer care team** **F/U domain 3: Physical health**	**Who:** Primary care team (i.e., oncology providers) **How:** in-person or EMR in-basket
F/U domain 4: psychosocial health	**Who:** AYA social workers **How:** EMR in-basket; AYA program pager when urgent
F/U domain 5: sexual health & reproductive health	**Who:** Fertility items go to Fertility Preservation Coordinator; Sexuality items go to AYA social workers **How:** EMR in-basket; pager when urgent
F/U domain 6: health behaviors & wellness	**Who:** AYA social workers **How:** AYA program pager when urgent
F/U domain 7: work & education	**Who:** AYA social workers **How:** AYA program pager when urgent
F/U domain 8: peer support & programming	**Who:** AYA social workers **How:** AYA program pager when urgent
F/U domain 9: finances & logistics	**Who:** AYA social workers **How:** AYA program pager when urgent

Implementation

During the second design team workshop, we also discussed the future implementation of AYA NA-SB, anticipating barriers to implementation and brainstorming strategies to address those barriers. **Figure 29** displays workshop attendees' ranking of barriers to AYA NA-SB implementation. **Table 20** describes the implementation determinants identified by the design team as most salient and the strategies deemed appropriate to address them. The first prioritized barrier was establishing AYA NA-SB's interface with the EHR or other documentation method. Incorporating changes into the EHR can take upwards of six months. Ultimately, the design team determined that pilot testing would be used to establish a detailed blueprint for EHR modifications needed to fully integrate AYA NA-SB into the EHR. The second prioritized barrier was related to variation in AYAs' treatment and appointment schedules. The design team worried that this variation would make it difficult to determine the appropriate timing and frequency of AYA NA-SB administration. To address this barrier, the design team determined that we would take a phased-in approach to implementation, for example, starting with one disease group and expanding outwards. The third prioritized barrier was related to the capacity of AYA social workers to respond to needs reported. A phased-in approach to implementation was also considered an appropriate strategy to ameliorate this challenge. Design team members also noted the importance of setting clear expectations with AYAs when AYA NA-SB is first introduced, communicating with them when they might expect follow-up to occur.

Figure 29. Design Team Workshop #2 attendee ranking of barriers to AYA NA-SB implementation

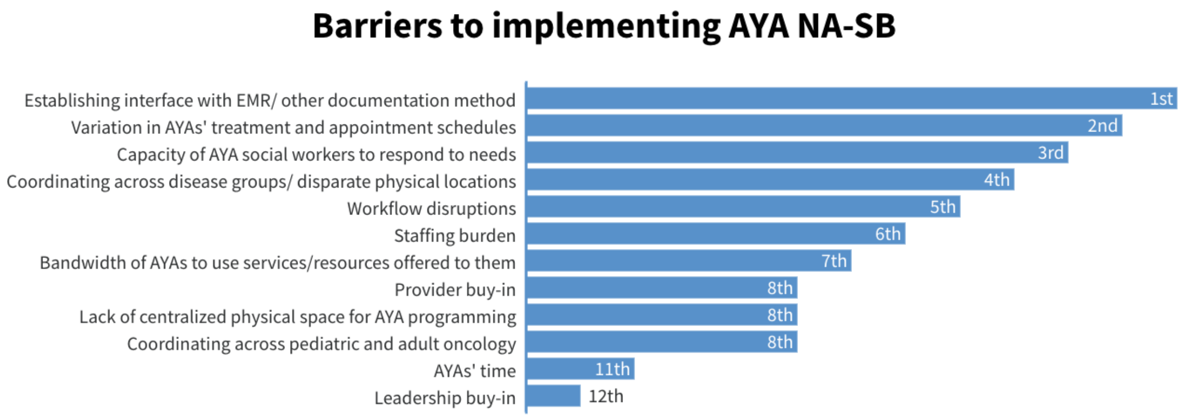


Table 20. AYA NA-SB implementation

Barrier	Proposed Strategy for Addressing Barrier
Establishing interface with EMR/ other documentation method	Use pilot testing to establish a blueprint for EMR modifications needed
Variation in AYAs' treatment and appointment schedules	During pilot testing, include three different arms with different intervals of administration: (1) every month, (2) every 3 months, and (3) with each significant change in clinical status Phase-in approach to implementation
Capacity of AYA social workers to respond to needs	Phase-in approach to implementation Set clear expectations about follow-up when AYA NA-SB is first introduced

Identifying new AYAs. Another implementation issue discussed by the design team was how to identify new AYA patients. Currently, there is no systematic process for doing so; the AYA team relies on referrals from disease group providers. The design team determined that, in the future, a function in the EHR should flag all new AYA patients. In the meantime, however, the design team discussed several strategies for strengthening referral pathways (e.g., take a phased-in approach, identify point person in each disease group clinic, provider education). Because each disease group has their own workflow, mapping out that workflow and identifying relevant contacts in each disease group will be an important component of implementation.

<u>Other discussion</u>

Item wording. The design team decided to reframe item wording so that items ask about help *wanted* rather than help *needed*. One AYA said, "*just because you have a need doesn't mean you necessarily want help with it*." Another said, "*I feel like sometimes it's hard to reflect and be like, 'do I actually need help?' Versus 'do I want help', it's more accessible*". Providers agreed that this shift in wording was more aligned with the goals of AYA NA-SB.

Because AYA NA-SB is intended to facilitate real-time service provision, the design team also decided to frame items in present tense rather than in past tense, deeming a specific lookback period (e.g., "in the past month") unnecessary.

Response scale. Design team members were opposed to collapsing response options into a binary (i.e., yes/no) scale. They argued that some level of gradation is needed to determine the urgency of response, particularly in contexts with staffing and resource constraints. "*Understanding if there are needs that can be met by somebody who doesn't have as high level of knowledge as, for instance, a core AYA team might have, could be helpful on the implementation side."* Additionally, they were concerned that a binary response option would result in a lot of false positives, with needs being flagged where help is not wanted. However, they agree that the five-response scale was too cumbersome and advocated for its consolidation into three response options.

One AYA member of the design team advocated for a "not sure" or "I don't know" response option saying, "*I don't think we always know what we're going to need. We don't always know what questions to ask*". Design team members also advocated for free response opportunities for AYAs to indicate needs not covered by the needs assessment.

CHAPTER 6: DISCUSSION

6.1 Discussion of Results

AYA NA-SB

By ensuring AYA NA-SB directly responded to features of users (i.e., AYAs, providers) and context (i.e., NCCH), we designed AYA NA-SB *for implementation* and minimized the need for post-hoc implementation strategies to address misalignment that may have otherwise existed. Furthermore, we designed AYA NA-SB *for scale-up*; by engaging users from other AYA cancer programs across the country to identify points of contextual variation for which AYA NA-SB would require flexibility in delivery, we ensured that the tool we created was not overly tailored to one unique context.

Our UCD process culminated in AYA NA-SB, a PROM-based care coordination intervention for AYAs with cancer, and guidance for its delivery and implementation (see **Appendix I**). The PROM component of the intervention is a 57-item needs assessment, divided into 9 follow-up domains. The PROM will be administered for the first time within one month of diagnosis by disease group nurse navigators at the beginning AYAs' visits. Subsequent administrations will occur at 1-month or 3-month intervals, depending on feedback received during pilot testing. During pilot testing, needs assessments will be administered on paper; in the future, iPads or other electronic formats will be used. Needs assessments will be collected by nurse navigators at the end of AYAs' visits. Nurse navigators will then triage needs reported, notifying service and resource providers through EHR messaging or pager, using the referral pathways outlined. They will record, as notes in the EHR, needs reported and follow-up actions and referrals made; service and resource providers will also document services and resources provided in their own separate EHR notes. During pilot testing, needs assessment data will be uploaded to a secure electronic database. Eventually, a flowsheet will be built into the EHR to consolidate and streamline documentation. A phased-in approach to implementation will be taken, starting with one disease group and expanding outwards.

UCD and implementation science

To date, efforts to improve healthcare quality have focused on implementing EBPs as originally designed.[195] A potential consequence of this emphasis on EBPs has been resistance to considering the implications of EBP design for implementation in practice. Implementation scientists often must facilitate the implementation of EBPs with features that clash with the diverse contexts to which they are scaled up. In response, implementation scientists turn to implementation strategies that can place undue burden on stakeholders in practice. In fact, the National Institutes of Health (NIH) defines implementation science as ""the scientific study of the use of *strategies* to adopt and integrate evidence-based health interventions into clinical and community settings".[196] In this study, we proposed that the pitfalls associated with ill-fitting EBPs and cumbersome implementation strategies may be avoided by placing equal emphasis on EBPs, the contexts in which they are to be implemented, and implementation strategies used. Just as embroidering requires compatible thread, fabric, and needle, implementation may be optimized by harmonizing EBP, context, and implementation strategies. Using UCD to attend equally to features of EBPs, context, and implementation strategies has the potential to limit the challenges associated with exceedingly complex EBPs and cumbersome implementation strategies that burden stakeholders.

As demonstrated by this study, UCD can help implementation scientists to operationalize the field's commitment to stakeholder engagement. For example, establishing a design team upfront ensured that users remained central throughout AYA NA-SB development and implementation planning. Design team members offered key insights to inform data collection (e.g., review of data collection instruments), data analysis (e.g., selection of concept mapping cluster map; prioritization of user and contextual requirements), and, ultimately, AYA NA-SB design (e.g., specification of AYA NA-SB content and delivery). Further, design team members proved critical to the recruitment of users for usability testing and ethnographic data collection efforts. UCD also offers methods for translating stakeholder feedback into design decisions. For example, the use of personas and scenarios of use during our second workshop, allowed our design team to translate ethnographic data into AYA NA-SB design features, in a way that group discussion without such engagement methods might not have facilitated. Finally, UCD demands an active and iterative approach to stakeholder engagement, often with the same group of users reviewing prototypes at multiple time points; this type of iteration may be a key moderator in the relationship between stakeholder engagement and improved EBP design.[193] This study demonstrates the feasibility of embedding extensive and iterative user engagement in EBP design. In terms of engaging AYAs specifically, this study offers key insights such as the broad willingness of AYAs to contribute to this kind of research and the viability of social media as a recruitment strategy for this population. The use of social media to recruit AYAs in this study builds on existing literature describing the high rates of social media usage among this population for seeking cancer-related information, and interaction with peers and providers.[197]

Usability testing of PROMs

In this study, *usability testing* elicited user concerns about the CNQ-YP's usability and usefulness that may have stymied its uptake in real-world cancer care practice. Our user groups identified many key usability and usefulness concerns, allowing our design team to produce design solutions which directly addressed user needs and preferences. For example, through concept mapping, AYA providers pinpointed needs assessed by the CNQ-YP which, as originally written, could not be addressed with available services or resources (e.g., "having cancer treatment staff who could have a laugh with me"); assessing these needs for which services or resources were not available would have produced additional burden for users, without improving care. Through the survey and cognitive interviews, AYAs identified important, actionable missing content (e.g., AYA sexual health), and other areas in which the CNQ-YP's content, length, wording, and response format were unacceptable. Of key importance to this study was considering PROM usefulness, or actionability in terms of service provision. Extant PROM literature suggests a limited consideration of usefulness in

PROM research and implementation.[82,104] However, the mere assessment of needs is not enough to influence patient outcomes if patient information is not subsequently used. As such, we prioritized usefulness in AYA NA-SB development, forging an explicit connection between PROM information and service delivery and outlining care processes required to deliver appropriate follow-up actions to AYAs. Concept mapping provided valuable source data to help the design team in forging this connection between needs and services in a systematic way. The use of 'cluster comparison worksheets' during the first workshop allowed design team members to easily digest concept mapping data, which can be difficult for stakeholders to interpret without a visual aid, and select a cluster solution which best grouped needs based on services or resources they should trigger. Ultimately, by identifying and addressing usability and usefulness concerns upfront, we developed a tool that is perceived as more feasible, acceptable, and appropriate to those who will use it in practice.

Ethnography to understand context

Because intervention characteristics like usability and usefulness cannot be considered in a vacuum, I leveraged UCD methods to describe both AYA NA-SB's specific implementation context (i.e., NCCH) as well as the broader context to which it may be scaled up in the future (i.e., other AYA cancer care programs in the United States). To explore context, UCD offers frameworks, such as Maguire's context-of-use framework used in this case example, as well as questionnaires (e.g., System Usability Scale [134]), and a menu of methods (e.g., ethnography, diary keeping, user surveys, etc.) [132] which are compatible with those used by implementation scientists in the assessment of barriers to and facilitators of implementation. Although there may be some overlap in UCD and implementation science methods, UCD tends to go a step further than traditional barriers/facilitators assessment by embedding users more deeply in the process. In this study, I used *ethnography*, an underused method in health services research,[172] to obtain a detailed understanding of users and context. Guided tours, for example, elicited rich details about users and context. However, it is important to note that the immersive experience of guided tours was, at times, difficult. During these tours, I found myself present for deeply sensitive and emotionally charged conversations. For example, I witnessed an oncologist delivery a terminal prognosis to an unsuspecting 22-year-old AYA. I quickly removed myself from the room to offer the AYA and her loved one some privacy. Still, though, I felt that I had intruded on a profoundly private moment. The interchange weighed on me heavily. As researchers, we may not be accustomed to navigating some of the difficult conversations that cancer care providers come up against daily. Taking an ethnographic approach can bring us face-to-face with the hardships and tragedies faced by the populations we study. In this sense, ethnography demands sensitivity, compassion, and a willingness to connect with others on a deeply human level.

For the ethnographic portion of this study, I leveraged Maguire's framework for contextual inquiry, which helped us to consider the array of user and contextual factors which might impact AYA NA-SB's usability or usefulness in practice. To make my summary of ethnography results more digestible to an implementation science audience, I embedded constructs from Maguire's framework into CFIR domains. In some cases, incongruence between the two frameworks made this integration challenging. For example, while Maguire's framework delves deeply into patient characteristics through many constructs, CFIR lumps these concepts into one construct in its "outer setting" domain. Ultimately, though, this combined use of frameworks allowed us to anchor our rich account of users and context to its implications for AYA NA-SB implementation. Additionally, I went further than traditional barriers/facilitators assessments by engaging users in analysis to co-create an understanding of context. Our multidisciplinary design team reviewed ethnography findings to ensure that the user interpretation of context remained central, as opposed to relying solely on the researcher's interpretation of contextual data. UCD also provides methods for translating *user and contextual factors* into *user and contextual requirements*—i.e., usability and usefulness determinants. [132] Translating contextual factors into contextual requirements using UCD *requirements engineering* approaches (e.g., the translation tables, 'personas', and 'scenarios-of-use' used in this case example) could help implementation scientists prioritize implementation determinants by focusing attention on the subset of contextual factors that influence EBP usability and usefulness.[122] In this study, the ethnography provided valuable source data for workshop materials, helping us to leverage the expertise of the design team to identify these usability determinants and prioritize contextual features to target with EBP redesign, context preparation, or implementation strategies. During the second design team workshop, I presented several alternative scenarios of use, or simple descriptions of plausible user interactions with AYA NA-SB, to inform the specification of AYA NA-B delivery (i.e., who should administer the needs assessment; when; where; how; how often). These scenarios provide user- and task-oriented information about the context in which an EBP has to operate,[198] and also offer concrete examples for design team members to react to. For example, scenarios helped our design team walk through different patient visit types (e.g., just infusion versus infusion + clinical visit) to ensure that design decisions about staffing and timing for PROM administration suited the range of potential AYA appointments. Likewise, presenting multiple personas, or hypothetical archetypes of actual users, to the design team helped them to envision the range of users that AYA NA-SB design features should support. For example, based on ethnography data pointing to key differences between patients receiving care in pediatric versus adult oncology, I developed personas to represent these user differences. Presenting these personas- complete with fake names and images- to the design team, allowed us to consider both user groups in AYA NA-SB design, ultimately ensuring that the tool met the needs of users receiving care in both pediatric and adult oncology.

Implementation strategies

Where EBP and context diverge, we can use UCD to tailor strategies which make EBP and context more amenable to each other. Through the UCD process employed in this case example, we were able to anticipate areas where AYA NA-SB provision may clash with user or contextual requirements, some of which could not be addressed by tweaking EBP design or preparing context. For example, AYA NA-SB – a tool that spans across multiple domains of care – will require the cooperation of multiple departments and disciplines at NCCH; although engaging users in its development likely generated some buy-in, additional implementation strategies targeting cross-department buy-in will likely be required (e.g., provider education; identifying AYA champions within each department). As we move towards implementing AYA NA-SB, such remaining gaps in EBP-context fit will inform the selection of implementation strategies to promote its uptake at NCCH. For example, in preparations for a pilot study, the design team might refer back to user and contextual requirements and collaboratively select implementation strategies to address outstanding areas of EBP-context misfit. Moreover, this project's use of UCD to enhance the usability and usefulness of AYA NA-SB likely reduced the number of post hoc implementation strategies needed to embed the tool in routine care; minimizing the brute force necessary to implement AYA NA-SB will minimize the burden placed on implementing organizations and providers. Leveraging UCD to identify user and contextual requirements and tailor implementation strategies accordingly addresses an articulated need in the field [123,199] and complements approaches for selecting and tailoring strategies that have recently been proposed in the implementation science literature (e.g., concept mapping, conjoint analysis, intervention mapping). [122] Future work will assess the extent to which UCD minimizes the need for complex implementation strategies or, when needed, aids in the selection or design of strategies that are contextually appropriate and minimally burdensome to users. We applied a UCD approach towards designing a needs assessment; future work will also assess the merits of UCD for refining and implementing more complex, multicomponent interventions.

AYA needs

This study illuminated the arduous work of being an AYA with cancer. Upon receiving a cancer diagnosis, AYAs found themselves responsible for juggling extensive appointment schedules and navigating complex health care systems, all while managing myriad symptoms and side effects. Moreover, they managed their cancer treatment in the context of busy lives including work or school demands, raising children, and navigating changing relationships with family members, partners, and friends. In doing all of this, AYAs were exhausted. It was apparent that any intervention for this population should be folded into the work they are currently doing, rather than adding more to their already overflowing task loads. Guided tours also shed light on the role of partners and family members in AYAs' cancer care, something that has been documented in previous qualitative studies.[200] AYAs' loved ones tracked their appointment schedules, accompanied AYAs to their appointments, and offered unyielding moral support. They were knowledgeable about AYAs' diagnoses and treatment plans and relentlessly advocated on AYAs' behalves. Loved ones paused their normal routines to support AYAs, missing work and forgoing other obligations to help AYAs manage the physical and emotional demands of cancer treatment.

Echoing extant literature on AYA needs,[1-5] AYAs in this study reported many diverse needs during and after cancer treatment. Based on survey results, Black AYAs may experience even more needs than their White counterparts, a disparity documented in existing literature.[1] Additionally, uninsured AYAs may experience greater need. This is problematic given that greater than 25% of AYAs are uninsured for some period of time in the 35 months after diagnosis.[201] Such disparities should be considered in developing and implementing interventions for AYAs with cancer. Certain cancer types may also increase the concentration of needs experienced by AYAs. In the AYA survey, non-Hodgkin lymphoma was associated with a higher burden of unmet of needs, while breast cancer was associated with having fewer unmet needs. Interestingly, in the survey, reporting greater need was associated with higher ratings of the CNQ-YP's actionability; this suggests that AYAs with high needs may be even more amenable to service and resource provision through AYA NA-SB.

Although AYA guided tour participants were pleased with their oncology providers' handing of their medical needs, they desired more discussion of non-medical needs during these visits. This parallels a study by Pannier et al. which found that the most frequently requested resource by AYAs was the provision of information on non-medical concerns.[180] Guided tour participants felt like it was on them to initiate conversations with their providers about non-medical needs, something they did not always have the awareness or capacity to do. AYA NA-SB has the potential to initiate important conversations about non-medical needs, by alerting providers to the individual needs of each AYA and triggering conversations about the full range of needs that AYAs experience during treatment.

During guided tours, financial needs were a major topic of conversation, echoing existing accounts of the unique financial burden faced by AYAs with cancer.[202] The financial hardships incurred by a cancer diagnosis extended beyond just medical bills. While undergoing treatment, AYAs struggled to shoulder the costs of transportation to and from appointments, parking at NCCH, and childcare. For those unable to work, the financial ramifications of cancer extended across all domains of life. However, those who could work often found themselves ineligible for financial assistance programs, placing them in a grey area where they could not afford their medical and living expenses but did not qualify for financial support resources. Importantly, the economic burden of cancer endures even after treatment ends and may disproportionately impact AYAs. One study found that, compared to older adult survivors of cancer, AYA survivors had excess annual medical expenditures of $3,170 per person and excess annual productivity losses of $2,250 per person.[203] This suggests the importance of continuing to monitor financial needs during survivorship. Interestingly, the CNQ-YP in its original form, does not address financial needs. By engaging users to review and refine the PROM, we identified such important gaps in content. The result is a PROM that more comprehensively captures important need such as financial burden.

AYA services and resources

NCCH is a comprehensive cancer center housed in a large academic medical center. As such, there is a high volume of services and resources available to NCCH patients. An environmental scan revealed a holistic suite of available services ranging from psychosocial care, to physical and occupational therapy, to fertility counseling, to financial navigation and assistance, among others. Available services and resources were particularly robust in pediatric oncology, where tutors, child life specialists, and other ancillary professionals were readily available to patients. In smaller, rural, or more resource-constrained hospitals, there may not be services and resources available to address the full scope of needs captured in the AYA NA-SB PROM. Such settings may consider pairing the AYA NA-SB down to address the subset of needs that are actionable at their institution. Ideally, though, AYA NA-SB could be used in these settings to identify areas for program development, or areas in which partnerships or referral networks should be forged with local organizations to fill in gaps in service and resource capacity.

Of note, five out of the nine follow-up domains in AYA NA-SB trigger follow-up by AYA social workers or other clinicians with AYA expertise. The role of these clinicians includes a secondary triaging of AYAs' needs. For example, at NCCH, PROM items related to issues navigating work and school will trigger an AYA social worker visit. This AYA social worker will then explore the AYAs' reported needs in more depth and connect them to appropriate services and resources (e.g., scholarship programs, loan repayment assistance, tutors). For smaller hospitals that do not have AYA-dedicated staff, filling this secondary triaging role may prove difficult. The extent to which social workers without AYA expertise can fill this role remains to be seen.

Despite the high volume of services and resources at NCCH, which undoubtedly exceeds that of smaller, more resource-constrained hospitals, AYAs' use of services was confined to only a small subset of what is available. A key barrier to AYAs' use of services and resources was awareness. "*You don't know what you don't know*." However, even once connected to services and resources, AYAs reported many barriers to using them including competing priorities, appointment fatigue, strict eligibility requirements, service capacity and timeliness, and concerns about the applicability of services and resources to their own unique needs. Previous studies have pointed to other downstream barriers to AYAs' use of services and resources, such as living in a rural area or living a longer distance from the hospital.[204] Although AYA NA-SB addresses key barriers to connecting AYAs to services and resources, it does not address many of these downstream barriers to service and resource use. Additional strategies may be required to remove outstanding barriers to AYAs' use of services and resources.

AYA programs

Cancer care is, by nature, complex, requiring coordination across multiple disciplines and departments within complex cancer care organizations. The complexity of care coordination is further heightened for AYAs, who span across disease groups and often occupy a “no-man’s land” between pediatric and adult oncology. This study illuminated a stark contrast between pediatric and adult oncology and pointed to the potential implications of receiving care in one setting versus the other. In pediatric oncology, staffing is robust and services and resources are concentrated to one physical space, facilitating easy communication among providers and more seamless integration of ancillary services into AYAs’ treatment. Because of these differences, designing AYA NA-SB to accommodate both pediatric and adult oncology represented a challenge for the design team. Ultimately, to account for heterogeneity across clinics, the design team opted for a phased-in approach to implementation, starting in one clinic and expanding outwards.

The AYA program at NCCH is relatively new and still grappling with the question of how to coordinate care without a “home” in terms of physical space for AYAs who are receiving care in disparate locations across the hospital. The development of a new, AYA-specific infusion space represents an exciting development for NCCH’s AYA program. Still though, developing AYA programming such that it accommodates existing workflows is no small task. The mere identification of new AYA patients is challenging. Furthermore, cancer treatment schedules are varied and complex, making it impossible to conceptualize AYAs’ interactions with the healthcare system in any singular way. In this context, intervention delivery and implementation pose a major challenge. Embedding an intervention within the complex labyrinth of AYA cancer care requires first unraveling that labyrinth to identify portions of the fabric amenable to new threads.

In this study, I leveraged ethnographic contextual inquiry to elucidate the complexities of AYA cancer care. This yielded insights on several key leverage points for AYA NA-SB delivery and implementation. For example, AYA guided tour participants pointed to several timepoints during which their appointments required extended periods of waiting. Embedding AYA NA-SB administration into these waiting times will alleviate some of the burden of PROM completion. Building on existing communication channels among patients and providers will minimize the burden associated with AYA NA-SB delivery. Leveraging the expertise of providers who are currently doing the work of needs assessment, although informally, will minimize workflow interruptions and the need for additional staffing. Finally, engaging various provider groups in AYA NA-SB development likely increased awareness of and buy-in for AYA NA-SB among those who will interface with the intervention in practice.

AYA-specific cancer care programs have emerged within cancer centers across the country to address the challenge of coordinating services to meet the unique needs of AYAs. However, there is broad variation in the structure, staffing, and functions of these programs. As such, other AYA programs will likely need to tailor AYA NA-SB to their own unique context. To do so, they might consider using elements of the UCD process we employed in AYA NA-SB development (e.g., user testing, design team collaboration). However, because we tried to design AYA NA-SB to accommodate multiple contexts, it is unlikely that other programs will need to engage in an extensive UCD process like the one we used.

Some AYA programs have implemented, or are in the process of implementing, interventions to assess the needs of their AYA patients. During semi-structured interviews, providers from these programs spoke to the challenges of delivering this kind of intervention. One challenge discussed at length was the electronic integration of these tools. Faced with back-logged EHR requests and disparate documentation processes across disease groups or departments, AYA programs were often using paper assessments paired with patchwork approaches for retrospectively documenting AYAs' needs and follow-up actions taken. Providers spoke to their desire to deploy tools electronically and achieve more systematic and traceable documentation systems. This issue of electronic integration represents a major organizational barrier to PROM implementation demonstrated in the literature;[205] addressing this barrier will require changes to existing documentation practices as well as collaboration with software vendors to embed the necessary changes into the EHR. PROM technology systems should be easy for providers to use and should enable quick access to PROM results for use at point-of-care, if needed.[205] In addition to discussing challenges to implementation, providers also offered lessons learned and recommended implementation strategies. For example, they described the importance of identifying AYA champions in each disease group, leveraging existing communication channels, and employing a phased-in approach to implementation. Existing PROM literature suggests the importance of establishing clinic teams to develop tailored implementation strategies that address the unique individual and organizational barriers at a given clinic.[205] Both UCD and implementation science offer theories, frameworks, and process models that can help guide and evaluate these efforts.

6.2 Limitations

Although I tried to engage users from across the country to increase generalizability, much of the tool's development did occur at NCCH, a large academic medical center in a relatively metropolitan area. Many non-NCCH users engaged also worked in comprehensive cancer centers (e.g., 73% of concept mapping participants). Key contacts, with whom semi-structured interviews were conducted, worked primarily in AYA programs; the ability to establish AYA-specific programs reflects the availability of institutional resources which many cancer programs do not have. It is important to note that the majority of AYAs do not receive care in institutions like NCCH but, rather, in smaller community hospitals. As AYA NA-SB undergoes further testing in the future, it will be important to ensure that a range of cancer care settings are engaged, such as small or rural community-based hospitals which may face bigger limitations than NCCH in terms of resources and capacity for implementing an intervention like AYA NA-SB.

For logistical reasons, AYAs ages 15 through 17 were not included in data collection activities for this study. However, I engaged AYAs from both pediatric and adult oncology to capture key differences between these two contexts. Future research will explore the acceptability and appropriateness of the revised PROM to adolescents.

During this study, the design team was unable to finalize certain aspects of AYA NA-SB delivery (e.g., frequency of PROM administration). Future pilot testing will inform the specification of these elements of delivery. Additionally, although the needs assessment itself underwent iterative refinement, the process for delivering AYA NA-SB did not. Although user data informed the design team's specification of AYA NA-SB delivery during the second workshop, future user testing is needed to refine this process and solidify the referral pathways triggered by each needs assessment follow-up domain.

6.3 Future Directions

Future testing of AYA NA-SB will inform its subsequent refinement and scale-up. The first step will be to conduct a small feasibility pilot test of AYA NA-SB, with a primary focus on implementation outcomes. Other objectives of this pilot study include (1) specifying outstanding aspects of AYA NA-SB delivery (e.g., frequency of PROM administration), (2) solidifying the process for following up on PROM-identified needs (e.g., determining the timeframe in which follow-up should occur and the process for ensuring that needs were followed up on), and (3) making other necessary refinements to AYA NA-SB to facilitate its acceptability, feasibility, and appropriateness in practice. Psychometric testing will also be conducted to assess the validity and reliability of the revised PROM. Should AYA NA-SB prove feasible, acceptable, and appropriate to implement, I will conduct broader testing of the intervention across multiple sites, including community-based hospitals.

Just as embroidery requires the alignment of thread, fabric, and needle, EBP implementation and sustainment requires harmonizing EBP, context, and implementation strategies. The importance of each of these has been acknowledged; however, methods for understanding the dynamic interplay among them and optimizing each *with respect* to the other two are lacking. UCD offers methods and approaches for achieving this which warrant consideration by implementation scientists. Future research should explore the utility of collaborating with UCD experts or embedding UCD approaches in implementation research. In particular, I argue that UCD's potential for promoting harmonization among EBP, context, and implementation should be tested empirically. To the extent that UCD helps facilitate this harmonization, it will advance us towards the overarching goal of the field which is to bridge the gap between research and practice.

6.4 Conclusions

Implementing change in dynamic healthcare settings is a complex endeavor; understanding the nuances of implementation undoubtedly requires a multimodal, multidisciplinary purview. To this end, implementation scientists have borrowed knowledge and approaches from systems science, [206,207] organizational studies, [208] cultural adaptation, [209] community-based participatory research, [210] behavioral psychology, [211] and quality improvement, [212] just to name a few. I argue that UCD can join the list of approaches available to implementation scientists. This may first require investigation of where UCD and implementation science converge and diverge. Fortunately, efforts to this effect are currently underway.[213] While points of divergence may represent barriers to integration of the two fields, they may also represent important new insights and approaches for implementation scientists to consider.

I leveraged UCD to develop an AYA needs assessment and care coordination intervention with high usability and usefulness. The result, AYA NA-SB, has the potential to improve care coordination at the individual level by allowing cancer care programs to tailor service delivery and resource provision to the individual needs of AYAs they serve. Additionally, AYA NA-SB addresses a critical measurement gap. In the past decade, AYA-specific programs have emerged at cancer centers across the country to better coordinate cancer care for AYAs,[18] but the impact of these programs has been largely unstudied to date.[24] In large part, the lack of evidence on AYA-specific programs is due to a lack of patient-centered metrics.[25,26] By eliciting patient-reported data on unmet needs at multiple timepoints during AYAs' treatment, AYA NA-SB will generate such patient-centered metrics to assess the effectiveness of AYA-specific programs in addressing AYAs' unmet needs as they emerge. Furthermore, AYA NA-SB will yield critical patient-reported data to inform the structure and functions of AYA-specific cancer programs as they emerge around the country.[20,27] In sum, by harnessing patient-reported data to facilitate the coordination of care for AYAs, AYA NA-SB has the potential to improve processes of care and subsequent outcomes for AYAs, an underserved and understudied population.[28]

APPENDIX A: CNQ-YP (ORIGINAL)

The following questions ask about any needs you may have had **at any time since your cancer diagnosis.**

1. Treatment Environment and Care

I had the following needs…						
BEFORE TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
1	about my diagnosis	○	○	○	○	○
2	what might happen during treatment	○	○	○	○	○
3	whether I had the option to decline treatment	○	○	○	○	○
4	about the short term side-effects of treatment	○	○	○	○	○
5	about the long term side-effects of treatment	○	○	○	○	○
6	my chances of a full recovery	○	○	○	○	○
7	what would happen when treatment finished	○	○	○	○	○
8	whether I would be able to have children	○	○	○	○	○
DURING TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
9	whether my treatment was working	○	○	○	○	○
10	my test results as soon as possible	○	○	○	○	○
11	the way I felt was normal	○	○	○	○	○
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
12	have time to myself	○	○	○	○	○

I had the following needs…						
AFTER TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
13	how to manage my medication	○	○	○	○	○
14	what I could do to stay healthy	○	○	○	○	○
15	what to do if I noticed a particular side-effect	○	○	○	○	○
THROUGHOUT TREATMENT						
	Having cancer treatment staff who:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
16	listened to my concerns	○	○	○	○	○
17	treated me as an individual	○	○	○	○	○
18	were respectful	○	○	○	○	○
19	were approachable	○	○	○	○	○
20	were friendly	○	○	○	○	○
21	could have a laugh with me	○	○	○	○	○
22	explained what they were doing	○	○	○	○	○
23	spoke to me in a way that I could understand	○	○	○	○	○
24	let me talk about my feelings	○	○	○	○	○
25	let me ask questions	○	○	○	○	○
26	let me make decisions about my treatment	○	○	○	○	○
27	talked to me in private, without my family	○	○	○	○	○

2.Education

I had the following needs…						
AT THE CANCER TREATMENT CENTRE						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
28	privacy	○	○	○	○	○
29	pleasant surroundings	○	○	○	○	○
30	good food	○	○	○	○	○
31	a choice of cancer specialists	○	○	○	○	○
32	the same cancer treatment staff throughout treatment	○	○	○	○	○
33	a choice of times for appointments	○	○	○	○	○

Since my cancer diagnosis, I have had problems enrolling at: *(please choose as many as apply)*

S1

- ○ school
- ○ TAFE
- ○ university/college
- ○ other place of study *(please write)*____
- ○ none of the above

Since my cancer diagnosis, I have attended: *(please choose as many as apply)*

S2

- ○ school
- ○ TAFE
- ○ university/college
- ○ other place of study *(please write)*____
- ○ none of the above *(go to Question S3)*

I had the following needs…						
WHEN STUDYING						
	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
34	attend classes	○	○	○	○	○

35	get extensions/special consideration	○	○	○	○	○
36	get guidance about study options or future career paths	○	○	○	○	○

3. Work

<u>Since my cancer diagnosis</u>, I have had problems finding work: *(please choose as many as apply)*

S3

○ full-time

○ part-time/casual

○ unpaid voluntary work

○ other type of work *(please write)*____

○ none of the above

<u>Since my cancer diagnosis</u>, I have been employed: *(please choose as many as apply)*

S4

○ full-time

○ part-time/casual

○ unpaid voluntary work

○ other type of work *(please write)*____

○ none of the above (*go to Question 40)*

I had the following needs…

WHEN EMPLOYED

	Knowing:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
37	how much work I would miss	○	○	○	○	○
38	how to ask managers/co-workers for support	○	○	○	○	○
39	that managers/co-workers had support to help them cope with my situation	○	○	○	○	○

4. Information and Activities

I had the following needs…						
DURING TREATMENT						
	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
40	spend time with people my own age	○	○	○	○	○
41	talk to people my age who had been through a similar experience	○	○	○	○	○
AT THE CANCER TREATMENT CENTRE						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
42	leisure spaces and activities	○	○	○	○	○
SINCE MY CANCER DIAGNOSIS						
	Finding information that:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
43	was specifically designed for me	○	○	○	○	○
44	described relaxation techniques	○	○	○	○	○

The next group of questions ask about any needs you may have had **in the last month.**

We realise that your needs may have changed during different stages of your cancer experience. Please only tell us about needs you have had in the last month. If you have not had any needs in the last month, please select 'No Need'.

5. Feelings and Relationships

I had the following needs…						
IN THE LAST MONTH						
	Feeling:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
45	frustrated	○	○	○	○	○
46	anxious or nervous	○	○	○	○	○
IN THE LAST MONTH						
	Worrying about:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**

47	my cancer spreading	○	○	○	○	○
48	my cancer returning	○	○	○	○	○
49	whether my cancer treatment has worked	○	○	○	○	○
50	having cancer treatment	○	○	○	○	○
51	how my family is coping	○	○	○	○	○
IN THE LAST MONTH						
Finding:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
52	inner strength	○	○	○	○	○
IN THE LAST MONTH						
Being able to:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
53	accept my diagnosis	○	○	○	○	○
54	be independent	○	○	○	○	○

S5 **Do you have:** *(please choose as many as apply)*

○ a spouse/partner or boyfriend/girlfriend *(please answer Question 55)*

○ sibling/s or step-brothers/sisters *(please answer Questions 56-58)*

○ none of the above *(go to Question 59)*

I had the following needs…

IN THE LAST MONTH						
Coping with:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
55	changes in my relationship with my partner	○	○	○	○	○
IN THE LAST MONTH						
Coping with:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
56	changes in my relationships with my sibling/s	○	○	○	○	○
IN THE LAST MONTH						

Knowing how to:		No Need	Low Need	Moderate Need	High Need	Very High Need
57	ask my sibling/s for support	○	○	○	○	○
58	give support to my sibling/s	○	○	○	○	○

6. Daily Life

I had the following needs…						
IN THE LAST MONTH						
Being able to:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
59	make plans or think about the future	○	○	○	○	○
IN THE LAST MONTH						
Coping with:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
60	changes in my physical ability	○	○	○	○	○
61	changes in my appearance	○	○	○	○	○
62	not being able to do the same things as other people my age	○	○	○	○	○
63	my parent/s being overprotective	○	○	○	○	○
IN THE LAST MONTH						
Managing:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
64	pain	○	○	○	○	○
65	medication	○	○	○	○	○
66	physical side effects of treatment	○	○	○	○	○
67	feeling tired	○	○	○	○	○
68	loss of mobility	○	○	○	○	○
69	to take part in social activities	○	○	○	○	○
70	to travel to social events	○	○	○	○	○

YOU HAVE NOW COMPLETED THE SURVEY

THANK YOU FOR YOUR TIME AND HELP

APPENDIX B: AYA SURVEY

Section 1: Demographics

1. How do you describe your sex and gender identity? *(mark all that apply)*
    a) *Female*
    b) *Male*
    c) *Cisgender*
    d) *Genderqueer*
    e) Intersex
    f) Transgender
    g) A gender not listed ___________
2. How old are you?
    a) Scroll bar 18-30
3. How long has it been since you were diagnosed with cancer?
    a) Less than 3 months
    b) Between 3 and 6 months
    c) Between 7 and 12 months
    d) Greater than 12 months
4. Are you currently in active treatment?
    a) Yes
    b) No
5. Please select the type of cancer you were diagnosed with from the list below.
    a) Non-Hodgkin Lymphoma
    b) Hodgkin Lymphoma
    c) Leukemia
    d) Sarcoma
    e) Cervical
    f) Other female reproductive
    g) Male reproductive
    h) Thyroid
    i) Brain
    j) Melanoma
    k) Colorectal
    l) Breast
    m) Other (please indicate): ________
6. Select the stage of your cancer at diagnosis.
    a) 0
    b) I/II
    c) III/IV
    d) Unknown/unstaged
7. With which racial/ethnic group do you most identify?
    a) Hispanic (all races)
    b) Non-Hispanic American Indian/ Alaska Native
    c) Non-Hispanic Asian or Pacific Islander
    d) Non-Hispanic Black
    e) Non-Hispanic White
    f) Other/unknown
8. Who do you live with? *Check all that apply.*
    a) Parent(s)
    b) Spouse
    c) Non-spouse partner

   - d) *Child/children*
   - e) *Roommate(s) (not parent, spouse, or child)*
   - f) *I live alone*
   - g) *Other*

9. What is your education level?
   - a) *Less than high school diploma*
   - b) *Completed high school*
   - c) *Some college/vocational training*
   - d) *Associate degree*
   - e) *College graduate*
   - f) *Graduate degree or some post-graduate education*

10. What is your insurance source?
   - a) *Self-pay*
   - b) *No insurance*
   - c) *Employer/school*
   - d) *Spouse's employer/school*
   - e) *Parent*
   - f) *Medicare*
   - g) *Medicaid*
   - h) *Military/TRICARE*
   - i) *Other*

Section 2 : CNQ-YP

We are now going to ask you to complete a survey tool that was developed in Australia to assess the needs of young adults with cancer, called the **Cancer Needs Questionnaire- Young People (CNQ-YP).**

As you complete the CNQ-YP, imagine that your doctor has asked you to complete this survey either during or before an appointment with them, as part of your clinical care. After you have completed the CNQ-YP, we will ask you just a few more questions about what you thought about it.

No Need	All my needs were met for this issue or this was not a problem for me.
Low Need	I needed a low amount of help with this problem but was not able to get it.
Moderate Need	I needed a moderate amount of help with this problem but was not able to get it.
High Need	I needed a high amount of help with this problem but was not able to get it.
Very High Need	I needed a very high amount of help with this problem but was not able to get it.

The following questions ask about any needs you may have had **at any time since your cancer diagnosis.**

1. Treatment Environment and Care

I had the following needs…						
BEFORE TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
1	about my diagnosis	○	○	○	○	○
2	what might happen during treatment	○	○	○	○	○
3	whether I had the option to decline treatment	○	○	○	○	○
4	about the short term side-effects of treatment	○	○	○	○	○
5	about the long term side-effects of treatment	○	○	○	○	○
6	my chances of a full recovery	○	○	○	○	○
7	what would happen when treatment finished	○	○	○	○	○
8	whether I would be able to have children	○	○	○	○	○
DURING TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
9	whether my treatment was working	○	○	○	○	○
10	my test results as soon as possible	○	○	○	○	○
11	the way I felt was normal	○	○	○	○	○
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
12	have time to myself	○	○	○	○	○

I had the following needs…						
AFTER TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
13	how to manage my medication	○	○	○	○	○
14	what I could do to stay healthy	○	○	○	○	○
15	what to do if I noticed a particular side-effect	○	○	○	○	○
THROUGHOUT TREATMENT						
	Having cancer treatment staff who:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
16	listened to my concerns	○	○	○	○	○
17	treated me as an individual	○	○	○	○	○
18	were respectful	○	○	○	○	○
19	were approachable	○	○	○	○	○
20	were friendly	○	○	○	○	○
21	could have a laugh with me	○	○	○	○	○
22	explained what they were doing	○	○	○	○	○
23	spoke to me in a way that I could understand	○	○	○	○	○
24	let me talk about my feelings	○	○	○	○	○
25	let me ask questions	○	○	○	○	○
26	let me make decisions about my treatment	○	○	○	○	○
27	talked to me in private, without my family	○	○	○	○	○

I had the following needs…						
AT THE CANCER TREATMENT CENTRE						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
28	privacy	○	○	○	○	○
29	pleasant surroundings	○	○	○	○	○
30	good food	○	○	○	○	○
31	a choice of cancer specialists	○	○	○	○	○
32	the same cancer treatment staff throughout treatment	○	○	○	○	○
33	a choice of times for appointments	○	○	○	○	○

2. Education

<u>Since my cancer diagnosis</u>, I have had problems enrolling at: *(please choose as many as apply)*

S1

○ school
○ TAFE
○ university/college
○ other place of study *(please write)*____
○ none of the above

<u>Since my cancer diagnosis</u>, I have attended: *(please choose as many as apply)*

S2

○ school
○ TAFE
○ university/college
○ other place of study *(please write)*____
○ none of the above *(go to Question S3)*

I had the following needs…					
WHEN STUDYING					
Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**

34	attend classes	○	○	○	○	○
35	get extensions/special consideration	○	○	○	○	○
36	get guidance about study options or future career paths	○	○	○	○	○

3. Work

Since my cancer diagnosis, I have had problems finding work: *(please choose as many as apply)*

S3

○ full-time

○ part-time/casual

○ unpaid voluntary work

○ other type of work *(please write)*____

○ none of the above

Since my cancer diagnosis, I have been employed: *(please choose as many as apply)*

S4

○ full-time

○ part-time/casual

○ unpaid voluntary work

○ other type of work *(please write)*____

○ none of the above (*go to Question 40)*

I had the following needs…

WHEN EMPLOYED

	Knowing:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
37	how much work I would miss	○	○	○	○	○
38	how to ask managers/co-workers for support	○	○	○	○	○
39	that managers/co-workers had support to help them cope with my situation	○	○	○	○	○

4. Information and Activities

I had the following needs…						
DURING TREATMENT						
	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
40	spend time with people my own age	○	○	○	○	○
41	talk to people my age who had been through a similar experience	○	○	○	○	○
AT THE CANCER TREATMENT CENTRE						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
42	leisure spaces and activities	○	○	○	○	○
SINCE MY CANCER DIAGNOSIS						
	Finding information that:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
43	was specifically designed for me	○	○	○	○	○
44	described relaxation techniques	○	○	○	○	○

The next group of questions ask about any needs you may have had **in the last month.**

We realise that your needs may have changed during different stages of your cancer experience. Please only tell us about needs you have had in the last month. If you have not had any needs in the last month, please select 'No Need'.

5. Feelings and Relationships

I had the following needs…						
IN THE LAST MONTH						
	Feeling:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
45	frustrated	○	○	○	○	○
46	anxious or nervous	○	○	○	○	○
IN THE LAST MONTH						

	Worrying about:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
47	my cancer spreading	○	○	○	○	○
48	my cancer returning	○	○	○	○	○
49	whether my cancer treatment has worked	○	○	○	○	○
50	having cancer treatment	○	○	○	○	○
51	how my family is coping	○	○	○	○	○
IN THE LAST MONTH						
	Finding:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
52	inner strength	○	○	○	○	○
IN THE LAST MONTH						
	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
53	accept my diagnosis	○	○	○	○	○
54	be independent	○	○	○	○	○

S5 **Do you have:** *(please choose as many as apply)*

○ a spouse/partner or boyfriend/girlfriend *(please answer Question 55)*

○ sibling/s or step-brothers/sisters *(please answer Questions 56-58)*

○ none of the above *(go to Question 59)*

I had the following needs…

IN THE LAST MONTH

	Coping with:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
55	changes in my relationship with my partner	○	○	○	○	○
IN THE LAST MONTH						

Coping with:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
56	changes in my relationships with my sibling/s	○	○	○	○	○

IN THE LAST MONTH

Knowing how to:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
57	ask my sibling/s for support	○	○	○	○	○
58	give support to my sibling/s	○	○	○	○	○

6. Daily Life

I had the following needs…

IN THE LAST MONTH

Being able to:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
59	make plans or think about the future	○	○	○	○	○

IN THE LAST MONTH

Coping with:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
60	changes in my physical ability	○	○	○	○	○
61	changes in my appearance	○	○	○	○	○
62	not being able to do the same things as other people my age	○	○	○	○	○
63	my parent/s being overprotective	○	○	○	○	○

IN THE LAST MONTH

Managing:		**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
64	pain	○	○	○	○	○
65	medication	○	○	○	○	○
66	physical side effects of treatment	○	○	○	○	○

67	feeling tired	○	○	○	○	○
68	loss of mobility	○	○	○	○	○
69	to take part in social activities	○	○	○	○	○
70	to travel to social events	○	○	○	○	○

Section 3: Usability Testing

You have completed the CNQ-YP. Now, we will ask you some questions about your experience filling out the CNQ-YP. As you are answering these questions, imagine that your doctor has asked you to complete the CNQ-YP either during or before an appointment with them, as part of your clinical care.

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
The CNQ-YP meets my approval.	○	○	○	○	○
The CNQ-YP is appealing to me.	○	○	○	○	○
I like the CNQ-YP.	○	○	○	○	○
I welcome the CNQ-YP.	○	○	○	○	○

Display This Question:

If Acceptability = The CNQ-YP meets my approval. [Completely disagree]

And Acceptability = The CNQ-YP meets my approval. [Disagree]

And Acceptability = The CNQ-YP is appealing to me. [Completely disagree]

And Acceptability = The CNQ-YP is appealing to me. [Disagree]

And Acceptability = I like the CNQ-YP. [Completely disagree]

And Acceptability = I like the CNQ-YP. [Disagree]

And Acceptability = I welcome the CNQ-YP. [Completely disagree]

And Acceptability = I welcome the CNQ-YP. [Disagree]

Please explain what you dislike about the CNQ-YP:

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
The CNQ-YP seems fitting as a needs assessment tool for adolescents and young adults with cancer.	○	○	○	○	○
The CNQ-YP seems like a suitable tool for my doctor to administer to me as part of my cancer care.	○	○	○	○	○
The CNQ-YP seems applicable to adolescent and young adult cancer care.	○	○	○	○	○
The CNQ-YP seems like a good match for adolescents and young adults.	○	○	○	○	○

Display This Question:

If Appropriateness = The CNQ-YP seems fitting as a needs assessment tool for adolescents and young adults with cancer. [Completely disagree]

And Appropriateness = The CNQ-YP seems fitting as a needs assessment tool for adolescents and young adults with cancer. [Disagree]

And Appropriateness = The CNQ-YP seems like a suitable tool for my doctor to administer to me as part of my cancer care. [Completely disagree]

And Appropriateness = The CNQ-YP seems like a suitable tool for my doctor to administer to me as part of my cancer care. [Disagree]

And Appropriateness = The CNQ-YP seems applicable to adolescent and young adult cancer care. [Completely disagree]

And Appropriateness = The CNQ-YP seems applicable to adolescent and young adult cancer care. [Disagree]

And Appropriateness = The CNQ-YP seems like a good match for adolescents and young adults. [Completely disagree]

And Appropriateness = The CNQ-YP seems like a good match for adolescents and young adults. [Disagree]

Please describe your concerns about the appropriateness of the CNQ-YP for adolescent and young adult cancer care.

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
The CNQ-YP seems like something my doctor could administer to all of their patients	○	○	○	○	○
The CNQ-YP seems possible for me to complete as part of my care	○	○	○	○	○
The CNQ-YP seems doable.	○	○	○	○	○
The CNQ-YP seems easy to use.	○	○	○	○	○

Display This Question:

If Feasibility = The CNQ-YP seems like something my doctor could administer to all of their patients [Completely disagree]

And Feasibility = The CNQ-YP seems like something my doctor could administer to all of their patients [Disagree]

And Feasibility = The CNQ-YP seems possible for me to complete as part of my care [Completely disagree]

And Feasibility = The CNQ-YP seems possible for me to complete as part of my care [Disagree]

And Feasibility = The CNQ-YP seems doable. [Completely disagree]

And Feasibility = The CNQ-YP seems doable. [Disagree]

And Feasibility = The CNQ-YP seems easy to use. [Completely disagree]

And Feasibility = The CNQ-YP seems easy to use. [Disagree]

Please explain your concerns about the feasibility of implementing the CNQ-YP in your cancer treatment center:

	Completely disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Completely agree (5)
My doctors would gain a good understanding of my needs from reviewing my answers to this survey.	○	○	○	○	○
I would consider using services/resources offered by my doctor if they matched them to the needs I identified in this survey.	○	○	○	○	○

Display This Question:

If Actionability = My doctors would gain a good understanding of my needs from reviewing my answers to this survey. [Completely diagree]

And Actionability = My doctors would gain a good understanding of my needs from reviewing my answers to this survey. [Disagree]

Please explain why your concerns about the CNQ-YP as a picture of your needs at any given time

Display This Question:

If Actionability = I would consider using services/resources offered by my doctor if they matched them to the needs I identified in this survey. [Completely diagree]

And Actionability = I would consider using services/resources offered by my doctor if they matched them to the needs I identified in this survey. [Disagree]

Please explain why you may not consider using services/resources offered to you by your doctor based on needs identified in the CNQ-YP

Are there any important needs which aren't captured in the CNQ-YP?

○ yes *(please list them here)* ____

○ No

Is there anything in the CNQ-YP that shouldn't be?

○ yes *(please indicate here):* ____

○ no

If you have any other thoughts about the CNQ-YP, please indicate them below:

APPENDIX C: COGNITIVE INTERVIEW GUIDE

INTRODUCTION

Thanks for agreeing to speak with me. We are developing a user-friendly tool to assess the needs of adolescents and young adults with cancer. This tool would be used by your cancer care providers to figure out what services and resources they should direct you to.

As a starting point for developing this tool, we are using the Cancer Needs Questionnaire-Young People (or CNQ-YP), which you may remember from the online survey you completed a few weeks ago. The purpose of today is to have you provide input on the CNQ-YP, and identify areas where it may need improvement. We are also interested in getting your thoughts about how this tool might be delivered in practice.

This interview might be a little different from others you've done. We are less interested in your answers to CNQ-YP questions and more interested in learning how usable the CNQ-YP is. We would like to know how you arrive at your answers and find out if any questions or response options are confusing or weird to you. There are no right or wrong answers to any of these questions.

For each question, what I would like you to do is read it aloud and then, please tell me what the question means in your own words. Then, please "think aloud" as you formulate your response. By "think aloud" I mean verbalize your thought process as you interpret each question, recall the information you need to respond, look through the response options, and decide your response.

When you are done "thinking aloud" I will ask you a series of questions about the CNQ-YP. Your participation is completely voluntary and you may skip any question. Please feel free to criticize this tool openly- I will not be offended. Your thoughts and comments about the tool are very important. This interview will last approximately 60 minutes. Do you have any questions for me before we begin?

During the interview, I will be taking notes. Since it is difficult to write as fast as people talk, I would like to audio record this discussion, as well. If at any time you would like me to stop audio recording, just tell me, and I will do so. The tapes will only be heard by the study team working on this project. Once we have used the tapes to make sure that my notes are accurate, the tapes will be destroyed.

Can we begin?

Before I ask you to look at the tool, I would like to ask you a "warm up" question to introduce you to the think-aloud process. I would like for you to visualize the windows in the place you live. As you count up how many windows you have, tell me what you are seeing and thinking about.

Example questions

1. Please tell me in your own words what this question means. Then proceed to "think aloud" as you formulate your response.
2. Are there any words here that seem ambiguous, or confusing?
    a. Which ones?
    b. How is the word ambiguous or confusing?

    c. What did you think the word meant?
3. Do you have the information in your memory to respond to this question?
    a. If yes, “think aloud” as you access this information in your memory?
    b. If no, who would have this information? How easy or difficult would it be to gather it?
4. Does this seem to you like an important question?
    a. How important would it be to get accurate information for this question?
5. How did you arrive at your answers?
    a. How easy or difficult is it to identify your most accurate response?
    b. Can you suggest any changes that would make it easier to identify your most accurate response?
6. Is there anything else about this question that you want to mention?
7. Are the choices of response adequate to capture your lived experience?
    a. If not, what choices would you like to see included?
8. Is the organization of the questions easy to follow?
    a. If not, how can the questions be best grouped together?
9. Are there additional questions you might add to this questionnaire to address needs that are not captured by the survey in its current form?

APPENDIX D: CONCEPT MAPPING ITEM LIST

1. Cancer treatment staff telling me about my diagnosis
2. Cancer treatment staff telling me about the short-term side effects of treatment
3. Cancer treatment staff telling me about the long-term side effects of treatment
4. Cancer treatment staff telling me what will happen when treatment finishes
5. Cancer treatment staff telling me whether I will be able to have children
6. Cancer treatment staff telling me about how my treatment is working
7. Cancer treatment staff telling me my test results as soon as possible
8. Cancer treatment staff telling me the way I feel is normal
9. Cancer treatment staff giving me information about sexual health
10. Cancer treatment staff giving me information about nutrition and exercise.
11. Cancer treatment staff telling me what to do if I noticed a particular side effect
12. Having cancer treatment staff who listened to my concerns and let me talk about my feelings
13. Having cancer treatment staff who treated me as an individual
14. Having cancer treatment staff who were respectable
15. Having cancer treatment staff who were approachable and friendly
16. Having cancer treatment staff who could have a laugh with me
17. Having cancer treatment staff who explained what they are doing in a way I could understand
18. Having cancer treatment staff who let me ask questions
19. Having cancer treatment staff who let me make decisions about my treatment
20. Having cancer treatment staff who talked to me in private, without my family
21. Being able to have privacy
22. Being able to have pleasant surroundings
23. Being able to have good food
24. Being able to have a choice of cancer care specialists
25. Being able to have the same cancer treatment staff throughout treatment
26. Being able to have a choice of times for appointments
27. Being able to attend classes
28. Being able to get extensions/special consideration
29. Being able to get guidance about study options or future career paths
30. Being able to get guidance about financial aid or loan repayment options
31. Knowing how much work I would miss
32. Knowing how to ask managers/coworkers for support
33. Worrying about my health insurance coverage
34. Being able to spend time with people my own age
35. Being able to talk to people my own age who had been through a similar experience
36. Being able to have leisure spaces and activities
37. Finding information that described relaxation techniques (e.g., yoga, meditation)
38. Feeling anxious or scared
39. Feeling depressed
40. Worrying about my cancer spreading
41. Worrying about my cancer returning or secondary cancers
42. Worrying about whether my cancer treatment has worked
43. Worrying about how my family is coping
44. Finding inner strength
45. Being able to accept my diagnosis

46. Being able to be independent
47. Coping with changes in my relationship to my partner
48. Coping with changes in my relationship to my sibling/s
49. Coping with changes in my relationship to my parent/s
50. Coping with changes in my relationship to my friend/s
51. Being able to make plans or think about the future
52. Coping with changes in my physical ability
53. Coping with changes in my appearance
54. Coping with not being able to do the same things as other people my age
55. Coping with my parent/s and/or partner being overprotective
56. Managing pain
57. Managing my medications
58. Managing physical side effects of treatment
59. Managing emotional side effects of treatment
60. Managing feeling tired/fatigued
61. Managing loss of mobility
62. Managing to take part in social activities

APPENDIX E: GUIDED TOURS QUESTION REPOSITORY & CODEBOOK

Appendix E1. Framework of user and contextual factors in UCD; guided tour question repository

User group characteristics	
Factors	**Example questions**
• User type • User role • Goals for intervention • Perceived benefits of intervention • Perceived costs of intervention • Experience with intervention • Related experience • Task knowledge • Organizational knowledge • Training • Input device skills • Qualifications	**Providers/Staff** • What is your role in caring for AYAs with cancer? • What experience do you have with cancer needs assessment tools or asking AYAs about their needs? • Are you familiar with the services and resources available at your institution for AYAs? **AYAs** • Have you ever been asked to complete survey that asks you about your needs? • What do you think the benefits of this intervention would be? • What do you think the costs of this intervention would be?
User tasks	
Factors	**Example questions**
• Task list o Task 1 o Task 2 o Etc. • For each task: o Task characteristics o Task goal/output o Task steps o Task frequency o Task duration o Task flexibility o Task dependencies o Task output o Risks resulting from error o Critical demands	**Providers/Staff** • Walk me through your daily patient care/ administrative tasks. o What are the goals of each task? o How long does each take? o How often is each performed? • Given your current task load, would you be able to administer a needs assessment to all AYAs? o When? As part of which task? **AYAs** • Walk me what a typical appointment looks like. • Would completing a survey be possible during any of these tasks?
Technical and physical environment	
Factors	**Example questions**
• Hardware • Software • Network • Reference materials • Other equipment • Physical environment • Space • Location	**Providers/Staff** • Where do you currently record information about needs expressed by AYAs? o In the electronic health record? o Is this information easy to find? • What kind of reference materials do you give to patients? • What kind of referral network does your institution have for AYAs? **AYAs** • Where do you currently seek information about resources and services available for AYAs?

	• Where do you wait before your appointments? • Do you typically open appointment reminders sent by email? • What kind of resources have you been given during appointments?
Organizational environment	
Factors	**Example questions**
• Structure • Group working • Work practices • Assistance • Interruptions • Management structure • Communications structure • Attitudes and culture • Computer use policies • Organization aims • Industrial relations • Job design • Job functions • Hours of work • Job flexibility • Performance monitoring and feedback	**<u>Providers/Staff</u>** • Does your institution support the establishment of systems or processes specifically for AYAs? • Who is in charge of AYA cancer care? • How do you communicate with other providers in your institution? • What information are you required to enter in patients' chart? • Has your institution implemented needs assessments for other patient groups? ○ If yes, how has that gone? • What barriers do you anticipate to implementing AYA NA-SB in your organization? ○ Staffing? Whose job is it to coordinate care for AYAs?

Appendix E2. Ethnography codebook

Code	Definition	Example
USER GROUP CHARACTERISTICS		
User type	Provider; AYA	
User role	For providers: primary job title; role in caring for AYAs For AYAs: role as patient in managing cancer. Any clinical or personal characteristics. Family members' roles in patient's management of treatment.	e.g., medical oncologist; primary role is dealing with medical concerns of patients, but also broaches psychosocial topics sometimes
Goals for intervention	What does user want a needs assessment & care coordination intervention to accomplish?	e.g., "I want a system in place that gets all providers on the same page as far as an AYA's needs"
Perceived benefits of intervention	What does user see as the main benefits of a needs assessment and care coordination intervention?	e.g., communication among multidisciplinary providers
Perceived costs of intervention	What does user see as the costs of a needs assessment and care coordination intervention? (includes financial and non-financial burden)	e.g., increased staffing hours will be needed
Experience with intervention	For providers: What is user currently doing/ what have they done in past in terms of assessing AYA needs? For AYAs: What experience does user have completing questionnaires about their cancer needs?	e.g., "I ask AYAs about their needs but not in a formal or standardized way" e.g., "I've never been asked to fill out a survey about my needs"
Related experience	For providers: Other experiences with patient reported outcome measures; or with assessing needs for other patient populations For AYAs: Other experiences completing surveys/standardized questionnaires given to them by their medical provider. Experience seeking and receiving services.	e.g., "I have experience using the Cancer Distress Screening tool" e.g., "I had to fill out a questionnaire about my medical information during my first appointment but that's all"/ "I have met with the child life specialist"
Task knowledge	For providers: Knowledge and skills related to engaging with patients about their medical, psychosocial, and practical needs; knowledge about resources and services available to meet those needs	e.g., "Because I've been here for so long, I'm really comfortable talking to AYAs about their needs, and I usually

	For AYAs: knowledge and skills related to communicating their needs to providers; knowledge about resources and services available to them	know where to point them to when they need something” e.g., “I’ve been depressed before but didn’t know where to find help”
Organizational knowledge	For providers: knowledge regarding organizational structure, aims, culture, or other facets of their organization For AYAs: knowledge about hospital	e.g., ability to easily cite information about patient flow, provider workflow, organizational efforts
Training/ qualifications	For providers: educational training or certifications related to PROMs, AYAs, or implementation For AYAs: educational training related to managing cancer diagnosis	e.g., “I took a CEE course on implementing evidence-based practices E.g., “I joined a peer support group focused on sharing lessons learned about managing cancer”
Input device skills	For providers: proficiency in any tool currently used or that could be used to document or transfer information related to AYA needs For AYAs: proficiency in any tool currently used or that could be used to document or transfer information related to AYA needs	e.g., proficiency in EPIC e.g., familiarity with navigating MyChart
USER TASKS		
Task:	Piece of work that the user carries out by interacting with the system	e.g., “I keep track of all my appointment times and drive myself to appointment”
Task characteristics	Any characteristics of a task which don’t fall under other codes in “user task” domain	e.g., “it is mentall exhausting for me to keep up with all of my appointment times”
Task goal/ output	Deliverable(s) associated with a given task	e.g., Effective management of appointments
Task steps	Steps required to complete a task	e.g., “to remember my appointment times, I first record them in my paper calendar and then set a reminder in my phone calendar”

Task frequency	How often a task is performed	e.g., “I have appointments 3 times per week”
Task duration	Length of time a given task requires to complete	e.g., “It takes me 20 minutes to drive to my appointments”
Task flexibility	extent that the task can be controlled by the user during implementation. Within this attribute a distinction is drawn between: • Performance freedom refers to the extent to which there are alternative ways to complete the task. • Reversibility refers to the possibility for undoing actions and returning to a previous state.	e.g., “I don’t have much of a say in when my appointment times will be”
Task dependencies	Other tasks that must be performed, or milestones that must be reached in order for a given task to be completed	e.g., “I have to let my boss know when I’ll be leaving for appointments.”
Risks resulting from error	The severity of consequences should a task not be performed, or be performed incorrectly	e.g., “If I miss an appointment, then my treatment regimen won’t be as effective”
	TECHNICAL & PHYSICAL ENVIRONMENT	
Hardware/ Software	Access to and use of computers, laptops, mobile devices, iPads, other technologies	e.g., “I have the MyChart app on my cellphone which I use to review my medical information”
Network	Any networks through which information is shared by AYAs or providers	e.g., “we have email threads in which all of a patient’s providers can share information and weigh in on a patient’s case” e.g., “I am a member of a Facebook group where AYAs with cancer share information about treatments and side effects they have experienced”
Reference materials	Where user seeks or acquires information related to cancer care; descriptions of the information they seek or use	e.g., internet, brochures, printed materials
Other equipment	Any other equipment used by users to perform their tasks	e.g., “I have a notebook where I record any questions about my treatment that come up; I take this

		notebook to all my clinical appointments so don't forget to ask my doctor these questions"
Physical environment/ Space	Any descriptions of the physical space	e.g., the waiting room for radiation is small and dimly-lit with 8 chairs, a TV, and some informational brochures hanging on the wall
Location	Any descriptions of where two places are in relationship to each other	e.g., labwork is done in the basement and then you have to take the elevator up to the 2nd floor for clinical appointments
ORGANIZATIONAL ENVIRONMENT (only pertinent for providers)		
Group working	extent to which the user interacts with other persons while working	e.g., social worker and psychiatrist sharing patient load
Work practices	Strategies user deploys to complete their work	e.g., "before a patient's visit, I skim through the notes in their medical chart to jog my memory on recent concerns they have had"
Assistance	the extent to which the user can count on help from other persons in the organization	e.g., "we just hired a second social worker to help me with my patient case load"
Interruptions	the degree to which the work of a user is interrupted by other persons in the organization	e.g., "sometimes when I am with a patient, I will get a page to attend to an urgent situation"
Management structure	Where user is positioned in the leadership hierarchy	e.g., "my supervisor is X; their supervisor is Y"
Communications structure	Avenues through which work-related communications occur	e.g., how one provider communicates with another provider about a patient's needs
Attitudes and culture	underlying beliefs, assumptions, values and ways of interacting that contribute to the unique social and psychological environment of an organization	e.g., "there is a general culture of innovation at NCCH"
Computer use policies	Organizational policies surrounding use of computers and other technologies	e.g., "I cannot access my phone during patient visits because of hospital policy"

		e.g., “all patient data must be entered in EPIC”
Organization aims	the intentions of the organization (NCCH) in regard to AYAs, patient-reported outcome measures or patient data in general	e.g., “the hospital has prioritized using patient-generated data to drive quality improvement projects”
Industrial relations	Interactions and relationships with external organizations	e.g., interactions with EPIC software vendor
Job design and functions	Functions assigned to user’s position	e.g., “as a social worker, my job is to help coordinate across all the other specialists to ensure that an AYA gets what they need”
Hours of work	User’s work schedule	e.g., “I work from 8-5 on Monday-Friday”
Job flexibility	the freedom granted to the user in terms of how to implement tasks	e.g., “as long as I complete the tasks assigned to me, my supervisor doesn’t mind how I go about completing them”
Performance monitoring and feedback	• Monitoring refers to supervision of the user's work by the organization • Feedback refers to information provided to the user in relation to their work	e.g., “at the end of each month, I receive a report that tells me XYZ information about my job performance for that month”

APPENDIX F: SEMI-STRUCTURED INTERVIEW GUIDE

At UNC, we are developing a care coordination intervention for AYAs with cancer. This includes a needs assessment which asks about physical, psychosocial and practical needs PLUS a set of explicit processes for connecting AYAs to services and resources based on the needs they report. I emailed you the most recent iteration of the needs assessment, which may still be tweaked a bit. It includes 56 items across 9 domains. Now that we are close to finalizing the tool itself, we have turned our attention towards how it may actually be rolled out in practice. As we iron out how this tool will be administered and used to drive service provision, and how the intervention will be implemented, we want to make sure we are not developing an intervention that is only applicable to UNC. Today, I want to talk to you about AYA care at your institution. Your input will help us to create an intervention that can be used across health care systems.

Before we begin, we would like to ask your permission to audio record our discussion for the purposes of future analysis. Would it be OK with you if I record this interview? The interview will be transcribed; however, your name or any personal identifiers will not be associated with any of the notes. The audio recordings will be deleted once the project is complete.

Do you have any questions before we begin?

First, I'd like to ask you some questions about AYA care at your institution.

Contextual feature	UNC	Your institution
AYA program structure	Under the umbrella of NCCH's Comprehensive Cancer Support Program which is directed by the Vice-Chair of General Hospital Psychiatry. There is not currently a designated space for AYA care. However, an AYA infusion space is in development.	
AYA program staffing	Medical director; program director/social worker; social worker	
AYA program functions	Coordinating across disease groups and across pediatric and adult oncology to provide age appropriate services and resources to AYAs	
AYA program funding	Primarily BeLoud Sophie Foundation	
How are new AYA patients identified?	AYA social workers rely on referrals from disease group providers.	
Who is involved in assessing AYAs' needs and coordinating their care?	patients rely on social workers for non-medical needs, saying that their oncology providers rarely ask them about non-medical concerns.	

When and where do these interactions take place?	Although sometimes AYA social workers schedule appointments with AYAs, they often just "pop in" while AYAs are in the hospital for appointments	
Are any standardized tools or questionnaires used to assess needs?	AYA needs are assessed informally/conversationally by the AYA social workers	
What does this look like for pediatric versus adult oncology?	i. AYA-specific social workers care for AYAs in both adult and pediatric oncology ii. In pediatric oncology, staffing is more robust and care provision is more centralized, facilitating communication among providers. In adult oncology, services and resources are more disparately located; there are fewer providers per patient. Thus, care coordination in adult oncology can be more challenging	
How do providers document AYAs' needs?	Information about patient needs is stored as notes in the EHR; each provider records their own separate note for each interaction with a patient. Providers would prefer that a needs assessment interface with the EHR so that it remains a one-stop shop for patient information	
How do providers communicate about AYAs' needs?	Providers communicate about AYAs' needs via phone, text, email, EHR messaging, and in-person.	

Now, I'd like to talk to you about how this needs assessment might be administered. I'm going to run through a few things I've heard from patients and providers at UNC and ask you the extent to which they match up with your experience at your institution.

Stakeholder preferences for needs assessment administration	**Your thoughts**
Important time points for administering the needs assessment include right after diagnosis, at the end of treatment, and somewhere in between.	
AYAs want to complete a survey during times when they are already waiting. These time points include: • After nurse takes them to exam room and assesses vitals; before oncology provider comes in	

• Infusion • Inpatient- anytime	
If given the option, many AYAs would prefer to complete a survey through technology (e.g., mobile phone, iPad) but are not averse to paper. AYAs are active users of MyChart (mobile-enabled patient information app), relying on it to track appointments, view test results, communicate with providers, and request prescription refills.	
Since social workers are already doing the work of needs assessment, although informally, it makes sense for social workers to be involved in needs assessment administration	

Now I’d like to ask you your thoughts on implementing this kind of needs assessment and care coordination intervention in your health care system.

How do you see this as an opportunity?	
What are the challenges in your health system that might influence the implementation of this intervention?	
Any thoughts about the needs assessment I sent to you	

APPENDIX G: DESIGN TEAM WORKSHOP #1 MATERIALS

Appendix G1. Design Team Workshop #1 Packet

AYA NA-SB

AYA NEEDS ASSESSMENT &
SERVICE BRIDGE

DESIGN TEAM WORKSHOP #1

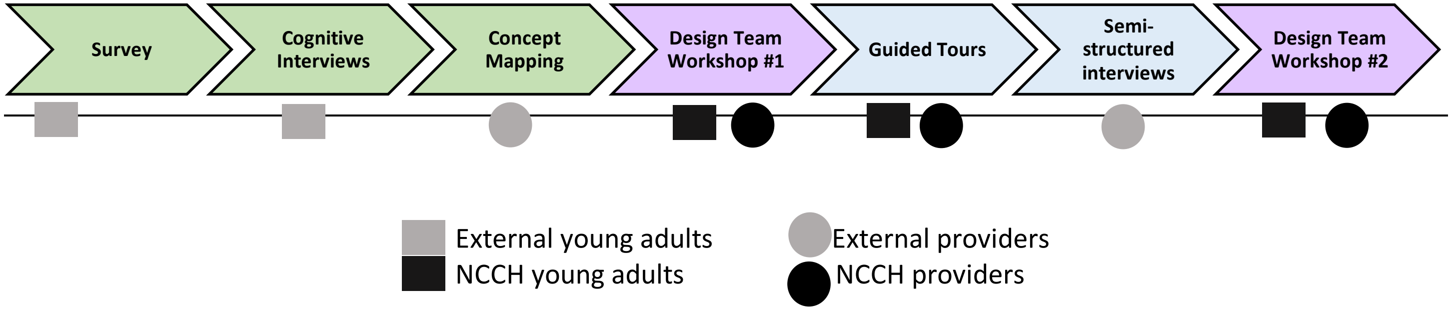
January 29, 2019
12:00-4:00pm EST
Michael Hooker Research Center 3005

Agenda

12:00-12:15	Welcome and introductions
12:15-12:45	Lunch (Panera) Project overview & objectives Summary of usability testing results
12:45-2:00	Needs list refinement
2:00-2:15	Break
2:15-3:00	Selection of concept mapping cluster solution Labeling of follow-up domains
3:00-3:30	Response options, format, sequencing
3:30-4:00	Discussion of Workshop #2 plan and attendees

Project Overview

UCD Aim	Method	Deliverable
Review and refine prototype	<u>Usability Testing</u> • AYA Survey • Cognitive interviews with AYAs • Concept mapping with providers/staff	Evidence of the usability and usefulness of the CNQ-YP
Identify user and contextual requirements	<u>Ethnography</u> • Guided tours with AYAs and providers/staff from NCCH • Semi-structured interviews with providers/staff from outside of NCCH	User and contextual requirements for AYA NA-SB's design and implementation
Design prototypes based on user and contextual requirements	<u>Design Team Workshops</u> • Workshop #1 • Workshop #2	AYA NA-SB prototypes and anticipated implementation strategies needed
RESULT		A usable and useful PROM linked to available services and resources + implementation guidance



CNQ-YP

For each question, please choose the answer that **best describes** your level of need. There are five choices:

No Need/ Need Met	All my needs were met for this issue or this was not a problem for me.
Low Need	I needed a low amount of help with this problem but was not able to get it.
Moderate Need	I needed a moderate amount of help with this problem but was not able to get it.
High Need	I needed a high amount of help with this problem but was not able to get it.
Very High Need	I needed a very high amount of help with this problem but was not able to get it.

The following questions ask about any needs you may have had **at any time since your cancer diagnosis.**

1. Treatment Environment and Care

I had the following needs…						
BEFORE TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
1	about my diagnosis	○	○	○	○	○
2	~~what might happen during treatment~~	○	○	○	○	○
3	~~whether I had the option to decline treatment~~	○	○	○	○	○
4	about the short-term side-effects of treatment	○	○	○	○	○
5	about the long-term side-effects of treatment	○	○	○	○	○
6	~~my chances of a full recovery~~	○	○	○	○	○
7	what will happen when treatment finishes	○	○	○	○	○

8	whether I would be able to have children	○	○	○	○	○
	About sexual health					
DURING TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
9	~~whether~~ how my treatment was working	○	○	○	○	○
10	my test results as soon as possible	○	○	○	○	○
11	the way I felt was normal	○	○	○	○	○
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
12	~~have time to myself~~	○	○	○	○	○
I had the following needs…						
AFTER TREATMENT						
	Cancer treatment staff telling me:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
13	~~how to manage my medication~~	○	○	○	○	○
14	~~what I could do to stay healthy~~ about nutrition and physical activity	○	○	○	○	○
15	what to do if I noticed a particular side-effect	○	○	○	○	○
THROUGHOUT TREATMENT						
	Having cancer treatment staff who:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
16	listened to my concerns and let me talk about my feelings	○	○	○	○	○
17	treated me as an individual	○	○	○	○	○
18	were respectful	○	○	○	○	○
19	were approachable and friendly	○	○	○	○	○
20	~~were friendly~~	○	○	○	○	○
21	could have a laugh with me	○	○	○	○	○

22	explained what they were doing before they did it in a way I could understand	○	○	○	○	○
23	~~spoke to me in a way that I could understand~~	○	○	○	○	○
24	~~let me talk about my feelings~~	○	○	○	○	○
25	let me ask questions	○	○	○	○	○
26	let me make decisions about my treatment	○	○	○	○	○
27	talked to me in private, without my family	○	○	○	○	○
I had the following needs…						
AT THE CANCER TREATMENT CENTER						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
28	privacy	○	○	○	○	○
29	pleasant surroundings	○	○	○	○	○
30	good food	○	○	○	○	○
31	a choice of cancer specialists	○	○	○	○	○
32	the same cancer treatment staff throughout treatment	○	○	○	○	○
33	a choice of times for appointments	○	○	○	○	○

2.Education

Since my cancer diagnosis, I have had problems enrolling at: *(please choose as many as apply)*

S1
- ○ school
- ~~○ TAFE~~
- ○ university/college
- ○ other place of study *(please write)*______________________________
- ○ none of the above

Since my cancer diagnosis, I have attended: *(please choose as many as apply)*

S2

○ school
~~○ TAFE~~
○ university/college
○ other place of study *(please write)*____
○ none of the above *(go to Question S3)*

I had the following needs…

~~WHEN STUDYING~~ WHILE ENROLLED IN SCHOOL

	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
34	attend classes	○	○	○	○	○
35	get extensions/special consideration	○	○	○	○	○
36	get guidance about study options or future career paths	○	○	○	○	○

3. Work

Since my cancer diagnosis, I have had problems finding work: *(please choose as many as apply)*

S3

○ full-time
○ part-time~~/casual~~
○ unpaid voluntary work
○ internship
○ other type of work *(please write)*____
○ none of the above

Since my cancer diagnosis, I have been employed: *(please choose as many as apply)*

S4

○ full-time
○ part-time~~/casual~~
○ unpaid voluntary work
○ internship
○ other type of work *(please write)*____
○ none of the above (*go to Question 40)*

I had the following needs…						
WHEN EMPLOYED						
	Knowing:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
37	how much work I would miss	○	○	○	○	○
38	how to ask managers/co-workers for support	○	○	○	○	○
39	~~that managers/co-workers had support to help them cope with my situation~~	○	○	○	○	○

4. Information and Activities

I had the following needs…						
DURING TREATMENT						
	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
40	spend time with people my own age	○	○	○	○	○
41	talk to people my age who had been through a similar experience	○	○	○	○	○
AT THE CANCER TREATMENT CENTER						
	Being able to have:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
42	leisure spaces and activities	○	○	○	○	○
SINCE MY CANCER DIAGNOSIS						
	Finding information that:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
43	~~was specifically designed for me~~	○	○	○	○	○
44	described relaxation techniques (e.g., yoga, meditation)	○	○	○	○	○

The next group of questions ask about any needs you may have had **in the last month.**

We realise that your needs may have changed during different stages of your cancer experience. Please only tell us about needs you have had in the last month. If you have not had any needs in the last month, please select 'No Need'.

5. Feelings and Relationships

I had the following needs…

IN THE LAST MONTH

	Feeling:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
45	~~frustrated~~ depressed	○	○	○	○	○
46	anxious or ~~nervous~~ scared	○	○	○	○	○

IN THE LAST MONTH

	Worrying about:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
47	my cancer spreading	○	○	○	○	○
48	my cancer returning or secondary cancers	○	○	○	○	○
49	whether my cancer treatment has worked	○	○	○	○	○
50	~~having cancer treatment~~	○	○	○	○	○
51	how my family is coping	○	○	○	○	○

IN THE LAST MONTH

	Finding:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
52	inner strength	○	○	○	○	○

IN THE LAST MONTH

	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
53	accept my diagnosis	○	○	○	○	○
54	be independent	○	○	○	○	○

S5	~~**Do you have:**~~ ~~*(please choose as many as apply)*~~ ~~○ a spouse/partner or boyfriend/girlfriend *(please answer Question 55)*~~ ~~○ sibling/s or step-brothers/sisters *(please answer Questions 56-58)*~~ ○ ~~none of the above *(go to Question 59)*~~

I had the following needs…

IN THE LAST MONTH

	Coping with:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
55	changes in my ~~relationship with my partner~~ dating or romantic life	○	○	○	○	○

IN THE LAST MONTH

	Coping with:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
56	changes in my relationships with my ~~sibling/s~~ family members	○	○	○	○	○

IN THE LAST MONTH

	Knowing how to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
57	~~ask my sibling/s for support~~	○	○	○	○	○
58	~~give support to my sibling/s~~	○	○	○	○	○

6. Daily Life

I had the following needs…

IN THE LAST MONTH

	Being able to:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
59	make plans or think about the future	○	○	○	○	○

IN THE LAST MONTH

	Coping with:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
60	changes in my physical ability	○	○	○	○	○
61	changes in my appearance	○	○	○	○	○

62	not being able to do the same things as other people my age	○	○	○	○	○
63	my parent/s or partner being overprotective	○	○	○	○	○
IN THE LAST MONTH						
	Managing:	**No Need**	**Low Need**	**Moderate Need**	**High Need**	**Very High Need**
64	pain	○	○	○	○	○
65	My medications	○	○	○	○	○
66	physical side effects of treatment	○	○	○	○	○
67	feeling tired or fatigued	○	○	○	○	○
68	loss of mobility	○	○	○	○	○
69	to take part in and enjoy social activities	○	○	○	○	○
70	~~to travel to social events~~	○	○	○	○	○

Needs list refinement

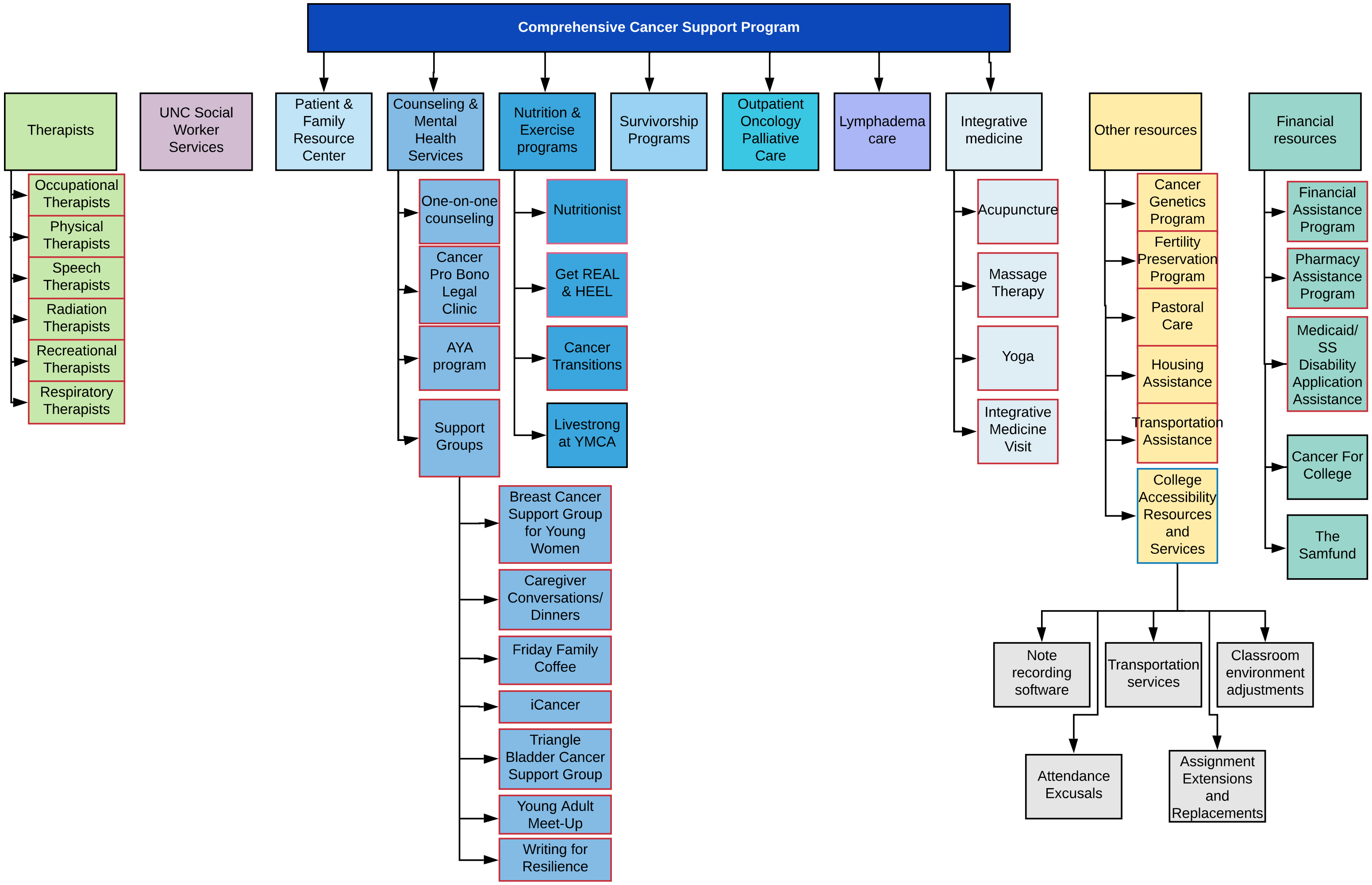
Items up for consideration:

1. Being able to have a choice of times for appointments
2. Being able to have the same cancer treatment staff throughout treatment
3. Being able to have a choice of cancer care specialists
4. Knowing how much work I would miss
5. Being able to have leisure spaces and activities
6. Knowing how to ask managers/coworkers for support
7. Being able to get guidance about study options or future career paths
8. Coping with my parent/s and/or partner being overprotective
9. Being able to be independent
10. Having cancer treatment staff who treated me as an individual
11. Having cancer treatment staff who talked to me in private without my family
12. Having cancer treatment staff who could have a laugh with me
13. Being able to have pleasant surroundings at the cancer treatment center
14. Being able to have good food at the cancer treatment center
15. Being able to have privacy at the cancer treatment center
16. Being able to attend classes (while enrolled in school)
17. Being able to get extensions/special considerations (while enrolled in school)
18. Worrying about whether my treatment has worked

Potential additional items:

1. Sexual health
2. Worrying about health insurance coverage
3. Physical therapy
4. Being able to get guidance about financial aid or loan repayment options
5. Other financial needs
6. Transportation
7. Coping with changes in my relationships with friends
8. If and how to tell my employer I have cancer

Services & Resources at UNC



- Comprehensive Cancer Support Program
  - Patient & Family Resource Center
  - Counseling & Mental Health Services
    - One-on-one counseling
    - Cancer Pro Bono Legal Clinic
    - AYA program
    - Support Groups
      - Breast Cancer Support Group for Young Women
      - Caregiver Conversations/ Dinners
      - Friday Family Coffee
      - iCancer
      - Triangle Bladder Cancer Support Group
      - Young Adult Meet-Up
      - Writing for Resilience
  - Nutrition & Exercise programs
    - Nutritionist
    - Get REAL & HEEL
    - Cancer Transitions
    - Livestrong at YMCA
  - Survivorship Programs
  - Outpatient Oncology Palliative Care
  - Lymphadema care
  - Integrative medicine
    - Acupuncture
    - Massage Therapy
    - Yoga
    - Integrative Medicine Visit

- Therapists
  - Occupational Therapists
  - Physical Therapists
  - Speech Therapists
  - Radiation Therapists
  - Recreational Therapists
  - Respiratory Therapists

- UNC Social Worker Services

- Other resources
  - Cancer Genetics Program
  - Fertility Preservation Program
  - Pastoral Care
  - Housing Assistance
  - Transportation Assistance
  - College Accessibility Resources and Services
    - Note recording software
    - Attendance Excusals
    - Transportation services
    - Assignment Extensions and Replacements
    - Classroom environment adjustments

- Financial resources
  - Financial Assistance Program
  - Pharmacy Assistance Program
  - Medicaid/ SS Disability Application Assistance
  - Cancer For College
  - The Samfund

AYA Survey Results

Table A1. AYA survey participants

Sex and gender identity	
Female	55 (78.6%)
Male	15 (21.4%)
Transgender	2 (2.9%)
Age	
Mean (SD)	24.24 (3.96)
Race	
Hispanic (all races)	10 (14.3%)
Non-Hispanic American Indian/ Alaska Native	3 (4.3%)
Non-Hispanic Asian or Pacific Islander	2 (2.9%)
Non-Hispanic Black	1 (1.4%)
Non-Hispanic White	49 (70.0%)
Other	5 (7.1%)
Cancer type	
Non-Hodgkin lymphoma	5 (7.1%)
Hodgkin lymphoma	15 (21.4%)
Leukemia	11 (15.7%)
Sarcoma	9 (12.9%)
Cervical	1 (1.4%)
Other female reproductive	3 (4.3%)
Male reproductive	1 (1.4%)
Thyroid	5 (7.1%)
Brain	5 (7.1%)
Melanoma	2 (2.9%)
Colorectal	1 (1.4%)
Breast	4 (5.7%)
Other	8 (11.4%)
Stage at diagnosis	
0	1 (1.4%)
I/II	24 (34.3%)
III/IV	22 (31.4%)
Unknown/ unstaged	23 (32.9%)
Time since diagnosis	
< 3 months	3 (4.3%)
3-6 months	9 (12.9%)
7-12 months	8 (11.4%)
>12 months	50 (71.4%)
In active treatment?	
no	51 (72.9%)
yes	19 (27.1%)
Cohabitants	
Parent(s)	29 (42.7%)
Spouse	12 (17.7%)
Non-spouse partner	7 (10.3%)
Child/children	4 (5.9%)
Roommate(s) (not parent, spouse, or child)	12 (17.7%)

Lives alone	8 (11.8%)
Education level	
< high school	2 (2.9%)
Completed high school	9 (13.2%)
Some college/ vocational training	23 (33.8%)
Associate degree	3 (4.4%)
College graduate	15 (22.1%)
Graduate degree or some post-graduate education	16 (23.5%)
Insurance source	
Self-pay	4 (5.9%)
No insurance	3 (4.4%)
Employer/ school	18 (26.5%)
Spouse's employer/ school	2 (2.9%)
Parent	25 (36.8%)
Medicare	3 (4.4%)
Medicaid	8 (11.8%)
Military/ TRICARE	8 (11.8%)
other	5 (7.3%)
	N=70

Figure A1. Number of needs reported as "high" or "very high" by respondent

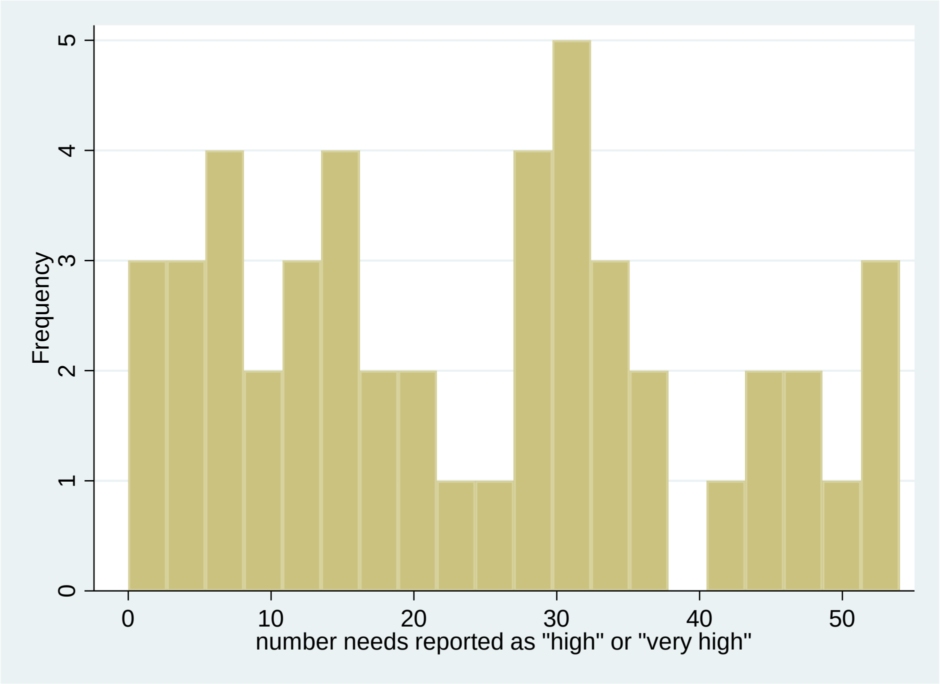


Figure A2. AYAs' evaluation of the CNQ-YP

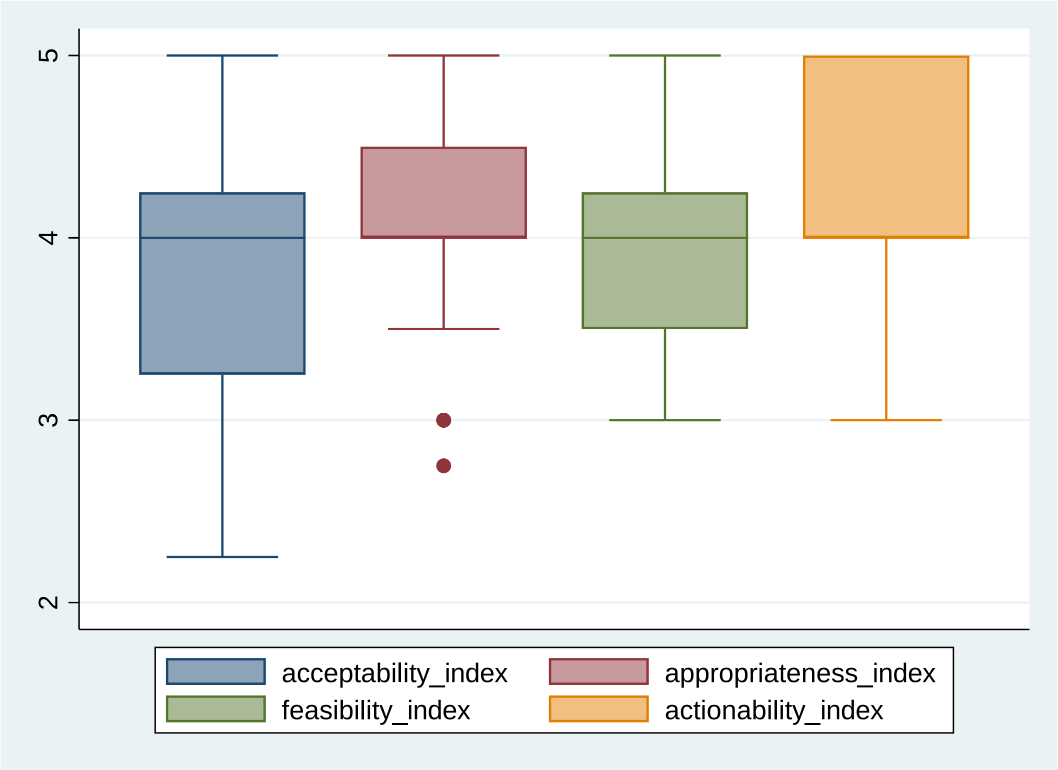


Figure A3. Average rating of needs: treatment environment & care section

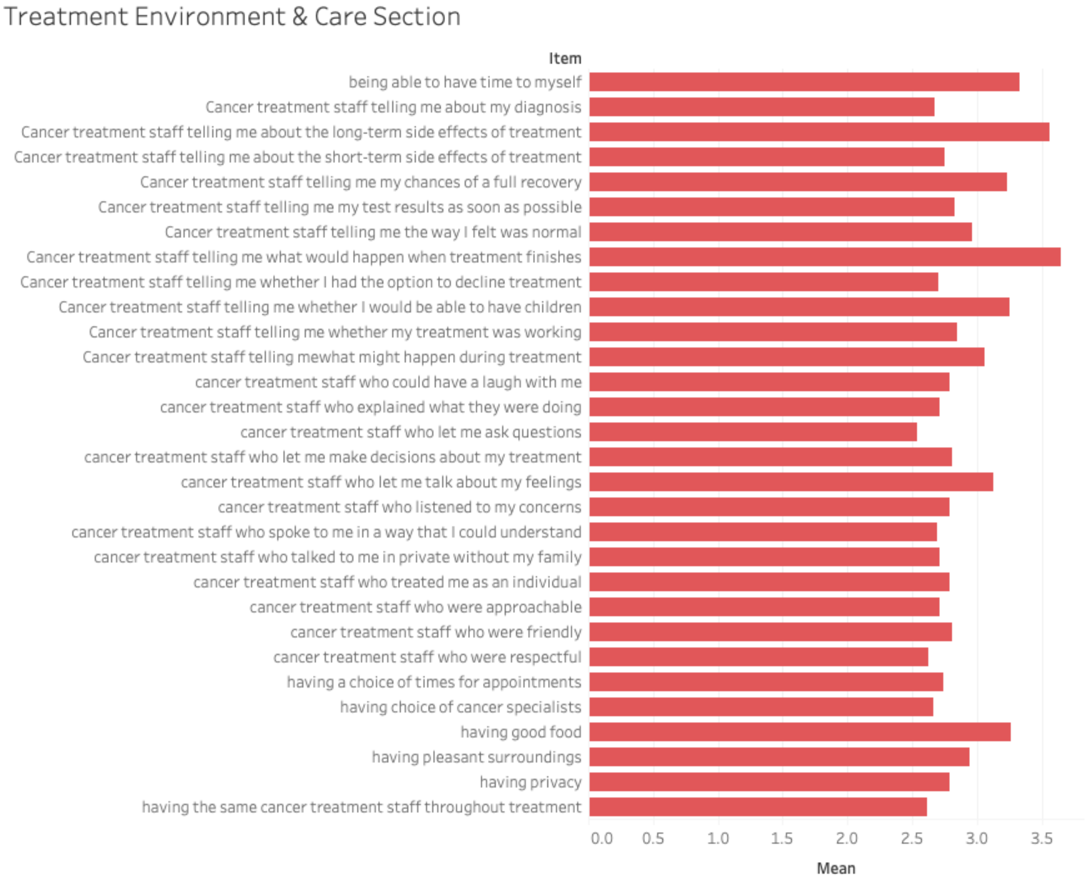


Figure A4. Average rating of needs: education section

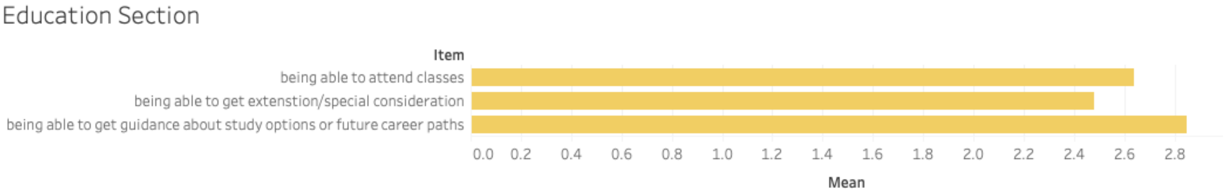


Figure A5. Average rating of needs: work section

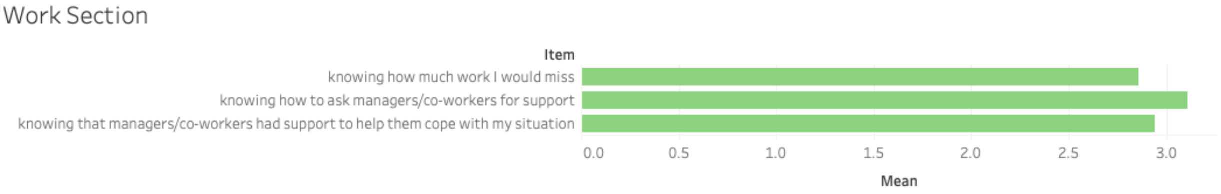


Figure A6. Average rating of needs: feelings & relationships section

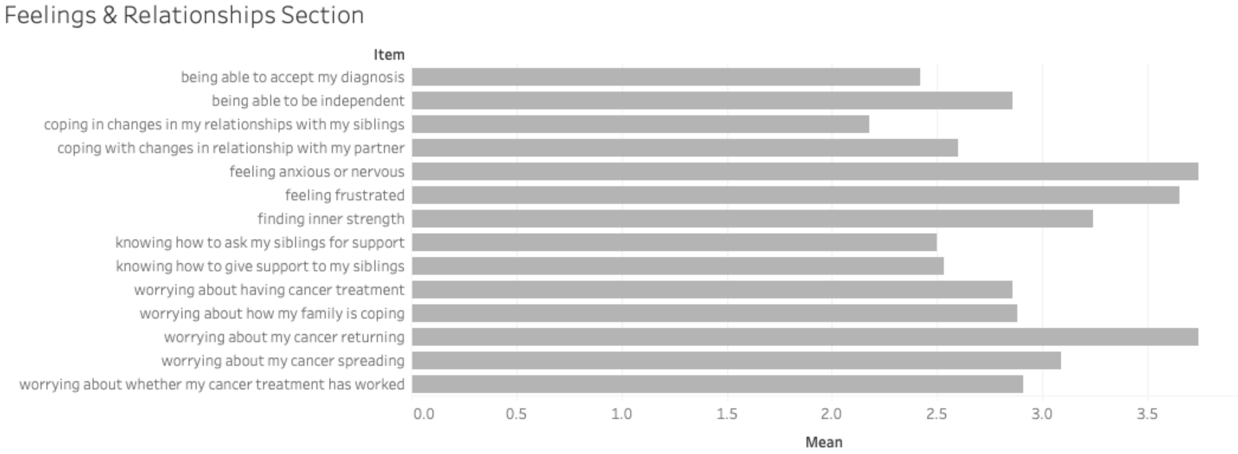
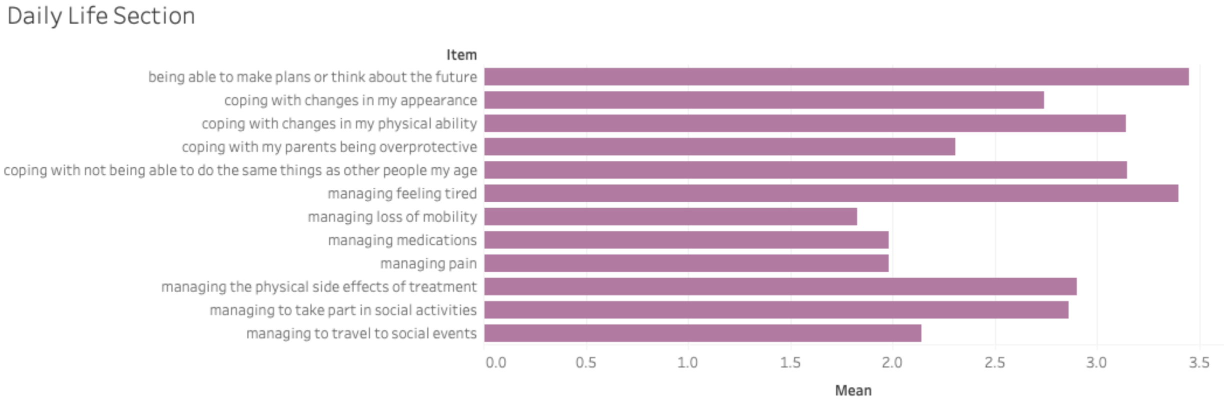


Figure A7. Average rating of needs: daily life section



Cognitive Interview Results

Table B1. Cognitive interview results

Category	Theme	Changes made
Response format	Confusion surrounding “no need” response option including both no need, and need already met	Changed the name of the “no need” response option to “no need/need met”
	Item S1 and S2 (“since my cancer diagnosis I have enrolled at/had problems enrolling at”) response option “TAFE” not understood	Removed response option “TAFE” from S1 and S2
	For items S1 and S2 (“since my cancer diagnosis I have enrolled at/had problems enrolling at”), AYAs wanted a response option related to internships	Added response option for S1 and S2: “internship (paid or unpaid)”
	In Items S3 and S4 (“since my cancer diagnoses I have been employed/ have had problems finding work”) response option “part-time/casual”, AYAs didn’t like the term “casual”	Removed the word “casual” so response option just reads “part-time”
	For Items S3 and S4 (“since my cancer diagnoses I have been employed/ have had problems finding work”), AYAs wanted a response option for trade school/apprenticeship	Added response option for S3 and S4: “trade school or apprenticeship”
Question format	Throughout the CNQ-YP the questions are broken up into different rows. For example, “I had the following need”, “before treatment”, “cancer treatment staff telling me”, and “about my diagnosis” are on separate lines. AYAs found this confusing.	All question wording consolidated onto one line.
Lookback periods	In general, AYAs found the multiple lookback periods (e.g., “before treatment”, “during treatment”, “after treatment”, etc.) confusing. Although they emphasized that needs do change depending on how far along you are in your treatment trajectory, these lookback periods were not considered helpful for informing current service provision	All needs items were anchored to needs currently being experienced (i.e., at the time of assessment completion). Redundancies stemming from the multiple lookback periods were removed.
Treatment Environment and Care section	Item 2 (“cancer treatment staff telling me what might happen during treatment”) interpreted the same as Item 4 (“about the short-term side effects of treatment”)	Removed Item 2
	Item 3 (“cancer treatment staff telling me whether I have the option to decline treatment”) perceived as less relevant/important	Removed Item 3
	AYAs did not like Item 6 (“cancer treatment staff telling me my chances of a full recovery”) because it is unclear what is meant by “full recovery”	Removed Item 6
	Section lacks item about sexual health	Added item assessing whether treatment staff provided information about sexual health
	Item 9 (“cancer treatment staff telling me whether my treatment was working”) is too narrow	Changed item to “how my treatment is working”
	Item 12 (“being able to have time to myself”) perceived as unimportant	Removed Item 12

	Item 14 (“cancer treatment staff telling me what I could do to stay healthy”) perceived as too vague; interpreted as putting the onus on AYAs to prevent secondary cancers which may be out of their control	Changed Item 14 to “cancer treatment staff giving me information about nutrition and exercise”
	Item 16 (“having cancer treatment staff who listened to my concerns”) and Item 24 (“ having cancer treatment staff who let me talk about my feelings”) perceived as redundant	Collapsed items 16 and 24 into “listened to my concerns and let me talk about my feelings”
	Item 19 (“having cancer treatment staff who were approachable”) and Item 20 (“having cancer treatment staff who were friendly”) perceived as redundant	Collapsed Items 19 and 20 into “having cancer treatment staff who were friendly and approachable”
	Item 22 (“having cancer treatment staff who explained what they were doing”) does not capture the importance of explaining *before* doing; redundant with Item 23 (“having cancer treatment staff who spoke to me in a way that I could understand”)	Collapsed Items 22 and 23 into “having cancer treatment staff who explained what they were doing before they did it, in a way that I could understand”
Education section	Items 34-36 had the question stem “I had the following needs when studying”. AYAs interpreted this as actively studying for a test.	Changed the question stem for Items 34-36 to “I had the following needs while enrolled at school”
	Section is missing an item related to financial aid or loan repayment	Added item “being able to get guidance about financial aid or loan repayment options”
Work section	Item 39 (“knowing that managers/co-workers had support to help them cope with my situation”) not perceived as important	Removed Item 39
	Section lacks item about health insurance, which is a major need with respect to employment	Added item “worrying about my health insurance coverage”
Information and Activities section	AYAs did not understand/like Item 43 “finding information that was specifically designed for me”	Removed Item 43
Feelings and Relationships section	Item 45 (“feeling frustrated”) not perceived as important relative to other psychosocial concerns	Removed Item 45
	Item 45 (“feeling anxious or nervous”) doesn’t fully capture the feeling of fear which is pervasive during treatment	Changed item 45 to “feeling anxious or scared”
	Section lacking item about depression	Added item “feeling depressed”
	Item 48 (“worrying about my cancer returning”) does not capture pervasive fear surrounding secondary cancers	Changed Item 48 to “worrying about my cancer returning or secondary cancers”
	Item 50 (“worrying about having cancer treatment”) too vague	Removed Item 50
	Section only includes items assessing changes in relationship with partner and siblings; not inclusive of all the important relationships that may be affected by cancer	Added items assessing changes in relationship with parent/s and changes in relationships with friend/s
Daily Life section	Item 63 (“coping with my parent/s being overprotective”) not relevant for many AYAs	Changed Item 63 to “coping with my parent/s and/or partner being overprotective”

	Section has item about physical side effects of treatment (Item 66) but none about the emotional side effects of treatment	Added item “managing emotional side effects of treatment”
	Item 67 (“feeling tired”) does not capture fatigue, which AYAs felt was more severe than tiredness	Changed Item 67 to “feeling tired/fatigued”
	AYAs did not understand or like Item 70 (“managing to travel to social event”)	Removed Item 70

Concept Mapping Results

Table C1. Concept mapping participants

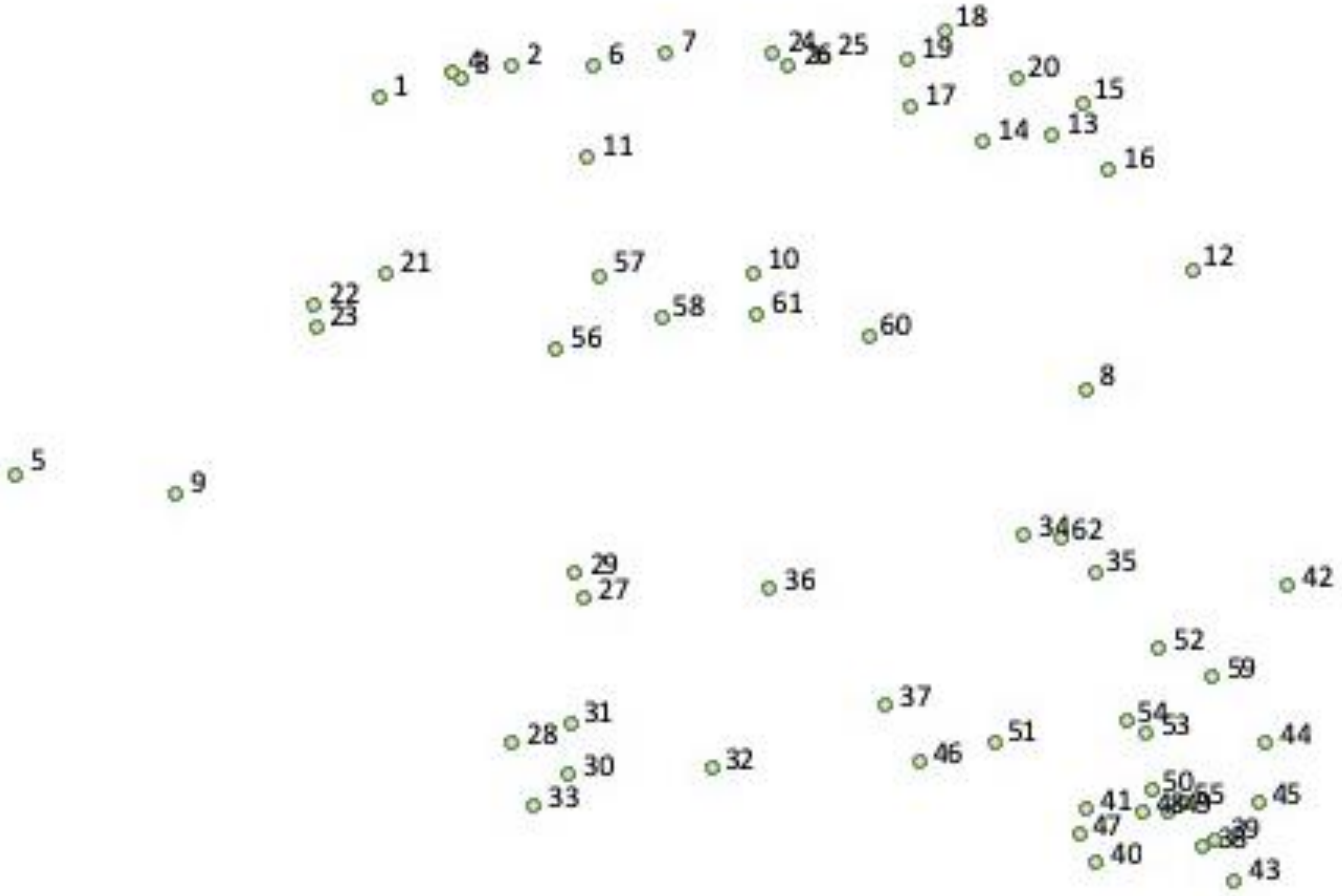
Location	
California	5
Florida	2
Illinois	3
Indiana	1
Michigan	1
Missouri	1
New York	1
North Carolina	2
Ohio	2
South Carolina	1
Tennessee	2
Texas	4
Utah	1
Cancer Program Type	
NCI-designated comprehensive cancer center	19
Teaching hospital cancer program	13
Veterans Affairs cancer program	0
Pediatric cancer program	14
Community cancer center	3
Hospital-based cancer program	15
Private oncology practice	0
Freestanding cancer center program	1
Role	
Oncologist	3
Physician (non-oncology)	1
Physician assistant	0
Nurse practitioner	1
Oncology nurse navigator	3
Nurse	1
Child life specialist	0
Dietician	0
Patient navigator	1
Social worker	7
Health educator	1
Other	8
Years in role	
Less than 5	16
Between 5 and 10	5
Between 10 and 20	2
Greater than 20	3
Does your cancer program provide care specifically to adolescents and young adults?	
Yes	24
No	2
	N=26

Table C2. List of needs sorted and rated by concept mapping participants

#	Statement
1	Cancer treatment staff telling me about my diagnosis
2	Cancer treatment staff telling me about the short-term side effects of treatment
3	Cancer treatment staff telling me about the long-term side effects of treatment
4	Cancer treatment staff telling me what will happen when treatment finishes
5	Cancer treatment staff telling me whether I will be able to have children
6	Cancer treatment staff telling me about how my treatment is working
7	Cancer treatment staff telling me my test results as soon as possible
8	Cancer treatment staff telling me the way I feel is normal
9	Cancer treatment staff giving me information about sexual health
10	Cancer treatment staff giving me information about nutrition and exercise.
11	Cancer treatment staff telling me what to do if I noticed a particular side effect
12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
13	Having cancer treatment staff who treated me as an individual
14	Having cancer treatment staff who were respectful
15	Having cancer treatment staff who were approachable and friendly
16	Having cancer treatment staff who could have a laugh with me
17	Having cancer treatment staff who explained what they are doing in a way I could understand
18	Having cancer treatment staff who let me ask questions
19	Having cancer treatment staff who let me make decisions about my treatment
20	Having cancer treatment staff who talked to me in private, without my family
21	Being able to have privacy
22	Being able to have pleasant surroundings
23	Being able to have good food
24	Being able to have a choice of cancer care specialists
25	Being able to have the same cancer treatment staff throughout treatment
26	Being able to have a choice of times for appointments
27	Being able to attend classes (if enrolled in school)
28	Being able to get extensions/special consideration (if enrolled in school)
29	Knowing how much work I would miss
30	Being able to get guidance about study options or future career paths
31	Being able to get guidance about financial aid or loan repayment options
32	Knowing how to ask managers/coworkers for support
33	Worrying about my health insurance coverage
34	Being able to spend time with people my own age
35	Being able to talk to people my own age who had been through a similar experience
36	Being able to have leisure spaces and activities

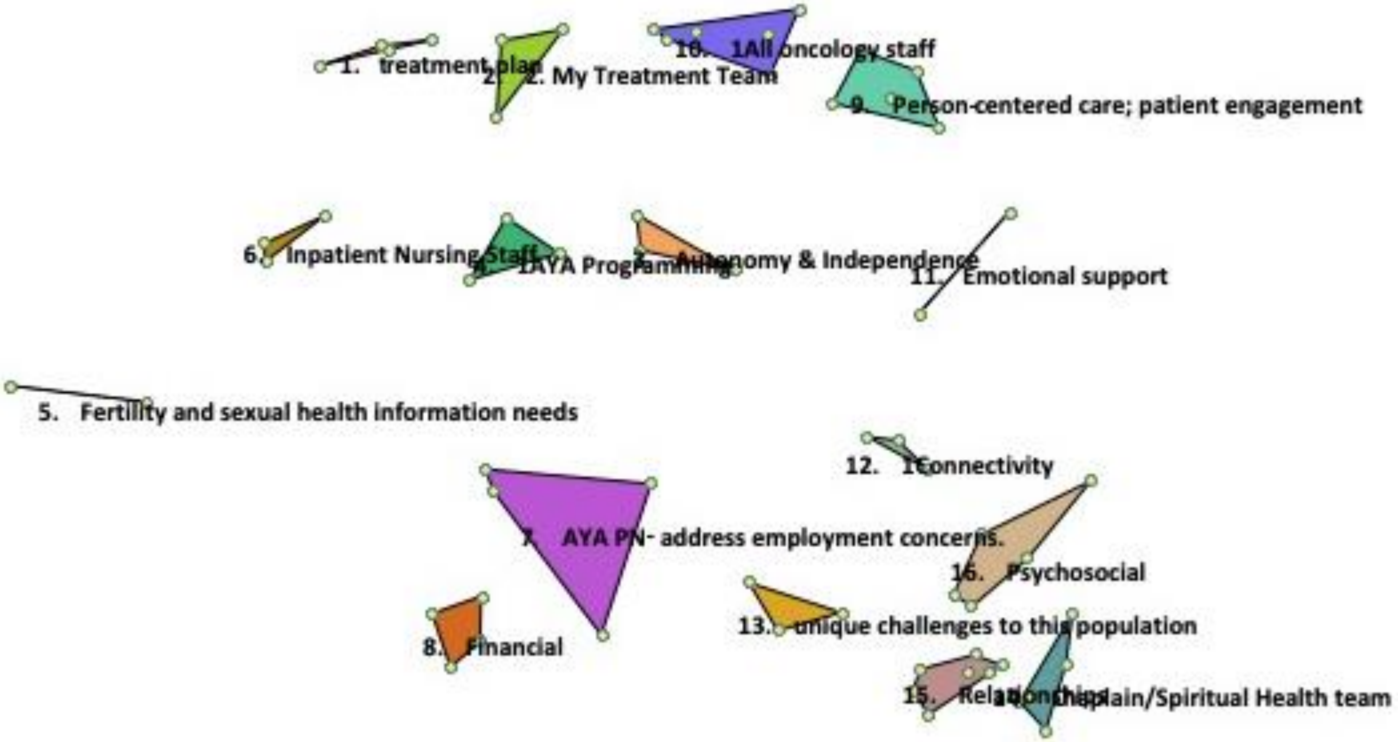
37	Finding information that described relaxation techniques (e.g., yoga, meditation)
38	Feeling anxious or scared
39	Feeling depressed
40	Worrying about my cancer spreading
41	Worrying about my cancer returning or secondary cancers
42	Worrying about whether my cancer treatment has worked
43	Worrying about how my family is coping
44	Finding inner strength
45	Being able to accept my diagnosis
46	Being able to be independent
47	Coping with changes in my relationship to my partner
48	Coping with changes in my relationship to my sibling/s
49	Coping with changes in my relationship to my parent/s
50	Coping with changes in my relationship to my friend/s
51	Being able to make plans or think about the future
52	Coping with changes in my physical ability
53	Coping with changes in my appearance
54	Coping with not being able to do the same things as other people my age
55	Coping with my parent/s and/or partner being overprotective
56	Managing pain
57	Managing my medications
58	Managing physical side effects of treatment
59	Managing emotional side effects of treatment
60	Managing feeling tired/fatigued
61	Managing loss of mobility
62	Managing to take part in social activities

Figure C1. Concept mapping point map



*Each point represents a needs item. They are numbered according to Table C2. The closer two points are in proximity, the more often those needs were grouped together as potentially addressable by the same service or resource.

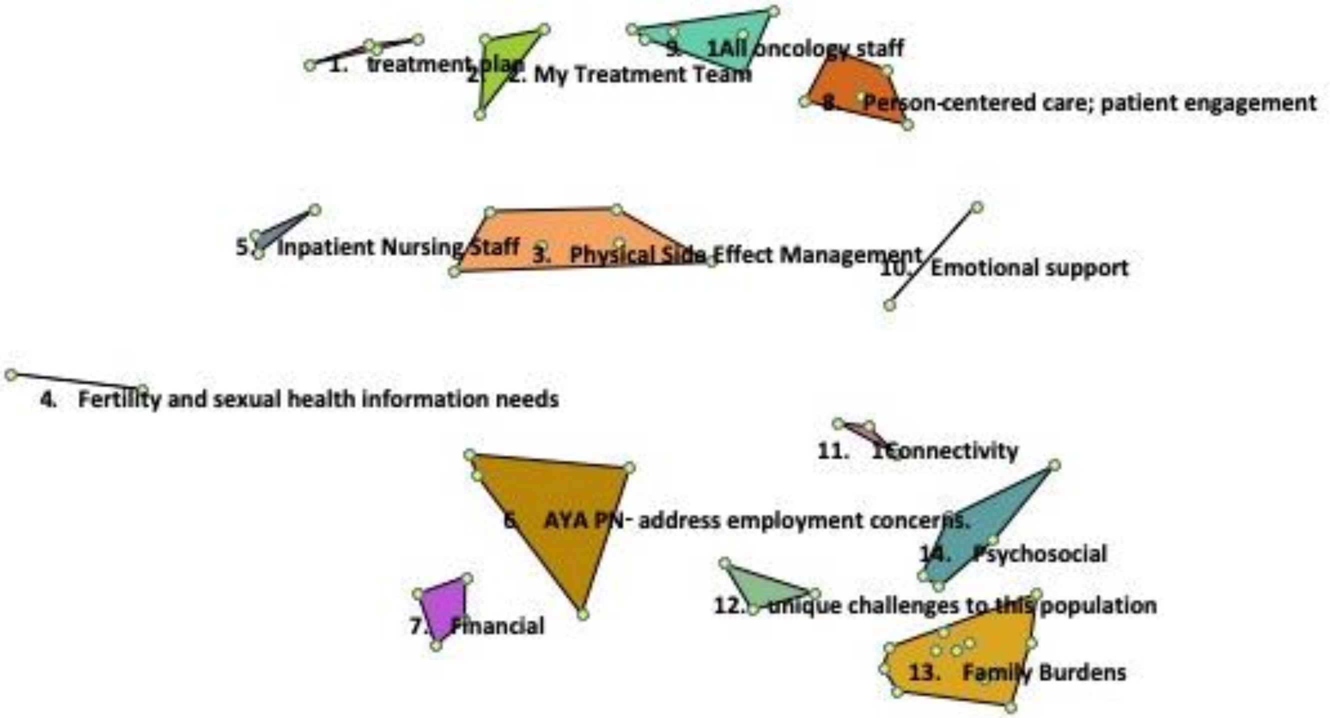
Figure C2. 16-cluster solution



Cluster		Statement
1. treatment plan		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
2. 2. My Treatment Team		
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
3. Autonomy & Independence		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
4. 1AYA Programming		
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
5. Fertility and sexual health information needs		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
6. Inpatient Nursing Staff	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
7. AYA PN- address employment concerns.		
	27	Being able to attend classes (if enrolled in school)
	29	Knowing how much work I would miss
	32	Knowing how to ask managers/coworkers for support
	36	Being able to have leisure spaces and activities
8. Financial		
	28	Being able to get extensions/special consideration (if enrolled in school)
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	33	Worrying about my health insurance coverage
9. Person-centered care; patient engagement		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	20	Having cancer treatment staff who talked to me in private, without my family
10. 1All oncology staff		
	17	Having cancer treatment staff who explained what they are doing in a way I could understand

	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	24	Being able to have a choice of cancer care specialists
	25	Being able to have the same cancer treatment staff throughout treatment
	26	Being able to have a choice of times for appointments
11. Emotional support		
	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
12. 1Connectivity		
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
13. unique challenges to this population		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
14. Chaplain/Spiritual Health team		
	38	Feeling anxious or scared
	39	Feeling depressed
	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
15. Relationships		
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	55	Coping with my parent/s and/or partner being overprotective
16. Psychosocial		
	42	Worrying about whether my cancer treatment has worked
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	59	Managing emotional side effects of treatment

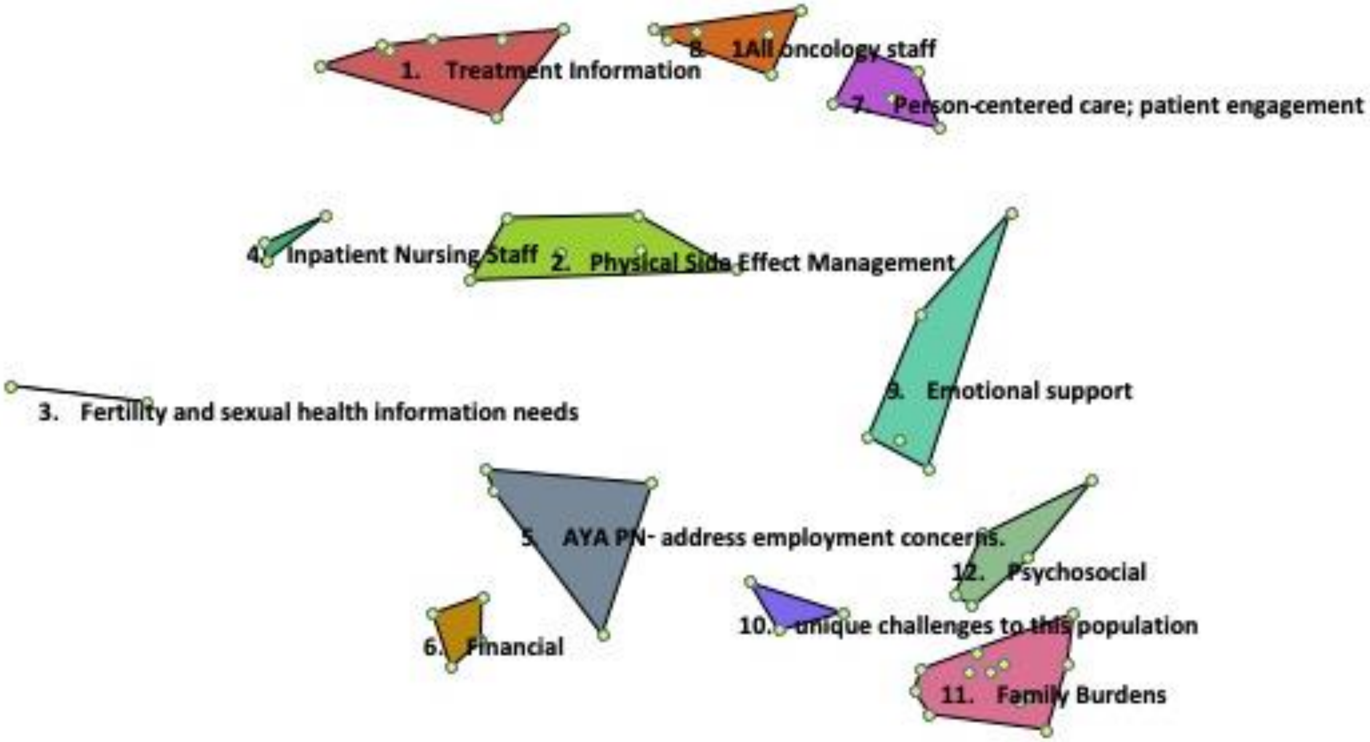
Figure C3. 14-cluster solution



Cluster		Statement
1. treatment plan		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
2. 2. My Treatment Team		
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
3. Physical Side Effect Management		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
4. Fertility and sexual health information needs		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
5. Inpatient Nursing Staff		
	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
6. AYA PN- address employment concerns.		
	27	Being able to attend classes (if enrolled in school)
	29	Knowing how much work I would miss
	32	Knowing how to ask managers/coworkers for support
	36	Being able to have leisure spaces and activities
7. Financial		
	28	Being able to get extensions/special consideration (if enrolled in school)
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	33	Worrying about my health insurance coverage
8. Person-centered care; patient engagement		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	20	Having cancer treatment staff who talked to me in private, without my family
9. 1All oncology staff		
	17	Having cancer treatment staff who explained what they are doing in a way I could understand
	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	24	Being able to have a choice of cancer care specialists

	25	Being able to have the same cancer treatment staff throughout treatment
	26	Being able to have a choice of times for appointments
10. Emotional support		
	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
11. 1Connectivity		
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
12. unique challenges to this population		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
13. Family Burdens		
	38	Feeling anxious or scared
	39	Feeling depressed
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	55	Coping with my parent/s and/or partner being overprotective
14. Psychosocial		
	42	Worrying about whether my cancer treatment has worked
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	59	Managing emotional side effects of treatment

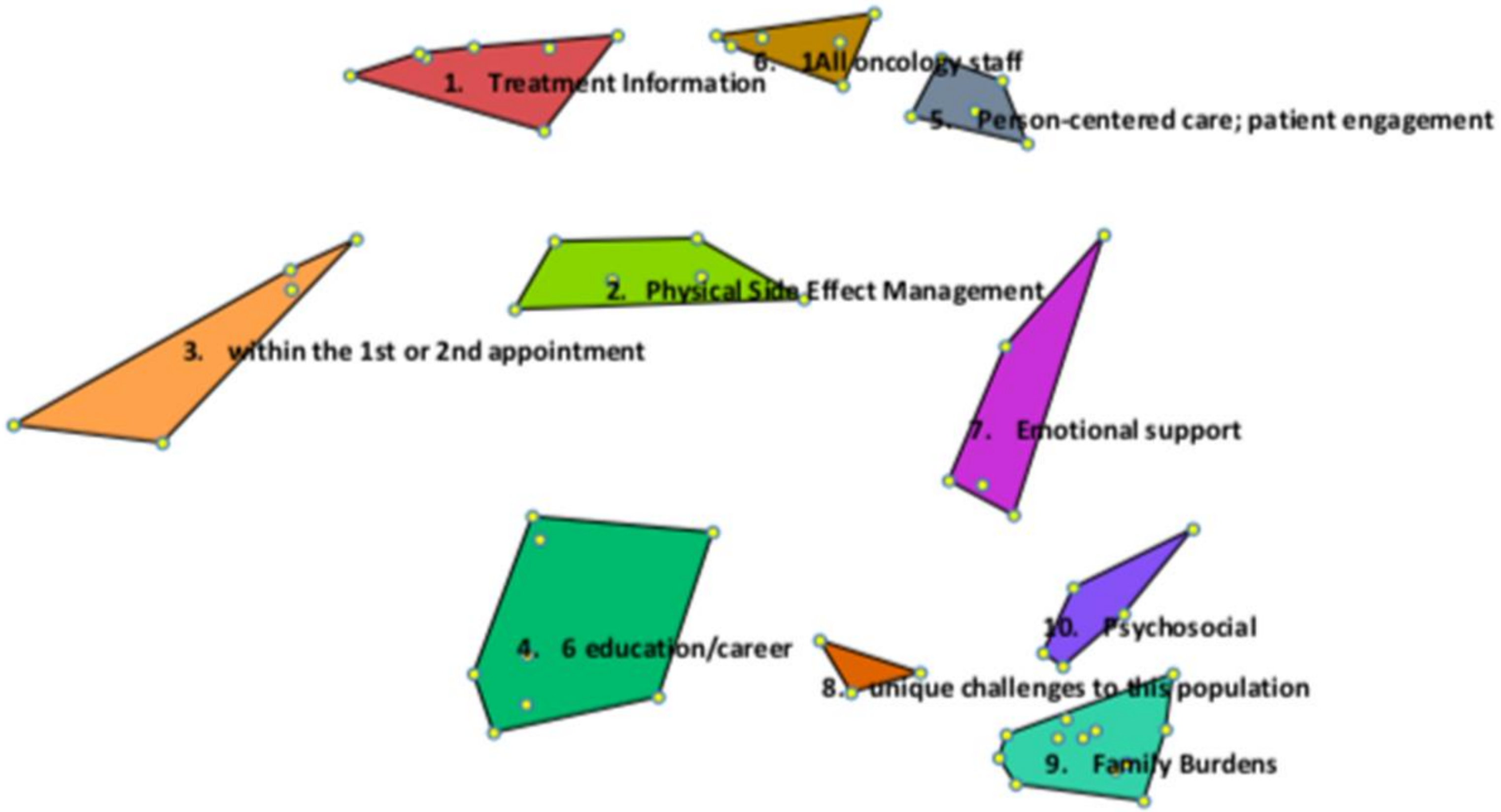
Figure C4. 12-cluster solution



Cluster		Statement
1. Treatment Information		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
2. Physical Side Effect Management		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
3. Fertility and sexual health information needs		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
4. Inpatient Nursing Staff		
	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
5. AYA PN- address employment concerns.		
	27	Being able to attend classes (if enrolled in school)
	29	Knowing how much work I would miss
	32	Knowing how to ask managers/coworkers for support
	36	Being able to have leisure spaces and activities
6. Financial		
	28	Being able to get extensions/special consideration (if enrolled in school)
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	33	Worrying about my health insurance coverage
7. Person-centered care; patient engagement		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	20	Having cancer treatment staff who talked to me in private, without my family
8. 1All oncology staff		
	17	Having cancer treatment staff who explained what they are doing in a way I could understand
	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	24	Being able to have a choice of cancer care specialists
	25	Being able to have the same cancer treatment staff throughout treatment

	26	Being able to have a choice of times for appointments
9. Emotional support		
	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
10. unique challenges to this population		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
11. Family Burdens		
	38	Feeling anxious or scared
	39	Feeling depressed
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	55	Coping with my parent/s and/or partner being overprotective
12. Psychosocial		
	42	Worrying about whether my cancer treatment has worked
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	59	Managing emotional side effects of treatment

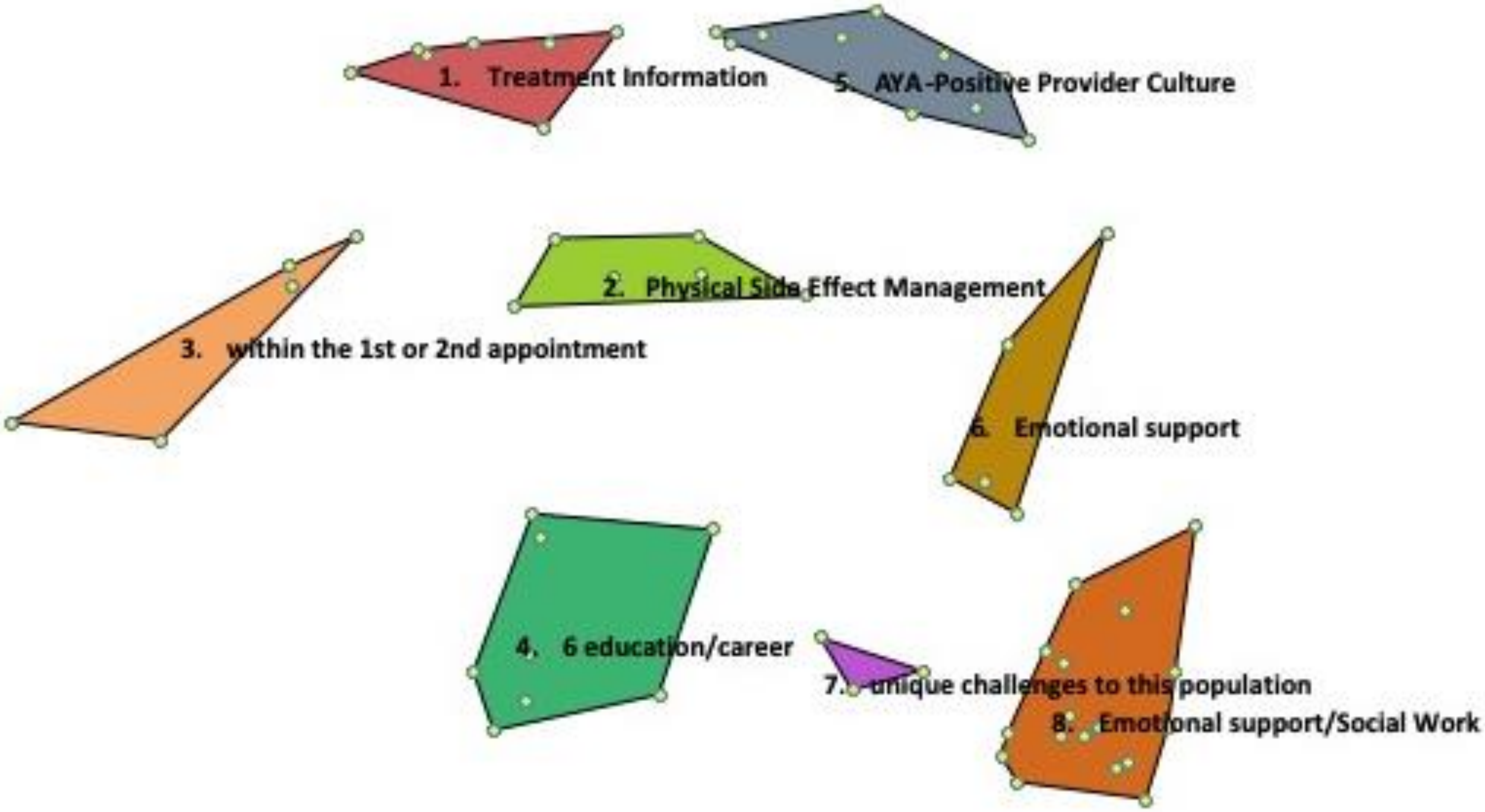
Figure C5. 10-cluster solution



Cluster		Statement
1. Treatment Information		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
2. Physical Side Effect Management		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
3. within the 1st or 2nd appointment		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
🟩		
4. education/ career	27	Being able to attend classes (if enrolled in school)
	28	Being able to get extensions/special consideration (if enrolled in school)
	29	Knowing how much work I would miss
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	32	Knowing how to ask managers/coworkers for support
	33	Worrying about my health insurance coverage
	36	Being able to have leisure spaces and activities
5. Person-centered care; patient engagement		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	20	Having cancer treatment staff who talked to me in private, without my family
6. 1All oncology staff		
	17	Having cancer treatment staff who explained what they are doing in a way I could understand
	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	24	Being able to have a choice of cancer care specialists
	25	Being able to have the same cancer treatment staff throughout treatment
	26	Being able to have a choice of times for appointments
🟪		

7. Emotional support	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
8. unique challenges to this population		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
9. Family Burdens		
	38	Feeling anxious or scared
	39	Feeling depressed
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	55	Coping with my parent/s and/or partner being overprotective
10. Psychosocial		
	42	Worrying about whether my cancer treatment has worked
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	59	Managing emotional side effects of treatment

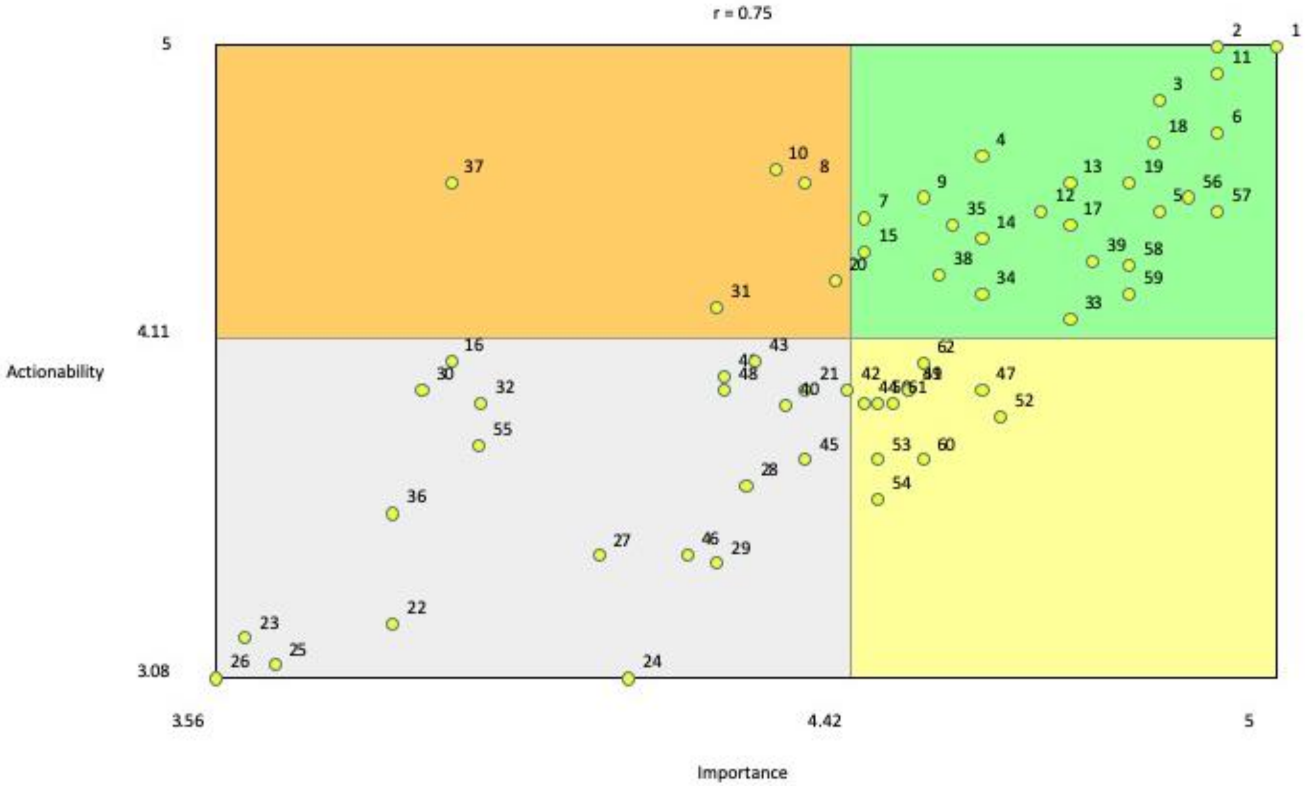
Figure C6. 8-cluster solution



Cluster		Statement
1. Treatment Information		
	1	Cancer treatment staff telling me about my diagnosis
	2	Cancer treatment staff telling me about the short-term side effects of treatment
	3	Cancer treatment staff telling me about the long-term side effects of treatment
	4	Cancer treatment staff telling me what will happen when treatment finishes
	6	Cancer treatment staff telling me about how my treatment is working
	7	Cancer treatment staff telling me my test results as soon as possible
	11	Cancer treatment staff telling me what to do if I noticed a particular side effect
2. Physical Side Effect Management		
	10	Cancer treatment staff giving me information about nutrition and exercise.
	56	Managing pain
	57	Managing my medications
	58	Managing physical side effects of treatment
	60	Managing feeling tired/fatigued
	61	Managing loss of mobility
3. within the 1st or 2nd appointment		
	5	Cancer treatment staff telling me whether I will be able to have children
	9	Cancer treatment staff giving me information about sexual health
	21	Being able to have privacy
	22	Being able to have pleasant surroundings
	23	Being able to have good food
🟩		
4. Education/career	27	Being able to attend classes (if enrolled in school)
	28	Being able to get extensions/special consideration (if enrolled in school)
	29	Knowing how much work I would miss
	30	Being able to get guidance about study options or future career paths
	31	Being able to get guidance about financial aid or loan repayment options
	32	Knowing how to ask managers/coworkers for support
	33	Worrying about my health insurance coverage
	36	Being able to have leisure spaces and activities
5. AYA-Positive Provider Culture		
	13	Having cancer treatment staff who treated me as an individual
	14	Having cancer treatment staff who were respectable
	15	Having cancer treatment staff who were approachable and friendly
	16	Having cancer treatment staff who could have a laugh with me
	17	Having cancer treatment staff who explained what they are doing in a way I could understand
	18	Having cancer treatment staff who let me ask questions
	19	Having cancer treatment staff who let me make decisions about my treatment
	20	Having cancer treatment staff who talked to me in private, without my family
	24	Being able to have a choice of cancer care specialists
	25	Being able to have the same cancer treatment staff throughout treatment
	26	Being able to have a choice of times for appointments
🟨		

6. Emotional support	8	Cancer treatment staff telling me the way I feel is normal
	12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
	34	Being able to spend time with people my own age
	35	Being able to talk to people my own age who had been through a similar experience
	62	Managing to take part in social activities
7. unique challenges to this population		
	37	Finding information that described relaxation techniques (e.g., yoga, meditation)
	46	Being able to be independent
	51	Being able to make plans or think about the future
8. Emotional support/Social Work		
	38	Feeling anxious or scared
	39	Feeling depressed
	40	Worrying about my cancer spreading
	41	Worrying about my cancer returning or secondary cancers
	42	Worrying about whether my cancer treatment has worked
	43	Worrying about how my family is coping
	44	Finding inner strength
	45	Being able to accept my diagnosis
	47	Coping with changes in my relationship to my partner
	48	Coping with changes in my relationship to my sibling/s
	49	Coping with changes in my relationship to my parent/s
	50	Coping with changes in my relationship to my friend/s
	52	Coping with changes in my physical ability
	53	Coping with changes in my appearance
	54	Coping with not being able to do the same things as other people my age
	55	Coping with my parent/s and/or partner being overprotective
	59	Managing emotional side effects of treatment

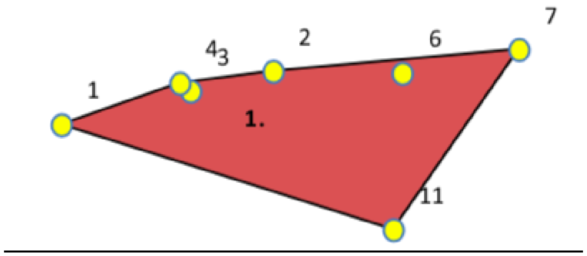
Figure C7. Concept mapping go-zone graph



Appendix G2. Cluster Comparison Worksheets

CLUSTER 1

10-cluster solution

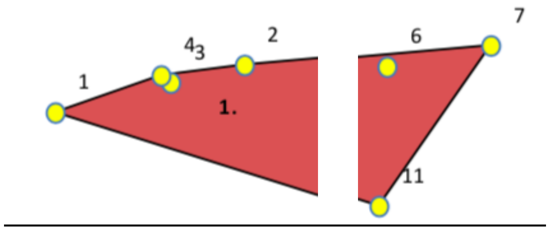


1	Cancer treatment staff telling me about my diagnosis
2	Cancer treatment staff telling me about the short-term side effects of treatment
3	Cancer treatment staff telling me about the long-term side effects of treatment
4	Cancer treatment staff telling me what will happen when treatment finishes
6	Cancer treatment staff telling me about how my treatment is working
7	Cancer treatment staff telling me my test results as soon as possible
11	Cancer treatment staff telling me what to do if I noticed a particular side effect

12-cluster solution

Same as 10-cluster solution

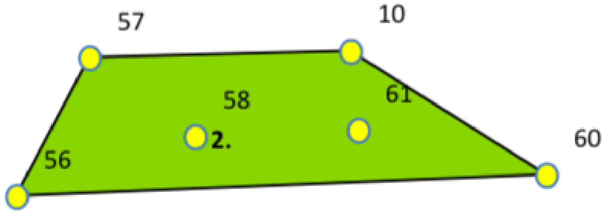
14-cluster solution



1	Cancer treatment staff telling me about my diagnosis
2	Cancer treatment staff telling me about the short-term side effects of treatment
3	Cancer treatment staff telling me about the long-term side effects of treatment
4	Cancer treatment staff telling me what will happen when treatment finishes
6	Cancer treatment staff telling me about how my treatment is working
7	Cancer treatment staff telling me my test results as soon as possible
11	Cancer treatment staff telling me what to do if I noticed a particular side effect

CLUSTER 2

10-cluster solution



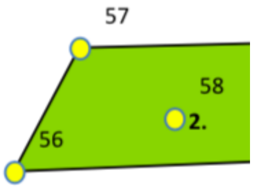
10	Cancer treatment staff giving me information about nutrition and exercise.
56	Managing pain
57	Managing my medications
58	Managing physical side effects of treatment
60	Managing feeling tired/fatigued
61	Managing loss of mobility

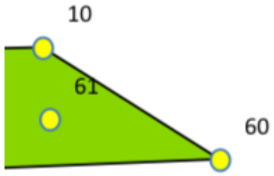
12-cluster solution

14-cluster solution

Same as 10-cluster solution

16-cluster solution

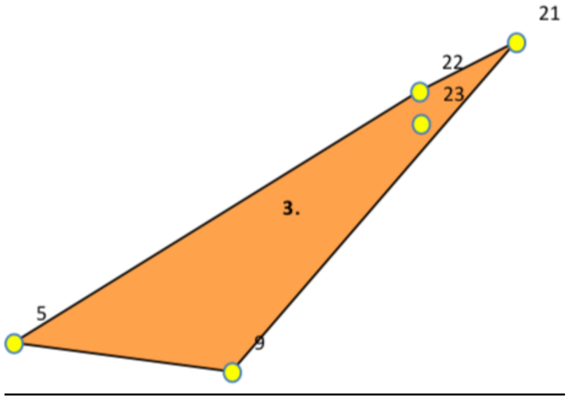




10	Cancer treatment staff giving me information about nutrition and exercise.
60	Managing feeling tired/fatigued
61	Managing loss of mobility
56	Managing pain
57	Managing my medications
58	Managing physical side effects of treatment

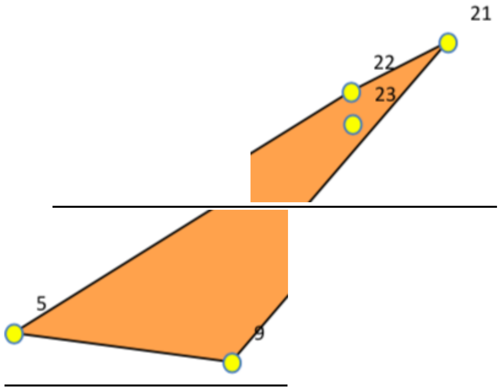
CLUSTER 3

10-cluster solution



5	Cancer treatment staff telling me whether I will be able to have children
9	Cancer treatment staff giving me information about sexual health
21	Being able to have privacy
22	Being able to have pleasant surroundings
23	Being able to have good food

12-cluster solution



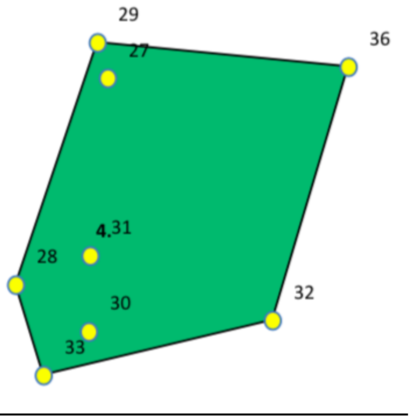
5	Cancer treatment staff telling me whether I will be able to have children
9	Cancer treatment staff giving me information about sexual health
21	Being able to have privacy
22	Being able to have pleasant surroundings
23	Being able to have good food

14-cluster solution

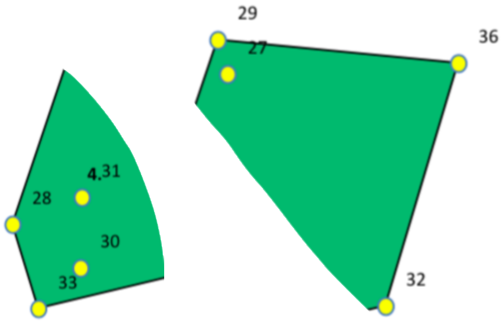
Same as 12-cluster solution

CLUSTER 4

10-cluster solution



12-cluster solution



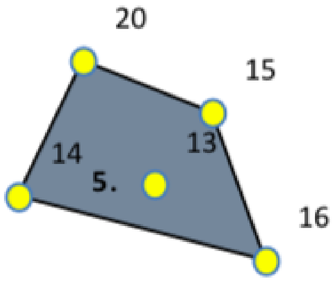
14-cluster solution

Same as 12-cluster solution

27	Being able to attend classes (if enrolled in school)	27	Being able to attend classes (if enrolled in school)
28	Being able to get extensions/special consideration (if enrolled in school)	29	Knowing how much work I would miss
29	Knowing how much work I would miss	32	Knowing how to ask managers/coworkers for support
30	Being able to get guidance about study options or future career paths	36	Being able to have leisure spaces and activities
31	Being able to get guidance about financial aid or loan repayment options		
32	Knowing how to ask managers/coworkers for support	28	Being able to get extensions/special consideration (if enrolled in school)
33	Worrying about my health insurance coverage	30	Being able to get guidance about study options or future career paths
36	Being able to have leisure spaces and activities	31	Being able to get guidance about financial aid or loan repayment options
		33	Worrying about my health insurance coverage

CLUSTER 5

10-cluster solution



13	Having cancer treatment staff who treated me as an individual
14	Having cancer treatment staff who were respectable
15	Having cancer treatment staff who were approachable and friendly
16	Having cancer treatment staff who could have a laugh with me
20	Having cancer treatment staff who talked to me in private, without my family

12-cluster solution

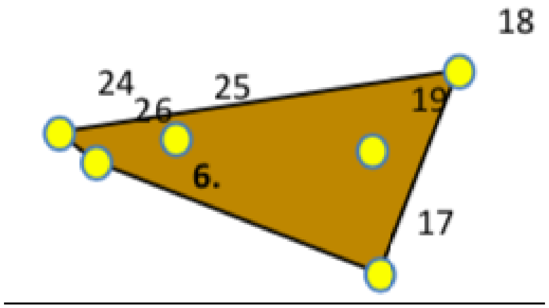
Same as 10-cluster solution

14-cluster solution

Same as 10-cluster solution

CLUSTER 6

10-cluster solution



17	Having cancer treatment staff who explained what they are doing in a way I could understand
18	Having cancer treatment staff who let me ask questions
19	Having cancer treatment staff who let me make decisions about my treatment
24	Being able to have a choice of cancer care specialists
25	Being able to have the same cancer treatment staff throughout treatment
26	Being able to have a choice of times for appointments

12-cluster solution

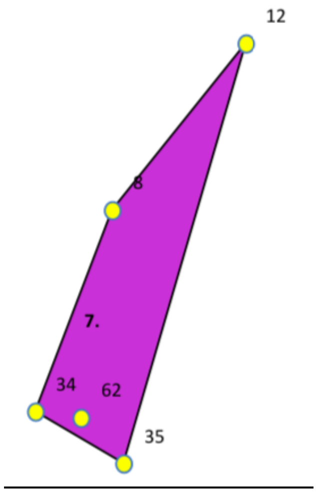
Same as 10-cluster solution

14-cluster solution

Same as 10-cluster solution

CLUSTER 7

10-cluster solution

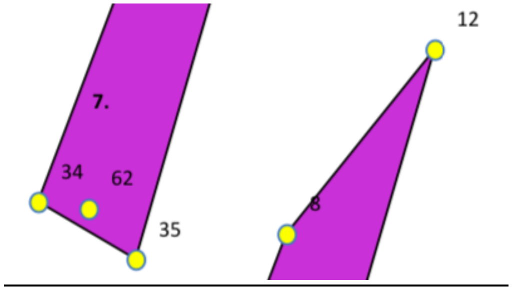


8	Cancer treatment staff telling me the way I feel is normal
12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
34	Being able to spend time with people my own age
35	Being able to talk to people my own age who had been through a similar experience
62	Managing to take part in social activities

12-cluster solution

Same as 10-cluster solution

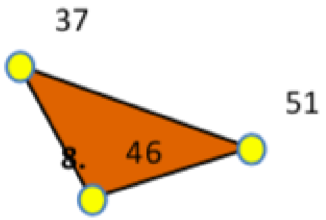
14-cluster solution



8	Cancer treatment staff telling me the way I feel is normal
12	Having cancer treatment staff who listened to my concerns and let me talk about my feelings
34	Being able to spend time with people my own age
35	Being able to talk to people my own age who had been through a similar experience
62	Managing to take part in social activities

CLUSTER 8

10-cluster solution



37	Finding information that described relaxation techniques (e.g., yoga, meditation)
46	Being able to be independent
51	Being able to make plans or think about the future

12-cluster solution

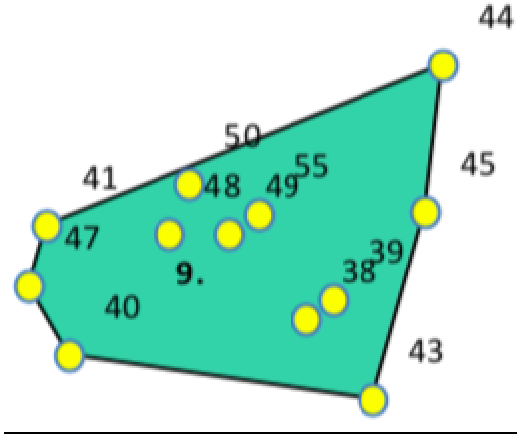
Same as 10-cluster solution

14-cluster solution

Same as 10-cluster solution

CLUSTER 9

10-cluster solution

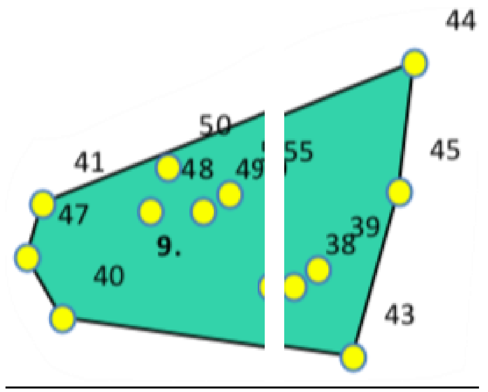


38	Feeling anxious or scared
39	Feeling depressed
40	Worrying about my cancer spreading
41	Worrying about my cancer returning or secondary cancers
43	Worrying about how my family is coping
44	Finding inner strength
45	Being able to accept my diagnosis
47	Coping with changes in my relationship to my partner
48	Coping with changes in my relationship to my sibling/s
49	Coping with changes in my relationship to my parent/s
50	Coping with changes in my relationship to my friend/s
55	Coping with my parent/s and/or partner being overprotective

12-cluster solution
14-cluster solution

Same as 10-cluster solution

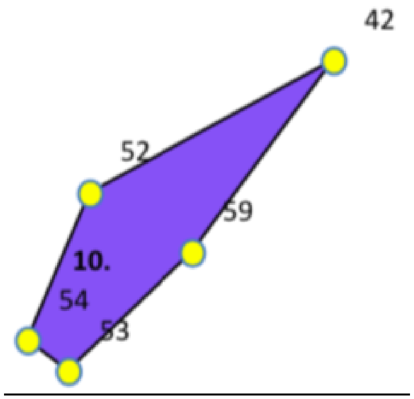
16-cluster solution



38	Feeling anxious or scared
39	Feeling depressed
43	Worrying about how my family is coping
44	Finding inner strength
45	Being able to accept my diagnosis
40	Worrying about my cancer spreading
41	Worrying about my cancer returning or secondary cancers
47	Coping with changes in my relationship to my partner
48	Coping with changes in my relationship to my sibling/s
49	Coping with changes in my relationship to my parent/s
50	Coping with changes in my relationship to my friend/s

			55	Coping with my parent/s and/or partner being overprotective

CLUSTER 10

10-cluster solution	**12-cluster solution**	**14-cluster solution**
	Same as 10-cluster solution	Same as 10-cluster solution

42	Worrying about whether my cancer treatment has worked
52	Coping with changes in my physical ability
53	Coping with changes in my appearance
54	Coping with not being able to do the same things as other people my age
59	Managing emotional side effects of treatment

APPENDIX H: DESIGN TEAM #2 MATERIALS

AYA NA-SB

AYA NEEDS ASSESSMENT &
SERVICE BRIDGE

DESIGN TEAM WORKSHOP #2

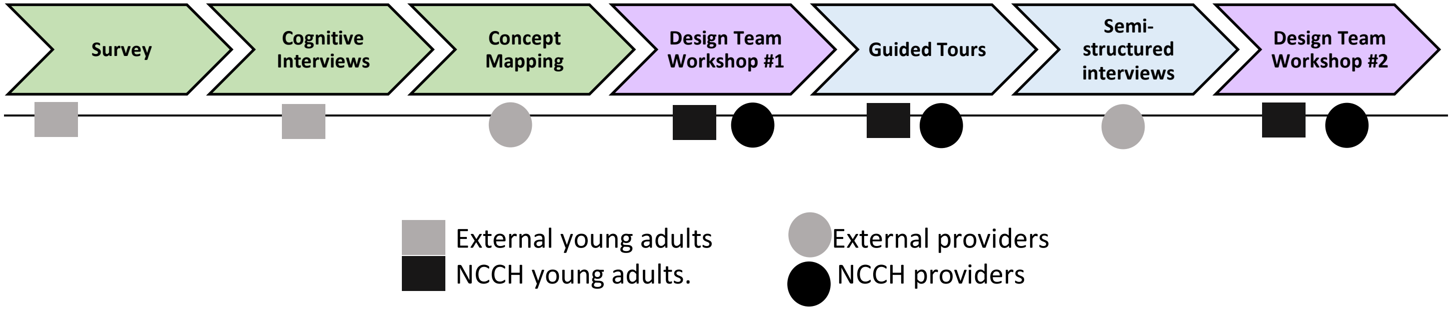
February 26, 2019
12:00-4:00pm EST
Starbucks Conference Room, NCCH

Agenda

12:00-12:15	Welcome and introductions Project overview & objectives
12:15-12:30	Overview of needs assessment Discussion re: response scale
12:30-2:00	Summary of user and contextual requirements Delivery specification with storyboard
2:00-2:15	Break
2:15-3:30	Vetting delivery specification with scenarios of use, personas
3:30-4:00	Ranking barriers to implementation

Project Overview

UCD Aim	Method	Deliverable
Review and refine prototype	<u>Usability Testing</u> • AYA Survey • Cognitive interviews with AYAs • Concept mapping with providers/staff	Evidence of the usability and usefulness of the CNQ-YP
Identify user and contextual requirements	<u>Ethnography</u> • Guided tours with AYAs and providers/staff from NCCH • Semi-structured interviews with providers/staff from outside of NCCH	User and contextual requirements for AYA NA-SB's design and implementation
Design prototypes based on user and contextual requirements	<u>Design Team Workshops</u> • Workshop #1 • Workshop #2	AYA NA-SB prototypes and anticipated implementation strategies needed
	RESULT	A usable and useful PROM linked to available services and resources + implementation guidance



Needs Assessment

INFORMATION

In the past month, I have needed information from my cancer care team about:		No need/Need met	Low need	Moderate need	High need	Very high need
1	My diagnosis					
2	The short-term side effects of treatment					
3	The long-term side effects of treatment					
4	What will happen when treatment finishes					
5	My disease status					
6	My test results					
7	What to do if I noticed a particular side effect					

CANCER CARE TEAM

In the past month, I have needed my cancer treatment team to:		No need/Need met	Low need	Moderate need	High need	Very high need
8	Respect me as an individual, not just a cancer patient					
9	Offer to talk to me in private, without my family					
10	Explain what they were doing in a way I could understand					
11	Encourage me to ask questions					
12	Engage me in decision-making about my treatment and respected my decisions					
13	Ask me about my treatment concerns					

PHYSICAL HEALTH

In the past month, I have needed help with:		No need/Need met	Low need	Moderate need	High need	Very high need
14	Managing pain					
15	Managing my medications					
16	Managing physical side effects of treatment					
17	Managing feeling tired/ fatigued					
18	Managing loss of mobility					

PSYCHOSOCIAL HEALTH

	In the past month, I have needed help with:	No need/Need met	Low need	Moderate need	High need	Very high need
19	Feeling anxious or scared					
20	Feeling depressed					
21	Having what I need to cope with my diagnosis					
22	Worrying about my cancer spreading					
23	Worrying about my cancer returning or secondary cancers					
24	Worrying about how my family is coping					
25	Coping with changes in my dating or romantic life					
26	Coping with changes in my relationships with my family members					
27	Coping with changes in my relationships with friends					
28	Feeling independent					
29	Coping with changes in my physical ability					
30	Coping with changes in my appearance					
31	Coping with not being able to do the same things as other people my age					
32	Managing the emotional side effects of treatment					
33	Being able to make plans or think about the future					

SEXUAL & REPRODUCTIVE HEALTH

	In the past month, I have needed information or counseling about:	No need/Need met	Low need	Moderate need	High need	Very high need
34	My risk for infertility and fertility preservation options					
35	Treating infertility and other options for having children (i.e., artificial insemination, in vitro fertilization, surrogacy, adoption, etc.)					
36	How my genetics may or may not have impacted my diagnosis and treatment					
37	Sexuality and intimacy during cancer treatment					
38	Sexual side effects of my treatment (e.g., sexual dysfunction)					
39	The effects of treatment on long-term hormone changes					

HEALTH BEHAVIORS & WELLNESS

In the past month, I have needed:		No need/Need met	Low need	Moderate need	High need	Very high need
40	Information about nutrition and exercise					
41	Help getting enough sleep					
42	Resources to quit smoking					
43	Information about drug and alcohol use during cancer treatment					
44	Spiritual support or faith-based resources					
45	Information on alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.)					

WORK & EDUCATION

In the past month, I have needed help with:		No need/Need met	Low need	Moderate need	High need	Very high need
46	Navigating my school life while going through cancer treatment					
47	Navigating my work life while going through cancer treatment					

PEER SUPPORT & PROGRAMMING

I had the following needs in the past month:		No need/Need met	Low need	Moderate need	High need	Very high need
48	Being able to spend time with people my own age					
49	Being able to talk to people my own age who have been through a similar experience					
50	Managing to take part in social activities					

FINANCES & LOGISTICS

I had the following needs in the past month:		No need/Need met	Low need	Moderate need	High need	Very high need
51	Paying my bills					
52	Getting guidance about scholarship or loan repayment options					
53	Worrying about my health insurance (e.g., access/eligibility, coverage, cost)					

54	Getting to and from my cancer care appointments					
55	Having childcare during my cancer care appointments					
56	Having stable housing					

User & Contextual Requirements

Domain	User/contextual factor identified through ethnography	Requirement for AYA NA-SB delivery	
User characteristics	AYAs desire a tool that is actually used to address their needs in a timely manner	AYA NA-SB follow-up actions should be delivered in a timely manner	○
	Needs change as AYAs move through their treatment trajectory. Time points when needs are particularly distinct include (1) after diagnosis, (2) end of treatment, and (3) somewhere in between	AYA NA-SB should be administered at multiple timepoints, including after diagnosis, during treatment, and at the end of treatment	○
	AYAs feel overwhelmed immediately following diagnosis and may not know what they need yet	AYA NA-SB should not be administered immediately upon diagnosis	○
User tasks	AYAs at NCCH rely heavily on social workers to address their nonmedical needs	AYA NA-SB delivery and follow-up should be done by those who are currently doing the work of assessing and addressing AYA needs (at NCCH, social workers). Other important characteristics include: • knowledge of referral pathways and relationship with providers to whom referrals will be triggered • rapport with AYAs assessment skills	○
	oncologists are primarily focused on medical concerns during patient visits		
	NCCH has two social workers dedicated to AYA patient care; AYA social workers are already doing the work of needs assessment, although informally/conversationally; AYA social workers have robust knowledge of services and resources available to AYAs		

	Appointments vary among AYAs, including some combination of the following: (1) labs, (2) imaging, (3) treatment, (4) clinical appointment	AYA NA-SB delivery should consider the various types of appointments AYAs have (i.e., labs/imaging/treatment/clinical appointment)	○
	AYA tasks are very different during outpatient visits versus inpatient stays	AYA NA-SB delivery should accommodate both inpatient and outpatient AYAs	○
	Users expressed the importance of not extending AYAs’ already long and exhausting appointments.	AYA NA-SB administration should occur during appointment waiting times	○
	AYA social workers identify new AYA patients through disease group referrals; since the referral process is not systematic, not all AYAs are reached	A process for identifying new AYA patients should be built into AYA NA-SB delivery	○
Technical & physical environment	Adult oncology appointments are scattered across the NCCH	AYA NA-SB administration should account for disparate physical locations	○
	NCCH is building an AYA-specific infusion space	AYA NA-SB could leverage the new AYA space for needs assessment administration and/or service provision, but privacy is an important consideration	○
	AYAs prefer technology, but are not averse to paper format	If possible, AYAs should have the choice to complete AYA NA-SB electronically, particularly if they are asked to complete it outside of the clinic	○
	AYAs are active users of MyChart	AYA NA-SB could interface with MyChart	
	Providers use EPIC for patient information documentation and communication across providers	If possible, AYA NA-SB should interface with EPIC, even if that just means retrospectively scanning needs assessment and uploading it	○
	AYA providers collaborate with providers across adult and pediatric oncology, and across disease groups.	AYA NA-SB should facilitate communication and the sharing of information across pediatric and adult oncology, and across disease groups	○

Organizational Environment		AYA NA-SB should specify clear referral pathways for follow-up on needs reported	
	the extent to which staff buy in to a new initiative or change is contingent upon how dramatically it impacts current workflow as well as staff members' perception of the initiative's merits.	AYA NA-SB development and implementation planning should involve key stakeholders who will interface with the intervention in practice	○
	NCCH's AYA program falls within the Comprehensive Cancer Support Program (CCSP). The CCSP has a catalogue of resources for patients and families	AYA NA-SB should leverage CCSP resources where applicable	○
	Leadership buy-in often hinges on measurable impacts	AYA NA-SB data should be documented somewhere to allow for the evaluation of its impact, and its use to inform program changes	○
	NCCH's AYA program is growing and expanding in scope		

Variation between NCCH & other institutions

Contextual feature of AYA Program	UNC	Variation
Structure	Under the umbrella of NCCH's Comprehensive Cancer Support Program which is directed by the Vice-Chair of General Hospital Psychiatry. There is not currently a designated space for AYA care. However, an AYA infusion space is in development.	• Some AYA programs have designated AYA spaces (e.g., infusion centers, inpatient centers), but some do not. • Some AYA programs are housed within pediatric oncology; some are housed within adult oncology. The extent to which there is interface between pediatric and adult oncology varies.
Staffing	Medical director; program director/social worker; social worker Patients rely on social workers for non-medical needs, saying that their oncology providers rarely ask them about non-medical concerns.	• Core members of the AYA care team vary across institutions. As such, who assesses and addresses AYAs' needs varies. A common element of those who do the work of AYA needs assessment is an expertise on the AYA population.
Funding	Foundation + grant funding	• Some AYA programs are largely health system supported, while others rely on foundation grants and other external funding.
Functions	Coordinating across disease groups and across pediatric and adult oncology to provide age appropriate services and resources to AYAs	• Some AYA programs are modeled as consultations services while others function more as their own entity
How are new AYA patients identified?	AYA social workers rely on referrals from disease group providers.	• In general, AYA programs rely on referrals from disease group providers. However, the reach of programs varies, with some AYA programs reaching every AYA patient and some only reaching a subset for whom referrals were initiated.
When and where does AYA needs assessment take place?	Although sometimes AYA social workers schedule appointments with AYAs, they often just "pop in" while AYAs are in the hospital for appointments	• AYA programs vary in the extent to which AYA visits are scheduled versus impromptu but most programs "meet AYAs where they are"
Are any standardized tools or questionnaires	AYA needs are assessed informally/conversationally by the AYA social workers	• Some AYA programs are working towards implementing distress screening/needs assessment tools

used to assess needs?		
How do providers document AYAs' needs?	Information about patient needs is stored as notes in the EHR; each provider records their own separate note for each interaction with a patient.	• Same
How do providers communicate about AYAs' needs?	Providers communicate about AYAs' needs via phone, text, email, EHR messaging, and in-person.	• Same

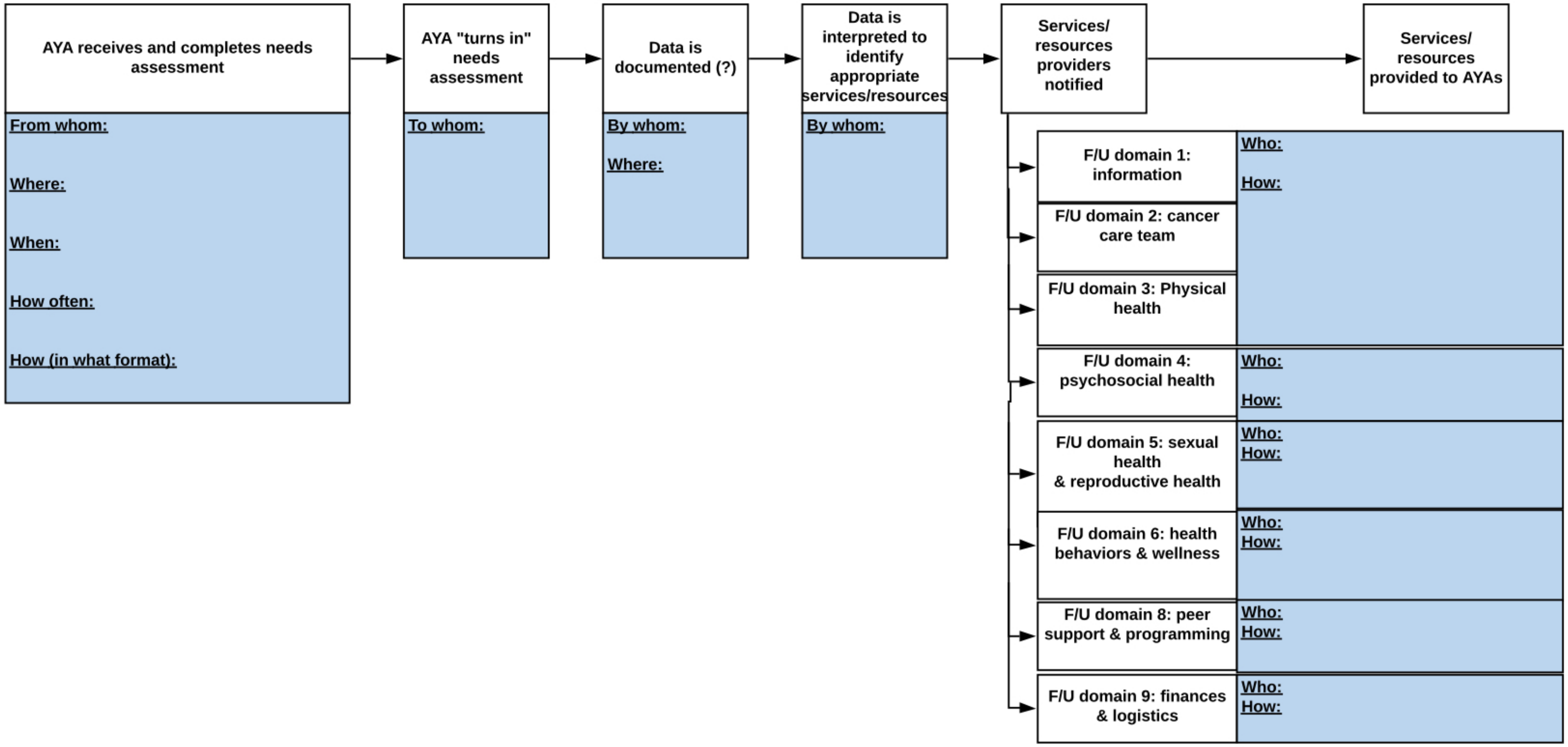
How other programs are doing it*

Stanford	Piloted a needs assessment developed in-house based on NCCN guildelines	- Offered assessment as Qualtrics survey but 9/10 patients opted to complete it on paper, in the clinic - Social worker had follow-up conversation during same visit
FWAYA	CanTeen Needs Assessment/ Distress Thermometer (month 2 of implementation)	- Child Life Specialist or nurse navigator administer paper assessment within first 2 weeks of diagnosis, at the beginning of patient visit - Child Life Specialist or nurse navigator try to get back in for follow-up conversation before doctor sees patient - Referrals made as needed o Need for referral determine based on distress score (e.g., score of 8+ automatically triggers social worker referral) - Needs assessment and referrals made documented in EPIC, with dot phrases to allow for a traceable trail - Timing of re-screening depends on distress level at initial screening (this information documented in an Excel spreadsheet) o Low distress: 6 months o Medium distress: 3 months o High distress: 1 month
University Hospitals	Trialing a Care consultation Model based on NCCN Distress Screening Tool (1 page, front and back)	- Social worker administers paper form immediately after diagnosis - Social worker waits in room while they complete and then has follow-up conversation - Pressing concerns are prioritized; takes several sessions to get through whole form - Social worker scans document into EMR - Social worker and AYA program manager review documentation daily to discuss necessary referrals/follow-up actions - If necessary, social worker follows-up with primary treatment team via email about actions made

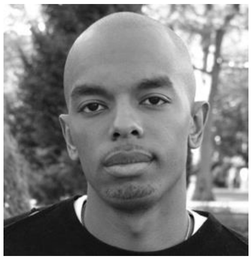
Tufts	Survivorship Needs Assessment	- Patient receives iPad when they first check in - Quick analysis of assessment before doctor sees patient o Informs doctor’s conversation o Referrals initiated on same day

* These data were elicited from semi-structured interviews with providers from other AYA programs. In some cases, providers described implementation efforts at their own institution. In other cases, they were describing implementation efforts occurring at other institutions that they were aware of.

AYA NA-SB Delivery Storyboard

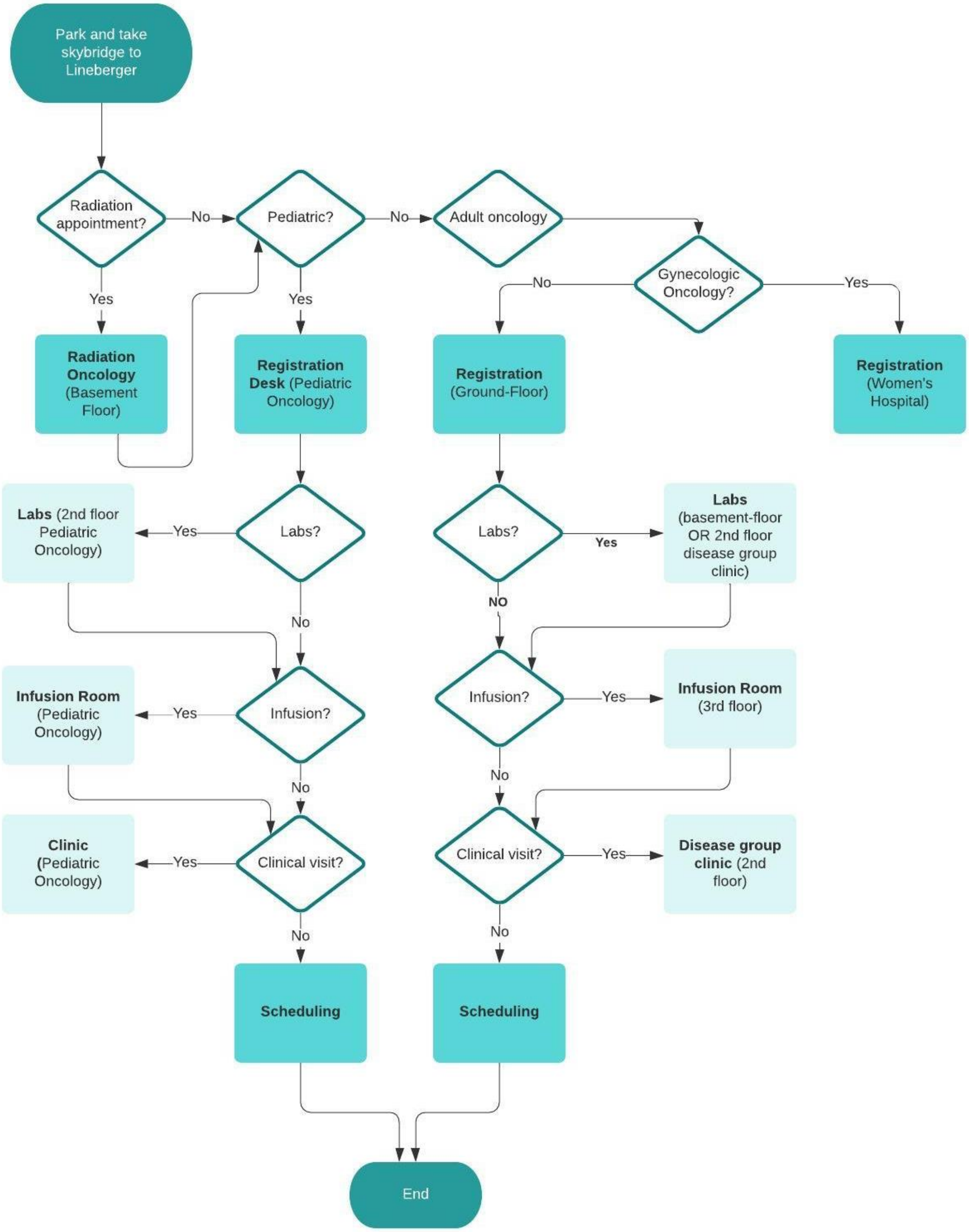


Personas

	**Bill** (frequent inpatient stays) • 22 years old • Osteosarcoma • Adult oncology • 11-week chemotherapy schedule with some off-weeks • Stays inpatient after infusion until methotrexate level falls
	**Amy** (infrequent appointments) • 25 years old • Chronic Myeloid Leukemia • Adult oncology (BMT clinic) • Maintenance treatment (oral chemotherapy) • Labs + clinical appointment every 3 months
	**Susie** (pediatric oncology) • 18 years old • Non-Hodgkin Lymphoma • Pediatric oncology • 4 three-week chemotherapy cycles → 2 months radiation
	**Matt** (quick treatment schedule) • 34 years old • Testicular cancer • Adult oncology (Multidisciplinary Clinic) • 80-day treatment schedule (4 cycles of chemotherapy)

	**Mary** (end-of-life) • 22 years old • Liver cancer • Adult oncology (Surgical Oncology)) • Monthly chemotherapy to slow disease progression • Prognosis: <1 year

Scenarios of use



Barriers to implementation

Barrier
Staffing burden
Workflow disruptions
Provider buy-in
Leadership buy-in
Patients’ time
AYAs’ bandwidth to use services/resources offered to them
Identifying new AYA patients
Variation in AYAs’ treatment and appointment schedules
Coordinating across disease groups/ disparate physical locations
Lack of centralized physical space for AYA programming
Coordinating across pediatric and adult oncology
Establishing interface with EMR/ other documentation method
Capacity of AYA social workers to respond to needs

APPENDIX I: AYA NA-SB INTERVENTION & IMPLEMENTATION GUIDANCE

AYA NA-SB

AYA NEEDS ASSESSMENT &
SERVICE BRIDGE

Intervention	Adolescent and Young Adult Needs Assessment & Service Bridge (AYA NA-SB)		
Why	To coordinate care for adolescents and young adults (AYAs) with cancer to meet their physical, psychosocial, and practical needs		
What	**AYA completes needs assessment**	**Provider interprets needs assessment data and notifies relevant service providers**	**Service providers render services to AYAs**
Materials	Needs assessment	Needs assessment Map of referral pathways	No additional materials required
Procedure	1. Needs assessment is dropped off with AYA 2. AYA completes needs assessment 3. Needs assessment is picked up from AYA	1. Provider reviews completed needs assessment to identify AYA's needs 2. For identified needs, provider notifies relevant providers using specified referral pathways, indicating the severity of need (i.e., need vs. somewhat need) 3. Provider documents identified needs and providers notified in electronic health record *(note: in the future, needs assessment will be embedded as flowsheet in electronic health record to enable more systematic documentation)*	1. Service provider provides service to AYA 2. Service provider documents services provided in the electronic health record
Who	Provider dropping off and picking up needs assessment should have an established relationship with AYAs at their institution; seeing AYAs during their visits should be part of this provider's existing workflow *(at NCCH, disease group nurse navigators)*	Provider triaging needs should have relationships with referral pathway providers; addressing AYAs' needs should be part of this provider's existing workflow *(at NCCH, disease group nurse navigators)*	Follow-up domain 1: primary cancer treatment team Follow-up domain 2: primary cancer treatment team Follow-up domain 3: primary cancer treatment team Follow-up domain 4: AYA social worker *(or other provider with AYA expertise)*

			<u>Follow-up domain 5 (items 35-36):</u> fertility coordinator <u>Follow-up domain 5 (items 37-39)</u>: AYA social worker *(or other provider with AYA expertise)* <u>Follow-up domain 6:</u> AYA social worker *(or other provider with AYA expertise)* <u>Follow-up domain 7:</u> AYA social worker *(or other provider with AYA expertise)* <u>Follow-up domain 8:</u> AYA social worker *(or other provider with AYA expertise)* <u>Follow-up domain 9:</u> outpatient social work *(note that service providers may vary depending on who provides relevant services at a given institution)*
How	Needs assessments to be administered by paper for pilot study; electronic administration will be enabled in the future	By electronic health record messaging or pager for more urgent concerns	Using existing care practices
Where	Dependent on provider's clinical judgment and existing workflow	Dependent on provider's clinical judgment and existing workflow	Dependent on provider's clinical judgment and existing workflow
When	First needs assessment is administered within 1 month after diagnosis;	Daily	Service providers should attempt to render services within one week

	subsequent needs assessments are administered at 1-month or 3-month intervals *(TBD based on feedback received during pilot test)* Needs assessment is dropped off with AYA at the beginning of their clinical appointment; exact timing will depend on provider workflow and discretion Needs assessment is picked up from AYA at the end of their clinical appointment; exact timing will depend on provider workflow and discretion.		of needs assessment for higher needs and within two weeks for moderate needs

NEEDS ASSESSMENT

1. INFORMATION

I want more information about:		Agree	Somewhat agree	I have enough information about this concern	Not sure
1	My cancer diagnosis				
2	The short-term side effects of treatment				
3	The long-term side effects of treatment				
4	What will happen when treatment finishes				
5	My disease status				
6	My test results				
7	What to do if I have side effects from my treatment				
8	How my genetics may or may not have impacted my diagnosis and treatment				

2. CANCER CARE TEAM

I want my cancer treatment team to do a better job of:		Agree	Somewhat agree	My cancer treatment team is doing this already	Not sure
9	Respecting me as an individual, not just a cancer patient				
10	Offering to talk to me in private, without my family or friends				
11	Explaining what they were doing in a way I can understand				
12	Encouraging me to ask questions				
13	Engaging me in decision-making about my treatment and respecting my decisions				
14	Asking me about my treatment concerns				

3. PHYSICAL HEALTH

I want more help with:		Agree	Somewhat agree	I have enough help with this concern	Not sure
15	Managing pain				
16	Managing my medications				
17	Managing physical side effects of treatment				
18	Managing feeling tired/ fatigued				

19	Managing loss of walking ability				

4. EMOTIONAL HEALTH

I want more help with:		Agree	Somewhat agree	I have enough help with this concern	Not sure
20	Feeling anxious or scared				
21	Feeling depressed				
22	Having what I need to cope with my diagnosis				
23	Worrying about my cancer spreading				
24	Worrying about my cancer returning or getting another type of cancer				
25	Worrying about how my family is coping				
26	Coping with changes in my dating or romantic life				
27	Coping with changes in my relationships with my family members				
28	Coping with changes in my relationships with friends				
29	Feeling independent				
30	Coping with changes in my physical ability				
31	Coping with changes in my appearance				
32	Coping with not being able to do the same things as other people my age				
33	Managing the emotional side effects of treatment				
34	Being able to make plans or think about the future				

5. SEXUAL & REPRODUCTIVE HEALTH

I want more information about:		Agree	Somewhat agree	I have enough information about this concern	Not sure
35	My risk of infertility and my fertility preservation options				
36	Treating infertility and other options for having children in the future (i.e., sperm/egg freezing, artificial insemination, in vitro fertilization, surrogacy, adoption, etc.)				
37	Sexuality and intimacy during cancer treatment				
38	Sexual side effects of my treatment (e.g., sexual dysfunction)				
39	The effects of treatment on long-term hormone changes				

6. HEALTH BEHAVIORS & WELLNESS

I want more information about:		Agree	Somewhat agree	I have enough information about this concern	Not sure
40	Nutrition				
41	Exercise or physical activity				
42	Getting enough or better-quality sleep				
43	Smoking or vaping during cancer treatment				
44	Drug or alcohol use during cancer treatment				
45	Spiritual support or resources				
46	Alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.)				

7. WORK & EDUCATION

I want more help with:		Agree	Somewhat agree	I have enough help with this concern	Not sure
47	Managing my school life while going through cancer treatment				
48	Managing my work life while going through cancer treatment				

8. PEER SUPPORT & PROGRAMMING

I want more help with:		Agree	Somewhat agree	I have enough help with this concern	Not sure
49	Being able to spend time with people my own age				
50	Being able to talk to people my own age who have been through a similar cancer treatment experience				
51	Participating in social activities				

9. FINANCES & EVERYDAY NEEDS

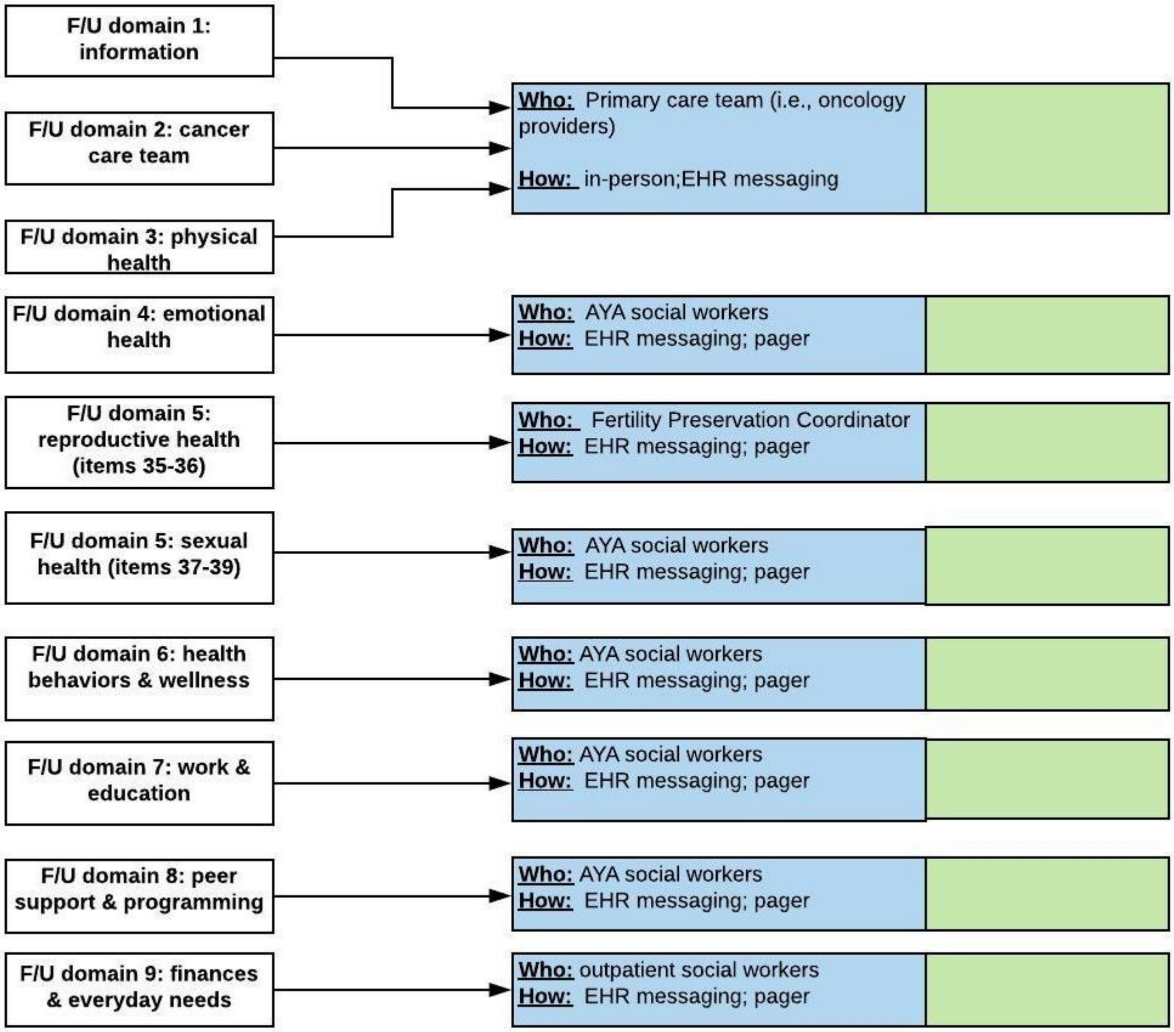
I want more help with:		Agree	Somewhat agree	I have enough help with this concern	Not sure
52	Paying my bills				
53	Scholarship or loan repayment options				

54	My health insurance (e.g., access/eligibility, coverage, cost)				
55	Getting to and from my cancer care appointments				
56	Having childcare during my cancer care appointments				
57	Having stable housing				

Please indicate anything else you want help with, below:

MAP OF REFERRAL PATHWAYS

In the green boxes, indicate the providers at your institution who best fill these roles.



IMPLEMENTATION STRATEGIES

Implementation strategy	Indicate how your institution will do this
Consider a phased-in approach to implementation, for example, by implementing within one disease group and expanding outwards	
Build buy-in by engaging in implementation planning any provider groups who will interface with AYA NA-SB in practice	
Build buy-in among leadership, emphasizing the potential benefits of AYA NA-SB for patient care, patient-provider communication, provider-provider communication, and program development	
Obtain a thorough understanding of services and resources available at your institution prior to implementation, identifying gaps that may hinder follow-up on needs reported by AYAs.	
Provide education across disease groups and identify champions within each disease group to facilitate referrals of AYAs to AYA program	
Obtain a thorough understanding of services and resources available at your institution prior to implementation, identifying gaps that may hinder follow-up on needs reported by AYAs on the needs assessment. For identified gaps, bolster existing services or tailor the needs assessment to address the subset of needs that your institution has the capacity to address.	
Explicitly outline referral pathways for each follow-up domain, identifying primary contacts, current workflow, and best method of communication for service/resource providers.	
Where possible, leverage existing communication and documentation channels in AYA NA-SB delivery. Modify communication and documentation processes as needed to allow for, at a minimum, traceable documentation of follow-up on needs.	
Leverage staff who are currently assessing and addressing the needs of AYA patients at your institution and thus, have the necessary expertise and time allocated towards these tasks.	
Identify approach for ensuring that services and resources are provided in a timely manner once needs are identified.	
Use pilot testing to tailor AYA NA-SB to your institution, for example, to:	

- Make additional refinements to the needs assessment tool to tailor it to your institution - Determine frequency of needs assessment administration that makes sense in your institution (1 month versus 3 months) - Map out changes needed to your institution’s EHR to facilitate systematic documentation	

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