



# MyPref: pilot study of a novel communication and decision-making tool for adolescents and young adults with advanced cancer

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## Abstract

**Purpose** Adolescents and young adults (AYAs) with cancer report feeling ill-informed about their cancer treatment options. Tools are needed to inform AYAs about treatment choices and amplify the AYA's voice in medical decision-making. We developed *MyPref*, a conjoint-analysis based tool that quantifies AYA preferences for future cancer treatments.

**Methods** We conducted a staged pilot study of *MyPref* utilizing an intervention mixed methods design. AYAs and their parent or trusted person (PTP) completed *MyPref* and received a summary report of their preferences for treatment-related factors. Participants later completed the Preparation for Decision Making Scale and *MyPref* Experience Questionnaire and engaged in semi-structured interviews. Oncologists reported on the perceived accuracy and utility of *MyPref*. We used a weaving technique for presenting mixed methods data.

**Results** Fifteen AYAs with advanced cancer, 7 PTPs, and 12 providers participated in this pilot; 32 (94%) completed all study items. AYA/PTPs stated study participation was useful and believed *MyPref* allowed for improved understanding of treatment factors and consideration, organization, and visualization of preferences. All providers agreed that *MyPref* made them think about patient's preferences and 9 (75%) reported they planned to change their approach to discussions about preferences for future treatments.

**Conclusion** *MyPref* is an objective way to estimate AYA and PTP preferences for future treatment characteristics. This novel tool may be a useful way to engage AYAs and PTPs in discussions around preferences for treatment and prepare AYAs for future decision-making. We are currently evaluating this tool longitudinally to determine the impact on actual treatment decisions.

**Keywords** Adolescents and young adults · Pediatric oncology · Decision-making · Communication · Advanced cancer

## Introduction

Despite substantial advances in oncology, up to 1 in 5 adolescents or young adults (AYA) will die from cancer [1]. AYAs

with advanced cancer face multiple treatment decisions throughout their illness course; a study of hospitalized AYAs with cancer found 43% of patients received 4 or more treatment regimens prior to death [2]. These patients and their

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parents or trusted persons (PTPs) make treatment decisions often without identification of preferences and priorities for care. The advent of new therapies has further increased the number and type of options available [3]. Given the experimental nature of many of these new treatment options, the potential benefits and burdens may be unknown, increasing the uncertainty faced by patients and families. Each treatment has a unique risk and benefit profile, which can lead to the need to trade one desirable outcome for another. Adding to the complexity of this decision, stakeholders (AYAs, PTPs, and providers) likely characterize and value the risk/benefit ratios differently.

Two-thirds of AYAs desire an active role in decision-making, yet they report not feeling well informed about their options [4]. The evolving paradigm of oncology treatment and the multiple, complex medical decisions faced by patients therefore require the development and use of novel tools to amplify the AYA's voice and role in decision-making. We propose that these tools must allow for explicit consideration of the various treatment factors, identification of the most important factors, support for patients as they uncover their own views about relative risk/benefit trade-offs and provision of tools to communicate these preferences with others. To our knowledge, there are no available clinical decision-making tools for use by AYAs with cancer and their families.

To address this need, we developed *MyPref*, an adaptive conjoint analysis (ACA)-based decision-making and communication tool. The conjoint analysis methodology assumes that each respondent chooses the option with the combination of attributes that gives him/her the highest utility. [5] ACA can be used to measure preferences in the face of multiple tradeoffs and provide a summary of preferences in real time [6]. Conjoint analysis-based interventions in adults have been shown to improve patients' knowledge of the risks and benefits of different treatment options, leading to improved shared medical decision-making [7, 8]. However, this methodology has not previously been used in AYAs or in patients with advanced cancer.

We have previously described the iterative, step-wise process for developing *MyPref* [9]. The tool asks participants to consider a situation in which their current treatment is no longer working. By allowing AYAs to consider their preferences using a hypothetical situation at a time of clinical stability, we hypothesized that AYAs, even those with a deep sense of immortality, may be willing to explore their preferences for future treatments. By outlining factors involved in treatment decision-making and using ACA methodology to consider trade-offs involved in treatment options, we further hypothesized that AYAs would have improved insight into their preferences and be better able to communicate those preferences and make medical decisions. *MyPref* is novel in three ways: it is designed specifically for AYAs, it provides immediate information about patient preferences, and it can be used to aid in communication between patients and family

members and to help with decision-making around further cancer treatment.

We conducted a single-arm, pilot study of *MyPref* in AYAs with advanced cancer, their PTPs, and oncology providers and assessed the utility of *MyPref* with a mixed methods design. A separate paper describes the preferred role in decision-making and preferences and priorities of AYAs and their PTPs identified using *MyPref* [10]. In this analysis, we sought to examine the clinical usefulness of *MyPref*, exploring if *MyPref* can help prepare AYAs to make medical decisions, if summary reports are understandable and useful in augmenting communication and decision-making, and the optimal timing of completion of *MyPref* during the treatment course.

## Methods

### Study recruitment and enrollment

Study methods have been described in full elsewhere [10]. Eligible participants included English-speaking patients aged 15–30 with a diagnosis of cancer that had progressed despite initial therapy. Patients were approached at a time of clinical stability, in which they had been on their current treatment regimen for at least 2 weeks without plans for routine radiographical evaluation in the upcoming 2 weeks. Eligible AYAs identified one PTP that may be helpful in decision-making, or they could participate alone. Informed consent was obtained from each participant. AYAs under 18 provided assent for enrollment and their legal guardians provided consent. The *MyPref* tool was initially piloted with 5 AYAs and their PTPs with resultant changes to the survey layout and design. Thereafter, we enrolled 10 additional AYAs and their associated PTPs.

Oncology providers were invited to participate if their patient participated in *MyPref*; additional oncologists were invited based on their clinical or research expertise. Eligible providers were sent an email inviting them to participate and verbal consent was obtained prior to the recorded interview.

### Study procedures

Participants independently completed the *MyPref* on a tablet computer; an RA was present to answer questions. Sawtooth™ software ([www.sawtoothsoftware.com](http://www.sawtoothsoftware.com)) was used to administer the survey and results. Participants received gift cards for participation.

Participants completed demographic questions and the Control Preferences Scale (CPS) [11] prior to the ACA survey. To introduce *MyPref*, participants were asked to imagine a situation in which their cancer/child's cancer is no longer responding to treatment and to consider the types of things

that would be important. Participants were then provided a list and description of the nine treatment attributes identified during study development [12]. After initial consideration of attribute preferences, participants were presented with a series of 12 unique combinations of attributes and asked to identify their preferred treatment and strength of preference. Estimates of the respondent's preferences were automatically updated after each question and used to generate a new combination of treatments to consider. Upon completion, participants received a printed version of their *MyPref* Summary Report, which included estimated calculated attribute importance, scaled from 0 to 100, with higher numbers indicating greater degree of preference. An example version of *MyPref* is available in Online Resource 1.

Approximately 1–2 weeks later, participants completed the Preparation for Decision-making (PrepDM) scale [13], the *MyPref* Experience Questionnaire (MPEQ), and participated in an audio-recorded semi structured interview. The interview guide further queried the domains assessed in the MPEQ and examined the participant's experiences with *MyPref*, clarity of the MPEQ, and how and in what ways the tool may be used.

Oncologists that agreed to participate were sent an example version of the *MyPref* to review. They met separately with the study investigator (JS) and completed the provider version of the MPEQ and participated in a recorded semi-structured interview, with a focus on the clinical utility and applicability of *MyPref*. Providers of AYAs that completed *MyPref* were shown a copy of their patient's *MyPref* Summary Report and asked to comment. Providers without paired AYA participants reviewed a generic Summary Report. This study was approved by the Dana-Farber Cancer Institute Institutional Review Board.

### Study instruments/outcomes

MPEQ participant-specific versions were developed de novo to characterize the utility and effectiveness of *MyPref* in decision-making and communication based on the International Patient Decision Aid Standards (IPDAS) Collaboration [14]; additional questions were adapted from surveys used in the PediQUEST trial [15]. The MPEQs addressed ease of understanding, accuracy, usefulness of *MyPref*, communication of preferences between patient/parent and patient/parent/provider, and potential stress or benefit experienced from participation. Participants also completed the 10-item, validated PrepDM scale, a tool commonly used in decision aid trials, to assess the utility of *MyPref* in preparing the patient to communicate with their healthcare provider and to make a healthcare decision [13].

### Analysis

MPEQ participant responses were measured on a 5-point Likert scale (1 = strongly disagree, 3 = neutral, 5 = strongly

agree) and used as a continuous variable in analyses. PrepDM scores ranging from 1 to 5 (correlating with answers not at all, a little, somewhat, quite a bit, and a great deal) were summed with higher scores indicating higher perceived preparation for decision making. We used a weaving approach to combine quantitative results with qualitative findings [16], focused on key domains of interest, perceived utility, and benefit.

Thematic analysis of interview transcripts was conducted utilizing both inductive and deductive approaches [17, 18]. An interdisciplinary team (GH, JS, AR) collaboratively and iteratively developed a comprehensive codebook. Initial coding was inductive, starting with open-coding, combined with prefigured codes from the interview guide. Two unique codebooks were developed to analyze participant interviews, one for the AYAs/PTPs and a second for oncology providers. The AYA/PTP codebook had 8 main domains, and the provider codebook included the same domains and included perspectives on integration of *MyPref* into practice. Each transcript was independently coded by two team members (GH, JS); the coders engaged in reflective discussion to resolve differences and refine codes until consensus was reached. Thematic analysis was also a collaborative team-based process that identified key impressions, contexts, and patterns across participants in relation to *MyPref*. An audit trail including coding dictionary and codebook adjustments was maintained to allow for scrutiny of the analytic process. Ethnographic software (NVivo 12) was used for data management and to facilitate analysis.

## Results

### Participant demographics

Thirty-four participants were enrolled, 15 AYAs, 7 PTPs, and 12 providers; 31 participants completed all study requirements. Thirty potentially eligible AYAs were identified. Table 1 includes demographic data for enrolled participants by group. Thirteen of the 15 AYAs (87%) that completed *MyPref* completed follow-up surveys, 1 died and 1 was lost to follow-up. No patients experienced further disease progression between *MyPref* and completion of follow-up study items. The median AYA age was 20 years (range 15–28). Most AYAs were male ( $n = 12$ , 80%), with a solid tumor ( $n = 9$ , 60%). AYAs had been on treatment 17 months on average. Nine AYAs identified a PTP; two PTPs were not available to participate. Of the 7 enrolled PTPs most were mothers (86%), white (71%), with some higher education. All PTPs completed follow-up items. Of the 15 providers invited to participate, 12 (80%) enrolled and completed all study items. Oncology provider participants were primarily female (80%), under 50 years old, had been in practice for

**Table 1** Participant demographics for pilot study of *MyPref*

Adolescents or young adults ( <i>N</i> = 15)			Parents or trusted person ( <i>N</i> = 7)			Oncology providers ( <i>N</i> = 12)		
	Median	Range		Mean	Range			
<b>Age</b>	20	15–28	<b>No. of months child has been receiving treatment</b>	17	3–42			
	<i>N</i>	%		<i>N</i>	%		<i>N</i>	%
<b>Gender</b>			<b>Gender</b>			<b>Gender</b>		
Female	3	20	Female	6	86	Female	9	80
Male	12	80	Male	1	14	Male	3	20
<b>Race</b>			<b>Race</b>			<b>Age range</b>		
White	11	69	White	5	71	31–40	7	58
Hispanic or Latino	3	20	Hispanic or Latino	2	29	41–50	3	25
Other	1	6				50+	2	17
<b>Cancer diagnosis</b>			<b>Marital status</b>			<b>Years of experience in pediatric oncology (including training)</b>		
Solid tumor	8	53.3	Married	4	57	0–4	2	17
Hematological malignancy	2	13.3	Divorced	3	43	5–9	5	42
Central nervous system tumor	5	33.3	<b>Education</b>			10–14	1	8
<b>Place of residence</b>			High school graduate	1	14	15–19	2	17
Boston or surrounding area	10	67	Some college	3	43	20+	2	17
Outside of Boston	4	27	Bachelor's degree	1	14	<b>Area of interest/practice within oncology</b>		
International	1	6.7	Master's, Ph.D., law, or medical degree	2	28	General oncology	1	8
<b>Severe Side Effects from Treatment?</b>			<b>Employment Status</b>			Solid tumors	4	33
Yes	12	80	Currently employed	3	43	Brain/central nervous system tumors	3	25
No	3	20	Self-employed	2	28	Leukemia/lymphoma	3	25
<b>Role of identified trusted person</b>			Out of work and not looking	1	14	Bone marrow transplant	1	8
Mother	8	53	Unable to work	1	14			
Father	1	7	<b>Total household income</b>					
No trusted person identified	6	40	Less than \$25,000	1	14			
			\$50,000 to \$74,999	2	28			
			\$100,000 or more	3	43			
			Prefer not to answer	1	14			

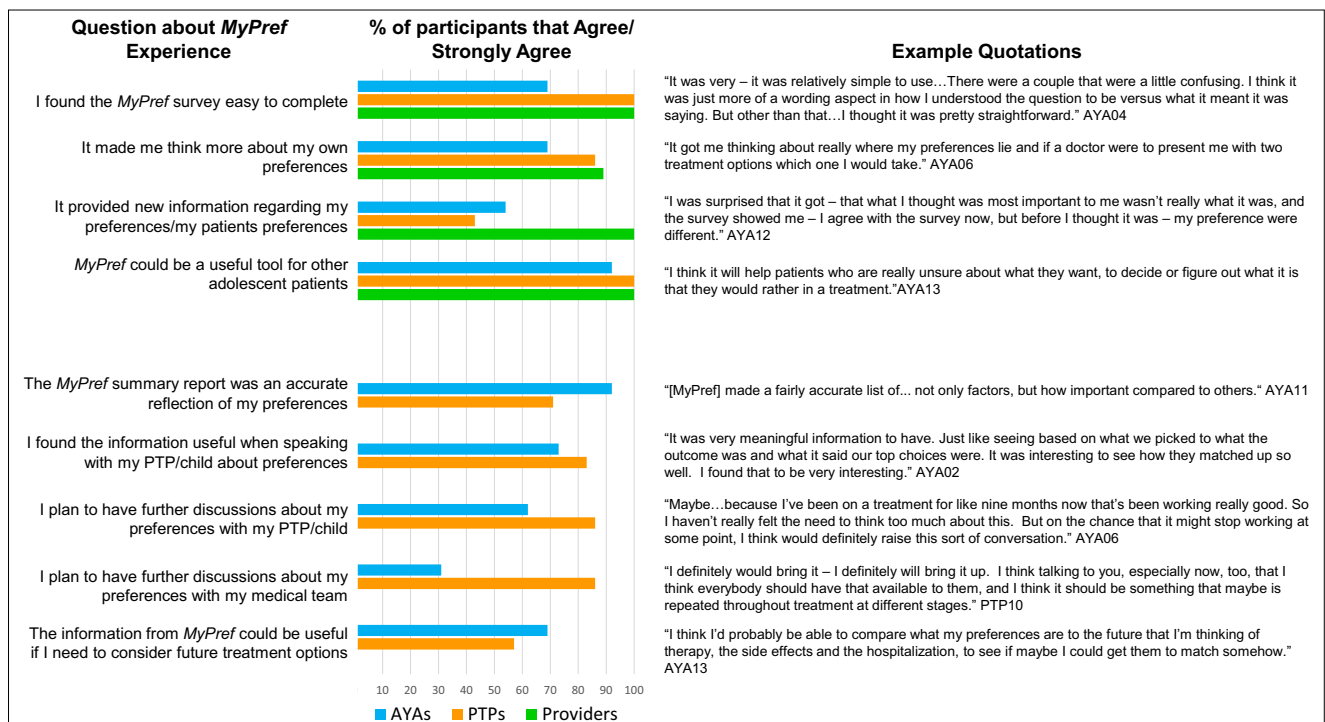
10 years or less, and had variable areas of practice in oncology.

### Experience with *MyPref* and timing of use

All AYAs and PTPs completed *MyPref* in one sitting with minimal assistance, with an average time of 28 min. All participants reported that the *MyPref* calculated preferences were an accurate reflection of their beliefs. Figure 1 shows participants' responses to select MPEQ questions with representative quotes from follow-up interviews. While almost all AYAs and PTPs agreed that the survey was easy to complete, a few stated that certain phrases were difficult to understand or that it was helpful to have a study team member present to answer questions. All but two participants stated that this tool would be helpful to repeat again later (2 strongly disagreed/

disagreed, 5 neutral, 13 agreed/strongly agreed). However, the interviews revealed that participants differed in opinion on when and how often *MyPref* should be repeated. Most emphasized the importance of repeating *MyPref* if a new treatment decision needed to be made, while several others thought there was benefit to repeating regularly regardless of clinical changes.

Provider responses to select MPEQ questions are summarized in Fig. 2. Three providers reviewed their patient(s)' *MyPref* summary reports during the interview; all agreed that the summaries matched their own impressions of their patient's priorities, while also noting the summary reports provided new information based on their MPEQ responses. Overall, all participants (13 AYAs, 6 PTPs, 12 providers) rated *MyPref* as helpful, with 23 (74%) characterizing it as 'quite a bit' or 'very helpful.'



**Fig. 1** Participant responses to select questions from the MyPref Experience Questionnaire with example quotations from follow-up interviews. Includes all pilot participants that completed follow-up

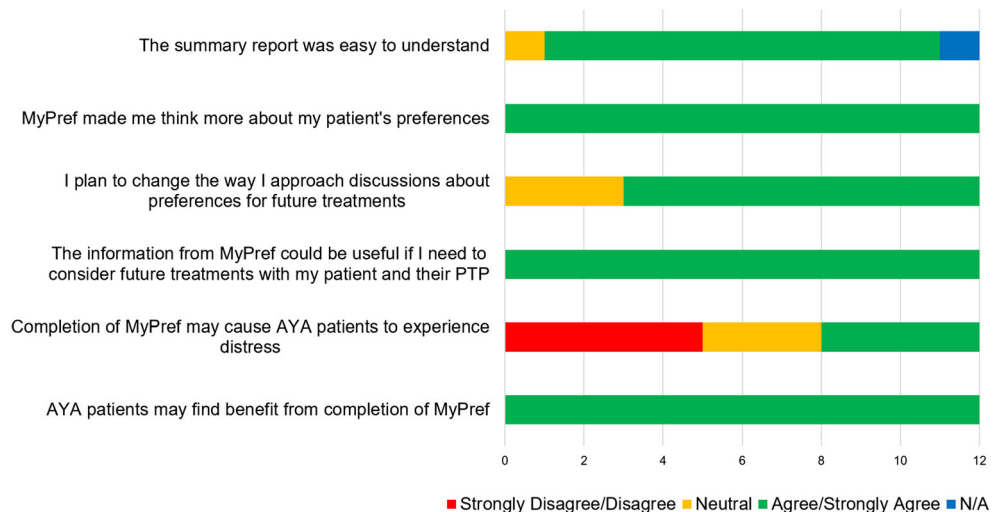
items,  $N = 13$  adolescents and young adults (AYAs),  $N = 7$  parent or trusted person (PTP),  $N = 12$  oncology providers

### Benefit, clinical utility, and integration of MyPref into practice

Almost all AYAs and PTPs reported experiencing benefit from study participation (3 neutral, 17 agreed/strongly agreed). Interviews indicated participants found benefit primarily through three mechanisms: being more aware of, learning new or meaningful information about, and starting conversations with others regarding their preferences. Only one participant experienced stress due to participation. All participants agreed that MyPref would be useful for other AYAs.

AYA and PTP MPEQ responses indicated that participants believed MyPref was useful in communicating with others around preferences for future treatments. Seventeen of the AYAs and PTPs had spoken with their parent/child about MyPref at some point between survey completion and follow-up; 13 (76%) agreed/strongly agreed that the information from MyPref was useful in this communication. Five AYAs had spoken with their medical team after completion of MyPref, 4 of these (80%) agreed/strongly agreed that information from the survey was useful in this conversation. Thirteen AYAs/PTPs (65%) agreed/strongly agreed that

**Fig. 2** Oncology providers' responses ( $N = 12$ ) to select items on the MyPref Experience Questionnaire



*MyPref* results could be useful if they needed to consider a new treatment in the future; 6 participants indicated a neutral response.

All 12 (100%) providers agreed that *MyPref* made them think more about their patient's preferences, the information from *MyPref* could be useful if they needed to consider future treatment options with their patient, and that other patients may find benefit from *MyPref* (Fig. 2). Nine of the 12 providers (75%) noted they planned to change the way they approach discussions about preferences for future treatments because of *MyPref* (6 agreed, 3 strongly agreed).

AYA/PTP participant's responses to PrepDM are summarized in Fig. 3. All 20 participants (13 AYAs and 7 PTPs) thought *MyPref* prepared them to make a better decision and helped them organize their thoughts, think about how involved they wanted to be in decision-making, identify questions to ask, and prepare for future conversations with their doctor. Most also thought *MyPref* helped them realize a decision needs to be made, think about pros/cons of each option and helped them know that the decision depends on what matters most to them.

The eight codes and example quotations from interviews describing how *MyPref* could be used clinically by AYAs and PTPs are presented in Table 2. Generally, participants believed *MyPref* facilitated consideration, organization, and visualization of preferences and improved understanding of both the factors involved and treatment options. Most AYAs and PTPs thought there was benefit in completing *MyPref* as a dyad, allowing for comparison of preferences. Finally, AYAs and PTPs noted that completion of *MyPref* may help prepare AYAs to follow-up with their providers and be more engaged.

For example, a PTP noted, “[laughs] [cries] – It opened up a conversation that needed to be opened. To not think about the what-ifs before they happen is not really a wise thing to do because then you're just in such an emotional state that it's

hard to make a true informed decision because your emotions are taking over. So, having it down on paper and having a conversation with your family about it, you've already broached the subject and it's going to be easier in the long run.”

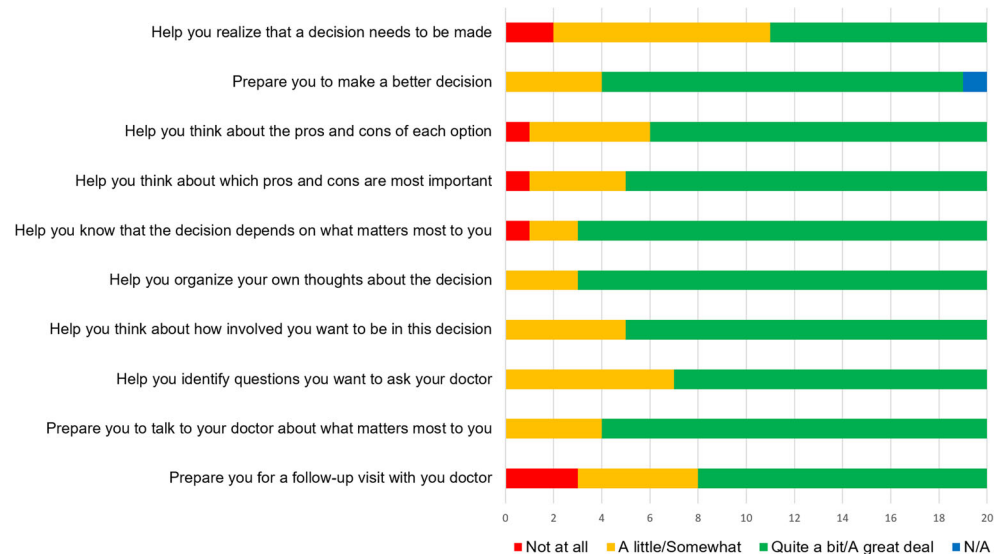
All participant groups identified that *MyPref* may help providers to better understand or confirm previous knowledge of the patient's preferences. Moreover, *MyPref* provided a way to initiate and structure conversations about priorities, engage AYAs in longitudinal discussions about preferences, and prepare patients for the possibility of further disease progression.

The codes describing how *MyPref* could be used clinically by oncology providers were grouped into three themes: *mypref* helped to “identify and understand preferences and priorities,” “augment communication with patients and families,” and “support decision-making.” The codes related to the first theme are presented in Table 2 given their overlap with concepts identified in AYA/PTP interviews. Table 3 includes the codes from the latter two themes. Providers saw *MyPref* as a tool to ascertain prognostic understanding and create time and space to reflect on the current treatment plan and if and how this aligns with identified preferences. Finally, providers noted that *MyPref* could be used to discuss postponing or halting further cancer-directed treatment for patients in which their preferences clearly did not align with available options.

## Discussion

Participants found *MyPref* easy to complete and useful in helping them think about their preferences. Most AYA/PTPs believed *MyPref* could augment communication around preferences and that completion of *MyPref* by both individuals allowed for comparison of preferences. AYAs and PTPs also indicated that *MyPref* helped them prepare to make a decision and to follow-up with the doctor, even though they were not

**Fig. 3** Adolescent and young adult ( $N=13$ ) and parent or trusted person ( $N=7$ ) participant responses for the Preparation for Decision Making (PrepDM) scale



**Table 2** Codes and example quotations related to how *MyPref* could be used clinically by adolescents and young adults and their parents or other trusted persons

Code	Example quotation
Elicit, consider, and understand preferences	“Just deciding what’s more important for me, like quality of life or time until cancer grows, sort of that that I favored more.” AYA05
Understand and consider treatment options	“I think it would be helpful if we were faced with another big decision to make. I could see it being a useful tool to compare the pros and cons in different situations and come up with our preferences.” PTP05
Examination, comparison, and discussion of others’ preferences	“I think that, especially in cases of discordance, when people sort of maybe disagree, that it might be helpful to say, your child really values being at home, and I know that you have heard that but they have said that they rather be at home even at the cost of their cancer growing, which we hope that that’s not the cost, but that’s how important it is to them and let us reframe our conversations thinking about the things that are most important to them too.” Provider304
Visualization of preferences; resource for future use	“I mean it’s another resource that gives – and it’s more understandable than doctors throwing a lot of things at you, something you can kinda look at.” AYA04
Space and time to consider preferences	“I think some adolescents have trouble verbalizing what their preferences are or they are able to but they so easily get overpowered by what their parents’ preferences are.... Yeah, I think it might be easier for them. Not only to understand their own preferences through this but also to express them in a safe space. Whereas in the clinical encounter there’s a lot of dynamics.” Provider302
Organize thoughts and provide framework for thought process	“Because I basically had to do this, this same exact survey you gave me, in my head. Without having a survey. I wish I had something like this to slow me down and help me break down my thoughts and see what really mattered to me at this point, you know? So, it’s gonna help, it does help.” AYA15
Empower AYAs in their care	“Well, me personally, I’d kinda feel like I would be able to see this and be like, oh – now that I’m more aware of what’s important to me, feel like I could go up to a doctor.” AYA11
Understand the factors involved in treatments	“Just some of the actual preferences; side effects, quality of life, time until cancer grows. That was kind of unique because that’s something I do not really think about.” AYA05
Assess understanding of cancer prognosis*	“And we are never – we are not really ever in a position where this information would not be helpful. Right? Like it would say – it would really identify if there was complete misunderstandings about reality versus prognosis – like I want to have no side effects and live 12 more months. And that’s another opportunity to be like, okay, let us reset and understand....So I think you could actually really identify if there was big differences in expectations and prognosis.” Provider311
Reflect on current care*	“I think there’s also a scenario where sometimes it’s appropriate to make changes even when it’s not because the treatment seems to not to be working from a cancer standpoint. I think sometimes it’s very appropriate to say wow – especially in this context where we are probably outside of the standard of care in pretty much everyone. Wow, I see here that being at home is really important to you and gosh we have been bringing you into the hospital every week for this cycle. Is it okay that we are doing this?” Provider310

\*Indicates code that was only identified in transcripts from oncology providers, not in AYA/PTP interviews

Abbreviations: AYA, Adolescent and young adult; PTP, parent or trusted person

facing an actual decision. Notably, less than half of the AYAs identified a PTP to participate in *MyPref*. This may indicate that AYAs may be or feel more alone in their decisional approach than previously recognized.

Providers noted that *MyPref* may be useful in initiating early discussions about preferences with AYAs that can be readdressed over time and to broach the ‘what ifs’ to help prepare patients for the possibility of further disease

**Table 3** Themes, codes, and example quotations related to how *MyPref* could be used clinically by oncology providers

Theme	Code	Example quotation
Augment communication with patients and families	Catalyst and framework for discussions about preferences	“Because I think when we have these difficult discussions with young people, often we do not tease out these issues, whether they be separate or in packages, we often focus on what treatments we have available. What may or may not be palatable to that young person? But I can think of very few situations in which I’ve even mentioned to the patient, how much would you be willing to go to another institution? ...And so, having this, I think, could just – it could be the backbone of a really important discussion. One in which – it’s clear that each person will factor each of these things differently.” Provider305
	Reassess preferences and priorities over time	“It’s interesting. And I sort of – so, I think the idea that people change their mind is definitely true. And so, I think it’s interesting to sort of do this at a time of stability when a lot of this is just talking, right? Like, quality of life and side effects is just talking about. And for my patient, I think it had been long enough ago that she remembered it, but not really. And I think once she started having the side effects and the unexpected admissions and everything that both her and her mom said, okay, this actually sucks a lot more than we remember. And so, I think if she filled out the survey at two different points, then her results would be quite different and I think you could do that. You could have somebody at stability fill it out. And then, somebody in sort of after relapse who say they have gotten a few and you could say like, sometimes people change their mind; this is what you said before. But it helps people to reassess. And then, have them fill it out then and see.” Provider304
	Prepare for the future	“It’s tricky because you wanna have some of these conversations ahead of time, so that you are not necessarily making decisions in that heightened stress time. You just pulled the rug out from under them because a scan is bad. You want them to know what the potential outcome is gonna be and what’s important in that interval. And I can think of some of my patients where we kinda did not have a chance to have that conversation...” Provider306
Support decision-making	Framework for discussion or presentation of treatment options	“So, I liked that this built in hospitalization versus not hospitalization, oral versus IV, changing a hospital, not changing – because these are things that we always think about. And not to limit the choices that we offer them, but maybe to change the order a little bit. And maybe look – if I have a patient who says, it’s really important that I’m not doing more IV stuff, but I’m okay going to another hospital. Maybe I’m looking at [another location], or some nearby hospitals, or even far away hospitals that are offering other experimental trials that are oral, versus something that they could – is just as experimental here but is an IV formulation. Kind of – I think it would not necessarily change the options that I give, but somewhat the order.” Provider306
	Introduce/discuss option of no further cancer-directed therapy	“Yeah. I guess I do not feel like I do a good job of it. I do not think we, as pediatric oncologists do a good job of that. And this may make it easier to broach that possibility. It should not – you should not offer no cancer-directed therapy because these things do not align. But it might give you a nice way to get to that in the discussion.” Provider302
	Create a safe space for AYAs to decline options provided by team	“This could be helpful for me, because I – particularly with adolescent patients it is – and I do not know if it’s just unique to my practice, but it is – I have struggled with creating an environment where I think the patient wants to say no, but they are not saying no. And I do not know if that’s like .... Whatever it is it’s – but it’s like I want to invite them to be honest and open and – but I do sense that there’s some hesitancy to saying, I’m done, Dr. [Last Name]...” Provider311

progression [19]. By providing a time and space to contemplate, compare, and discuss their preferences when less emotionally stressed, AYAs may be better prepared to engage in decision-making later. *MyPref* was seen by providers as a way to structure conversations around treatment options, including more explicit and focused discussion around risks and benefits that matter most to the patient. Furthermore, AYAs, PTPs, and providers also noted *MyPref* could be used to assess the

current treatment and discuss ways it does or does not align with identified preferences.

For patients whose preferences clearly do not align with available treatment options, *MyPref* may provide an opportunity to discuss discontinuing further cancer-directed treatment, perhaps earlier on than this would have otherwise been considered. Conversations linking *MyPref* identified preferences with larger goals for care may be useful in promoting



advanced care planning in this population. Importantly, providers also indicated that *MyPref* may allow AYAs to identify their own preferences separate from the influence of their parents, other family members, and medical team and even empower them to decline treatment offered if the treatment does not align with their preferences.

Notably, participants identified several barriers to integration and use of *MyPref* in clinical settings. First, they did not agree on the ideal time to use *MyPref*. While many AYAs and PTPs indicated the best time would be around an actual decision, they also noted that timeframe is highly stressful. Some providers thought *MyPref* would be best completed at a time in which there is no treatment decision to allow patients and family members to think about preferences in a less emotional context. However, other providers were concerned about causing distress for patients and families by asking them to consider a time in which the cancer had progressed.

There may be differences in how and when to utilize *MyPref* based on the cancer type, given distinctions in treatment options and timelines. For hematologic malignancies, decisions around a new treatment are often made quickly after relapse. It may not therefore be feasible to use *MyPref* before making a treatment decision. Also, this study did not evaluate if preferences change over time (i.e., are preferences different in a hypothetical scenario compared with when facing a real treatment choice?) Based on clinical experience and the feedback from participants, we recommend that *MyPref* be introduced when there is not an upcoming decision, allowing consideration of their preferences at less stressful time. If the patient's cancer progresses or relapses, AYAs/PTPs should be offered the chance to repeat *MyPref* to examine if preferences are stable over time; new summary reports can be used in discussion around treatment decisions. We are currently conducting feasibility study of this two-phased approach to *MyPref* in AYAs with advanced cancer.

One provider highlighted that translating the information from the summary report into a clinical decision may be difficult. For example, predicting the amount of time until cancer grows can be challenging as the efficacy of many treatments may be unknown. Additionally, AYAs and PTPs may express almost near equal preference for options that may be dichotomous (e.g., time until cancer grows and side effects).

Lastly, the findings of this study may be limited given the lack of racial and ethnic diversity in the participants as well as the single-institution pilot study design. Despite these limitations, we believe that *MyPref* provides an important insight into the preferences of AYAs and seems to be useful to patients, parents, and providers alike.

## Conclusion

AYAs with advanced cancer require tools to help them engage and actively participate in their cancer care. The results from

this pilot study indicate that *MyPref* may be useful in allowing AYAs time and space separate from their parents and medical team to contemplate future treatments and the relative importance of the factors under consideration. This tool not only allows AYAs and their PTPs to consider, organize, visualize and better understand their preferences but also may be helpful in initiating and conducting conversations with others around preferences and priorities. *MyPref* may be a useful way for providers to engage and empower AYAs during conversations over the disease course and help prepare them to make future medical decisions. Incorporating feedback from pilot participants, we began enrolling participants in a two-phased examination of *MyPref* including use around an actual treatment decision in July 2020.

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## Compliance with ethical standards

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

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