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ORIGINAL ARTICLES

Development of a Stakeholder Driven Serious Illness Communication Program for Advance Care Planning in Children, Adolescents, and Young Adults with Serious Illness

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Objectives To develop a generalizable advance care planning (ACP) intervention for children, adolescents, and young adults with serious illness using a multistage, stakeholder-driven approach.

Study design We first convened an expert panel of multidisciplinary health care providers (HCPs), researchers, and parents to delineate key ACP intervention elements. We then adapted an existing adult guide for use in pediatrics and conducted focus groups and interviews with HCPs, parents, and seriously ill adolescents and young adults to contextualize perspectives on ACP communication and our Pediatric Serious Illness Communication Program (PediSICP). Using thematic analysis, we identified guide adaptations, preferred content, and barriers for PediSICP implementation. Expert panelists then reviewed, amended and finalized intervention components.

Results Stakeholders (34 HCPs, 9 parents, and 7 seriously ill adolescents and young adults) participated in focus groups and interviews. Stakeholders validated and refined the guide and PediSICP intervention and identified barriers to PediSICP implementation, including the need for HCP training, competing demands, uncertainty regarding timing, and documentation of ACP discussions.

Conclusions The finalized PediSICP intervention includes a structured HCP and family ACP communication occasion supported by a 3-part communication tool and bolstered by focused HCP training. We also identified strategies to ameliorate implementation barriers. Future research will determine the feasibility of the PediSICP and whether it improves care alignment with patient and family goals. *(J Pediatr 2021;229:247-58)*.

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Growing numbers of children, adolescents, and young adults are living with serious illness such as congenital anomalies, metabolic disorders, cystic fibrosis, neurodegenerative diseases, prematurity sequelae, and cancer.[1-4] For many, early death is an inevitable outcome of their disease, making advance care planning (ACP) a key component of optimal care. ACP, which involves communication about prognosis and formulation of care plans to honor patient and family goals, has been shown to facilitate shared decision making, adaptation to illness realities, and improved quality of life throughout the trajectory of a serious illness.[5,6] ACP is also an important determinant of high-quality end-of-life (EOL) care among adults with serious illness, and adolescents with HIV, and cancer.[7-13] In patients with serious illness, ACP is also associated with superior parent-reported outcomes including improved preparedness for their child's EOL, the ability to plan their child's location of death and superior child quality of life at EOL.[14] Additionally, ACP that includes assessment of family goals is associated with both a decrease in perceived child suffering and parental decisional regret.[14]

Interest in ACP is high, with parents indicating that the opportunity for ACP was a poorly met need.[14-20] Parents of seriously ill children desire earlier, longitudinal ACP opportunities, by both pediatric subspecialists and primary care clinicians.[14,18] Unfortunately, ACP discussions often occur too late and typically during an acute clinical deterioration where there is insufficient time to consider a family's goals and values.[15,21] Additionally, many pediatric health care providers (HCPs) who are not palliative care subspecialty trained report a lack of ACP communication training.[15,16,22,23]

ACP	Advance care planning
BCH	Boston Children's Hospital
EMR	Electronic medical record
EOL	End-of-life
HCP	Health care provider
PediSICG	Pediatric Serious Illness Conversation Guide
PediSCIP	Pediatric Serious Illness Communication Program
SCIP	Serious Illness Care Program

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Successful ACP interventions establish processes for approaching medical decisions, which are updated longitudinally throughout the illness course, and account for patient and family goals and values, age, and underlying medical conditions.[24] The primary objective of this study was to use stakeholder-driven qualitative methods to further conceptualize, develop, and refine a multicomponent, structured ACP intervention, the Pediatric Serious Illness Communication Program (PediSICP), to support nonpalliative care HCPs in communicating with children, adolescents, and young adults with serious illness and their families to ensure that care is aligned with patient and family goals and values.

Methods

We used a previously described process for engaging stakeholders in intervention development combining community-based participatory research principles and qualitative research (**Figure 1**; available at www.jpeds.com).[25,26] First, we convened a 16-member national expert panel for a 3-hour conference to discuss best practices in ACP communication and key elements of the proposed ACP intervention. The diverse panel consisted of parents from Boston Children's Hospital (BCH) Patient and Parent Advisory Council and the Courageous Parents Network, an organization created by parents, to support and guide families as they care for a seriously ill child, as well as local and national clinical researchers in oncology, critical care, adult and pediatric primary care and palliative care and multidisciplinary health care professionals.[27] Using input from this panel and thorough review of published and unpublished adaptations of Ariadne Lab's Serious Illness Conversation Guide, we then developed a first draft of our ACP guide, the Pediatric Serious Illness Conversation Guide (PediSICG), with different versions for adolescent/young adults and parents.[28-33] In the parent guide, words referring to the parent-child relationship were used and for the adolescent and young adult guide, developmentally appropriate language was used. The PediSICG addresses topics including eliciting illness understanding, gaining a shared understanding of hopes and fears, sharing prognosis, exploring care priorities, and providing goal-concordant recommendations.

Based on panel input, we also developed our preliminary ACP intervention, the PediSICP. We designed the PediSICP, modeled after Ariadne Lab's Serious Illness Care Program (SICP), to facilitate structured ACP communication occasions between HCPs and adolescents and young adults with serious illness and/or parents of seriously ill children. The preliminary PediSICP intervention, tentatively triggered by a prolonged inpatient hospitalization (>2 weeks) or a hospital readmission, consisted of the PediSICG and a patient and family information sheet describing the conversation objectives (**Figure 2**; available at www.jpeds.com).

After the development of the preliminary intervention, we conducted focus groups and individual interviews with a unique set of multidisciplinary HCPs; seriously ill adolescents, young adults, and parents to explore perceptions about ACP communication, to obtain feedback on the proposed PediSICGs and PediSICP, and to explore facilitators and barriers to implementation of the ACP intervention. Based on this feedback, we refined the PediSICP intervention, including the PediSICGs, which was subsequently revised and finalized through re-review by the expert panel.

Participant Eligibility, Recruitment, and Sampling

Eligible adolescents and young adults were those with a serious illness, ages 13-35 years, English speaking, and deemed cognitively able to participate by their attending physician. To identify children, adolescents, and young adults with serious illness, we used the complex chronic conditions definition from Feudtner et al, defined as a child or young adult from 1 month of age with a medical condition reasonably expected to last at least 12 months (unless death intervenes) and to involve either several organ systems or 1 system severely enough to require specialty pediatric care and hospitalization in a tertiary care hospital.[34] This definition encompasses those with technology dependence and children with cancer or other chronic conditions, such as cystic fibrosis, who may be asymptomatic but are at risk for sudden clinical decline. We chose this cohort to encompass a broad range of children, adolescents, and young adults with life-limiting and/or life-threatening conditions for whom ACP is relevant. Eligible parents included English speakers of any aged child living with serious illness. Potential patient and parent participants were either self-referred after viewing study flyers in outpatient or inpatient settings or on the Courageous Parents Network website or they were referred by the BCH palliative care service. Participants not self-referred were approached in person, after gaining attending approval, and invited to participate. Child-parent dyads were permitted but not required.

Multidisciplinary HCPs at BCH and Dana-Farber Cancer Institute, including physicians, nurse practitioners, nurses, and psychosocial clinicians (chaplains, social workers, psychologists, child-life specialists), were considered eligible if they practiced in a location or specialty that commonly cares for seriously ill children, including intensive care, cardiology, pulmonary, surgery, oncology, complex care, and psychiatry. Eligible providers were identified through a hospital email database and those meeting eligibility criteria were invited by email to participate.

HCP and adult participants indicated consent by participating in interviews or focus groups. For minors, parental permission and child assent were obtained. All participants received a one-time $50 retail gift card after interview or focus group completion. This study was approved by BCH's Institutional Review Board.

We used purposive sampling based on illness type, duration of illness, and sex to incorporate information-rich perspectives, maximize variation and include critical cases.[35] For HCPs, we prioritized inclusion of diverse disciplines, specialties, and experience.

Interviews and Focus Groups

We conducted in-person focus groups and interviews with 3 distinct stakeholders; seriously ill adolescents and young adults, parents of seriously ill children, and HCPs at 2 centers from December 2018 to April 2019. Data collection was semistructured, audio recorded, and professionally transcribed. We developed 3 versions of the semistructured interview guides (HCPs, parents, and patients), reflecting a social ecological model, which posits that individual behavior is shaped by intrapersonal, interpersonal, and societal factors.[36,37] To inform interview guide development, we used a literature review and our expert panel to identify key topics and to elicit systemic and local factors informing their perspectives on ACP and the proposed PediSICP intervention. The interview guides were then iteratively designed with review and input from all research team members to ensure appropriate language and tone (**Figure 3**; available at www.jpeds.com). Because the interview guides ask general questions about ACP and the proposed PediSICP intervention, they were purposefully not adapted across different populations; the intervention is intended to be applicable across diverse disease states. We selected interviews for patients and parents, recognizing subject matter sensitivity and potential burdens. For HCPs, we conducted focus groups for the dynamic peer-to-peer interaction, which enabled identification of shared experiences, debate, and idea generation. To avoid potential interdisciplinary hierarchies, we conducted separate physician and nonphysician focus groups.[35,38,39] One physician was interviewed owing to scheduling conflicts. Interviews were conducted by a trained interviewer, lasting approximately 60 minutes. Focus groups were conducted by an experienced facilitator and lasted approximately 85 minutes. Another researcher reviewed a sample of early interviews and focus groups to ensure data collection process integrity.

Data Analyses

An interdisciplinary team, consisting of a sociologist, a physician/clinical researcher, and a trained research assistant conducted thematic analysis on transcripts from 7 focus groups and 17 interviews incorporating both inductive and deductive dynamics, borrowing from framework analysis.[35,40,41] Through an iterative process, 3 comprehensive coding structures were developed incorporating prefigured and emergent codes, for HCPs; adolescents and young adults; and parents. Coding structures were then systematically applied and coded independently by 2 coders who examined the text for feedback on the language and content of the proposed PediSICGs and PediSICP, and to explore facilitators and barriers to implementation of the ACP intervention including optimal timing and participants. Discrepancies were identified and discussed weekly, with the third coder adjudicating, achieving high interrater reliability (kappa of >0.85).[39] Data analysis, assisted by NVivo12 (QSR International, Doncaster, Australia), prioritized the identification of key concepts, contexts, and patterns to understand predominant themes within and across stakeholder groups. Methodologic rigor was established through prolonged engagement and peer debriefing following the Consolidated Criteria for Reporting Qualitative Research.[42]

Results

Of the 12 parents and 11 patients identified, 9 of the 10 parents and 7 of the 11 adolescent and young adults were approached and completed interviews, including 15 distinct families with 1 patient-parent dyad. Eighty-four HCPs were invited to participate, 41 indicated willingness and ultimately, we conducted 7 focus groups with 33 HCPs (3 multidisciplinary and 4 physician groups) and 1 physician interview. Specialties represented included critical care (n = 16), general pediatrics (n = 6), pulmonary (n = 4), cardiology (n = 3), surgery (n = 2), hepatology (n = 1), oncology (n = 1), and psychiatry (n = 1). Participant characteristics are shown in **Table I**.

Stakeholder Responses to the PediSICGs and PediSICP

Augmenting Current Practice. Overall, participants expressed positive perspectives toward the PediSICP, citing both the guides and the intervention as an opportunity to

Table I. Demographics of community stakeholders (focus group and interview participants)

Participants	Parents (n = 9)	Adolescents and young adults (n = 7)	HCPs (n = 34)
Participant characteristics			
Patient age, years	17.6 (20, 6-26)	23.9 (25, 17-32)	–
Male sex	5 (55.5)	2 (28.6)	8 (23.5)
Duration of illness	15.7 (18, 2-26)	22.4 (20, 15-32)	–
White race	9 (100)	6 (85.7)	33 (97.1)
Disease category			
Congenital and chromosomal	4 (44.4)	1 (14.3)	–
CNS static encephalopathy	1 (11.1)	0 (0)	–
CNS progressive	0 (0)	0 (0)	–
Neuromuscular	1 (11.1)	1 (14.3)	–
Cancer	1 (11.1)	1 (14.3)	–
Pulmonary and respiratory	2 (22.2)	3 (42.9)	–
Other	0 (0)	1 (14.3)	–
Provider type			
Physician	–	–	18 (52.9)
Nurse practitioner	–	–	4 (11.8)
Nurse	–	–	6 (17.6)
Social worker	–	–	3 (8.8)
Child life specialist	–	–	1 (2.9)
Respiratory therapist	–	–	1 (2.9)
Psychologist	–	–	1 (2.9)
Provider years of experience			
≤5	–	–	11 (32.4)
>5	–	–	23 (67.6)
Provider specialty			
Critical care	–	–	16 (47.1)
General pediatrics	–	–	6 (17.6)
Pulmonary	–	–	4 (11.8)
Cardiology	–	–	3 (8.8)
Surgery	–	–	2 (5.9)
Hepatology	–	–	1 (2.9)
Oncology	–	–	1 (2.9)
Psychiatry	–	–	1 (2.9)

CNS, central nervous system.
Values are mean (median, range) or number (%).

initiate and engage in ACP discussions (Table II). Specifically, adolescents, young adults, and parents described the PediSICGs as "thorough," "really important," and a "great idea." Intervention materials were described as demonstrating caring, social and emotional awareness, and including important topics. A few parents noted that they would have liked to have this guide earlier in their child's illness. Reactions to the PediSICP by HCPs were also largely positive, with praise for the unique goals and values structure of the PediSICGs, differentiating it from usual family discussions.

Parents, adolescents, young adults, and HCPs alike described the PediSICP as having the potential to augment current practice and reduce variation by providing a framework and specific language to engage in ACP discussions. Most participants appreciated that the PediSICP would allow patients and parents to prepare for the conversation and asserted that it would facilitate longitudinal planning and serve as a framework for future care. Additionally, parents, adolescents, and young adults expressed that the PediSICGs would serve as a "toolkit" for providers, especially those uncomfortable with ACP discussions. Likewise, HCPs valued the specific language in the PediSICGs to help "get the words out" because "it's really hard just getting started when you don't have a structure."

Parents, adolescents, and young adults across interviews described the PediSICP as an opportunity to discuss their hopes and goals with HCPs and appreciated the focus on what is most important to them if their health or that of their child worsens. Although many parents, adolescents, and young adults acknowledged that being asked about fears was hard, they also viewed it as an opportunity to verbalize their worries. Likewise, HCPs also valued the focus on eliciting fears to explore taboo topics and the "we" statements, which create an opportunity to "open the door" while concurrently aligning with the family. Additionally, HCPs described the PediSICGs as a "win-win" enabling them to "gauge where the patient or parents are" and clarify prognostic awareness.

Last, HCPs felt that the PediSICP could provide an opportunity to normalize ACP conversations making them more routine and acceptable, "like a vaccination schedule."

Response Considerations and Guide Content. Several HCP participants emphasized that a "one-size-fits all" framework may not work for all families given the variations in how people like to receive information. Specifically, some HCPs expressed fear of causing harm and underscored the need to ask permission to have this conversation because "some families may not be open to this" and initiating an ACP discussion "could cause anxiety." Notably, this concern was not shared by parents, because "there is little we have not already considered and worried about" and addressing uncertainty together provides an opportunity "to have some fears allayed."

Some HCPs were also concerned that the conversation could be contrived or seem insincere if the PediSICGs were followed verbatim. Although most HCPs appreciated "stock phrases," opinions were divided on the prescriptive nature of the PediSICGs that some HCPs felt could limit flexibility when adapting the conversation to situational factors, such as an acute clinical deterioration. These reservations were also not shared by parents and most patients, although one adolescent questioned the usefulness of the PediSICG, asserting that "I personally wouldn't use it" but "it can help some people for sure."

Implementation Considerations. Although most HCPs agreed on the importance of ACP, several noted that ACP communication was not part of their current workflow. One physician expressed concern that if the intervention is voluntary it may not be used by those who feel it's "not their job" or "think they are doing a fine job already." Another physician expressed concern that these skills cannot be taught, and that ACP should be left to the palliative care service. One parent echoed this suggestion with concern that not all doctors would be good at having ACP discussions.

HCPs also highlighted logistical complexities as possible deterrents to the success of the PediSICP. First, they were concerned about the additional time required for ACP discussions, despite near universal agreement across groups that "we need to make time for it." Second, other multidisciplinary providers, as opposed to physicians, worried about the need for buy-in from senior management to provide time for training. Last, HCPs expressed concern about where ACP discussions would be documented because "I'm not spending an hour talking to the family, and then another hour documenting it and then it is all for nothing because no one can find it." Parents also requested a consistent location for ACP documentation to avoid redundancy and to ensure information is shared across care settings.

Stakeholder Recommendations for PediSICGs and PediSICP

Overall, participants advocated for simplifying the PediSICGs and creating flexibility in the PediSICP to account for patient and family characteristics or needs, HCP experience, and logistical considerations (Table III).

Enhance Provider Knowledge and Learning. HCPs across groups reported minimal formal instruction in ACP communication and a majority endorsed training in the use of the PediSICGs as critical. Suggestions about the format of training varied across groups, but most recommendations included provision of feedback, an option for online training, and the use of role play or simulation. Most HCP groups agreed that although uncomfortable at times, role play is integral to learning how to have effective ACP conversations "so individuals are able to watch their body language and sentence structure."

Make Conversation Timing Flexible. When considering the optimal timing of PediSICG-guided ACP conversations, adolescents, young adults, parents, and HCPs offered diverse opinions, but 3 timeframes emerged: at the end of a

Table II. Key stakeholder responses to the PediSICGs and proposed ACP intervention (PediSICP)

Themes	Illustrative quotes
Augmenting current practice	
Empowering patients, families, and HCPs to engage in ACP by providing a framework	"These are really good questions. Like this, 'our team likes to start talking about this when patients are doing okay', because it's not when things are going haywire. So, I appreciate this framework. He's doing okay right now so let's take a look at what we're looking at as we move ahead. (Parent#5)
	"I really think the most difficult thing is just getting started. And there's lots of different reasons why that is for providers and families, but I think there's just so many excuses to avoid these conversations. It's just really just hard when you don't have a structure." (Physician Interview #1)
	"I think that this is so helpful because actually getting words out I find very challenging, even when I do it a lot…I never walk away from one of these conversations and don't feel like I could have said something better, so I think it's very helpful to have actual text and suggestions." (Physician FG#2)
	"I think integrating the child's perspective is so important. I think that's one perspective that sometimes gets avoided because it's so hard to think about talking to kids directly." (Provider FG#2)
	"When [NAME] was younger, it was difficult for me to make decisions that the doctors would tell me I have to make– that's a heavy thing to put on the parent. You're dealing with decisions that's going to change how she lives for the rest of her life, and who am I to make that decision? But if someone recommended what is best for her, I would feel better about making those decisions." (Parent# 2)
Eliciting hopes, fears and goals	"I think the suggested language in the guide is very helpful for unifying the way that we talk to patients and their families, because there is a lot of variation across units, diagnoses, individual providers. Some people are great communicators about the medical information, but not so good at eliciting hopes and fears, and some people are really good at the hopes and fears and but can't be quite as clear with the medical information. I think having a tool sort of could potentially level the playing field in terms of how we have these types conversations" (Provider FG#3)
	"I would like to have this conversation. I mean, I would like someone to talk to me like that, because they're kind of asking you everything you need to know about what your goals and your fears are. You might have a fear and they might be able to say 'no, I wouldn't worry about that because right now we don't have to go down that road.' Because as a parent you always think the worst." (Parent#1)
	"I especially like the what are your biggest fears and worries, especially if you're unsure about where you're at. I have a lot of anxieties surrounding my health and when your health is out of control, you just get more and more anxieties about what's gonna happen… So I think that's a really important thing to address, especially upon discharge, if I'm leaving with a new health status than I was prior." (Patient#5)
	"I'm fine with this…. Talk to you about the illness as well as your hopes, fears and goals. That's good. And I like that you say start talking about this when your patients are doing okay. I really think that's good… serious but stable, so now's a good time." (Parent #1)
Normalization of longitudinal ACP conversations	"Yeah. This is great. I think the guide and proposed intervention provides a way to normalize and standardize the conversation which is important because I think there's just so many roadblocks and easy excuses not to have this conversation on the part of the provider or caregiver or patient." (Provider FG#3)
	"I actually think ideally, it should happen for more patients than it does right now. You have the opportunity and window to talk about advance care planning without the family feeling like oh, the providers want to talk about this because they think my child is going to die tomorrow. They want to know whether or not we should do CPR or something. It's because this is a expected meeting." (Physician FG#2)
	"And there's opportunity to normalize it, like this is going to happen regularly and you could almost say, this is something that is important in your child's care and we encourage you to bring it up again, almost like a vaccine schedule. Give them the – I don't want to say ownership, but something that allows them to say, 'I want to have this conversation again' with their continuity providers" (Physician FG#2)
Response considerations and guide content	
How families like to receive information and share what is most important	"I do think we have to be really cognizant of whatever we're carrying into that conversation. I think it might be helpful if there were questions framed that would help us get a handle on how much information people want to have or how much autonomy they want with decision making." (Physician Interview #1)
	"I'm a planner. I like to know what's coming, what's ahead of me. I want to share what our goals are for our family, because we have thought about it. We have ideas of what we'd like to have for our son's life–his quality of life." (Parent#6)
	"As far as your question about what the best way is to open this, I don't think it's a one phrase fits all families or situations-type of thing. I think it's going to have uses interpersonal relationships to kind of gauge where the parents are, what the context is." (Physician FG#1)
	"I think the intervention is a great idea. Because if people knew going in what we felt was important for our son's quality of life, that would guide our decision-making and if we picked up on that on our next unplanned admission, I think that would be hugely helpful." (Parent#1)

(*continued*)

Table II. Continued

Themes	Illustrative quotes
Scripted language	"I worry that it could come off as contrived, especially if somebody sits with a guide in front of them to prompt them with what to say. It may not be a natural conversation." (Physician FG#3) "I like that it has succinct suggestions for how to approach parts of the conversation, especially for people who may not be used to having these conversations very often with families. It is a useful prompt to think about how to word questions in a neutral way." (Physician FG#2) "I think actually that's what more senior clinicians often do. They have these stock phrases to get a conversation going, a sort of a script they build over time. So, I think this is lovely because it gives you that script and I think it actually very naturally is something that people will take on over time." (Physician FG#2) "We want to talk about the future, and we don't like it when the medical team comes in, drops a bomb, and then leaves without explaining what it means for my son, what it means for our family. I would so appreciate if the staff could sit down and take the time to discuss this guide with us on a regular basis just as they do other medical things." (Parent#3) "It seems a little convoluted just to write this whole guide to having conversations. I just – me personally, I would not use a guide. I'm not that type of a person. -It's just personal preference. I mean, I'm certain it can help some people for sure. Just I personally wouldn't use it." (Patient #4)
Implementation considerations	
Not my job	"My instinct is that it's uncomfortable because that's not our practice– it also sounds like it's probably the right thing to do. This makes more sense, but this will be a change. It's certainly not the way that we approach those conversations most of the time." (Physician FG#2) "I mean, I guess my main concern would be that you would get a lot of early adopters who maybe need this guide less who would be signing up at first, and that people that feel like it's not their job or it's – or they do a fine job already are just not going to sign up and not going to use it." (Physician Interview#1) "That's very different in the ICU…I mean, advance care is to get people out of the ICU. That's about as far as it goes." (Provider FG#2) I mean, there is a reason why there's certain providers who are – work more frequently with these types of population, and there's certain providers that go into PACT because there are some of these skills that you just can't teach people. You know what I mean? (Physician FG#2)
Competing demands	"I think we're so busy just trying to keep afloat every day and making sure everyone is getting the care that they need and – but I think we need to make time for it." (Provider FG#2) I think the demands of patient care and just kind of volume and needing to see a bunch of patients in a small window makes – is a barrier. So I think a lot of times it's like an added thing to do that's very hard to integrate into practice. (Provider FG#2)
Buy-in	"So if you don't have that buy-in from our directors, then you can put this out and it's going to be voluntary and it's going to be people who really do feel like they want to do it. But I think that everybody should know how to do this…It should be as important as medications that we give." (ProviderFG#2) I think just in order to be able to have all the training, you have to have the buy-in of senior management from whatever group somebody belongs to. That director or manager has to agree that there's going to be time blocked off so people can get to trainings, because –they need to do this because they believe that this is a good investment in what we are doing for our patients and families." (ProviderFG#1)
Documentation	I think one problem is that people sometimes don't discuss it, but when they do, they document things like this in their progress note, but you can't find them because there's 7000 notes, and who has time to read them all when you are trying to make important decisions with the family." (Physician FG#1) "If it is not documented in some central place, it's going to feel like sticking yourself in the eye with a pen because you're going to feel like it's futile – that it's going to just drift into the ether and…it's lost." (Physician FG#2) And you wonder, what are you doing with the information? Because someone just asked us all that. Do they not put in her chart? Like you don't want to be redundant. I think is our main thing. (Parent#2)

ICU, Intensive Care Unit; *PACT*, Pediatric Advanced Care Team (Palliative Care).

prolonged admission, at the "beginning," and in the outpatient setting. Most HCPs and parents acknowledged that ACP conversations typically occur during an acute deterioration and advocated for discussions earlier in the illness course. Several HCPs also emphasized normalizing discussions alongside therapeutic options so that ACP "becomes one facet of a patient's ongoing care plan and is not introduced at emotionally charged moments." Many participants agreed that toward the end of a prolonged admission or an unplanned readmission were appropriate times to hold ACP discussions, but some expressed concern about holding up discharge because "it gets a bit hectic" and "people just want to go." "Beginning" preferences incorporated 2 distinct time frames, the beginning of an admission "once things are settled in," as well as at diagnosis. A third subgroup of participants felt that ACP conversations should occur in outpatient settings, but HCPs reported that this "doesn't often happen," and parents conveyed that appointments following a prolonged admission "can be exhausting." In all circumstances, adolescents, and young adults, parents and HCPs endorsed that using PediSICG earlier in the illness course and having conversations longitudinally would provide an opportunity for patients and parents to "think about the topics at hand and make them more comfortable approaching these topics."

ACP Conversations Should Occur with a Trusted Provider. During discussions about which providers should use the PediSICGs with patients and families, a variety of HCPs were identified. Most participants agreed, when possible, that conversations should be held with "a trusted provider" but qualified that in an acute situation "probably anyone could utilize it." Further, most participants agreed that patients and/or families should be asked to identify their preferred provider, highlighting the importance of longstanding relationships and care continuity. HCPs also noted that inclusion of a trusted provider may help with patient and family "buy-in" to ACP discussions. Several participants also suggested a team-based approach; however, they noted that team-based care can complicate both the coordination of ACP discussions and standardization of messaging across providers and settings. Interestingly, one parent noted that "timing is more important than who conducts the conversation," and one adolescent asserted that it does not matter who has the conversation with them.

ACP Conversations Should Be Easy to Document and Locate. HCPs requested that resultant ACP conversations be easily documented and readily located to facilitate emergency accessibility and to reduce patient and family burden. Most HCPs stressed than an electronic medical record (EMR) template would make ACP conversations accessible over the child's illness trajectory.

Prepare Patients and Families for ACP. Last, HCPs, adolescents, young adults, and parents alike asserted that the PediSICP could be empowering by allowing patients and families to prepare, reflect on "where they are at," and consider what is most important moving forward. As such, several participants suggested the creation of a worksheet to accompany preparatory documents so that patients and/or parents could write down their thoughts or concerns prior to the conversation. One parent also suggested having parents complete a questionnaire indicating how much information they want to share with their child.

Adaptations and Finalization of the PediSICGs and ACP Intervention

Feedback from the focus groups and interviews was analyzed, summarized, and discussed by the research team. There was limited discordance between parents, patients, and providers. Issues and suggestions that emerged most frequently across stakeholder groups were prioritized for discussion and resulted in adaptations to the PediSICG language and content as well as the proposed PediSICP intervention, before finalization by the expert panel.

Several HCPs and parents noted the guide and preparatory information sheet had a "daunting amount of text." In response, unpopular question prompts were eliminated and the text was simplified. Additionally, several HCPs requested querying about patient and family supports, including spirituality. We therefore added a question to explore supports, which also reminds families of their coping resources and facilitates a discussion of faith when applicable. Several families disliked the word fears and some suggested concerns or worries. We therefore replaced worries for fears in the guides. Last, based on participant suggestions, we made the decision to create a worksheet to accompany PediSICP preparatory information where families could record their thoughts before the ACP conversation. The completed worksheet will be circulated to the patient's HCPs before the discussion to help them "get on the same page." The final PediSICGs are presented in **Figure 4**, A and B.

In response to concerns around serious illness communication training, the finalized PediSICP will include a pragmatic clinician training program to teach multidisciplinary HCPs how to have ACP conversations using the PediSICGs.

Given discussions around competing demands of HCPs and varied opinions regarding the optimal timing of the PediSICP intervention, we are suggesting that a prolonged admission or unplanned readmission should be a trigger, but that ACP conversation timing should be flexible to ensure inclusion of a trusted provider, begin early in the illness course and continue longitudinally over a child's illness trajectory.

Last, in response to participant concerns about documentation, the final PediSICP will include a structured template to document PediSICG discussions in the EMR to ensure resultant ACP conversations can be viewed by all involved providers.

Based on feedback from focus groups and interviews and re-review by the expert panel, the finalized PediSICP intervention will consist of a communication occasion guided by a 3-part conversation tool consisting of stakeholder approved PediSICGs, a preparatory patient/family worksheet (**Figure 5**, A and B; available at www.jpeds.com) and a structured EMR template to document resultant ACP conversations.

Discussion

Medical societies and guidelines recommend that HCPs and families engage in early ACP discussions to ensure seriously ill children, adolescents, and young adults receive goal-concordant care.[16,43,44] There has been considerable work to promote pediatric ACP addressing singular elements like advance directives or ACP targeting specific patient populations such as those with HIV or cancer.[12,13,16,22,45-50] There have also been tools developed to help children, adolescents, and young adults explore their EOL preferences such as Voicing My Choices.[51] Here, we describe the process and outcomes of a stakeholder driven development of a structured, pediatric ACP communication intervention (PediSICP) assessing preferred content, optimal timing of program introduction, and possible barriers for implementation. The finalized intervention consists of a communication occasion guided by a 3-part conversation tool including a stakeholder

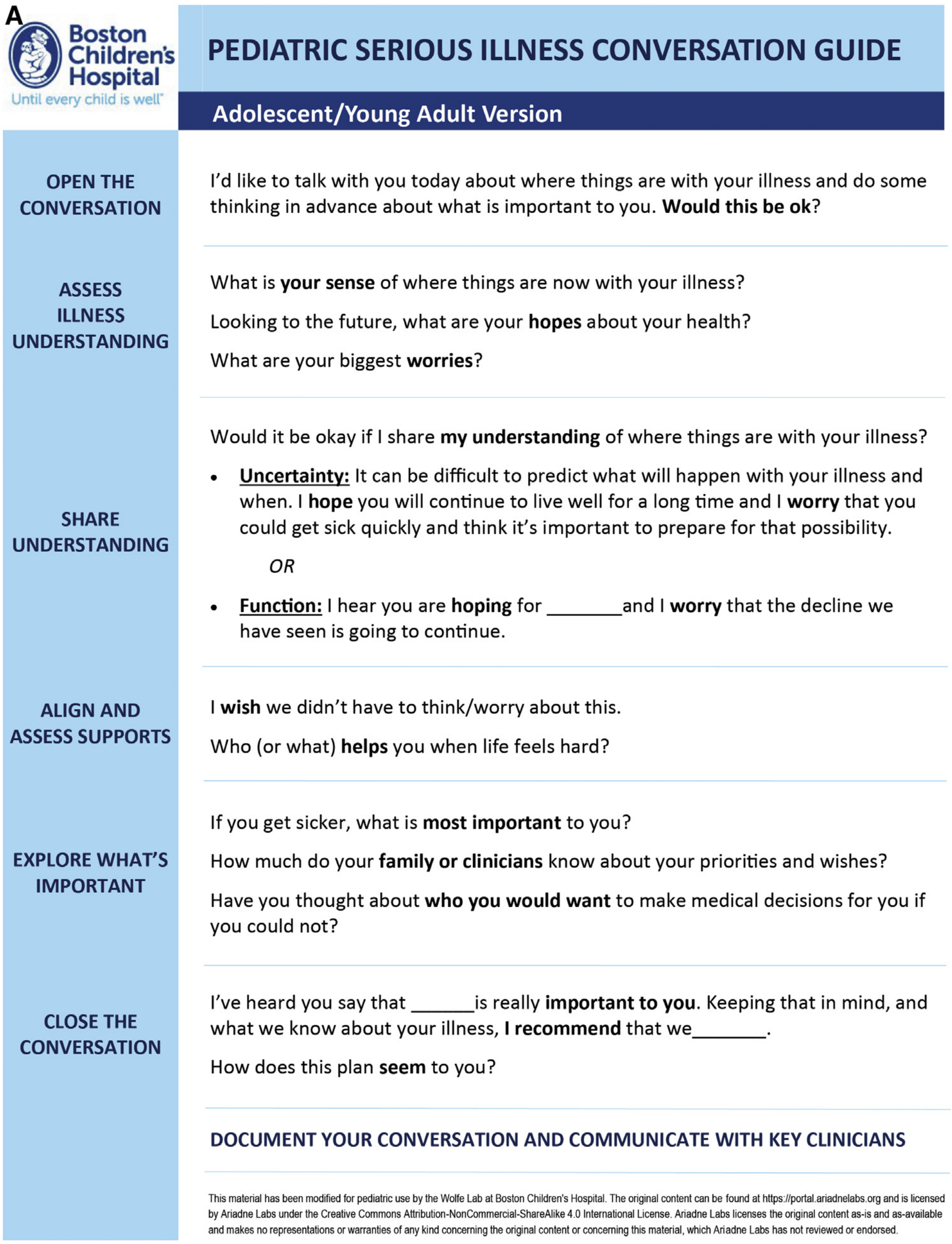
Table III. Key stakeholder recommendations for the proposed ACP intervention (PediSICP)

Recommendations	
Enhance provider knowledge and training	"It's a skill and we can all learn so much about how to do it different, better, tailor it but no one really teaches you" (Physician FG#1) "I think that people actually need to be in a simulated environment of – and it doesn't mean you have to be anywhere special. You can be in this room and practice it – but that that has value. Because then you actually have to come out with the words and you actually have to say – go through the guide. I would want to practice that way." (Provider FG#2) "I think it's hard for trainees to get any experience having these conversations, because you have to be in the right place at the right time. And I think that you could go through all of your training and not have anything like that, depending on who's mentoring you." (PhysicianFG#4) "I do feel like training is what people would want because some – this is an uncomfortable situation and people tend to – not avoid it, but it kind of puts pits in stomachs. But if you know how to do it, you feel better about approaching it. So, I think this is something that people will actually want to get training on, for sure." (Provider FG#2)
Make conversation timing flexible	"I think this –at the end of the prolonged admission part - logistically can be hard, because oftentimes, there's such a pressure to just get children out of the ICU, but I do think that the ICU physician who was a significant part of a prolonged hospitalization should be involved in that conversation….I think along with that kind of logistics thing, oftentimes after those hospitalizations, every consulting service wants to see the patient back soon after and it's just exhausting for families." (Physician FG#2) "These children are only getting worse and you need to have this conversation. So I think like this [timing at discharge] would certainly be helpful for some patients, but there's going to be an unmet need if it's only saved for the child that's better and ready to go home." (Physician FG#1) "These sort of long-term planning things are great and essential and I can see – it applies to certain populations really well. Like I think about our patients with cystic fibrosis, people who we know are going to have this expected decline. But this is the kind of conversation that I would expect to happen as an outpatient. I don't know that it often happens though." (Physician FG#2) "I think timing might be difficult, because certainly with – like right now with thinking about going home it gets a little bit hectic right at the end because the nurses want to get going. The doctors want to get going." (Parent #6) "Because our practice is to get children out of the hospital when they're healthy and to avoid ACP conversations – to deal with conversations about long-term planning at moments of acuity – heightened acuity. And I think that's probably at the end of the day not the most logical approach." (Provider FG#4)
ACP should occur with a trusted provider	"I think the people who know them would be best. Whether it is like the ICU team or whether it's outpatient teams or whomever. But the people who know them best, because that's who they're going to feel like they trust because these are hard conversations. And you can't just have that with – oh, I met you five minutes ago. That's not a very good dynamic to have." (Provider FG#2) "I should be asked 'who you might want to chat with?' Because I think if some social worker that I don't know comes in and starts talking to me about this stuff, I'm going to be like 'I don't want to talk to you.'" (Parent# 6) "If we're about to embark on these conversations and start coming up with big plans, like their goals I don't want to start taking away that primary relationship. .I think you need to have buy-in from– their primary outpatient providers. And I think they'll – there's groups that will love this." (Physician FG#1)
ACP conversations should be easy to document and locate	"Yeah. I think it will be of the utmost importance to have some sort of pre-form or documentation set up so that – I'm not spending an hour talking to the family, and then another hour documenting it and then it is all for nothing because no one can find it." (Provider FG#4) "Yeah, you have to have an easily accessible standard place to document these discussions…Because in the middle of the night when this kid rolls in through the ER and these conversations have been documented, you ought to be able to find it as opposed to sifting through a million notes." (Physician FG#1)
Prepare patients and families for ACP	"I like the idea of a worksheet with the preparatory document. I'm really digging the idea of a worksheet with it…I like that this gives you control-right here and it also talks about bringing other people into the conversation." (Patient#5)

ICU, Intensive Care Unit.

approved provider PediSICG, a preparatory patient/family worksheet, and a structured EMR template to document resultant ACP conversations, which can be used alongside existing tools.

Implicit in a focus on improving the process and provision of ACP is the understanding that ACP is a series of conversations, often with different providers, and that people's goals change over time to reflect changing health status.[52] The Pedi-SICP was designed to balance brevity and augment scalability, while at the same time addressing issues that matter most to patients and their families. Although this study did not determine true ownership for ACP communication or optimal timing, adolescents and young adults with serious illness, parents, and multidisciplinary HCPs endorsed its



A

Boston Children's Hospital
Until every child is well

PEDIATRIC SERIOUS ILLNESS CONVERSATION GUIDE

Adolescent/Young Adult Version

OPEN THE CONVERSATION	I'd like to talk with you today about where things are with your illness and do some thinking in advance about what is important to you. **Would this be ok**?
ASSESS ILLNESS UNDERSTANDING	What is **your sense** of where things are now with your illness? Looking to the future, what are your **hopes** about your health? What are your biggest **worries**?
SHARE UNDERSTANDING	Would it be okay if I share **my understanding** of where things are with your illness? • **Uncertainty:** It can be difficult to predict what will happen with your illness and when. I **hope** you will continue to live well for a long time and I **worry** that you could get sick quickly and think it's important to prepare for that possibility. *OR* • **Function:** I hear you are **hoping** for _______and I **worry** that the decline we have seen is going to continue.
ALIGN AND ASSESS SUPPORTS	I **wish** we didn't have to think/worry about this. Who (or what) **helps** you when life feels hard?
EXPLORE WHAT'S IMPORTANT	If you get sicker, what is **most important** to you? How much do your **family or clinicians** know about your priorities and wishes? Have you thought about **who you would want** to make medical decisions for you if you could not?
CLOSE THE CONVERSATION	I've heard you say that ______is really **important to you**. Keeping that in mind, and what we know about your illness, **I recommend** that we_______. How does this plan **seem** to you?
	DOCUMENT YOUR CONVERSATION AND COMMUNICATE WITH KEY CLINICIANS

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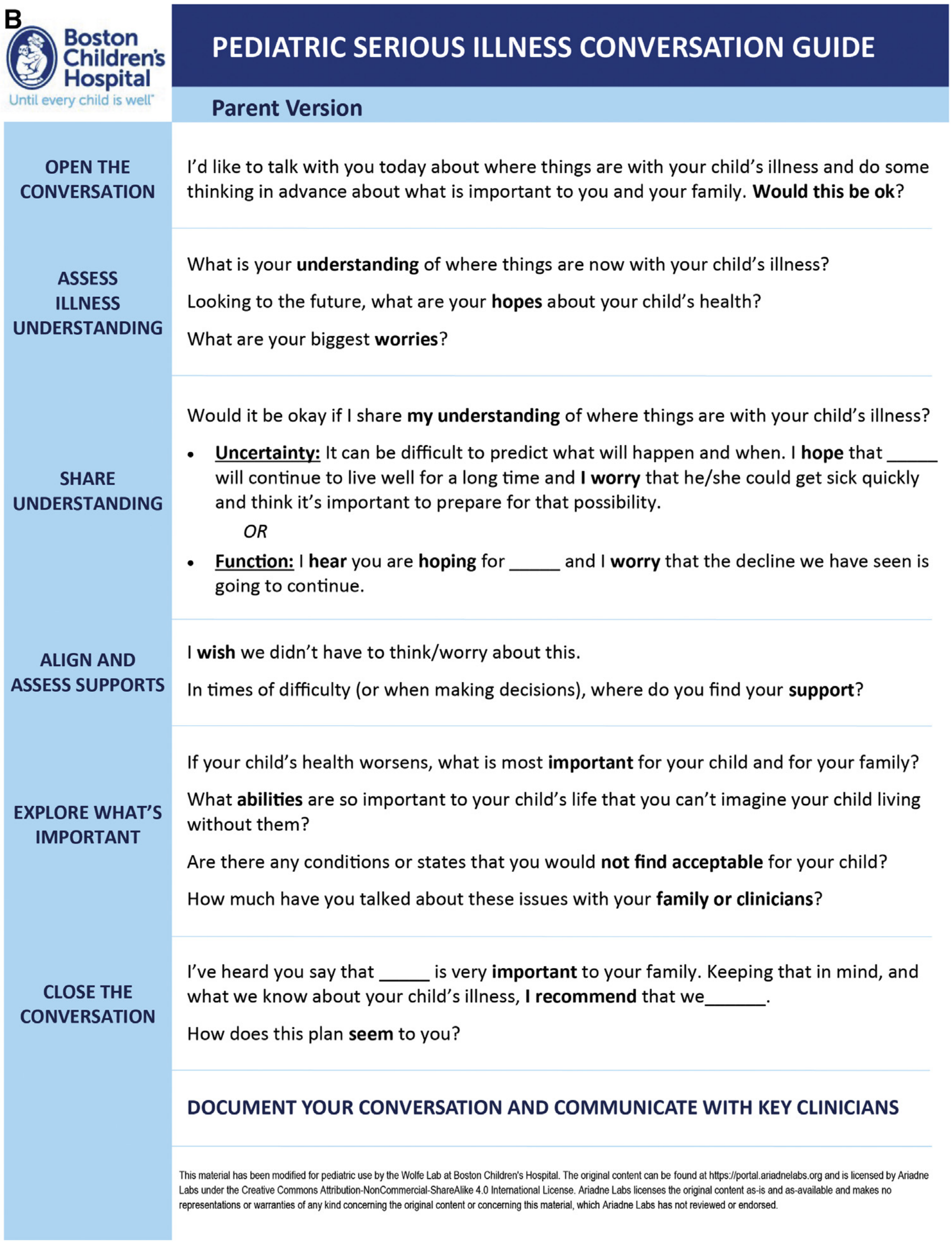
Figure 4. **A,** PediSICG: adolescent and young adult version. **B,** PediSICG: parent version. *(Continues)*

critical importance. Additionally, there was broad agreement across focus groups that training in ACP communication is essential given the reported lack of formal training described by multidisciplinary HCPs. As such, to further address concerns regarding the need to enhance provider communication skills, a companion training program will be developed to teach multidisciplinary HCPs how to have ACP conversations using the PediSICGs as a framework. We anticipate the training program will include a brief didactic session on ACP value, demonstration and discussion of the PediSICP, followed by skills practice with individual feedback and coaching.

Although adolescents, young adult and their parents indicated willingness to lengthen visits or attend additional visits to participate in these ACP conversations, HCPs preferred the intervention be fitted into existing work patterns. In addressing provider concerns about time constraints, there is evidence that use of the guides allows for more thorough conversations and is similar in duration to prior practices typically lasting 14-19 minutes.[29,32,53,54]

The challenges we encountered highlight some of the study's limitations. First, generalizability is limited by several factors. This study describes the opinions of participants from 2 academic hospitals and did not include nonacademic



B

Boston Children's Hospital
Until every child is well

PEDIATRIC SERIOUS ILLNESS CONVERSATION GUIDE

Parent Version

OPEN THE CONVERSATION

I'd like to talk with you today about where things are with your child's illness and do some thinking in advance about what is important to you and your family. **Would this be ok**?

ASSESS ILLNESS UNDERSTANDING

What is your **understanding** of where things are now with your child's illness?

Looking to the future, what are your **hopes** about your child's health?

What are your biggest **worries**?

SHARE UNDERSTANDING

Would it be okay if I share **my understanding** of where things are with your child's illness?

- **Uncertainty:** It can be difficult to predict what will happen and when. I **hope** that _____ will continue to live well for a long time and **I worry** that he/she could get sick quickly and think it's important to prepare for that possibility.

OR

- **Function:** I **hear** you are **hoping** for _____ and I **worry** that the decline we have seen is going to continue.

ALIGN AND ASSESS SUPPORTS

I **wish** we didn't have to think/worry about this.

In times of difficulty (or when making decisions), where do you find your **support**?

EXPLORE WHAT'S IMPORTANT

If your child's health worsens, what is most **important** for your child and for your family?

What **abilities** are so important to your child's life that you can't imagine your child living without them?

Are there any conditions or states that you would **not find acceptable** for your child?

How much have you talked about these issues with your **family or clinicians**?

CLOSE THE CONVERSATION

I've heard you say that _____ is very **important** to your family. Keeping that in mind, and what we know about your child's illness, **I recommend** that we______.

How does this plan **seem** to you?

DOCUMENT YOUR CONVERSATION AND COMMUNICATE WITH KEY CLINICIANS

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Figure 4. Continued.

general pediatricians. Additionally, although this tool was created in an academic pediatric hospital, some pediatric patients with serious illness are cared for outside tertiary care children's hospitals and future work will include adaptation of this tool, complementary policies, and training for nonacademic centers. Further, the PediSICP may not be comprehensive as recruitment of adolescents, and young adults was limited owing to high medical burden. Finally, parent, adolescent and young adult participants lacked racial and ethnic diversity, eligibility was limited to English speaking participants owing to the language abilities of our study personnel, and we did not collect additional sociodemographic data, such as education or household income; therefore, this intervention may not fully reflect the needs of underrepresented groups. We are now planning adaptations of the PediSICGs into other languages and will use methods gleaned during adult adaptations of the guide to enhance both cultural and language diversity.[55,56] Additionally, data exist that specific communication practices may improve ACP across cultures through enquiry about religious and cultural beliefs and how they inform patients' illness understanding, respectful assessment of individual goals and values, and exploration about the desired role of family in ACP.[57] These areas are currently addressed by the

PediSICGs. To limit researcher bias and ensure trustworthy data and analysis, our interdisciplinary team adhered to rigorous methods, including maintaining an audit train, open communication, and adherence to the Consolidated Criteria for Reporting Qualitative Research guidelines. Despite limitations, this study provides new insights into ACP preferences and priorities of HCPs, adolescents, young adults, and parents of seriously ill children while at the same time supporting the use of the PediSICP to facilitate ACP.

Over the past decade, the adult SICP has been adapted to diverse patient populations, care settings and hospital systems including primary care, oncology, chronic critical illness, and end stage renal disease where it is feasible and acceptable to clinicians and patients, has increased discussions about patients' goals and values, and was associated with a reduction in patient anxiety.[29,53,54,58,59] There has been no evidence widescale application of the SICP has led to widening disparities in EOL care. We believe the PediSICP also may have the potential to become a pragmatic, scalable ACP intervention given its broad use across adult populations and settings. We intend to first pilot the Pedi-SICP in the inpatient setting at the end of a prolonged admission or hospital readmission with a trusted provider to determine its feasibility for clinicians and its acceptability for patients and their families. Through pilot studies, we anticipate learning how to enhance flexibility in training and determine best practices about who "owns" and conducts these conversations. Further research may be necessary before adapting the intervention for additional settings across serious illness types and in more diverse patient populations with plans to evaluate the PediSICP on important patient and family outcomes including shared decision making, quality of communication, and psychological distress while monitoring for disparities in receipt of EOL care.

Stakeholder engagement impacted the design of the PediSICGs and the PediSICP into a multicomponent ACP intervention. Future work is needed to determine the implementation feasibility and impact of the PediSICP on important patient and family outcomes in more diverse patient populations and settings. ■

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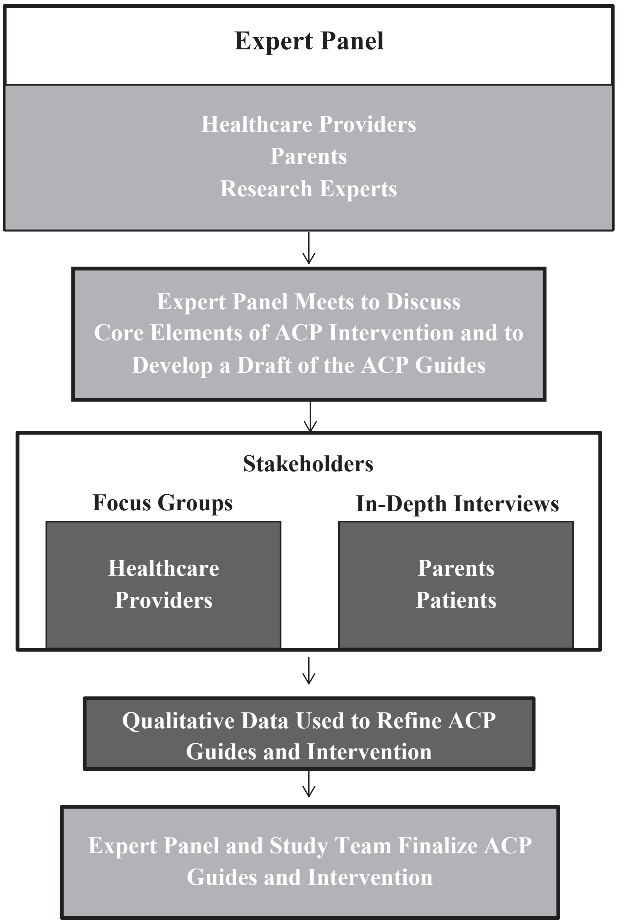

Figure 1. ACP guide and intervention development process.

Talking with your child's medical team about the future

At the end of this admission, your child's medical team would like to talk with you about your child's illness as well as your hopes, worries, and goals for your child's care. This is an important part of the care we provide for all of our patients.

Our team likes to start talking about this when patients are doing okay. Your child's illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Families who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

Before this appointment

Please prepare for your visit by thinking about these things:

- What would you like to know about your child's illness and what is likely to be ahead?
- What kind of information would help you make decisions about your child's future?
- What is most important for your child to have a good quality of life?
- What are you afraid of about your child's illness?
- What kinds of medical care do you not want for your child?
- What do you think it would be like to share these thoughts with your family?

Why is this important?

Thinking about and sharing your wishes will give you more control over the care your child gets.

Talking about the future won't change your ongoing care

Talking about the future won't change the plans we have made so far about your child's treatment unless, of course, you want to. We will keep providing the best possible care to control your child's disease.

You may find it helpful to bring other people to this conversation

You can choose to bring other family members so they can be a part of the conversation. You can also bring other trusted providers such as your nurse practitioners, social workers, or chaplains if you like. Please let us know if you would like to bring others.

We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions.

If you have questions before you visit, please contact the study staff at 617-919-7357

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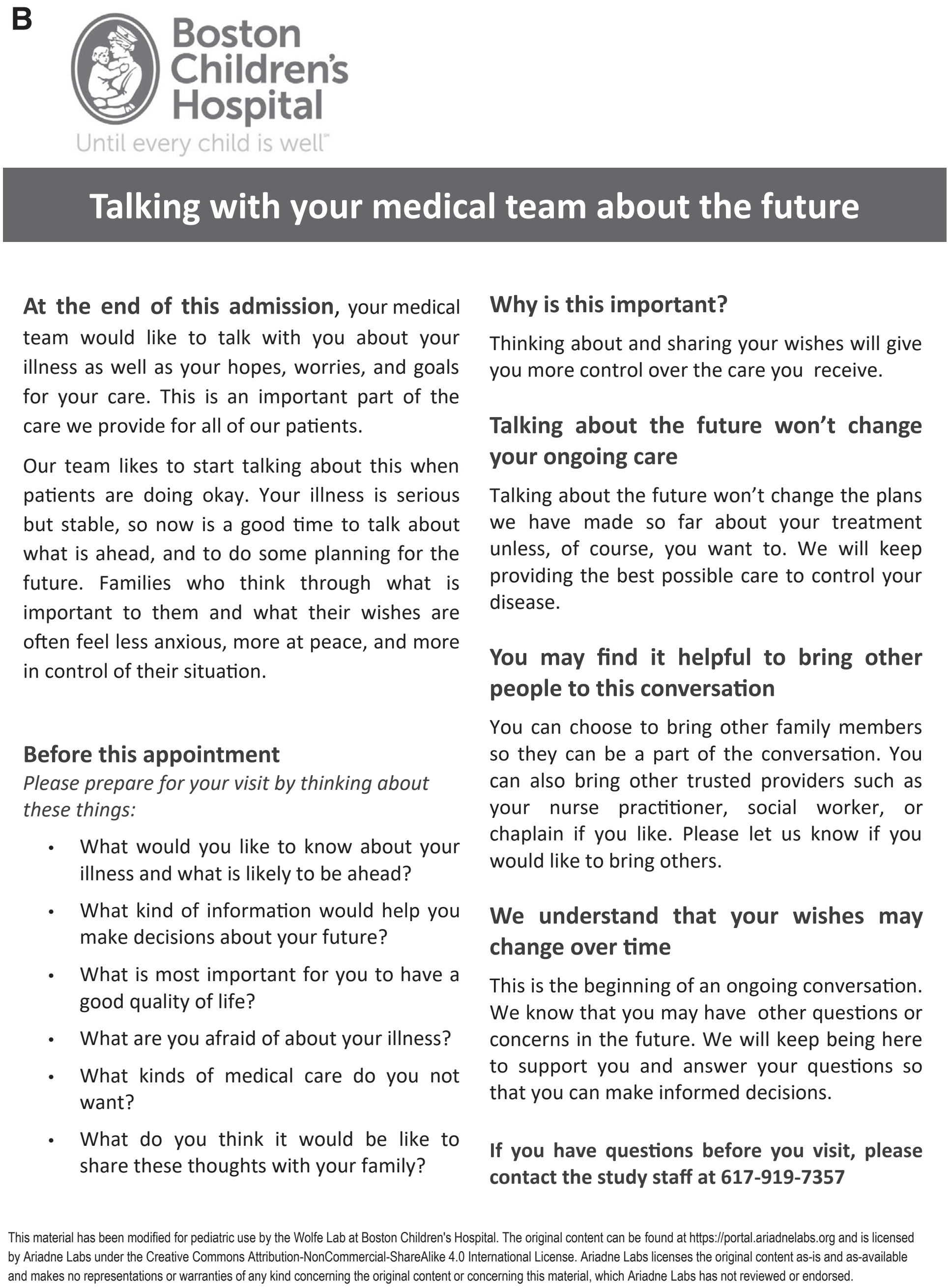
Figure 2. Patient and family preparatory PediSICP information sheet. *(Continues)*



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Talking with your medical team about the future

At the end of this admission, your medical team would like to talk with you about your illness as well as your hopes, worries, and goals for your care. This is an important part of the care we provide for all of our patients.

Our team likes to start talking about this when patients are doing okay. Your illness is serious but stable, so now is a good time to talk about what is ahead, and to do some planning for the future. Families who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

Before this appointment

Please prepare for your visit by thinking about these things:

- What would you like to know about your illness and what is likely to be ahead?
- What kind of information would help you make decisions about your future?
- What is most important for you to have a good quality of life?
- What are you afraid of about your illness?
- What kinds of medical care do you not want?
- What do you think it would be like to share these thoughts with your family?

Why is this important?

Thinking about and sharing your wishes will give you more control over the care you receive.

Talking about the future won't change your ongoing care

Talking about the future won't change the plans we have made so far about your treatment unless, of course, you want to. We will keep providing the best possible care to control your disease.

You may find it helpful to bring other people to this conversation

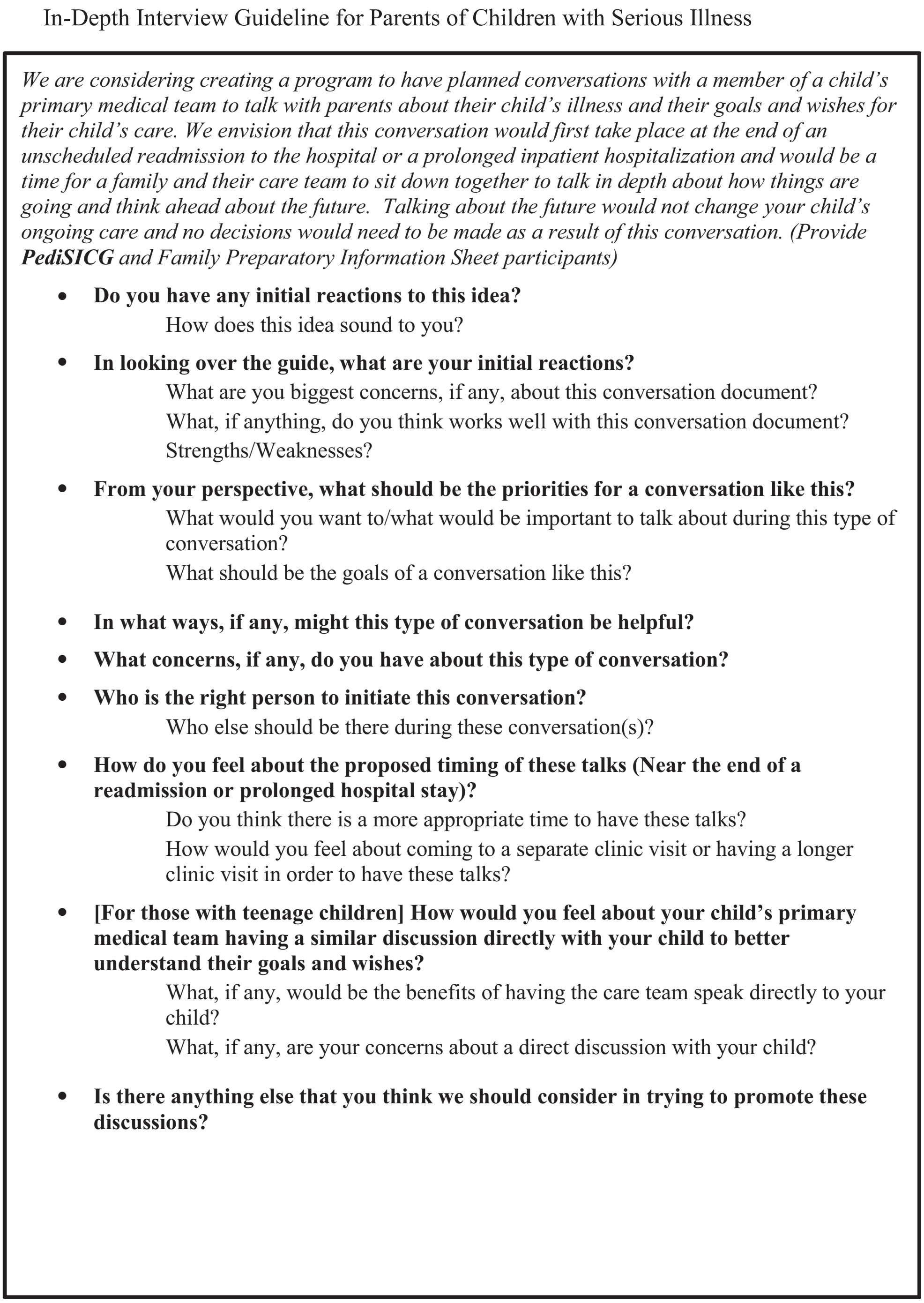
You can choose to bring other family members so they can be a part of the conversation. You can also bring other trusted providers such as your nurse practitioner, social worker, or chaplain if you like. Please let us know if you would like to bring others.

We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions.

If you have questions before you visit, please contact the study staff at 617-919-7357

Figure 2. Continued.

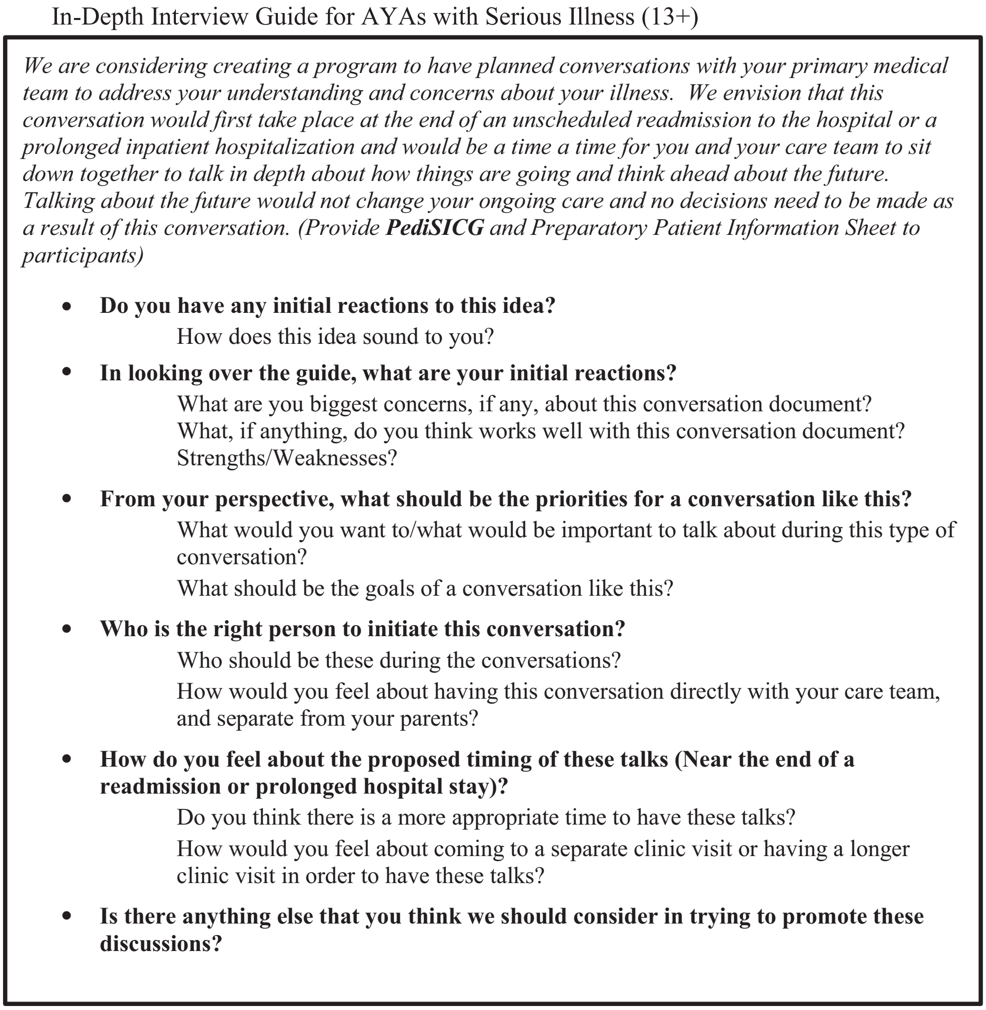


In-Depth Interview Guideline for Parents of Children with Serious Illness

We are considering creating a program to have planned conversations with a member of a child's primary medical team to talk with parents about their child's illness and their goals and wishes for their child's care. We envision that this conversation would first take place at the end of an unscheduled readmission to the hospital or a prolonged inpatient hospitalization and would be a time for a family and their care team to sit down together to talk in depth about how things are going and think ahead about the future. Talking about the future would not change your child's ongoing care and no decisions would need to be made as a result of this conversation. (Provide ***PediSICG*** *and Family Preparatory Information Sheet participants)*

- **Do you have any initial reactions to this idea?**
  How does this idea sound to you?
- **In looking over the guide, what are your initial reactions?**
  What are you biggest concerns, if any, about this conversation document?
  What, if anything, do you think works well with this conversation document?
  Strengths/Weaknesses?
- **From your perspective, what should be the priorities for a conversation like this?**
  What would you want to/what would be important to talk about during this type of conversation?
  What should be the goals of a conversation like this?
- **In what ways, if any, might this type of conversation be helpful?**
- **What concerns, if any, do you have about this type of conversation?**
- **Who is the right person to initiate this conversation?**
  Who else should be there during these conversation(s)?
- **How do you feel about the proposed timing of these talks (Near the end of a readmission or prolonged hospital stay)?**
  Do you think there is a more appropriate time to have these talks?
  How would you feel about coming to a separate clinic visit or having a longer clinic visit in order to have these talks?
- **[For those with teenage children] How would you feel about your child's primary medical team having a similar discussion directly with your child to better understand their goals and wishes?**
  What, if any, would be the benefits of having the care team speak directly to your child?
  What, if any, are your concerns about a direct discussion with your child?
- **Is there anything else that you think we should consider in trying to promote these discussions?**

Figure 3. Interview and focus group guides. *(Continues)*

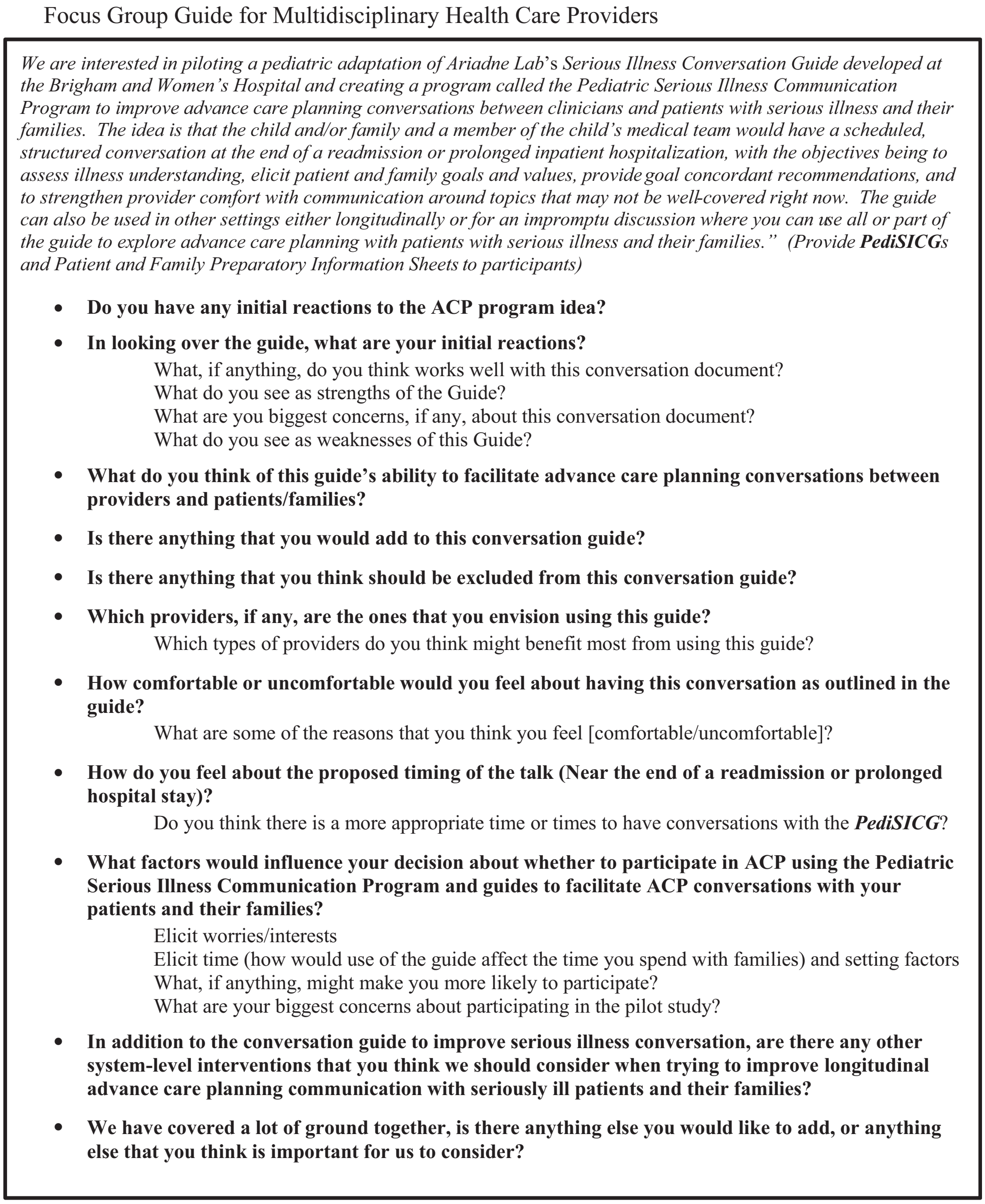


In-Depth Interview Guide for AYAs with Serious Illness (13+)

We are considering creating a program to have planned conversations with your primary medical team to address your understanding and concerns about your illness. We envision that this conversation would first take place at the end of an unscheduled readmission to the hospital or a prolonged inpatient hospitalization and would be a time a time for you and your care team to sit down together to talk in depth about how things are going and think ahead about the future. Talking about the future would not change your ongoing care and no decisions need to be made as a result of this conversation. (Provide ***PediSICG*** *and Preparatory Patient Information Sheet to participants)*

- **Do you have any initial reactions to this idea?**
  How does this idea sound to you?
- **In looking over the guide, what are your initial reactions?**
  What are you biggest concerns, if any, about this conversation document?
  What, if anything, do you think works well with this conversation document?
  Strengths/Weaknesses?
- **From your perspective, what should be the priorities for a conversation like this?**
  What would you want to/what would be important to talk about during this type of conversation?
  What should be the goals of a conversation like this?
- **Who is the right person to initiate this conversation?**
  Who should be these during the conversations?
  How would you feel about having this conversation directly with your care team, and separate from your parents?
- **How do you feel about the proposed timing of these talks (Near the end of a readmission or prolonged hospital stay)?**
  Do you think there is a more appropriate time to have these talks?
  How would you feel about coming to a separate clinic visit or having a longer clinic visit in order to have these talks?
- **Is there anything else that you think we should consider in trying to promote these discussions?**

Figure 3. Continued.

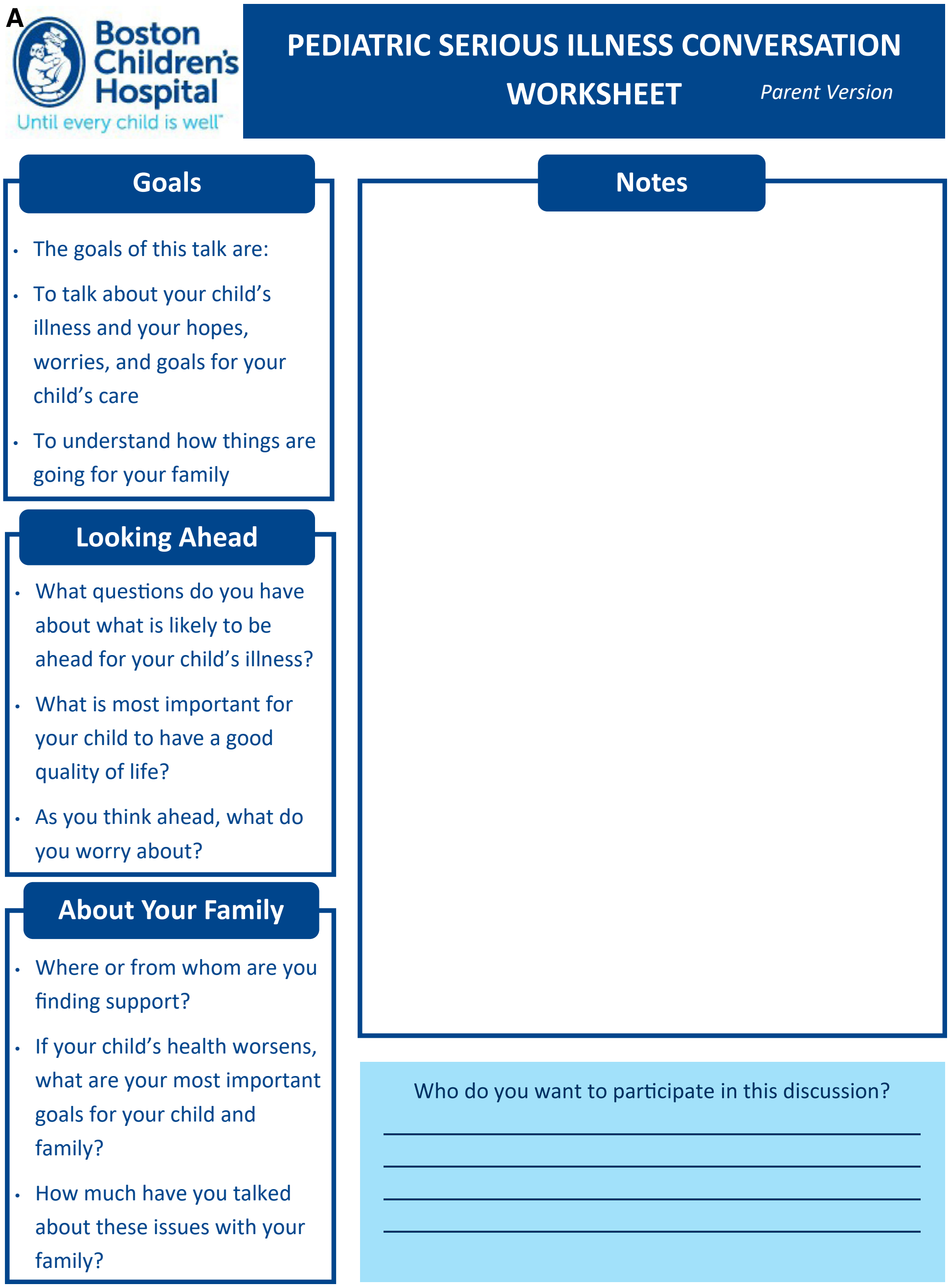


Focus Group Guide for Multidisciplinary Health Care Providers

We are interested in piloting a pediatric adaptation of Ariadne Lab's *Serious Illness Conversation Guide developed at the Brigham and Women's Hospital and creating a program called the Pediatric Serious Illness Communication Program to improve advance care planning conversations between clinicians and patients with serious illness and their families. The idea is that the child and/or family and a member of the child's medical team would have a scheduled, structured conversation at the end of a readmission or prolonged inpatient hospitalization, with the objectives being to assess illness understanding, elicit patient and family goals and values, provide goal concordant recommendations, and to strengthen provider comfort with communication around topics that may not be well-covered right now. The guide can also be used in other settings either longitudinally or for an impromptu discussion where you can use all or part of the guide to explore advance care planning with patients with serious illness and their families." (Provide* ***PediSICGs*** *and Patient and Family Preparatory Information Sheets to participants)*

- **Do you have any initial reactions to the ACP program idea?**
- **In looking over the guide, what are your initial reactions?**
    - What, if anything, do you think works well with this conversation document?
    - What do you see as strengths of the Guide?
    - What are you biggest concerns, if any, about this conversation document?
    - What do you see as weaknesses of this Guide?
- **What do you think of this guide's ability to facilitate advance care planning conversations between providers and patients/families?**
- **Is there anything that you would add to this conversation guide?**
- **Is there anything that you think should be excluded from this conversation guide?**
- **Which providers, if any, are the ones that you envision using this guide?**
    - Which types of providers do you think might benefit most from using this guide?
- **How comfortable or uncomfortable would you feel about having this conversation as outlined in the guide?**
    - What are some of the reasons that you think you feel [comfortable/uncomfortable]?
- **How do you feel about the proposed timing of the talk (Near the end of a readmission or prolonged hospital stay)?**
    - Do you think there is a more appropriate time or times to have conversations with the ***PediSICG***?
- **What factors would influence your decision about whether to participate in ACP using the Pediatric Serious Illness Communication Program and guides to facilitate ACP conversations with your patients and their families?**
    - Elicit worries/interests
    - Elicit time (how would use of the guide affect the time you spend with families) and setting factors
    - What, if anything, might make you more likely to participate?
    - What are your biggest concerns about participating in the pilot study?
- **In addition to the conversation guide to improve serious illness conversation, are there any other system-level interventions that you think we should consider when trying to improve longitudinal advance care planning communication with seriously ill patients and their families?**
- **We have covered a lot of ground together, is there anything else you would like to add, or anything else that you think is important for us to consider?**

Figure 3. Continued.



A

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PEDIATRIC SERIOUS ILLNESS CONVERSATION WORKSHEET *Parent Version*

Goals

- The goals of this talk are:
- To talk about your child's illness and your hopes, worries, and goals for your child's care
- To understand how things are going for your family

Looking Ahead

- What questions do you have about what is likely to be ahead for your child's illness?
- What is most important for your child to have a good quality of life?
- As you think ahead, what do you worry about?

About Your Family

- Where or from whom are you finding support?
- If your child's health worsens, what are your most important goals for your child and family?
- How much have you talked about these issues with your family?

Notes

Who do you want to participate in this discussion?

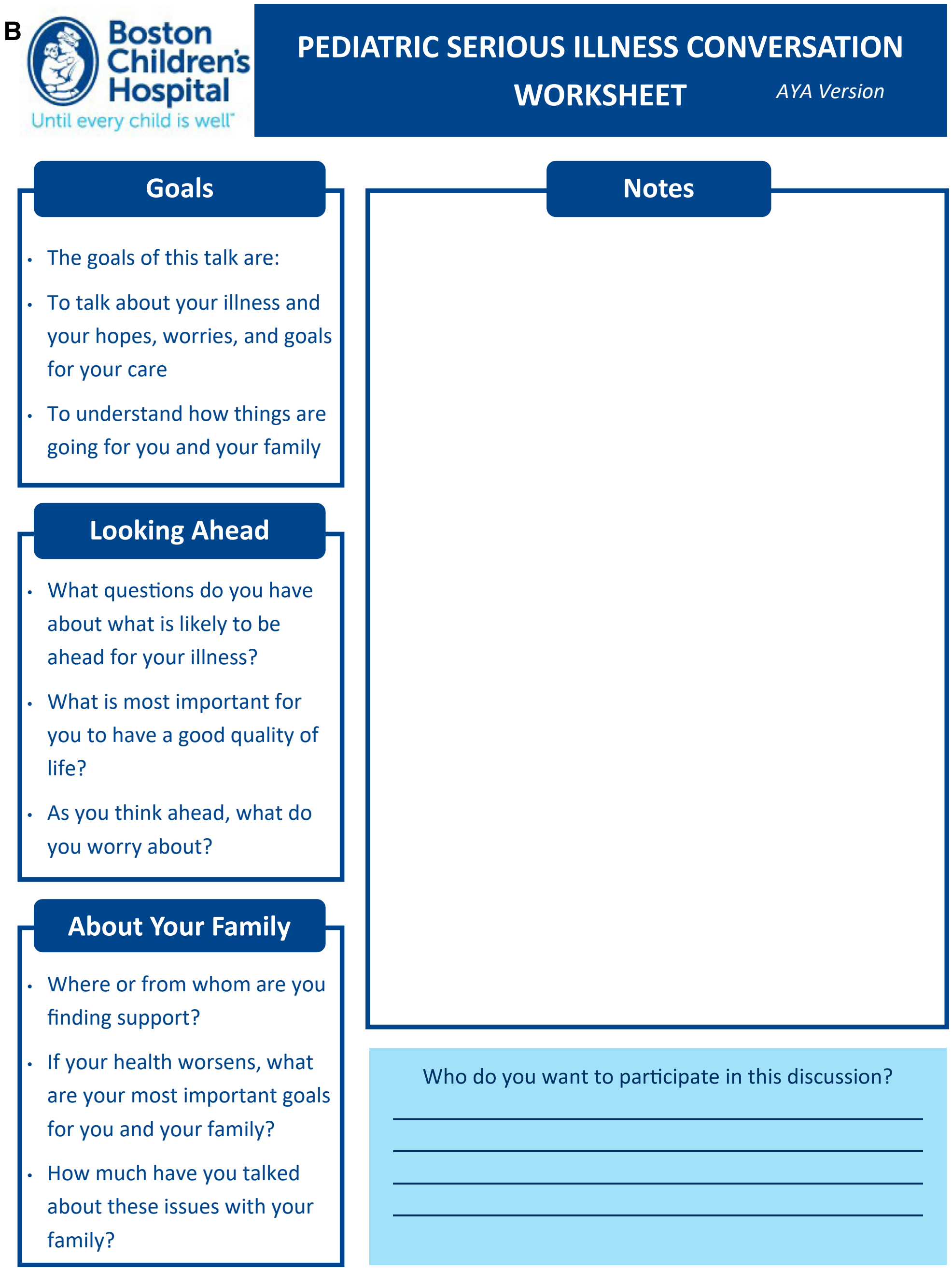
____

____

____

____

Figure 5. Pediatric serious illness conversation worksheets. *(Continues)*



B

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PEDIATRIC SERIOUS ILLNESS CONVERSATION WORKSHEET *AYA Version*

Goals

- The goals of this talk are:
- To talk about your illness and your hopes, worries, and goals for your care
- To understand how things are going for you and your family

Looking Ahead

- What questions do you have about what is likely to be ahead for your illness?
- What is most important for you to have a good quality of life?
- As you think ahead, what do you worry about?

About Your Family

- Where or from whom are you finding support?
- If your health worsens, what are your most important goals for you and your family?
- How much have you talked about these issues with your family?

Notes

Who do you want to participate in this discussion?

Figure 5. Continued.