# Supporting collaborative goal-setting for hospitalized adolescent patients

Yiran Zhao

A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Science

University of Washington

2019

Committee:

Chair: Wanda Pratt

Member: Ari Pollack

Program Authorized to Offer Degree:

Biomedical and Health Informatics

University of Washington

## Abstract

Supporting collaborative goal-setting for hospitalized adolescent patients

Yiran Zhao

Chair of the Supervisory Committee:
Wanda Pratt
Biomedical and Health Informatics

Collaborative goal-setting is an effective way to encourage patient engagement and facilitate patient-provider communication. However, few studies have explored how hospitalized patients understand and use collaborative goal-setting to communicate with their care teams. Even less is known for how adolescent patients perceive collaborative goal-setting. This paper presents a technology probe study aiming to explore how adolescent patients perceive and use collaborative goal-setting during hospitalization. We conducted this study with 4 patient families and 3 clinicians. We discussed the design process of the probe application, which featured 1) goal management based on levels of abstraction and timeline and 2) discussion board to help patients speak-up for their preferences. We found that adolescent patients use goal-setting as 1) a self-reflection process, 2) a way to reveal different perspectives between them and their caregivers and to grow independence, and 3) a tool to facilitate collaboration with their care teams by giving them more control over patient-provider communication. Our contribution provides insights into how to design informatics tools to promote adolescents to participate in their care.

# Introduction

Current health care fields aim to reform the traditional provider-centric, disease-centric model to the new patient-centric, goal-centric model. The new model sees the patient as an active collaborator, instead of a passive receiver, in their care. Collaborative goal-setting between care provider and patient is a key component to such patient-centric model. [1, 2, 3]

Collaborative goal-setting has been studied extensively in health-related fields and shown to be an effective way to encourage patient participation. Disciplines such as rehabilitation, physical therapy, primary care, and chronic condition management have identified the benefits of collaborative goal-setting for care outcomes and have incorporated collaborative goal-setting into their general practice guidelines. [4, 5, 6, 7] However, little work was conducted to explore how hospitalized patients (inpatients) perceive and use collaborative goal-setting. Despite the lack of understanding of how collaborative-goal setting affects patient-provider communication in hospital, health informatics study has shown that inpatients want to share their personal goals in addition to receiving provider-centric medical goals, and want their perspectives to be heard and incorporated into care plan. Inpatients feel more in-control and encouraged to participate in care when they are able to express personal goals and perspectives. [8]

Despite the wide recognition of the importance of patient participation, children and adolescents have limited opportunities to make decisions for their care, especially during hospitalization. [9] Hospitalized children and adolescents often receive less-than-optimal opportunity to involve in communication with care team or to participate in decision making. [10, 11] Although studies have shown that children and adolescents patients want to be members in decision-making, and that respectful communication with children and foster their decision-making ability and enhances their self-efficacy, there's a lack of informatics tools to help children and adolescent express their perspective and participate in conversations relating to their care. [12, 13, 14]

We identified two factors preventing children and adolescents from participating in clinical conversation during hospitalization: 1) hospitalization is a high-stress, high-pace environment where patients are situationally impaired, which increase the difficulty for patients to engage in clinical communication; 2) clinical care mostly utilize family-centered care instead of children-centered care, which causes the patient's voice to be replaced by the family's voice. [14]

Because of the effectiveness of collaborative goal-setting in non-hospital medical setting, we saw collaborative goal-setting as an opportunity to help adolescent inpatients to express their perspectives, communicate about their preferences and participate in clinical decision making. We identify two knowledge gaps: 1) how inpatients perceive and use collaborative goal-setting and 2) within inpatients, how adolescents perceive and use collaborative goal-setting. To explore this opportunity, we aimed to investigate the following research questions (RQs):

- RQ1: How to model goals from adolescent inpatients?
- RQ2: How to design a system (tool) to facilitate communication based on collaborative goal-setting for adolescent inpatients?
- RQ3: How does such system impact collaborative goal-setting and communication in adolescent inpatient care unit?

To address these RQs, we conducted a three-phase technology probe (tech probe) study. In phase one, we analyzed existing interviews with adult and adolescent inpatients to build goal models for inpatients to study RQ1. In phase two, we designed user interfaces (UI) from goal models and developed an iPad application to address RQ2. In phase three, we deployed the app as a technology probe in a local hospital with 4 adolescent patients and their families and 3 clinicians to answer RQ3.

We provided the following contributions: 1) 10 dimensions to model inpatients' goals; 2) a detailed understanding of how adolescent inpatients use goal-setting to self-reflect, to communicate with their caregivers and to collaborate with their care teams. We hoped these contributions can inform the design of future adolescent-facing informatic tools, facilitate their participation in care and better their care outcome and hospitalization experience.

# Related Work

There're two elements in collaborative goal-setting, collaboration and effective goal-setting. To design for goal-setting, we explored related work on effective goal-setting and how other health disciplinaries model care-related goals. To account for collaboration, we identified the challenges and opportunities of sharing patients' personal goals with care teams.

## Effective goal-setting

Various works on goal-setting aim to model goals and identify how goal models change their effects.

The most renown goal structure is perhaps S.M.A.R.T (SMART) developed by management professionals. It characterizes effective goal setting to be focusing on a Specific improvement, to be Measurable, to have clear Assignment on who's responsible, to be Realistically achievable, and to be Time-sensitive. It was designed to make goals easy-to-grasp and enhance goal accomplishment. [15]

Locke and Latbam recognized that goals are most effective when they are important to the individual, realistic, displays progress, and when an individual receives positive feedback when a goal is met. [16] To ensure goals are relevant to individuals, they recommended the individual to initiate goal-setting and to self-assign goals instead of being assigned goals. [17]

We absorbed that, to effectively set goals and promote goal accomplishment, 1) goals need to set to be easy-to-grasp and specific, and 2) individuals should initiate goal setting and set their own goals.

## Model health-related goals

To help patients conceptualize their goals in a way that can best facilitate their communication with their care teams, we explored how other medical disciplinaries model health-related goals.

Various works have determined that goals have levels of abstractions. Health-related self-tracking tools have adapted the hierarchical goal structure developed by Power et al. [18, 19] This goal structure is based on levels of abstraction. The most abstract level is *system* concept, or an idealization or value of self, relationship or society. To achieve certain idealization, an individual comes up with *principles*, such as *be fit*, or *be productive*. The next level of abstraction is *program*, or the specific activities that are qualities of a principle. For example, the program associated with the principle *be fit* can be *run three times a week*. To perform a program, one needs to complete a set of actions, such as *put on running shoes* or *get a running machine;* this level is referred to as *sequence*. In primary care, goals can either by general, such as "exercising more", or can be specific, such as "walking 15 minutes four times a week". Specific goals are referred to as actions and are effective at promoting patient adherence to the care plan. [6]

Health goals of different abstract levels are connected. Rehabilitation goal-setting has noticed that it's important to show the connection between goals so that patients can see how short-term rehabilitation goals can benefit their long-term personal goals. [4]

In addition to levels of abstraction, health goals can be modeled by other dimensions such as timeline. Rehabilitation professionals have determined that health goals are multi-dimensional and have at least two axes with one axis being time. This means that all goals can be modeled by their expected accomplishing date as short-term goals or long-term goals. [4]

We absorbed the following design considerations: 1) goals are multi-dimensional, and we need to identify goal dimensions that are applicable to hospitalized patients; 2) goals are naturally separated by a level of abstraction and timeline, and it’s important to show the connections between specific, short-term goals and abstract, long-term goals.

## Opportunity and challenges in health goal-setting

The key element of collaborative goal setting is collaboration. We referred to related work to learn how patients and care teams perceive sharing their goals and learning about the other side's goals.

Works on inpatient informatics tools reveal the motivational effect of patients sharing their personal goals and preferences. Haldar et al. found that for inpatient, in addition to medical goals that patients must meet before discharge, patients want to display their personal goals in the patient portal. Traditional goals in the hospital setting have been provider-focused for short-term recovery. To shift the care model to be patient-centric and to be aware of patients’ long-term life quality, informatics tools can explicitly prompt and display personal goals and preferences. This concept gives patients more ownership in their care, thus encourages patient participation and supports collaboration between patients, caregivers and care teams. [8]

Patients’ personal goals can convey patient's values and guide the care team to structure the priority of care. Berry et al. studied how to best design for patients with multiple chronic conditions. They found that patients with multiple chronic conditions often have conflicting goals because they face complex health conditions. Thus, patients often need to make decisions on their healthcare priorities. Berry identified 7 dimensions of personal values to help patient

structure and communicate their priorities with their care provider. Inpatients faced a similar situation where they are often dealing with multiple health demands, sometimes conflicting, at the same time. Their personal goals and preferences can be a guide for the care team to prioritize their care plan on considerations that are more important to their life quality.

In addition, rehabilitation professionals have discovered that the patients' personal goals might be conflicting with medical goals. For example, a surgeon might set a goal for a patient to exercise 30 minutes per day, but this goal might conflict with a patient's 16-hour workday. This conflict encouraged rehabilitation professionals to incorporate collaborative goal-setting and discussion around conflict goals as their standard practice. [6]

We learnt from the opportunities and challenges in health goal-setting that 1) a collaborative goal-setting tool be explicit in displaying personal goals and preferences; 2) the care team should be able to view patients' personal goals and able to learn about patients' priority from their goals; 3) there are natural conflicts in long-term personal goals and short-term medical goals, so collaborative tools should design to help patients and care teams to negotiate their conflicts.

# Method

There are 3 stages to our study: (1) analyzing existing data to identify the goals and goal structures of inpatients; (2) designing the user interface and developing the application and (3) deploying the application as a technology probe in a local pediatric hospital.

## Phase One: Analyzing existing data

To address RQ1, we analyzed two existing interview datasets from the Patient As Safeguard project, a project aiming to improve inpatients' safety through designing informatics tools to support patients acting as their own safeguards. Dataset A was a semi-structured interview with 30 inpatients and caregivers to discover their need for patient portals using feature cards as prompts for possible features that could be supported. Dataset B was a follow-up of Dataset A with higher fidelity prototypes conducted with 21 inpatients and caregivers to explore how can design best address the unmet needs identified by Dataset A. We chose these datasets because displaying patient-centric goals emerged as a need for inpatients and informed various works on how to design patient-facing tools to address this need. [6]

We re-coded the above-mentioned datasets to extract inpatients and caregivers' goals. We first coded goals based on levels of abstraction because prior work as identified this goal structure for health management. We then coded focusing on goal categories and had iterative affinity diagramming sessions to derive 10 dimensions of goals (see Design of Tech Probe – Goal Dimensions).

We designed 5 goal models based on the 10 dimensions of goals we identified. From the five models, we synthesized the features into 3 interfaces (see Design of Tech Probe – Goal Models) and built mid-fidelity wireframes using Balsamiq (version 3.5.17).

## Phase Two: Tech Probe Design and Development

To address RQ2, we conducted a one-hour expert review workshop. 8 people participated in the workshop, including one clinician, one information science professor, and six graduate students studying information science and/or human-centered design. We chose 3 wireframes and asked experts to 1) freely draw on, annotate and comment on the design, 2) rank their preferences of the 3 designs, and 3) share what they like and don't like about each design with the group. Based on the experts' review, we chose one wireframe design that was the most light-weight and directly displayed the comparison between the patient and clinician's perspective.

After we finalized the wireframe design, we developed an iOS application for iPad Air 2, iOS version 12.2 using Xcode version 10.2. We chose the iPad as the deployment device because it's easy-to-sanitize, has large screen for easy viewing and interacting, and can be held by the patient in bed. The tool was a local tool that did not require the internet connection because the internet connection in the deployment site might be unstable and might cause data security concerns.

## Phase Three: Tech Probe Deployment

### Deployment process

To address RQ3, we deployed the application, named Plan&Talk (PT), in a pediatric hospital in a metropolitan area of the United States. Because our deployment site was a pediatric hospital, all patient participants were escorted by their caregiver(s). This study was approved by the University of Washington and the hospital's Institutional Review Boards.

Each participating family participated in a two-or-more-day study, depending on their medical situation (Figure 1). On day one, we approached, consented and conducted pre-deployment interview with the patient and/or the patient's caregiver. On the clinician side, we approached the patient's primary physician and asked for the care team' goals for the patient. We onboarded the patient to the PT app right after conducting the pre-deployment interview, and we input the physician's goals to the PT app. We left the iPad with PT app installed with the patient. On the second and later days in the study, we conducted two observation sessions per day: one during the patient's rounds, the other during a follow-up session, or when the patient's physician approached the participating family for further discussion. Before the participating family-care team interaction happened, we reminded both sides that our tool was in the patient's hand, and they were welcomed to use it during discussion. Also on the second day or later days, we conducted post-deployment interview with the patient and/or the patient's caregiver to learn about their experiences with the PT app. After the deployment with the participating family, we conducted interviews with the corresponding physicians.

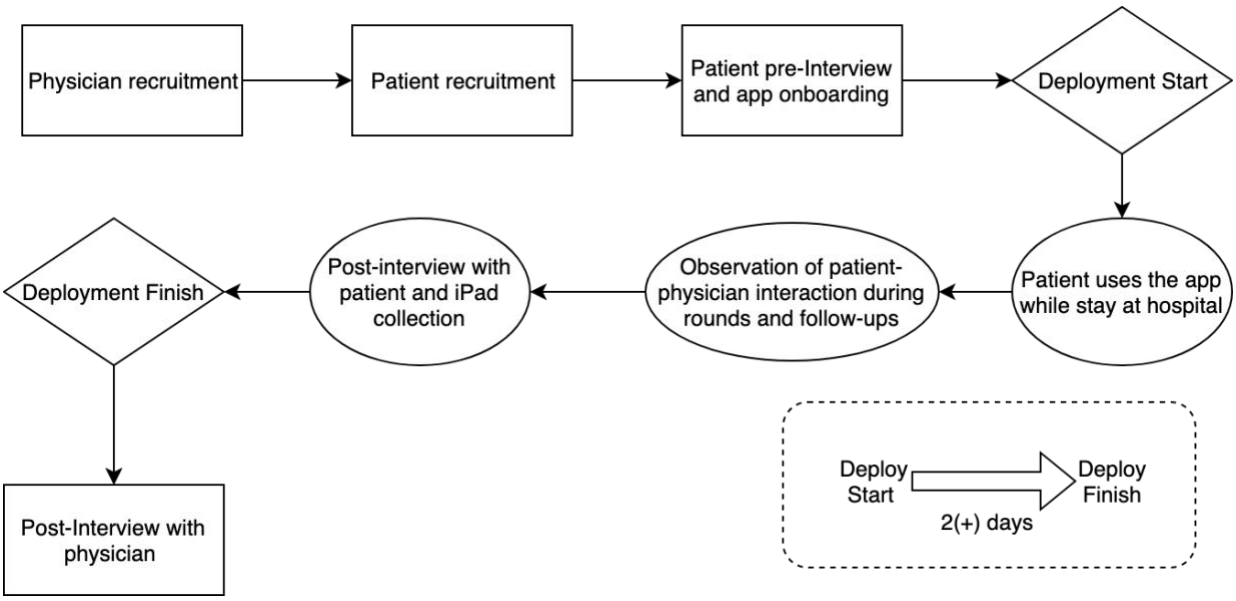


Figure 1. Flow chart of our deployment study.

### Participants

For this thesis, we conducted our study with 4 participating families and 3 physicians.

The 4 patient participants are between the ages of 12-18; all patient participants self-identified as white/Caucasians; 2 of them self-identified as male and 2 of them self-identified as female. All patients have previous hospital experiences. All of the patients were under medical service: 3 patients were admitted under nephrology, and 1 patient was admitted under general medicine. The 3 physicians included 2 attending physicians and 1 interning physician. 2 of the physicians were nephrology physicians, and 1 physician was general medicine physician.

### Data Analysis

We collected three forms of data from deployment: 1) transcription of pre-deployment and post-deployment interviews; 2) observation took during interviews and observation sessions; these notes focused on non-verbal interactions, such as app interaction, gesture, atmosphere, and emotion; 3) PT usage data, including patients‘ textual inputs and the time of input.

We performed qualitative, thematic analysis on interview transcriptions and observation notes, referred to as textual data. [20] We first iteratively coded a subset of the textual data. In this process, we conducted 4 review sessions, grouping codes in affinity process and combining codes to build larger themes. After we agreed that we’ve reached thematic saturation, I coded the remaining textual data. we grouped the codes from this subset and conducted affinity process to identify themes and build codebook.

# Design of Tech Probe

To support collaborative goal-setting, we designed our tech probe to 1) feature effective goal-setting and 2) facilitate communication between the patient and the care team. We extracted goal dimensions to categorize goals, utilized goal dimensions to model goals, and designed the app interface based on the most suitable goal models reviewed by experts.

## Design Rationale

Based on related work on effective goal-setting and health goal-setting discussed in the Related Work section, we synthesized the following design rationale:

- RA1: Displays goal structures with multiple levels of abstraction, timeline, and other dimensions.
- RA2: Emphasizes patients' sense of ownership.
- RA3: Facilitates collaboration between patients and care teams for prioritize care plan and discuss conflicting perspectives.

## Goal Dimensions

we identified 10 dimensions of inpatients and caregivers' goals: 1) level of abstraction, 2) hospitalization timeline, 3) patient's goals or care team's goals, 4) level of importance, 5) medical goals or non-medical goals, 6) negotiability, 7) achievability, 8) discharge, lifestyle or recovery-related goals, 9) daily activities, 10) to-learn, to-track or to-perform. We explained the two most important ones, level of abstraction and timeline, below:

We combined the hierarchical goal model developed by Power et al. and SMART goal-setting to come up with 3 level of abstraction dimension for inpatients. High-level goals are similar to system-concept or principle-level goals; they are abstract, not-actionable, and are about an idealization or value. For example, "try to stay healthy" or "have no fears" are high-level goals. Mid-level goals are specific, actionable, but not quantifiable. Examples of mid-level goals are "be able to walk on my own" and "transfer to oral antibiotics". Low-level goals are similar to SMART goals because they are specific, actionable, assignable and measurable. However, because the events in hospital are unpredictable, low-level goals do not need to be time-specific. Examples of low-level goals are "walk 10 minutes twice a day" or "I have to write down the liters of urine I produce".

In addition to levels of abstraction, goals in hospital have a time dimension. Figure 2. depicts a timeline of hospitalization. The start of the timeline is admission, or event which the patient is admitted to the hospital. Between the admission event and the discharge event is a period named hospitalization. After discharge, there's a one month at-home observation period. During this period, the patients are expected to be recovering and observing their conditions. Because this period is a continuation of hospitalization, and the patient may not fully return to their normal daily lives we assigned this period as a unique period. After this one-month at-home period, we named a period future to capture the goals that patients are thinking about but are still far away in time.

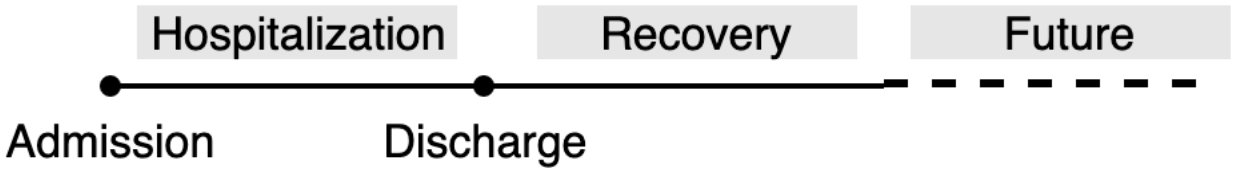


Figure 2. Timeline dimension of goals from inpatients. A goal can either belong to a period, which means to accomplish a goal during hospitalization, during recovery or sometime future, or related with an event, such as a goal for discharge.

## Goal models

Based on goal dimensions, we created 5 goal models and presented 3 most distinctive ones for experts' review. In each model, we represented 3-5 goal dimensions that we consider useful in hospital setting and incorporated features to foster sense of patients' ownership and personality.

### Model 1: Goals on top

Model 1 (Figure 3) combined levels of abstraction, timeline, goal's origin and daily activities. This model combined mid- and low-level goals and displays them as actions. Actions were categorized by daily activities, such as medication, food, or personal items. This model emphasized patient's ownership by displaying patient's preferences and goals, and showing icons on actions to represent who comes up with each action.

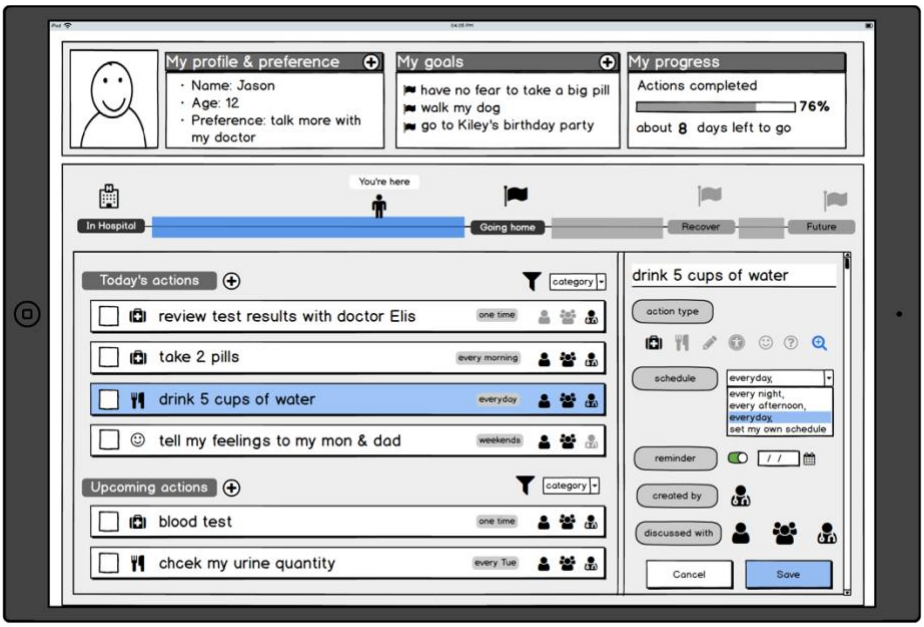


Figure 3. Interface designed based on Model Goals on top.

### Model 2: Goal-task connection

Model 2 (Figure 4) combined levels of abstraction and timeline dimensions. This model displayed each high-level goal on the hospitalization timeline and assumed mid- and low-level goals are steps toward accomplishing high-level goals. Each mid- and low- level goals were

attached to a corresponding high-level goal. This model emphasized patient's ownership by displaying patient's profile and a dedicated About Me section.

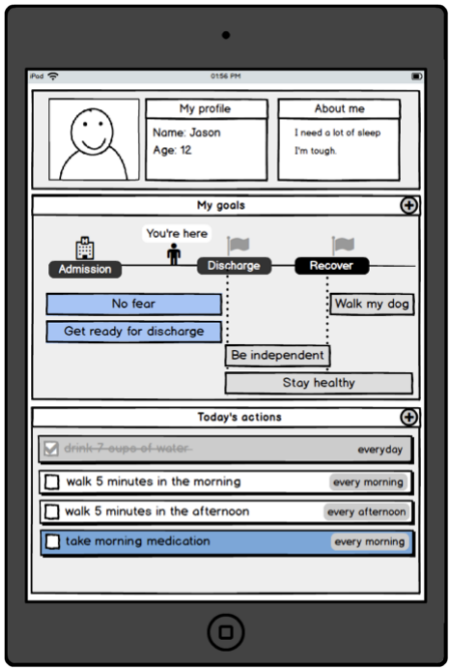


Figure 4. Interface designed based on Model Goal-task connection.

### Model 3: Need/Want

Model 3 combined levels of abstraction, timeline and medical/non-medical dimensions (Figure 5). It combined mid- and low- level goals and referred them as actions. This model displayed high-level goals without the timeline, and put actions on to the timeline that's divided by "now, discharge and recovery". Actions were also divided to "need to" and "want to", which are combinations of medical/non-medical goals, as well as care-team/patient's goals. This model also supported a discussion board for patients to quickly marks actions that they want to discuss with their care team. This model emphasizes patient's ownership by using phrases "I need to" and "I want to", as well as by displaying patient's profile and a dedicated About Me section.

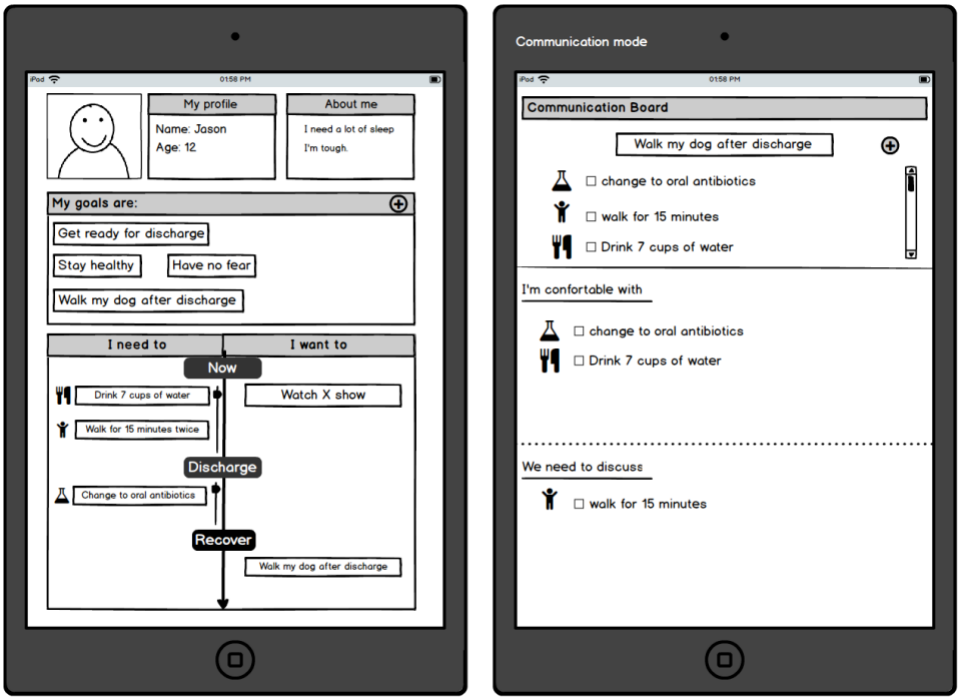

Figure 5. Interface designed base on Model Need/Want.

Most experts advocated for Model 3 because: 1) it has a light-weight and intuitive design, which suits the high-stress, high-pace hospital setting; 2) it conveys a strong sense of patient ownership by displaying "about me", "my goals are", "my profile" and “I need/want to”; 3) it features a parallel display of the medical side and the personal side, which fosters sense of equality and displays both agreement and conflicts clearly; 4) it encourages communication by providing a dedicated discussion board. They advised that the "Need To" can be rephrased as "care team's want me to" because action items from the care team are most likely to fall into this side, and they suggested adding a section to display the high-level goals from the care team next to the patient's personal high-level goals. Overall, they considered this model to best address the design rationales on facilitating effective goal-setting, expressing patient's perspective, and encouraging collaboration.

## App Interface

The PT app has 4 sections, About Me, Goals, Let’s Plan timeline and Let’s Talk discussion board. The Goals and the Let’s Plan timeline display the care team’s perspective and the patient’s perspective side-by-side. Figure 6 shows the overview of the PT app.


Figure 6. Overview of the PT app. This app features two screens, Let's Plan and Let's Talk. Let's plan displays a timeline for patient's and care team's actions, which are mid- or low- level goals. Let's Talk is a board to display actions on the Let's Plan timeline, either under "We need to talk about" or "Things going well". Sections to display patient's high-level goals and patient's preferences (About Me) are always on top the top section of the screen.

The patients can have the following interactions with the app:
To support RA1:

- Add, modify or delete action items, or low-level goals, to the timeline. Each action item appears as a card in the Let's Plan timeline, which is divided to In Hospital, At Home and Someday (Figure 7).

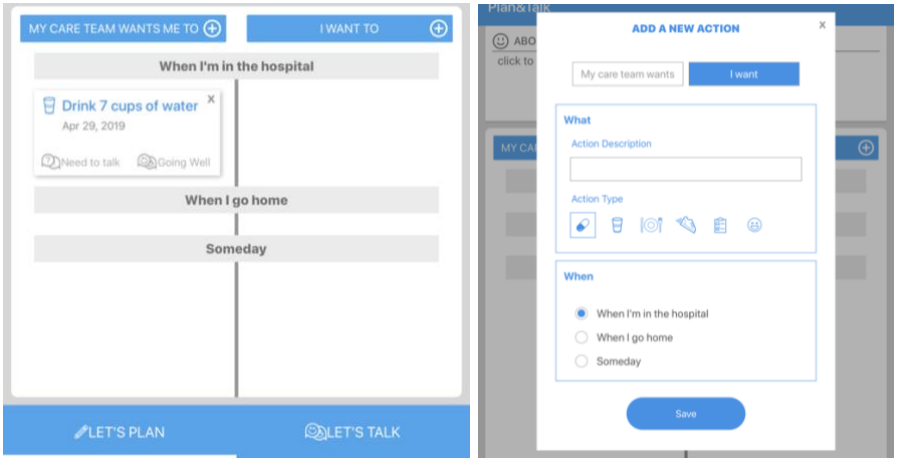


Figure 7. LEFT: Let's Plan timeline has a timeline to display actions, which are mid- and low-level goals. The screen is split to the care team's side and the patient side while both sides share the same timeline. The timeline is designed to categorize actions into when the patient is in the hospital, when the patient is discharged and goes home, and sometime in the future. RIGHT: User can add either care team actions or patient actions into any of the three sections on the timeline. PT also supports an action type selection to help patients organize actions.

To support RA2:

- Edit the About Me section to express their preferences, values or personalities (Figure 8).
- Add, modify or delete their high-level goals in the goals section (Figure 8).

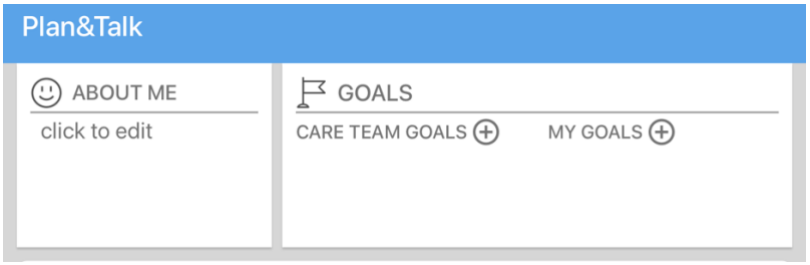


Figure 8. On top of the app's screen, there is an "About Me" section for patients to put in their preferences, and a "goals" section to display the high-level goals from the care team and the patient side-by-side.

To support RA3:

- Mark or unmark an action item card as *Need To Talk* or *Going Well*. This interaction will make an action item card appears in the corresponding section in the Let's Plan discussion board (Figure 9).

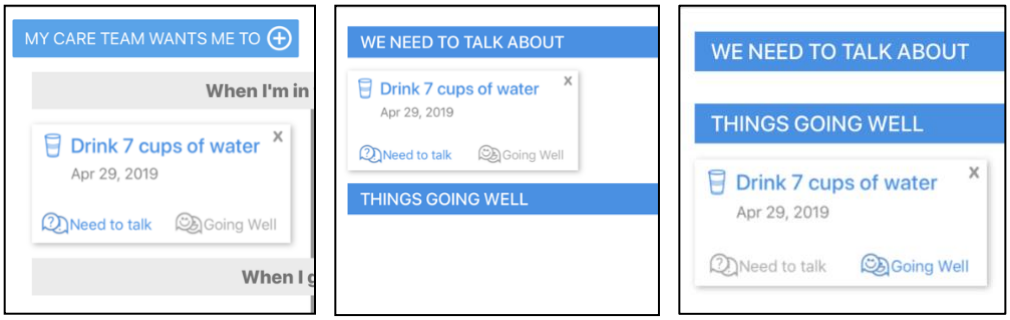


Figure 9. LEFT: the user assigns either a *Need to Talk* mark or a *Going Well* mark to an action card in the Let's Plan tab. MIDDLE: when the user does so, the action card will appear in the corresponding section in the Let's Talk tab. RIGHT: The user can directly select the other mark on the card, and the card will change its' position on the Let's Plan tab. The user can also remove a card from the Let's Plan tab by de-select either mark.

- Add topic cards to either section (*Need To Talk* or *Going Well*) in the Let's Talk discussion board (Figure 10).

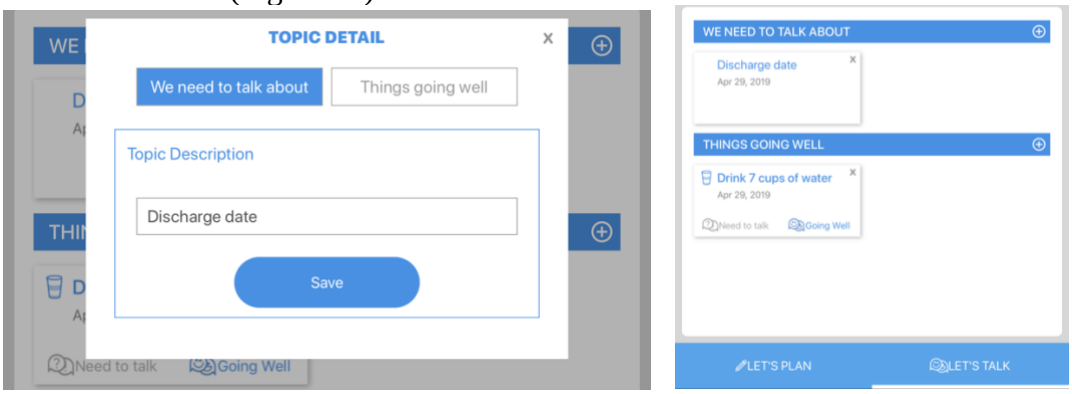


Figure 20. LEFT: the user can use the Let's Talk tab as a note-taker and add cards to either "We need to talk about" or "Things going well". RIGHT: The card will appear in the corresponding sections in the Let's Talk tab.

# Deployment Study Findings

Our tech probe reveals how adolescent patients use goal-setting to communicate with themselves, their caregivers and the care team: 1) adolescent uses goal-setting as a coping mechanism for negative emotion and celebration for their care progress; 2) goal-setting helps caregivers see the differences between their perspectives and patients' perspectives, and facilitate caregivers to foster independence in adolescent patients; 3) patients perceives goal-setting as an asynchronous, indirect way to communicate with their care teams and developed strategy to share decision-making with their care teams.

We use the following nomenclature to differentiate the quotes from participants: the first letter (P or C) indicates whether the participant is a member of the participating family or a member of the clinical care team; the second and third numbers are assigned by the research team to uniquely identify each participant. The participating family side has an additional letter (-P or -C) which indicates whether the participant is a patient or caregiver.

## Patient and self-reflections

### Goal setting as emotional support

Patients used goal-setting with PT as a coping mechanism in the high-stress hospitalization environment. It served both as a way to process frustration and other negative emotions, and as a way to celebrate the progress of care.

Hospitalization is a high-stress environment in which patients may not have access to their normal channels for stress release or emotional support. Conceptualizing goals through PT helped patients to process their emotions by feeling a way out of the hard situation they are in and toward the daily lives they look forward to. P03-C observed that "*[the patient] was really mad*" and the patient started to interact with P&T as a distraction. When the patient was putting down her goals in the app, "*she was calmer.*" P03-C reflected that "*[the patient] needs to have small goals, big goals, especially when she's feeling down, depressed, sad, angry, isolated.*"

Coming up with actionable steps helps the patient sees a way out of the undesirable situations she was in. For example, the patient put down goals such as "*Work with urology to determine when foley catheter removed*" and "*Find emotional support to dealing with transplant*", which are steps that could better her condition. Furthermore, putting down future goals help the patient focuses on what she looks forward to after hospitalization, and the actionable nature of goals conveys a realistic feeling of these mental pictures. For instance, P03-C input "*Eat healthier [and] grow garden food*" and "*Find some smoothies I like*", which are elements of the daily life she looked forward to having after discharge. Conceptualizing goals helps patients cope with negative emotions by helping patients see the steps out of the uncomfortable situation they are in and reminding them of the positive part of their lives that they look forward to.

In addition to being a coping mechanism for negative emotions, setting goals serves as a celebration of treatment progress that conveys a sense of accomplishment. Patients look forward to being discharged from the hospital, and they view goals as small progress that lead to their ultimate goal. As P04-P states, "*I'm pretty excited to get out. That's the biggest goal.*" This is also supported by our previous findings in Dataset A, which I observed the patient listing "*the discharge to me is the main goal*". Patients view action items and goals they inputted as a journey, which "*everything, every single day leads up to being able to get out and be healthy enough to go home.*" This evokes a sequence of emotions: 1) patients feel they are making progress, and 2) patients feel that they are moving toward their ultimate goal. P03-C states that "*I like this for [the patient] because it's something … to chart her progress, and right now she needs something like that.*" Goal-setting is a way for patients to celebrate their progress that evokes a sense of accomplishment.

## Patient and caregivers

Caregivers often have a large sense of control in adolescent care. They described themselves as their children's "*advocate*" and actively engage in conversation with the care team for the patients. For instance, 3 out of 4 rounds we observed were conducted with the caregiver only. However, caregivers want to foster patients to have control over their care. Goal-setting helps the caregivers see the differences in their perspectives and the patients' perspectives and encourage patients to be independent.

### Goal setting reveals the gap of understanding between patients and caregivers

Caregivers have different expectations on how patients perceive goal-setting. P03-C expected P03-P to use the PT app as a venting space because P03 had undesirable events with the care team and had been in difficult emotions. P03-C thought the patient would "*put more negative things about her care team*", such as "*I'm going to sue the hospital*". Surprisingly for P03-C, the patient put down thoughtful and realistic goals, such as "*Drink 3 liters of water*" or "*Know meds to use in case of rejection*". Despite feeling distressed and irritated, the patient demonstrated that she set goals to improve her involvement in decisions and better her condition. Patients sharing their goals helps their caregivers realize that the patients perceive goal-setting with seriousness and that the patients are willing to set goals that are applicable for collaborative goal-setting.

Goal setting helps the caregiver to see patients' goals that they are not aware of and the priority of goals in the patient's perspectives. Patients use goal-setting to speak about the preferences they don't share with their caregiver directly. P04-C did not know the patient wanted to swim

before she checked the PT app and saw the patient put "*Go swimming in the therapy pool*." Knowing this, the caregiver was able to bring this goal up during rounds for the patient. In addition to revealing what the caregivers do not know, goal-setting helps patients express what they think is important. P03-C thought the patient would put "*get [the] Foley out*" because she felt the patient has been repeating that demand. However, the patient did not put this goal into the PT app. P04-C thought that the patient did not like "*people holding her hands down*". P04-C perceived this preference as very important to the patient because P04-C thought the patient "*has to be in control of her body*" or the patient would "*panic*". However, the patient did not put this preference into the app. P04-P shared that she only put goals that are "*important things that [she cared] about more*" and "*[wanted the care team] to see*" into the app. Sharing patients' goals improves their communication between caregivers and patients and helps caregivers to better understand patients' desires and priorities.

### Caregivers perceive goal-setting as a way to foster independence

Caregivers felt the necessity of training their children to take ownership of their care. P03-C shared her stress about she *"[has] had control of [the patient's] life in a lot of ways*" and "*[has] advocated for [the patient] whole life*". As P03-P approaches adulthood, P03-C worried if the patient would be able to take care of the complex medical condition on her own. To help P03-P to participate more in her care, P03-C has encouraged P03-P to take small steps, such as to call the pharmacy and to talk to the care team.

Goal-setting with PT helps caregivers foster independence by encouraging patients to steps in their care. P03-C emphasized that the willingness to participate in care "*has to come from [the patient]*". She cannot push her child to make decisions on the care plan; rather, she would like to see her child actively sets goals for her care and works toward each goal. Goal-setting encourages patients to plan for their care by improving the patients' self-efficacy when patients *"[don't] have a lot of control*" over "*the smallest thing*". P03-C described this as a sequence of emotions: the patient can feel *"I've got this", "this is what I need to do", "I've done it", "I feel good about it"*, and I can *"move on to the next thing"*. P03-C thought this process no only helps the patient feels in control and accomplished, but also is "*important for [the patient's] self-esteem*". For example, P03-P put a goal for "*[drinking] 3 liters of water*". It was one of a few controls she was able to have on her daily life, but it helped her to "*feel good about herself*" because she was accomplishing a goal that she decided on. Goal-setting serves as positive conditioning: patients attempt to take ownership in their care by setting goals, working toward their goals, and feeling accomplished by doing so. This process couples a good feeling with making decisions and participating in their care. For adolescent patients who are learning to take care of themselves, goal-setting can foster their independence from their caregiver by increasing their self-efficacy and encouraging them to make decisions for themselves.

## Patient and the care team

Patients are situationally impaired in hospital, which results in them to sometimes have limited ability to raise their voices or to process information. Adolescent patient might feel more overwhelmed in hospital because, as P03-C stated, "*little things that may be little to [adults weren't] little to [the patient]*." Communicating with patients without being aware of the patient's condition can create distress both mentally and physically. For example, P03-C

observed that her daughter was anxious about knowing her biopsy results was ready and tightened her posture, which caused her catheter to move out of place and "*made it more uncomfortable*". Goal-setting with PT provide a way for patients to indirectly communicate with the care team, which accommodated their communication need when they were situationally impaired, and facilitated shared decision-making between patients and care teams.

### Goal-setting provides indirect communication

Displaying the care team's goals gives patients the choice to receive information at their own pace. Patients may experience periods when they are not comfortable to receive information. P04-C observed that her daughter can be in stages which she "*[didn't] want to hear*" the updates of her care and "*[didn't] like what [the care team] have to say.*" With the care team's goals and action plans shown in the PT app, the patient was able to "*go back and relook*" on the care team's plan when the patient "*was more mellow*" and more ready. Showing the care team's goals in a hand-held device empowers patients to initiate information-receiving, which makes learning about the care team's perspective more comfortable.

The other direction of communication is patients providing information to the care team. Goal-setting gives patients the option to indirectly speak up. P04-C thought that her daughter "*[felt] more comfortable to discuss things"* using the PT app because *"sometimes [the patient] may not want to directly discuss"* her goals. P04-P reflected that she liked the PT app because she could show what she "*wanted to do*" to her care team "*without having to physically talk to them*". Displaying patients' goals on the app served as an indirect communication for the care team and caregivers to learn about the patient's perspective when the patient does not want to engage in a conversation.

### Goal setting fosters collaboration

One of PT's feature is displaying patient's and care team's perspective in parallel so that users can view both perspectives at the same time. This feature helps patients collaborate with the care team to make decisions on their care plan when patients feel discouraged to speak up about their preferences.

Patients can feel distressed or discouraged to communicate and collaborate with the care team because of differences in their perspectives. The patient's goals are not always aligned with the care team's goals because what makes the patient comfortable might not be medically feasible. For example, one of P04's goal was to have "*ng [feeding] tube out*" because "*it was hurting [her]".* However, this goal was hard to accommodate given her health condition, and the patient naturally felt upset and irritated when she had to remain comfortable. Worsen the condition, the care team can overpower the patient on decisions in patient's care, such as telling the patient to "*be quiet*" when the patient questioned about her next examination, or inferring the patient's feeling by saying "*you are not bloated*" when the patient was feeling so. This results in patients to sometimes have negative impressions toward communicating with the care team, which creates obstacles in collaboration. For example, we observed incidences which the patient asked the care team to leave because she was too stressed, or "*shut down*" and stopped trying to communicate because she was upset that her feeling was not valued. Collaboration is hard to achieve if patients feel that communication does not better their conditions, or are not comfortable with communicating about their perspectives.

Goal-setting facilitates collaboration by creating a platform to ground communication. Displaying the patient's and the care team's goals in parallel enables the patient and the care team to observe both sides at the same time. This helped the patient to see the commonality between their perspectives and the care team's perspectives, thus creates a sense of agreement. P01 commented that his goals and his care team's goals "*seem to match up pretty well*" after he viewed the PT app. In addition, checking on the care team's goals was a way for the patient to assess the level of agreement. P04-P expressed that looking at the care team's side helped her "*know if [the care team] are on the same page as [her]*". Moreover, patients used the care team's goals to identify sources of agreement and disagreement. For example, P04-P read the care team's goals to identify "*what [the care team was] opposed to, and how that [coordinated] with what [she was] thinking*". She then "*[came] up with her own strategies that can go hand in hand with what the [care team wanted]*". We observed she and her physician collaborating on her goal of getting "*ng [feeding] tube out*" when they looked at the PT app together. This goal also appeared on the care team's side as "*[be able to] take [medication] without feeding tube*", so the patient was able to sense the agreement between her and her physician. The physician explained that her goal was for the patient to "*get enough calories*" and "*to get [the patient] healthy*". They went on the discussion, and their collaboration gave the patient a choice to receive higher volume through the feeding tube in a shorter period of time so that the patient can receive enough food while having time off the feeding tube. Although the patient didn't decide on that plan, she liked that this collaboration allowed her "*to decide what's going on*" because she didn't like other people to be "*in complete control of [her] body*". Showing the patients' and the care teams' sides in parallel helps the patient to prepare for discussion about their care plan; patients can identify the sources of agreements and conflicts, and both patients and care teams can orient their discussion around these agreements and conflicts. Their discussion gives patients choices on patients' care plan and helps patients feel more in control.

# Limitation and Future Work

Our study faced limitations in both participant sampling and probe design. We had a limited sample size, and we were only able to recruit white/Caucasian patients. Besides, we were only able to recruit gender-binary patients. As for the recruitment site, our recruitment site was a children's hospital in an urban area. These limited our understanding of patients of other demographics and hospital environments. Future studies should consider a border sampling across genders, ethnicities and types of hospitals. Our tech probe did not support real-time access to electronic health record (EHR) or cloud-synchronization to support real-time input from the care team. With the high-pace hospitalization environment, this might result in that the information displayed in the app were out-of-date for the patient, which might cause obstacles for discussion over goals. Future studies can consider supporting real-time input from the care team or fetching data from EHR.

In addition to study design, more work can be done to synthesize design implications based on the observed perception and role of collaborative goal-setting for hospitalized adolescents. These observations can also be connected to collaborative goal-setting in other medical disciplinaries to fill in the knowledge gap on how collaborative goal-setting is unique for inpatient care unit.

# Conclusion

In this tech probe study, we designed and deployed an iPad app, Plan&Talk, to facilitate adolescent patients' communication during hospitalization through collaborative goal-setting. We characterized that adolescents set goals as a coping mechanism for negative emotions and a celebration of their care progress. Their goals help the caregivers to see the differences between caregiver perspectives and patient perspectives, as well as to foster patients' independence. Collaborative goal-setting with care teams gives patients the power to initiate communication when they are comfortable and facilitate collaboration. Using the app during hospitalization helped adolescents felt more comfortable with communication, participated in more decision-making, and felt more control over their care. Our contribution provides insights into how adolescent patients perceive and use collaborative goal-setting and informs future work on how to design informatics tools for adolescents to help them engage in their care.

# Acknowledgment

We would like to thank our advisors for amazing guidance and support. We'd like to thank our research group for collaboration, ideas and warm cookies. We'd like to thank Seattle Children's Hospital and all participants for accommodating our study and sharing their experiences. We'd like to thank Cui Chen for helping to make this app possible.

# References

[1] Paget, L., Han, P., Nedza, S., Kurtz, P., Racine, E., Russell, S., ... & Von Kohorn, I. (2011). Patient-clinician communication: Basic principles and expectations. NAM Perspectives.
[2] Waterworth, S., & Luker, K. A. (1990). Reluctant collaborators: do patients want to be involved in decisions concerning care?. Journal of advanced nursing, 15(8), 971-976.
[3] Lafata, J. E., Morris, H. L., Dobie, E., Heisler, M., Werner, R. M., & Dumenci, L. (2013). Patient-reported use of collaborative goal setting and glycemic control among patients with diabetes. Patient education and counseling, 92(1), 94-99.
[4] Wade, D. T. (2009). Goal setting in rehabilitation: an overview of what, why and how.
[5] Baker, S. M., Marshak, H. H., Rice, G. T., & Zimmerman, G. J. (2001). Patient participation in physical therapy goal setting. Physical Therapy, 81(5), 1118-1126.
[6] Bodenheimer, T., & Handley, M. A. (2009). Goal-setting for behavior change in primary care: an exploration and status report. Patient education and counseling, 76(2), 174-180.
[7] Berry, A. B., Lim, C. Y., Hirsch, T., Hartzler, A. L., Kiel, L. M., Bermet, Z. A., & Ralston, J. D. (2019, April). Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (p. 470). ACM.
[8] Haldar, S., Mishra, S. R., Khelifi, M., Pollack, A. H., & Pratt, W. (2019, April). Beyond the Patient Portal: Supporting Needs of Hospitalized Patients. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (p. 366). ACM.
[9] Van Dulmen AM (1998) Children's contributions to pediatric outpatient encounters. Pediatrics 102, 563–568.
[10] Coyne I (2006) Consultation with children in hospital: children, parents' and nurses' perspectives. Journal of Clinical Nursing 15, 61–71.
[11] Tates K, Meeuwesen L, Elbers E & Bensing J(2002b) I've come for his throat': roles and identities in doctor-parent-child communication. Child Care Health and Development 28, 109–116.

[12] Andersen, C. S., & Dolva, A. S. (2015). Children's perspective on their right to participate in decision-making according to the United Nations Convention on the Rights of the Child article 12. Physical & occupational therapy in pediatrics, 35(3), 218-230.
[13] Sjöberg, C., Amhliden, H., Nygren, J. M., Arvidsson, S., & Svedberg, P. (2015). The perspective of children on factors influencing their participation in perioperative care. Journal of clinical nursing, 24(19-20), 2945-2953.
[14] Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: children and young people's experiences in a hospital setting. Journal of clinical nursing, 20(15-16), 2334-2343.
[15] Doran, G. T. (1981). "There's a S.M.A.R.T. Way to Write Management's Goals and Objectives", Management Review, Vol. 70, Issue 11, pp. 35-36.
[16] Locke EA, Latbam GP. Building a Practically Useful Theory of Goal Setting and Task Motivation: A 35-Year Odyssey. American Psychologist, 2002;57(9): 705-17
[17] Schank, R.C. & Abelson, R.P. Scripts, plans, goals, and understanding. Hillsdale, NJ: Erlbaum, 1977.
[18] Powers, W.T. Behavior: The control of perception. Chicago: Alidine, 1973.
[19] Li, I., Dey, A. K., & Forlizzi, J. (2011, September). Understanding my data, myself: supporting self-reflection with ubicomp technologies. In Proceedings of the 13th international conference on Ubiquitous computing (pp. 405-414). ACM.
[20] Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers?. International journal of qualitative studies on health and well-being, 9.