Supplemental Data

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Supplemental Data 1. BMT Roadmap Project: Phases 1, 2, 3

	Research Method	Product	Publications
Phase 1	Semi-structured interviews	Experimental paper-based prototype	Keusch et al *BBMT* 2014[14] Kaziunas et al *CSCW* 2015[15] Kaziunas et al *JAMIA* 2015[3]
		↓	
Phase 2	Design Groups	Low fidelity prototype	Maher et al *JMIR Res Protoc* 2015[15]
	Design, Development User-Centered Techniques	High fidelity prototype	Maher et al *BBMT* 2016[13]
		↓	
Phase 3	Intervention	BMT Roadmap	Current Manuscript
		↓	
		Dissemination	

Supplemental Data 2. BMT Roadmap Brochure

A Pilot Study of Caregiver Participation through a Patient-Centered Health Information Technology System in the Context of Hematopoietic Cell Transplantation

Hi Michael!

My Checklist

0/8 Items completed on your list!

Items Remaining

- Know how to clean your central line catheter
  Watch video
  ○○○○
  NOT READY
- Eating real food
  ○○○○
  NOT READY
- Can give IV infusion
  ○○○○
  NOT READY
- No active infection
  ○○○○
  NOT READY
- Don't need daily blood transfusions
  ○○○○
  NOT READY
- Go to the bathroom on my own
  ○○○○
  NOT READY
- Taking oral medication
  ○○○○
  NOT READY
- Off IV narcotics
  ○○○○
  NOT READY

Who?

-Caregivers undergoing first transplant

What?

-Application designed for iPad

When?

-During inpatient stay

How?

-Discuss with BMT coordinator and complete consent form

Why?

-Tool to improve patient/caregiver understanding and engagement with transplant process

What's Required of Me?

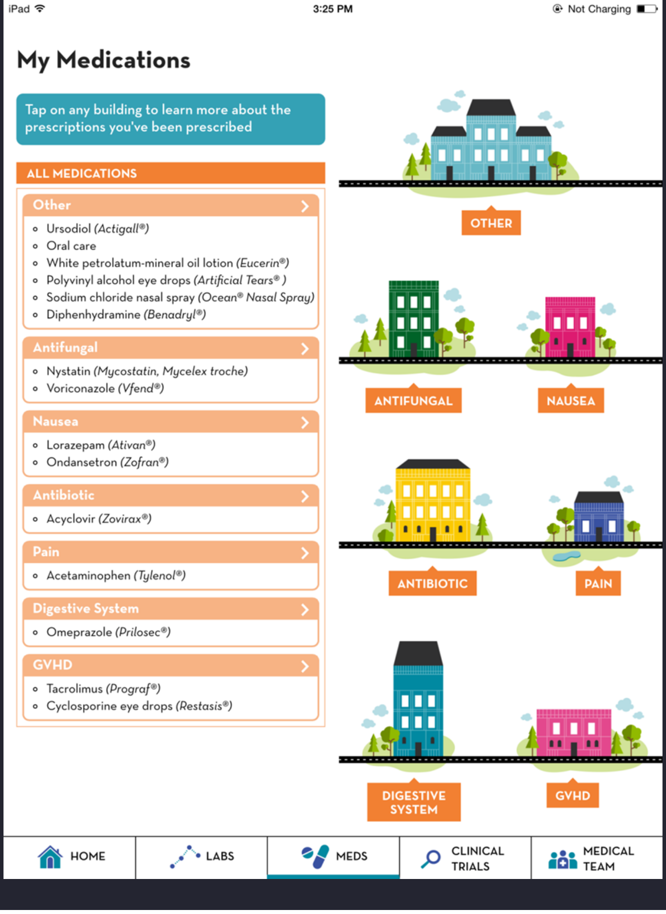
- **Use BMT Roadmap freely during child's inpatient hospitalization**
- **Qualitative interviews:**
  - Baseline (pre-health IT tool)
  - Weekly while inpatient
  - Day 100

White blood-cell count
Latest Count: 15.2
Previous Count: 12.8

Hemoglobin
Latest Count: 10.5
Previous Count: 10.7

Platelets
Latest Count: 155
Previous Count: 143

ANC
Latest Count: 13.7
Previous Count: 11



My Medications

Tap on any building to learn more about the prescriptions you've been prescribed

ALL MEDICATIONS

Other
- Ursodiol (*Actigall®*)
- Oral care
- White petrolatum-mineral oil lotion (*Eucerin®*)
- Polyvinyl alcohol eye drops (*Artificial Tears®*)
- Sodium chloride nasal spray (*Ocean® Nasal Spray*)
- Diphenhydramine (*Benadryl®*)

Antifungal
- Nystatin (*Mycostatin, Mycelex troche*)
- Voriconazole (*Vfend®*)

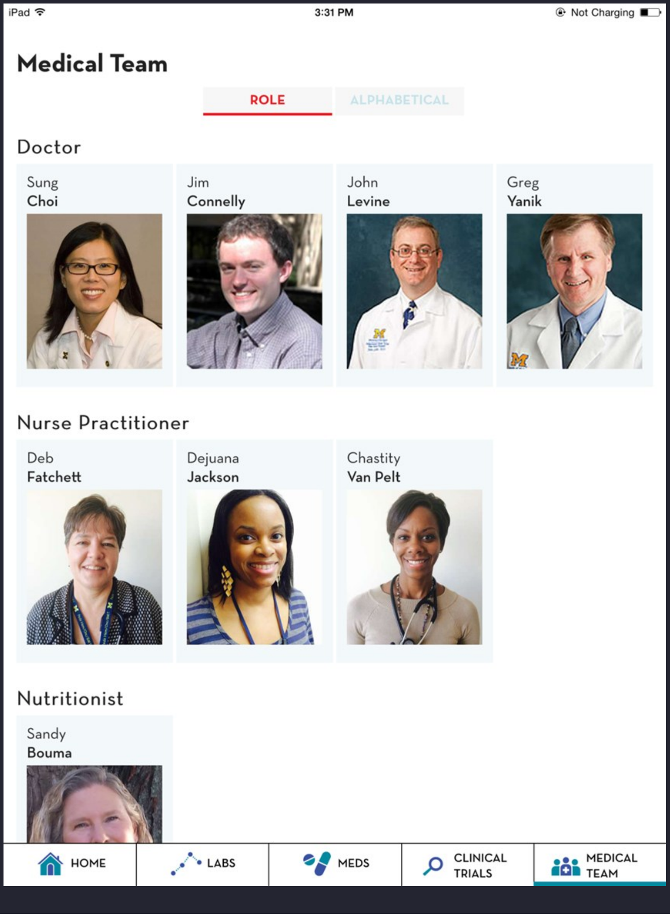
Nausea
- Lorazepam (*Ativan®*)
- Ondansetron (*Zofran®*)

Antibiotic
- Acyclovir (*Zovirax®*)

Pain
- Acetaminophen (*Tylenol®*)

Digestive System
- Omeprazole (*Prilosec®*)

GVHD
- Tacrolimus (*Prograf®*)
- Cyclosporine eye drops (*Restasis®*)



Medical Team

Doctor
- Sung Choi
- Jim Connelly
- John Levine
- Greg Yanik

Nurse Practitioner
- Deb Fatchett
- Dejuana Jackson
- Chastity Van Pelt

Nutritionist
- Sandy Bouma

Supplemental Data 3. Qualitative Assessment Domains

Assessment Domain	(Caregiver [CG]or Health Care Provider [HCP]) and sample item
Subject experience of transplant process and use of BMT Roadmap	(CG) What has it been like to undergo transplant and use BMT Roadmap? (HCP) How has BMT Roadmap affected the way you conduct your workflow?
Role of BMT Roadmap on interactions between patients, caregivers, and providers	(CG) How has BMT Roadmap affected your interactions with your child or other family members? (HCP) How did BMT Roadmap affect the patient-provider interaction?
Strengths/weaknesses of BMT Roadmap	(CG) What did you like least of BMT Roadmap? (HCP) Did BMT Roadmap change your bedside rounds or management of health care?
Strategies to improve BMT Roadmap	(CG) What would you like to change about BMT Roadmap? (HCP) How could BMT Roadmap be made more sustainable in the inpatient setting?

Supplemental Data 4. BMT Roadmap *Qualitative Interviews for Caregivers*

OVERVIEW

Process:

- Before each timepoint, review previous field notes, audio and transcript as available; adjust question outline to reflect the previous interview; integrate any necessary questions to reach goals overall and for that timepoint;
- Take notes on outlined question printout; after, summarize in few sentences for field note
- Every few weeks, more if multiple patients enrolled, hold coding session to review transcripts
- Adjust outlines and goals after each coding session

Definition of timepoints:

- **Baseline:** Patient/family has already been consented, but ideally has not been "trained" or "onboarded" to the BMT Roadmap
- **Weekly:** Try to avoid interviewing only first thing in the morning if it is a bad time for the particular participant – try to do proximity to event, i.e. come right near morning rounds, or be in the unit and have a nurse tell you if something (transfusion, medication change) is happening. However, it is likely interviews will happen randomly each week.
- **Discharge:** Attempt to come to the day of discharge, or within three days if it is upcoming.
- **100 days:** Attempt to make the clinical appointment scheduled for the 100 day mark.

Overall goals:

- Find specific examples of information, social and emotional work in the inpatient experience
- Gather context of the family dynamics and perspectives on the experience of BMT
- Document the ways that families have or have not used the BMT Roadmap, why, and what else they may utilize to supplement or replace it in information work
- Sense any barriers or facilitators to information work including health literacy/numeracy, psycho-social impact of experience, family issues, social support, faith, etc.

Timepoint specific goals:

- **Baseline:** Learn story of background: ask about how much they're understanding their condition and treatment, their sentiments as they embark on BMT experience
- **Weekly**: Ask about clinical and social updates: how is the patient, has anything significant changed this week, anything minor, any visitors, changes at home, etc; Ask about use of the BMT Roadmap or other information management, with grounded examples
- **Discharge**: Ask about use of the BMT Roadmap and discharge goals; Ask if they felt prepared to go home, surprised about the timing, ready for the next few weeks of at-home recovery; Discuss information management plans for post –BMT Roadmap

(including plug for portal use); Ask if now, post hospitalization period, they have items they'd change in the Roadmap

- **100 days:** See how they're progressing clinically and psycho-socially; ask if they've replaced any BMT Roadmap functions with other information management

Supplemental Data 4. BMT Roadmap *Qualitative Interviews for Caregivers*

QUESTION OUTLINE

BASELINE

- Let's start by talking about your general story, your path to BMT that brings you to the hospital today.
- For caregivers – are you the typical caregiver for your son/daughter? Who else is around?
    - How has it been for you?
    - Depending on diagnosis/path – how has it been to learn about this new condition/new part of treatment? Where do you get your information from? Do you feel you've been receiving the right amount of information? Did you do anything to prepare for this hospital stay?
- For patients – so you have your mom/dad/grandparent here today. Have they been the one to help you the most so far?
    - Who else do you keep in touch with?
        - Have you told your friends? School?
    - Did you do anything to prepare for this hospital stay?
    - What are you thinking about the most today?
    - Depending on diagnosis/path – how has it been to learn about this new condition/new part of treatment? Where do you get your information from? Do you feel you've been receiving the right amount of information?

WEEKLY

- Recap/integrate in what I'd learned from baseline if relevant to a question
- For first week: Walk me through your day yesterday
    - Is that how most the days have gone so far?
    - Probe about rounds, information gained
        - Did any of that surprise you? How did you feel when you heard your counts? Do you remember what they were?
- Have you been using the iPad? Tell me about the last time you remember using it, what did you do? What made you think to do that? Tell me how it worked for you.
- Have you been keeping track of the hospital experience any other way?
- Do you share back information with other caregivers, friends?
- Have you been getting information anywhere else?

DISCHARGE

- You're close to discharge...when this was mentioned as the next step, did it seem like the right time, did you expect to be discussing discharge when you did?

- Do you feel prepared for discharge? Tell me why or why not.

- When you go home, you'll have to manage some things for yourself/your child...can you describe to me some of those things and how confident you are to begin managing them? [meds, diet, physical activity, psycho social, cleanliness]

- Related to that, can you describe to me what you expect to be going through when outpatient, what's your new medical routine going to be like, what is expected of you?

- So now that you'll be out of the hospital, do you have a sense of potential causes and likelihood for readmission? under what circumstances might you come back in and what leads to that?

- So we've talked about a lot of management and tasks you have to take on...as well as a lot of information to remember. We want to integrate what you would need to best understand, remember the information and keep track of your tasks. Can we talk about what that might look like? (use prototypes or participatory activities)

100 DAY

- What has happened since I last saw you? How'd the appointment go today? What is left for you all to do?
- Walk me through your day yesterday – what did you do?
    - How was the management of your medications at home? How did you do that?
    - Did you struggle with line management at all?
    - Did you find you sought out new places for information? Did you call U-M often?
- Call back and probe about any particular comments from discharge.

Supplemental Data 5. BMT Roadmap *Qualitative Interviews for Healthcare Providers*

Before we get started, I'll remind you that I'm audiotaping. You may skip any questions you don't feel comfortable answering, and we may stop or pause at any time if needed. I'll also turn off the recorder if you want to answer off-record. Before I jump into too many questions, I'll introduce myself and my project interests- then will ask for your introduction to get us started.

I'm Molly Maher. I'm entering my second year in the Master of Health Informatics program here at U-M. My interests are in creating research-informed technologies for clinical settings. I've been working on the BMT Roadmap since January and we're trying to make sure this pilot application will allow for increased thoughtful care for both patient-families ... and care professional needs. It's important that we get your understandings and concerns as part of a baseline before rolling the application out.

Now, it would be great if you could give me a brief introduction into your position here, your background and how long you've been here, and your main interests [specialities?] are.

Great. I'll go ahead into our questions now. I'm going to start by talking to you about information, patient education, and your workflow and opinions.

- We're interested in your opinions on and participation in the education of patients and families on their condition while they're in the hospital.
    - Remember back to the last time you gave a caregiver or patient the blood counts. How did the patient take it?
        - Can you recall a time when they didn't take it well or you had to explain the scores? Was that typical?
        - Can you recall a time when they asked questions that didn't seem to make sense? Was that typical?
        - How do you structure giving the caregiver or patient their blood counts?
            - What is the workflow that your team follows to give the patients their blood counts? Other test scores?
            - Do you think your team is the primary source of information for understanding the blood counts? Do you recall any time your patients or caregivers had other sources (friends, family)? How about the Internet?
                - Can you think of a time when you had to discuss the validity of these sources with patients? How did that discussion go? Is this experience common?

    - Can you think of the last time you discussed the discharge criteria and what progress needed to be made before discharge with patient/family went really well or really badly?
        - Is that common? Do you have any opinions on why or why not it is common/why it happens at all?
        - How was your experience of discussing with them what they needed to do to be discharged? Challenging, simple?

- Similarly, think of the last time you discussed a significant change in medication with a family. How did you inform and help the patient-family understand this change?
    - How did that go? Is that common?
        - If not, what is common?
    - How did you approach the conversation about medication changes? Were there related things you had to do, like tests? Did you have materials to use in discussion?
    - Did the conversation require follow up? Is that typical?

Now I'd like to discuss our tool in particular. [Introduce BMT Roadmap, allow clicking around a bit; if not exploring, ask to complete simple tasks on each screen; *1"Take a moment to read the descriptions of a couple of "BMT phases" and the discharge list on the homescreen."* 2 *"Can you review the lab results, expanding the three types."* 3 *"Can you find the details on pain medications this patient is on? Show me."* 4 *"By selecting the clinical trials tab you can see the enrolled trials and the consent forms and descriptions – select one for an example."* 5 *"If you were a patient looking for the name of a nurse, where would you go? Show me."*]

- This tool, which is meant for a caregiver of a child so maybe different than your typical population. It's meant I be used at their leisure while inpatient here.
    - Imagine your last stint on service. Could you picture a particular caregiver or patient? Can you describe that person for me?
    - Now imagine that patient (probably only a couple in this study design but for hypotheticals we will expand) have this tool.
        - What's your initial reaction to that?
        - Are there any features you see as helpful?
        - Are there any features you concerns with?
            - [Review the functions of that feature]
            - Why do you feel that is/is not helpful?
                - Can the barriers be addressed by changing the feature?
        - What would you change?
        - What about your workflow would change with the introduction of this tool?
            - In what ways? (push on getting details)
        - How would it change care?
        - How about the inpatient experience
    - Do you think that patient would be typical (if yes repeatly, drop the question; if no, ask why)
- Now that you've seen this tool, what concerns, if any, do you have with it? (after they list any concerns, go through each item) What would you change in it to reduce that concern – what needs to be removed, added, or modified in your opinion?

Supplemental Data 6: Codebook

Index	Code Name	Abbreviation	Parent/Child Code	Description with Definition and Inclusion/Exclusion Criteria
1	Patient History	PHIST	Parent	Discussion of prior history and experiences
2	Emotions	EMOTION	Parent	Discussion of feelings regarding the experience in general
3	Confidence in Knowledge	CONFKNOW	Child of EMOTION	Caregiver expresses confidence in their knowledge surrounding treatment/transplant process
4	Communication	COM	Grandparent	Discussion of communication, communication strategies, or timing of communication regarding patient health or treatment
5	Two-Way Communication with Family and Friends	FAM/FRIEND	Child of COM	Discussion of communication with family or friends (including the patient)
6	Two-Way Communication through Social Media	SM	Child of FAM/FRIEND	Discussion of communication through social media; Can include communication with ANYONE as long as it's via social media
7	Two-Way Communication with Caregiver Team	CGT	Child of COM	Discussion of communication with the caregiver team
8	Communication with Caregiver Team regarding Discharge	DISCHARGE	Child of CGT	Discussion of any information about discharge plan (such as criteria for discharge, expectations of care at home, etc.) with the care team
9	Timing of Communication	TIMING	Child of COM	Discussion of when communication occurs (during rounds, throughout the day, etc.) with ANYONE (care team, family, friends, social media)
10	Roadmap Uses	MAPUSE	Parent	Discussion of which application features are being used and instances when the use wouldn't be desired
11	Share Information	INFOSHARE	Child of MAPUSE	Discussion of sharing information from the app with family/friends
12	Look at Labs	LABS	Child of MAPUSE	Discussion of helpfulness of lab results within the app
13	Look at Medications	MEDS	Child of MAPUSE	Discussion of helpfulness of medication list, dosing, and explanation within the app
14	Usage Patterns	PATTERN	Child of MAPUSE	Discussion of when caregivers utilize the app (mornings, nights, discussion of a routine of any sort)
15	Look at Yearbook Photos	PHOTOS	Child of MAPUSE	Discussion of helpfulness of Yearbook Photos
16	Look at Videos	VIDEOS	Child of MAPUSE	Discussion of helpfulness of Videos
17	App Issues/Malfunctions	ISSUES	Child of MAPUSE	Discussion of malfunctions with the app
18	Roadmap Suggestions for Improvement	IMPROVE	Parent	Suggestions for improvment regarding Roadmap features and displays
19	Data Presentation	PRESENT	Child of IMPROVE	Suggestions regarding improvment of data presenation, focused on the data interface
20	Data Quantity	QUANTITY	Child of IMPROVE	Suggestions regarding changes in data quantity (more or less detailed information); includes ONLY suggestions to change quantity of data in an already existing app module. For example, adding a new lab test to the lab page on the app would be Data Quantity
21	Additional/New Features	NEWFEAT	Child of IMPROVE	Suggestions for new features in the app that do not currently exist
22	Patient Reported Outcomes	OUTCOMES	Child of NEWFEAT	Suggestions for recording patients' symptoms within the application
23	Organization and Managment Strategies	STRAT	Parent	Caregiver/Patient strategies for managing treatment excluding Roadmap Use (e.g. creating calendars, medication lists, etc.)