# Appendix C. Summary of Feedback From Phase 1 Interviews With MGH Patients, Clinicians, and Stakeholders

## Personalized Chemotherapy Plan/Medication Reminders

- Identify patients who are taking the same oral chemotherapy/disease cohort and connect them to serve a support system
- Stratify patients by line of chemotherapy if variation exists in the patient populations
  - Example: oral chemotherapy as a first line of therapy versus not first line or first time taking oral chemotherapy versus treated with oral chemotherapy previously
- Allow patients to create a window of time (i.e. 7am-9am) during which they can take their medication, rather than an exact time (on the hour)
- Give patients the ability to alter the frequency of medication reminders (i.e. daily/weekly/x per week)
- Make sure that treatment plan is editable
- Include patient/treatment information in treatment plan: primary clinician, NP, who to contact on weekends, general contact info
- Specify "since your last visit to the **application**..."
  - $\circ$  Ask once every ~30 days ask every time patient opens the app until they answer it

## Symptom Management

- One goal for this section should be to empower patients to report symptoms and hopefully speak up more during clinic visits regarding symptom management
- Establish a method of tracking patient phone calls to clinic regarding symptoms and compare between study arms
- List only the common/ "red flag" side effects
- Use a slider scale for symptom support frequency and severity (0-10 for each symptom)
- Have the symptoms reorder according to endorsement
- Give specific definitions and anchors for symptoms
- Option for stable patients: "my symptoms have not changed over the last week/since my last report"
- Add sexual symptoms sexual dysfunction
- Notify clinician when a symptom is unacceptable

## **Daily Tips**

• Give patients the option to receive daily or weekly tips

#### Resources

- Track patient hits on educational resources
- Consider collaborating/partnering with a pharmaceutical company to provide

relevant and reliable information to patients – many companies have portals for patients and partners, as well

- Drive educational content based on common side effects of the patient's specific disease/drug
- Provide links to inspire.com for each disease message board(s)
- Provide information for PFAC
- Include link to website and location of Cancer Resource Room

### Patient/Physician Communication

- The study can serve as an opportunity to foster communication between the patient and the care team (i.e. MD, PA, NP, etc...)
- This could be an opportunity to measure patient satisfaction on an ongoing basis, as well as satisfaction with care team communication
- Provide patients with information on how to communicate with their care team effectively
- Promote patient advocacy through this app
- Capture patient-physician communication as an outcome
- Have a point person to triage patient messages via app NP, RN, PA
- Collect data on MDs who follow up on patient symptom reports and how (i.e. EMR)
- Look at past information on how MDs act upon new or worsening symptoms
- Make sure that communication is non-judgmental in regards to feedback on adherence

## Usability, Acceptability, and Feasibility

- Ensure that this program is rewarding for patients
- Collect baseline data on patient's beliefs and expectations regarding oral chemotherapy, as well as coping styles
- Assess whether patients see oral chemotherapy as a quality of life treatment or burdensome
- Inquire about patient's unmet needs and gather them throughout the study
- Provide patients with feedback on how their adherence is compared to other patients using the mobile app
- Examine subgroups/cohorts of patients who might benefit more than others compare their data examine age/meds/age
- It is important to recognize that patients' symptoms can be debilitating so they might have a hard time reporting some days
- Pilot the actual application with patients and clinicians before the RCT
- Assess how much the app has enhanced or burdened care for patients
  - What proportion of patients in RCT liked or disliked the application this section could be called "Patient Engagement"
  - Ask questions like "does reading about side effects make you more anxious?"
- Incentivize patients for every survey, give them \$20

- Find an alternative way to measure ED/Urgent Care visits because if patients do not go to MGH ED/UC, then it will not show up in their electronic medical record
- Flesh out "point person" for app in great depth some barriers could arise if this is not organized
  - What will a patient do if they report a severe symptom on a Friday afternoon when no one is there to receive the message?
  - What is the point person is on vacation?
  - Ensure that there is a clear disclaimer that the app does not replace when patient should call their doctor regarding severe symptoms
- Conduct clinician assessments on how acceptable the app is for them
  - Clinicians might think it's a great idea during a focus group, but once they actually have a busy schedule, during the RCT, they could neglect it
  - Clinicians who are not researchers might have a hard time accepting this
- Stratify for different oral agents
- Not necessary to exclude by line of chemotherapy, but worth collecting and noting/stratifying
- Exclude patients who are enrolled in a clinical trial clinical trial patients at MGH do not receive "standard care"
- Thus, exclude trial/experimental drugs

## **General Suggestions**

- Train Research Assistants and study staff in the app to give an instructional seminar for participants using the app
- Possibly include a training video in the app on how to use the app
- Assess if patients are taking oral chemotherapy for a short period of time or indefinitely engage both of these populations and get feedback on how to make this app ongoing for both populations
- MD referrals are not ideal for RCT query electronic medical records, then approach physicians regarding eligible patients – develop a cross-Cancer Center protocol for recruitment in various disease groups
- Involve clinicians throughout app development and RCT so that they are interested and invested in the project, thus more likely to dedicate time to utilizing the patient/physician features on the mobile app
- Ensure that clinicians are addressing patient-reported symptoms on the app during clinic
- Make sure that patients are reminded to refill their medication ahead of time so they don't run out and miss doses because of this reason
- Attempt to forward patient symptom reports to EMR
- Gather information from pharmaceutical or insurance companies that might have their own cell phone call system regarding medication adherence and instructions
- Look into liability of symptom reporting important for fever, neutropenia, etc...

- Change exclusion criteria language from "owns a smartphone" to "uses a smartphone" – some people will own an iPhone/Android, as well as an incompatible phone – could be confusing
- Make certain parts of the app email/print friendly
- Add a "notes" section for patients to store information regarding their next clinic visit, etc.
- Best time to start app is at beginning of oral chemo prescription
- Include a disclaimer that this app is not an emergency service app and that patients should call 911 if they feel their symptoms/situation is urgent
- Provide patients with contact information if they are struggling with the app's technical features
- Use the term "oncology clinician" rather than "doctor"
- Utilize drop down menus when possible