Addressing the Mental Health Disparities of Families of Cancer Patients from Rural Kentucky

A clinical study on the efficacy to reduce mental trauma using the mobile app intervention FamCarePlus

University of Kentucky College of Health Sciences College of Medicine

Making Family Point-of-Care Portable, Personal, & Equitable

Anthony **Faiola, PhD**; Zhonglin **Hao, MD**; Ashley **Montgomery-Yates, MD**; Saira **Soroya, PhD**;
Samantha **Lenox**; Sabrina **Piekarski**; Gabriella **Tenuta**; Sheridan **Schrader**

BACKGROUND – *THE PROBLEM*

When cancer patients are admitted to a critical-care inpatient facility (pulmonary, cardiology, bone marrow treatment, chemotherapy, etc.), their medical condition is urgent. As such, families or next-of-kin (NOK) of patients receiving cancer treatment require medical updates and communication from staff, *which offers a sense of proximity to their loved one.*

☐ Research shows that **54% of families** had poor comprehension of the patient's diagnosis and treatment due to the lack of communication with healthcare providers.

☐ Research has demonstrated that patient NOK are at high risk for developing mental trauma such as post-traumatic stress disorder, anxiety, depression, or disruptions to family relationships, due to the lack of communication from the bedside.

THE PANDEMIC: During the COVID-19 pandemic hospital visitation privileges were limited/suspended, resulting in a severity of mental health conditions, even 3 months after patient discharge. Isolation due to the pandemic exacerbated the mental health of NOK of cancer patients as visiting restrictions continued.

RURAL FAMILIES: Although rural families use smartphones, socioeconomic disparities still exist. **ADDED** to other socioeconomic inequalities, NOK must travel long distances to stay connected to the bedside.

A HEALTH EQUITY SOLUTION: To support access to bedside updates for NOK, we developed the mobile app FamCare+, a mobile health service that:
- Enhances coordination between (remote) families/NOK and healthcare staff at point-of-care.
- Provides cancer patient NOK a real-time link to those most responsible for the care of their loved one.

FAMILY APP: Families outside the clinical setting, in remote locations, are provided 4 tools: Vitals/Wellness updates, Video conferencing, Chat/Texting, and Counseling (Social//Mental Health Services).

CLINICIAN APP: Clinicians at the bedside, inside/outside the patient's room, have the ability to input real-time vitals/wellness information (sent to family members in qualitative measures), along with the option to chat and video conference.

AIMS:

#1—To form a planning committee of community stakeholders referred to as MERCCI (mHealth Equity Research for Community Connected-Health Impact)—to:

(1) Identify a long-term strategy to study the efficacy of FamCare+ on cancer patient NOK mental health throughout rural Kentucky, particularly those w/ socioeconomic disparities.

(2) Plan a small clinical pilot study at 2 Markey Cancer Center Research Network (MCCRN) sites.

(3) Execute co-design (human-centered) studios for multi-stakeholder (family/community) participation for feedback.

#2—To set long-term sustainable goals and partnering opportunities, transcending the proposed pilot study—to:

(1) Produce inclusive/effective research approaches throughout the study, leading to meaningful future collaborations that benefit community/family mental health of cancer patients.

(2) Develop efforts to facilitate a shared purpose/identity as we progress toward our stated objectives, including an application for future NIH funding that will expand the study to other MCCRN locations, and throughout Kentucky.

METHODS

- MERCCI's planning will be followed by a clinical pilot study using FamCare+ at two MCCRN locations, with 10 families. (*in-progress*)
- MCCRN physicians/nurses and research staff will be recruited to co-manage the study.
- Pilot findings will be followed by co-design studios/focus-groups with multi-stakeholder family / community participation.

PRE-CLINICAL USABILITY / UX STUDY

Recent FamCare+ user-experience and feasibility study provided extremely positive findings.

Usability Study

1. **Participants**: N = ~8 Nurses and Healthcare Workers.
2. **Observation/Interview guide** — Using a three-part clinical scenario, participants**:**
   - Filled out two validated measures (i.e., NASA TXL Cognitive Load test, System Usability Scale test),
   - Personalized 10-Likert questions,
   - An interview with 10 open-ended questions.
3. **Analysis**: Thematic analysis of the 10 interview questions and the responses to Likert scale questions (Usability Scale is: 1= Strongly Disagree to 5=Strongly Agree).

Results

- **Usability / user experience findings provided consistent positive outcomes for all quantitative and qualitative data.**
  - Using a three-part clinical scenario, clinician participants engaged in using all the features of both the FamCare+ smartphone (for families) and tablet (for clinicians).
- **Outcomes measures:**
  - **NASA Cognitive Load Test**: mean score: 1.74 (Range: 1 [low demand] to 20 [high demand]) (**LOW DEMAND**)
  - **System Usability Scale**: mean score: 4.81 (Range: 1 [low usability] to 5 [high usability]). (**HIGH USABILITY**)
  - **Interviews**: Study concluded with ten open-ended questions that was concluded with a single personalized Likert question.
    - Nearly 100% of the responses were consistently positive. Interviewees felt that FamCare+ has the high potential to "improve family mental health if they had the option to talk to someone" at the bedside.

CLINICAL STUDY DESIGN (Forthcoming)

Participants: Family members recruited from two MCC Research Network locations (Owensboro Health and MCC Lexington) cancer infusion centers from list of family volunteers.

Study Phases: **1 & 2**: Family and nurse volunteers use FamCare+ for 3 weeks. Family and nurse volunteers mid-study review – checking-in with participants. **3**: Complete the study, with post-intervention co-design studios (focus groups), including questionnaires, interviews, and co-designing exercises with all stakeholders.

Protocol: Administer Hospital Anxiety and Depression Scale (**HADS**) to experimental/control groups before/after the study protocol, after 3-4 weeks of weekly app use. Establish baseline data on the mental health status of the family members.

Experimental Group and Participating Nurses: Participate in two additional questionnaires following app use.

1. **Usability study** will be executed with the NASA and Usability System Tests
2. **Semi-Structured Interviews** will allow participants to freely express any concerns with FamCare+ and their personal UX.

Anticipated data collection: Late spring/summer 2023.
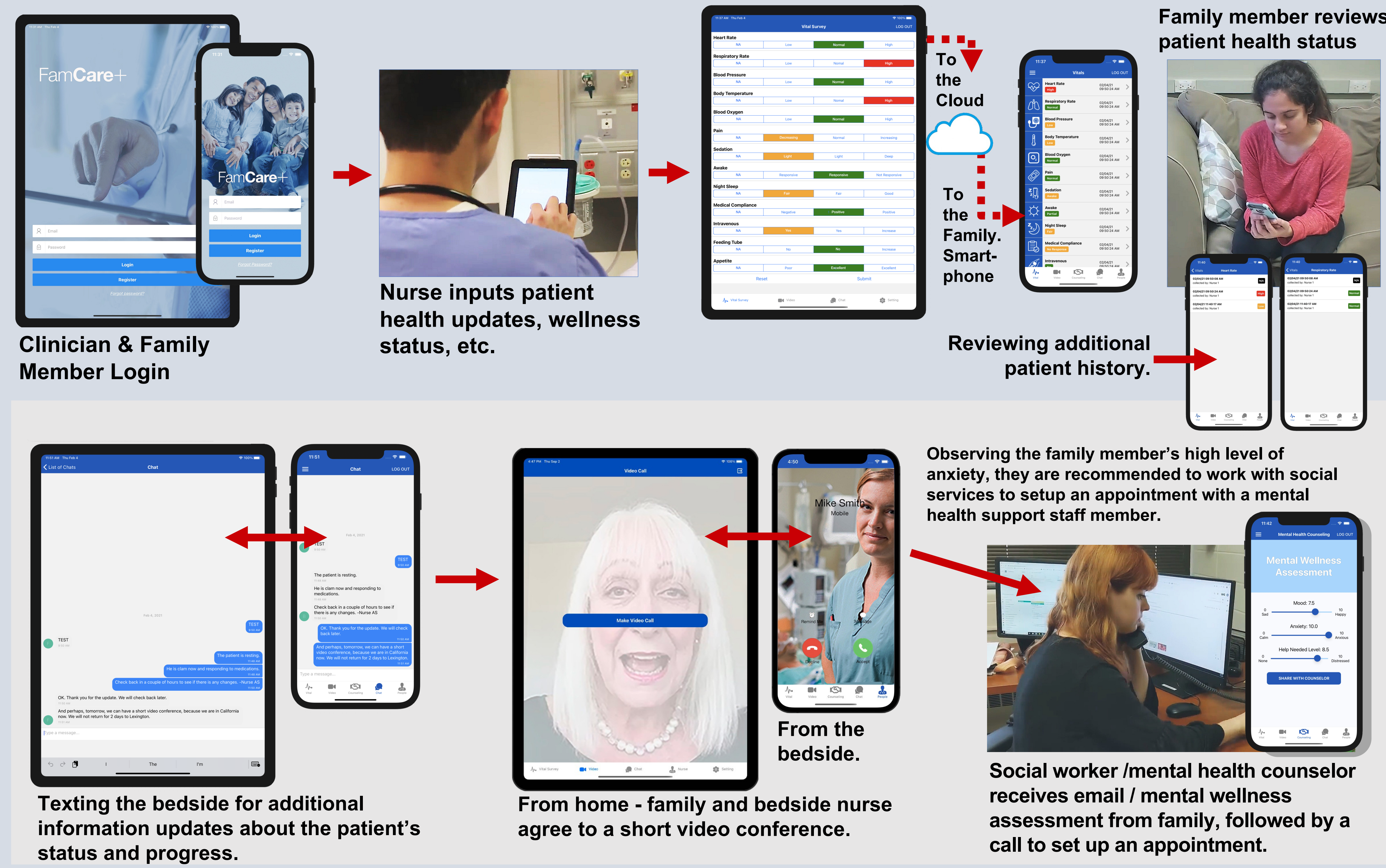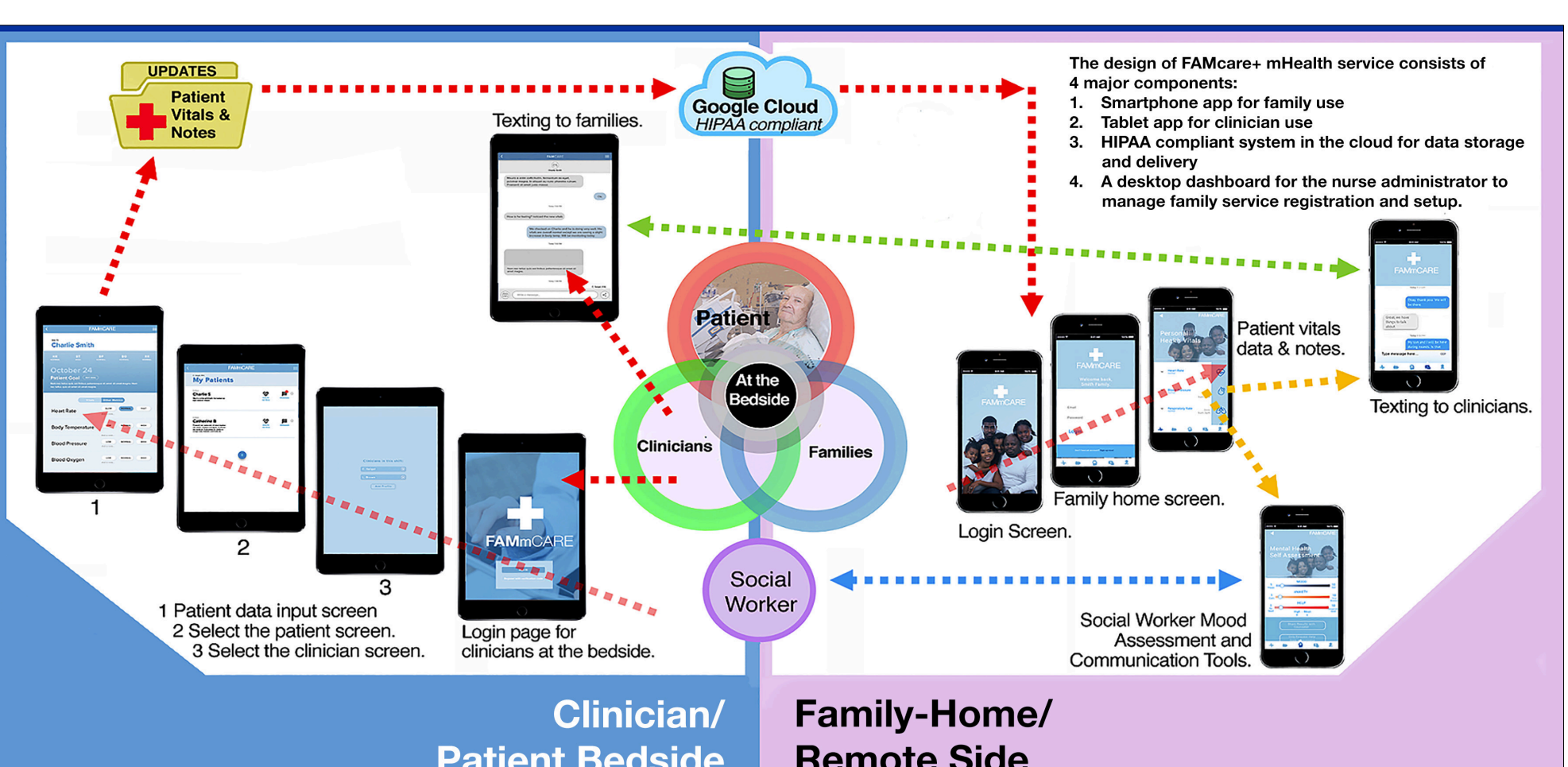
ANTICIPATED OUTCOMES

(1) Study findings: **(a)** A significant improvement in NOK mental health of those using FamCare+ **(b)** New knowledge that can inform new design changes/revisions to FamCare+.

(2) New and sustainable partnerships with community collaborators that are bound with a common vision to leverage mHealth to improve cancer patient NOK mental health in Kentucky.

(3) Meaningful and inclusive approaches and lessons learned throughout our collaboration as we study the research problem of how mHealth can support community needs and reduce health disparities throughout Kentucky.

Clinician & Family Member Login

Nurse inputs patient health updates, wellness status, etc.

To the Cloud
To the Family, Smartphone

Family member reviews patient health status

Reviewing additional patient history.

Texting the bedside for additional information updates about the patient's status and progress.

From home - family and bedside nurse agree to a short video conference.

From the bedside.

Observing the family member's high level of anxiety, they are recommended to work with social services to setup an appointment with a mental health support staff member.

Social worker /mental health counselor receives email / mental wellness assessment from family, followed by a call to set up an appointment.

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UPDATES: Patient Vitals & Notes
Google Cloud HIPAA compliant
Texting to families

The design of FAMcare+ mHealth service consists of 4 major components:
1. Smartphone app for family use
2. Tablet app for clinician use
3. HIPAA compliant system in the cloud for data storage and delivery
4. A desktop dashboard for the mental wellness manage family service registration and setup.

Patient vitals data & notes.

Family home screen.

Social Worker Mood Assessment and Communication Tools.

1 Patient data input screen.
2 Select the clinician screen.
3 Select the clinician screen.

1 Patient data input screen.
2 Text you're the update. We will check back later.
3 Select the clinician screen.

1 Login page for clinicians at the bedside.
2 to the clinicians.

Login Screen.

Clinician/ Patient Bedside

Family-Home/ Remote Side