Implementation of an Electronic Care Plan for People With Multiple Chronic Conditions
Final Report

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Executive Summary

Background

Individuals with multiple chronic conditions (MCC) constitute more than 25 percent of the U.S. population. Not only do MCC cause decreased quality of life and earlier mortality, but they also result in increased complexity and cost of care. Those who have five or more chronic conditions make up 12 percent of the population but represent more than 41 percent of healthcare spending. To improve outcomes for people and reduce consequences for people living with MCC, improved tools must be implemented to render treatment that is effective, focuses on the needs of the patient, and excludes unnecessary interventions.

The shared electronic care (eCare) Plan (eCP) app seeks to enable more effective communication and coordination about patient goals, preferences, social context, and health data among clinicians, patients, and caregivers. Work on an eCare plan app began as early as 2013 and in 2019, the Agency for Healthcare Research and Quality (AHRQ) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) were funded by the Patient-Centered Outcomes Research Trust Fund, managed by the Office of the Assistant Secretary for Planning and Evaluation, to develop and test a suite of eCP tools for adults with MCC.[1] This work included the creation of two shareable, interoperable eCP apps: one for patients and one for clinicians. To support the implementation of both apps, an implementation guide specifying relevant data standards and value sets for key use case conditions was created.

For ease of access and deployment, this project placed the containerized apps within the infrastructure of the Oregon Health & Science University (OHSU) electronic health record (EHR) for use and evaluation by a select number of clinicians and patients. The apps used middleware to interact with the EHR to transform requests and ensure interoperability. Primary care clinicians and patients were recruited for participation in a two-phase user acceptance testing approach from May 2021 to February 2022.

Implementation Details

The testing plan included providing access to the eCP apps to participating sites, clinicians, and patients, which included a range of primary care practices, specialty care practices, and additional care settings such as long-term post-acute care and dialysis centers. The technical implementation focused on the OHSU EHR vendor system environment and the native Epic Fast Healthcare Interoperability Resources (FHIR) application programming interface (API) and was positioned to leverage an extended network as available (e.g., using Epic's CareEverywhere health information exchange). Targets for number of testing participants included 7–10 clinicians and 8–12 patients. The testing plan focused on usability concerns and was conducted in two phases: the first phase in the test environment

at OHSU with clinicians accessing test patient data using each eCP app, and the second in the production environment with patients accessing their own data in the eCP app.

Evaluation Methods

Because the combined elements of the eCP system were novel and complex, we applied the Consolidated Framework for Implementation Research Process Redesign (CFIR-PR) to track the implementation process and clinical outcomes. An overarching project framework mapped the research questions, project activities, and work products to the CFIR-PR domains and constructs and was used to guide the development of specific interview questions and the quantitative approach.

Evaluation data were sought from 9 clinicians and 11 patients using mixed methods including questionnaires, log data, and open-ended interview questions.

The evaluation of the tool followed the CFIR-PR and focused on five core evaluation questions (EQs):

- **EQ1:** What were the key issues for *designing* (using a user-centered design approach with a patient-centered focus) interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
- **EQ2:** What were the key issues for *developing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
- **EQ3:** What were the key issues for *implementing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
- **EQ4:** What *effects (or outcomes)* did the MCC care coordination tools have on management of MCC across settings?
- **EQ5:** What *lessons learned* arose from the project's experiences with developing and implementing interoperable and publicly shareable MCC care coordination tools for patients and clinicians?

Results and Lessons Learned

During the project and the testing period, our multimethod analysis yielded important lessons learned for each phase of the project, outlined in ***Table ES-1***.

Table ES-1. Lessons Learned by Project Phase

CFIR Construct	Lesson Learned
Patient-centeredness	User-centered development will result in an end product that is more well accepted and perceived to be more useful. The limited implementation of patient-centered health data standards (e.g., FHIR goal resource) in clinical contexts represents a barrier to patient-centeredness.
Effectiveness	Patient-reported outcomes must also be considered when designing a solution to prioritize features that will capture the most useful information rather than the most accessible information.
Fidelity	A method for measuring impact should be designed into every tool, so its effectiveness can be measured to reinforce its use or reveal its inadequacies. Incorporating data capture in the design phases is an essential path toward collecting the relevant data. Incorporating initial design reviews using wireframes/mockups allows for early engagement with and refinement of the apps. Patients and clinicians strongly desire a platform to collect patient-reported outcome measures and examine how they change over time. Development of a robust persona provides a shared understanding of the goal of the work and a vision for its execution. Defining the goals and the shape approach of the mixed-methods evaluation at the outset is crucial to developing collecting the desired data.
Shareability	Contractual agreements must be considered when developing tools to be shared with third parties to avoid licensing infringement issues.
Feasibility	Modern EHRs allow only very limited ability to write discrete data into a patient's chart. Middleware was required to enable implementation. Evaluation plans must flex and adapt to changing circumstances, because the delivered context may be different from the one envisioned.
Generalizability	A containerized solution worked for the purposes of this round of testing, although a cloud-based solution might be preferable for a widespread rollout. Developers are often asked to build a specification based on simulated data rather than real-world data, resulting in models that are not able to process data in production environments.
Performance	Input from clinicians and health IT professionals is essential to the early development of solutions like the eCP apps to reduce the time and work needed to implement once complete. Consistency of task leadership from the start of the project is important for the development and implementation of the evaluation plan.

CFIR = Consolidated Framework for Implementation Research; eCP = electronic care plan; EHR = electronic health record

Conclusions

This project demonstrated the feasibility of a solution for the problem of care coordination for patients with MCC. Through close collaboration, the research development and EHR development teams were able to implement software and middleware to enable standards-based sharing of some data and reveal areas where current standards are insufficient or incompletely implemented.

Most importantly, this project demonstrated patients' and clinicians' desires to have patient-reported data available for tracking over time and to find a way to incorporate the generation and review of these data in day-to-day routines and workflows.

Although EHR vendors are often unwilling to open their systems to interact with the wider data world, applicable standards and EHR capabilities continue to develop, bringing more and more of the MCC care model into reach.

Future Research

Future research into electronic tools to assist in the development and use of care plans for patients with MCC should include—

- preplanning evaluation activities before completing the design work allows for a more thoughtful and efficient design process.
- establishing a mechanism for the apps to report user actions, and any errors that may occur within them, back to the MCC-application programming interface system on the server (or similar), which can then be written to log files that can be accessed and analyzed using Splunk.
- using an agile process to prioritize and incorporate technical and user interface/user experience modifications that can significantly contribute to better usability and functionality.
- increasing the reach of care planning to include community-based organizations and allied health professionals.
- operationalizing each type of patient data as soon as EHR vendors and health systems implement standards-based interfaces.
- incorporating data elements from COVID-19 to encompass the chronic effects of infection.
- including the role of caregiver as a part of the care team to determine how to best balance the exposure of sensitive information with the caregiver's role in goal setting and fulfillment.

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1. Introduction, Background, and Goals

1.1 Multiple Chronic Conditions

More than 25 percent of Americans have multiple chronic conditions (MCC), combinations of medical and behavioral health diseases and conditions that require consistent monitoring or treatment.[2] Consequently, people with MCC use health services comparatively more than most. Americans with five or more chronic conditions make up 12 percent of the population, but they account for 41 percent of total healthcare spending.[2] These individuals have complex health needs and receive care from a range of clinicians across multiple settings, which often results in fragmented, poorly coordinated, and inefficient care. The consequences of this fragmentation grow in proportion to the number of MCC: the more chronic conditions a person has, the higher their risk of (1) mortality, (2) avoidable hospitalizations, and (3) conflicting treatment plans from healthcare clinicians.[3] Patients and their caregivers are often tacitly tasked with managing multiple treatment plans, communicating updates between clinicians, and facilitating remediation when these plans conflict. This work is burdensome even for patients with the requisite time, energy, and knowledge; for less privileged patients, it is impossible.

1.2 Care Coordination Around Multiple Chronic Conditions

An electronic care (eCare) plan (i.e., eCP) is one component of a multifaceted care coordination intervention that could not only reduce mortality and hospitalization, but also improve disease management and patient satisfaction.[4] Although there are a variety of eCPs with unique characteristics, most share broad commonalities. At minimum, a care plan must document an individual's health needs and care received. The International Organization for Standardization emphasizes that a care plan is dynamic and personalized, edited as needed to reflect an individual's changing goals and health status.[5] Dykes and colleagues[6] added the need for a care plan to be holistic. Many care plans have been developed for specific sectors or for a single disease or setting, like the Pharmacist eCP,[7] the Electronic Chronic Kidney Disease (CKD) eCP,[8] the Electronic Longitudinal Services and Supports Plan,[9] and the Post-Acute Care Interoperability Project (focused on exchange of functional status data elements).[10] These narrowly focused care plans may not meet the full needs of MCC patients or their clinicians.

In 2016, the U.S. Department of Health and Human Services (HHS) outlined its vision for a comprehensive shared eCP[11] that enables clinicians to view relevant information electronically and enables individuals to access their personal health information directly, so that clinical and nonclinical needs are addressed. Crucially, a comprehensive MCC eCP would support care coordination, communication, and collaboration for care team members across *all* settings, including the home. To date, there have been multiple attempts to meet this goal, many of which are ongoing. Current hurdles for a MCC eCP include a lack of key

terminology standards surrounding social determinants of health, limited real-world use of existing data standards for person-centered goals and other key information, internal barriers to writing data into the EHR (also known as write-back), and the current absence of a comprehensive reference architecture to guide the integration of the diverse set of health IT tools.

1.3 Vision and Scope of This Report

To fill this critical need, the Agency for Healthcare Research and Quality (AHRQ) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) were funded by the Patient-Centered Outcomes Research Trust Fund, managed by the HHS Office of the Assistant Secretary for Planning and Evaluation, to develop and test a suite of eCP tools for adults with MCC,[1] including an eCP implementation guide specifying data standards and value sets for key use case conditions and two open-source eCP apps (one for patients and one for clinicians). This joint initiative supported the work to develop and test these apps, which are intended to facilitate aggregation and sharing of critical patient-centered data across home-, community-, clinic-, and research-based settings by extracting data from point-of-care health systems and allowing transfer of those data across settings.[12] In addition to furthering the direct benefits of care coordination, the deployment of these apps will build the data capacity for patient-centered outcomes research (PCOR). This work is a direct result of prior efforts by NIDDK on the aforementioned Electronic CKD eCP, which included a clinician-facing app design informed by wireframe testing with clinicians conducted in collaboration with the Veterans Affairs Human Factors Engineering team.[8]

Key domains were identified to help frame the design of these apps. The National Quality Forum[13] identified optimal components of a care plan to support patient-centric interoperable information exchange, including (1) prioritized health and social concerns (e.g., active problems, social risks, bothersome symptoms), (2) goals (e.g., desired outcomes), (3) interventions (e.g., dietary changes), and (4) health status (e.g., functional status of an individual across all care settings). A complete list of the patient's care team was added to the care plan components to give the five domains of the eCP apps.

1.4 Chronic Kidney Disease as a Case in Point

CKD is common, costly, and consequential,[14] and people with CKD often have MCC.[15-19] Care plans are crucial tools to address and coordinate health needs of people with MCC.[20] The complexity of care coordination for those living with CKD in particular highlights the degree to which data silos limit coordination and planning. Even today, care coordination and information flow between dialysis centers and nephrologists depend substantially on hand data entry and fax transmissions. Further, nephrologists frequently receive incomplete data on patients who are referred to their care. Care coordination still relies heavily on workflow, specifically a warm handoff that can happen by phone or in person. The advent of the

United States Core Data for Interoperability (USCDI) provides an unprecedented opportunity to start moving these data more seamlessly between electronic systems. During this project, the team continued to focus on CKD as a critical case in point.

1.5 Use of Standards to Improve Interoperability

These eCP apps use Substitutable Medical Applications, Reusable Technologies (SMART) on Fast Healthcare Interoperability Resources (FHIR) to automatically pull together and share health data. Specifically, FHIR[21] provides a uniform data model for health information of different types (specified as "resources") and an application programming interface (API) specification for how systems can interact with the data. When FHIR resource elements are bound to concepts in standard terminologies (e.g., Logical Observation Identifiers Names and Codes [LOINC] for observations, RxNorm for medications), different systems can understand and process the clinical content in those structures. SMART[22] specifications enable FHIR to work as an app platform by providing techniques for user scope and authorization (OAuth 2.0), sign-on capabilities (OpenID Connect), and user interface integration with existing health IT systems (e.g., electronic health records [EHRs], patient portals, native apps). Together, SMART on FHIR and standard terminologies present health data simply, reliably, and consistently. This approach enables a single app to run on multiple platforms throughout the health IT ecosystem, which will provide actionable information for achieving health and wellness goals. Only by using interoperable data elements do personalized eCP apps have the potential to simplify sharing and dynamic updates, improve concordance of patient and clinician perspectives and clinical (and care) decision support (CDS), and facilitate future PCOR.

2. Integration and Implementation of the eCare Plan Apps for Prototype Testing

Building on prior work, the eCP project was envisioned to address two separate but related perspectives on the complex problem of MCC management: the clinician perspective and the patient perspective. These two perspectives are linked with substantial overlap in data but have distinct requirements in the form of display characteristics, context, and language. For this reason, two separate apps were contemplated: one to be used by the clinician and another to be used by the patient.

2.1 Clinician Facing

Upon logging in to the EHR, the clinician has the option to select "eCare Plan" from a submenu and search for a patient within Epic. When the patient is selected, the SMART on FHIR single sign-on capability authenticates to the eCP app, preventing the need for the clinician to sign into the app separately. The information about the patient is then submitted via the EHR's FHIR API to the app, which is built inside a Docker container. The app

processes this information and returns a web app in the clinician's default web browser (e.g., Microsoft Edge).

The app itself consists of five distinct tabs (described in ***Table 1***). Demographic information about the patient is displayed across the top of the screen, and the information from the currently selected tab is displayed in the lower half.

Table 1. Application Content, by Tab

Category (Tab)	Content
Health and Social Concerns	Diagnoses, social concerns (e.g., homelessness)
Goals and Preferences	Patient- and clinician-entered goals, target laboratory and clinical values (e.g., HbA1C), patient choices (e.g., resuscitation preference, renal replacement therapy modality)
Health Maintenance and Interventions	Active medications and other orders, such as education, referrals, and counseling
Health Status Evaluation and Outcomes	Clinical data, including trends of laboratory values and most recent scores on questionnaires
Care Team	Contact information for each of the clinicians involved in care

2.2 Patient Facing

To access the patient-facing app, the user first needs to be recruited into the study. Recruitment is done during a patient visit and results in a message being sent to the patient's inbox on the patient portal. The user accesses the patient portal, proceeds to the Messages section, and clicks on the link that was sent to them. The patient portal then uses SMART on FHIR to authenticate to the eCP app as in the clinician app (***Section 2.1***). The patient app contains similar data, but those data are arranged differently to be more accessible to patients. Additionally, the language used in the patient-facing app is simplified to make it more accessible to patients regardless of education level. For the purposes of this project and this report, a caregiver app was out of scope.

2.3 Electronic Health Record Integration

Use of an eCP for MCC requires a clinical context. Oregon Health & Science University (OHSU) was identified as a partner for the work because of its reputation and experience as an EHR innovator.

2.3.1 Coordination with the Developer

As a contractor for AHRQ, RTI was responsible for evaluation of the apps that were developed under a separate source of funding. A developer (Cognitive Medical Systems) was

contracted by NIDDK to develop a containerized solution for prototype testing and to publish an implementation guide (IG) for MCC care plans through Health Level Seven (HL7).

The developer began work around September 2019. Through biweekly meetings with RTI starting in April 2020, the development team kept the implementation/evaluation team (RTI/OHSU) apprised of progress in the form of wireframes. The eCP apps were delivered as containerized solutions in September 2020, with the IG finalized in November 2020 in a pre-ballot state.

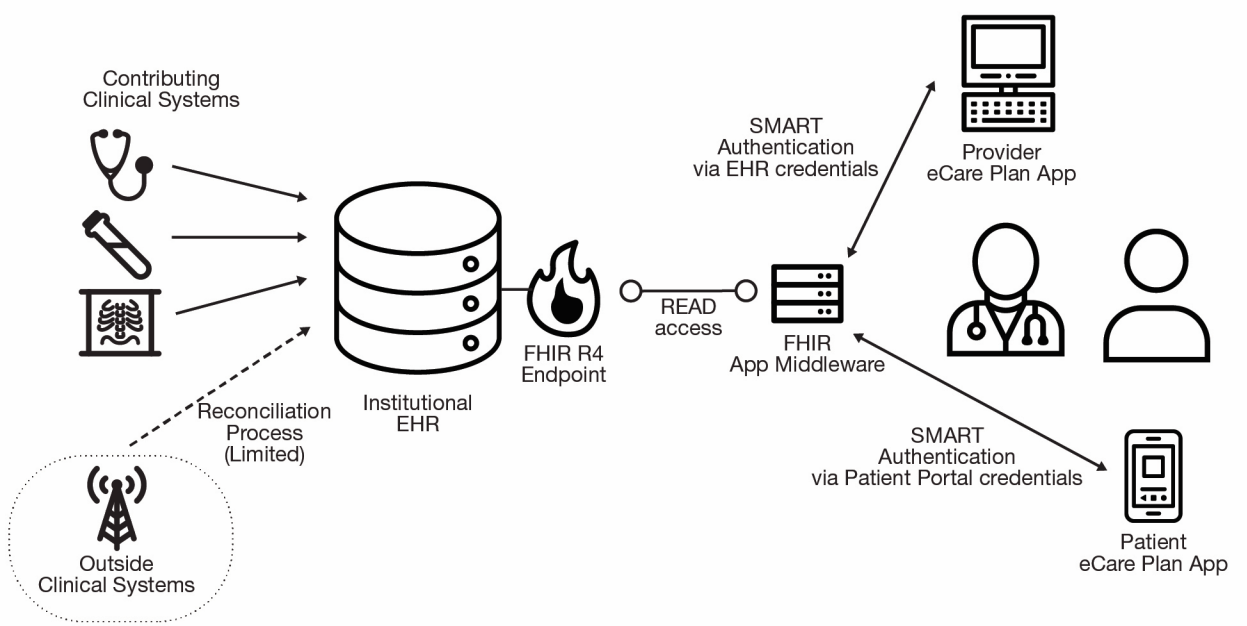
2.3.2 Oregon Health & Science University Environment

OHSU is an elite health research institution with reach into various clinical settings, including inpatient, outpatient, and emergency room settings and a history of successfully implementing experimental electronic health record tools. The EHR in use at OHSU at the time of implementation was Epic Hyperspace. The prototype testing occurred from November 2021 to April 2022 and included only a convenience sample of patients and clinicians.

2.3.3 USCDI and the Native FHIR Application Programming Interface

Growing out of the desire to standardize medical data across the country, USCDI aimed to regulate how data would be transmitted from one interested party to another by specifying a format (FHIR) and specific data elements. The first version of this standard dictated what data types (such as care team members) would be available for transmission to avoid penalties from the information-blocking statute. These types specified by USCDI Version 1 were expected to be available for use through the native FHIR interface provided by Epic. This interface, as specified by the FHIR standard, is a RESTful interface that operates much like a web application. FHIR servers and clients send requests, which are received, processed, and responded to according to a standard set of commands. This process works like a web application would; only the data that the server is instructed to reveal are accessible, while all other data remain hidden and inaccessible. The communication also occurs over an encrypted channel to protect patient privacy. Such native FHIR interfaces are available for most major EHRs, although health systems may need to pay a fee to have access to the software module and unusually must manually activate the interface to have it accessible to the outside world. A simplified system diagram is included as ***Figure 1***.

Figure 1. eCare Plan System Architecture



However, the native FHIR interface did not include all expected data within those types, such as care team member contact information, and often split the remaining data across endpoints, such as diagnoses. However, by querying multiple endpoints, all data types specified by USCDI were found to be available to read from the patient record. Middleware was used to transform requests to ensure all needed endpoints were queried correctly, to suppress extraneous error messages, and transform responses to ensure successful processing.

2.3.4 Testing of Interoperability Specifications

The MCC FHIR IG defines the building blocks (i.e., FHIR resources) that enable the data exchange for health technology solutions, in this case for the eCare Plan applications. To support FHIR IG development, the HL7 FHIR community hosts FHIR Connectathons to provide opportunities for hands-on testing of the HL7 FHIR IGs and the apps that use them in a sandbox environment or with proof-of-concept systems that do not use real patient data. This provided critical opportunities for standards experts outside the project team to comment on the generalizability of our approach by comparing it against potential data requestors and receivers. Testing of the eCare Plan applications in the OHSU health system with clinicians and patients extended the MCC FHIR IG Connectathon testing. The data element crosswalk (Section 3.3.1) is the product of applying the MCC FHIR specification in a real-world setting.

2.4 Development of a Training Approach

2.4.1 Approach

To prepare for executing the prototype testing and as part of the design, training materials were developed based on change management principles and best practices for implementing health IT. The training framework incorporated the use of personas and use cases to support the end users in understanding how the apps integrate with clinical workflows and influence patient–clinician interactions. Training resources include tip sheets, informational flyers, a training slide deck, and on-demand videos (see ***Appendix B***). Separate tip sheets, flyers, and a training slide deck were created for clinicians/clinic staff and for patients/caregivers.

2.4.2 Personas and Use Cases

To ground the training and testing discussions, the team used a persona named Patricia Noelle. Patricia is a 65-year-old retired schoolteacher who lives with her daughter, Rose, after her husband passed away a few years ago. Patricia's health concerns include chronic kidney disease, diabetes, chronic heart failure, chronic low back pain, and depression. Patricia feels nervous and overwhelmed managing her MCC, which also affects her depression. Patricia's social risks include food insecurity and transportation insecurity. Patricia relies on Rose to drive her to the doctor and therefore can schedule appointments only when Rose is not working.

During both the pre- and post-prototype testing interviews, patients, caregivers, and clinicians were asked to consider three scenarios that describe Patricia's healthcare encounters and use of the clinician- and patient-facing eCPs.

- **Scenario 1**: Patricia has a visit with her primary care provider (PCP) to evaluate her current care. She also has a consultation with her dietitian and her nephrologist to manage her chronic kidney disease. All three clinicians make corresponding updates to Patricia's shared care plan.
- **Scenario 2**: Patricia has fallen and broken her hip. After her hip fracture repair, she is admitted to a skilled nursing facility. Patricia does well with her physical and occupational therapy, and on her seventh day, she is ready to be discharged with home health physical and occupational therapy. Her clinicians update her care plan upon discharge to reduce fall risk, manage pain, and continue rehabilitation.
- **Scenario 3**: Patricia's chronic kidney disease has progressed to renal failure, and her care planning is extended to include dialysis coordinated with partner care clinicians. Coordinated care plan changes are made by her dialysis center and PCP. Adjustments to other aspects of the care plan include accommodating in-person visits to the dialysis center and addressing challenges with transportation.

2.4.3 Testing Recruitment and Support

OHSU and affiliated sites elected to use a variety of resources to support implementation, including training materials in the form of slide decks for the apps, training sessions to

introduce the apps to users, and tip sheets to support users in the field. In addition, the prototype testing process was guided by structured protocols to support introduction of the apps, to elicit key factors that affect usability of the apps, and to collect additional input on suggested improvements. Based on the performance of the apps in the production environment and guidance from the clinical stakeholders, all users of the apps accessing real-world data were carefully selected, invited, trained, and observed for prototype testing.

2.5 Planning for Evaluation

To understand the impact of the eCP apps on care coordination, a robust sociotechnical evaluation was conducted. This evaluation leveraged inputs from key stakeholders, the development process, the integration and implementation team, and the usability testing from the prototype testing period.

3. Evaluation Methods

A complex implementation project, especially one that uses newer technologies like SMART and FHIR, which has yet to achieve significant mainstream use in the health system environment, has many moving parts. Additionally, other challenges to successful implementations of health IT solutions often go well beyond the technology itself. To track some of those other factors, the evaluation required a broad sociotechnical framework as a guide.

3.1 Goal of the Evaluation

The goal of the project was to assess the challenges of and solutions to developing, implementing, and using the eCP apps and their associated outcomes. The approach to this project evaluation is outlined as follows, including the evaluation framework (see ***Figure 2***), the evaluation questions (EQs), data collected and methods for collecting those data, the approach to analysis and synthesis across data sources, and the results of the evaluation by EQ.

3.2 Evaluation Framework and Questions

Guided by the Consolidated Framework for Implementation Research Process Redesign (CFIR-PR), the evaluation framework and EQs tracked design, development, implementation, effects or outcomes, and lessons learned. Additional information is included in the sections that follow.

3.2.1 Evaluation Framework

This section reviews Figure 2 as an organizing framework for the evaluation and ***Table 2***, which maps specific framework constructs targeted in this work. The team selected the CFIR-PR because it is flexible enough to apply to other implementation science frameworks,

it is replicable and practical, and it addresses the factors for implementation success or failure. The CFIR-PR uses constructs and defined theoretical concepts that help focus implementation evaluations (e.g., adaptability, complexity). Evaluators identify applicable constructs according to characteristics and goals particular to the implementation. The framework is composed of seven domains:

- **Intervention characteristics**: the characteristics and features of the intervention being implemented into a particular organization or organizations, including core components (the elements that are essential and indispensable to the intervention itself). These components may be fixed or mutable, they are considered and assessed prior to implementation, and they influence adoption decisions.
- **Outer setting**: the economic, political, and social context within which an organization resides.
- **Inner setting**: tangible and intangible manifestation of characteristics of the organizations involved in the intervention, including structural characteristics, networks and communications, culture, climate, and readiness, which all interrelate and influence implementation.
- **Characteristics of individuals and teams**: the individuals (as carriers of cultural, organizational, professional, and individual mindsets, norms, interests, and affiliations) involved with the intervention or implementation process, including patients and caregivers.
- **Process of implementation**: the course of actions (e.g., planning, engaging, reflecting) to achieve individual- and organizational-level use of the intervention as designed.
- **Measures of implementation**: known as what Proctor and colleagues[23] call "implementation outcomes," these are intermediary outcomes that describe how well the implementation was carried out and the prospects for sustainability.
- **Outcomes**: the results of the PR implementation, defined as the targets of the PR intervention.

Figure 2. Consolidated Framework for Implementation Research Diagram

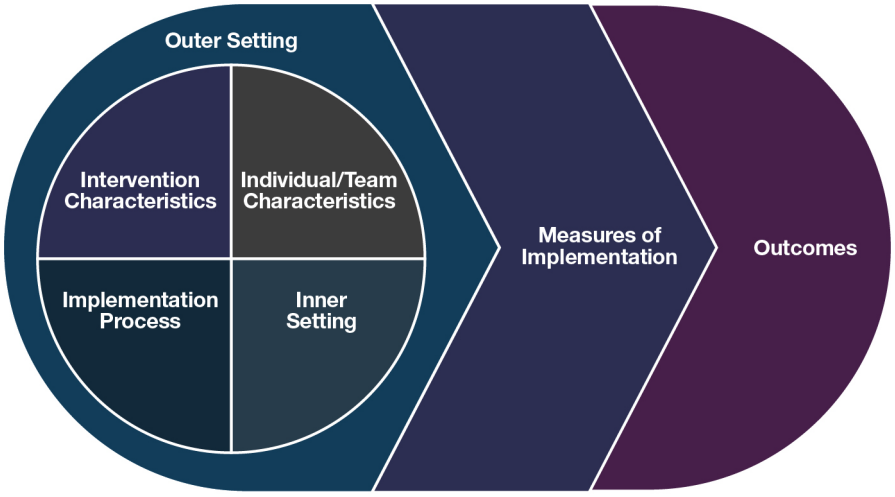


Table 2. eCare Plan App Evaluation: Mapping CFIR-PR Domains to Constructs

Framework Domains	Relevant Constructs for Evaluation
Intervention characteristics	Adaptability, feasibility, relative advantage, evidence strength
Outer setting (the broader community and state context within which the sites operate)	Policy, regulatory guidelines
Inner setting (organizational characteristics of the sites themselves)	Staff commitment, access to information, training and education, IT and health IT resources
Characteristics of individuals and teams	Skills and competencies, team and network characteristics
Process of implementation	Reflecting and evaluating
Measures of implementation	Acceptability, usage or reach, appropriateness, adoption, fidelity
Outcomes	Implementation outcomes: acceptability, usage or reach, appropriateness, adoption, fidelity Intervention outcomes: utilization and experience, performance

CFIR-PR = Consolidated Framework for Implementation Research Process Redesign; IT = information technology

3.2.2 Evaluation Questions

The RTI team developed five EQs to drive the approach to the evaluation:

1. What were the key issues for *designing* (using a user-centered design [UCD] approach with a patient-centered focus) interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
2. What were the key issues for *developing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
3. What were the key issues for *implementing* interoperable and publicly shareable MCC care coordination tools for patients and clinicians, and how did the project address those issues?
4. What *effects (or outcomes)* did the MCC care coordination tools have on management of MCC across settings?
5. What *lessons learned* arose from the project's experiences with developing and implementing interoperable and publicly shareable MCC care coordination tools for patients and clinicians?

3.3 Data Sources and Data Collection

This section references and briefly summarizes the data sources and data collection process.

Planned prototype testing goals were adjusted to the practical capabilities of the apps. To better understand the potential of the apps to support care coordination, the prototype testing scope centered on the usability of the eCP apps with a group of clinicians and patients.

The goal was to quantify progress and qualify deficiencies. In this way, a few important questions were addressed: (1) Has the tool under study reached the necessary usability goals? (2) Is the user gestalt positive toward the tool? (3) What specific deficiencies can be identified for correction? The last two endpoints are optimally obtainable using qualitative methods during prototype testing.

3.3.1 Data Sources

Several methods were used to supply data for the evaluation, and most of the data collected were qualitative. These data included a series of early stakeholder working group sessions, data collected from app integration into the EHR environment, usability testing during the prototype testing process, a brief analysis from log files of app performance, and followup interviews with key stakeholders at the end of the prototype testing period.

Multistakeholder Working Group Sessions

The purpose of the stakeholder working groups was to provide input and inform the eCP apps' development. The team from RTI International convened multiple stakeholder groups to provide input to AHRQ/NIDDK and their app developer. The stakeholders included a variety of end users and other industry experts whose input was critical in developing the apps and IG.

Four stakeholder groups provided iterative feedback to the app developer based on their role and perspective (***Table 3***). The stakeholder working groups addressed topics that included issues and challenges to consider during app implementation and use, requirements for workflow and data, usability, and feedback on the apps' design.

Table 3. Overview of Multistakeholder Groups, Participant Types, and Format

Clinicians/ Leadership	IT Staff	Other Health Professionals/ Clinicians	Patients/ Caregivers
▪ 1 nurse manager ▪ 1 primary care clinician ▪ 1 nephrologist ▪ 1 veterans' health administrator	▪ 8 IT staff and/or administrators	▪ 1 long-term and post-acute care nurse ▪ 2 physicians ▪ 1 social worker ▪ 1 pharmacist ▪ 1 geriatrician ▪ 1 nephrologist	▪ 5 patients living with chronic pain and MCC (or care for a patient with MCC)

MCC = multiple chronic conditions

The stakeholder participants were from OHSU, the health system and primary implementation site partner, the extended community network, and other specialized industries with relevant expertise as described in Table 3. RTI recruited research experts and other industry representatives. Details are provided in ***Table 4***.

Table 4. Description of Sites Approached for Multistakeholder Group Representatives

Sites	Type	EHR System	Relationship to OHSU
OHSU	▪ Acute care ▪ 11 primary care clinics ▪ 90 specialty clinics	Epic	Primary contractor
Fresenius	Dialysis center	Acumen	OHSU joint owners
DaVita	Dialysis clinician: inpatient and transfer	Falcon	Business Associate Agreement for dialysis services
Holladay Park	LTPAC	Set of LTPAC systems	OHSU clinicians with privileges
Mirabella	LTPAC	Set of LTPAC systems	OHSU clinicians with privileges
Northwest Primary Care	5 primary care clinics	Greenway Health	History of collaborations
211	Community resource specialist organization	Non–health IT system	History of collaborations

LTPAC = long-term and post-acute care; OHSU = Oregon Health & Science University

RTI used a phased approach for meeting topics and discussions. Phase 1 focused on understanding the problem, Phase 2 focused on requirement gathering and feedback, and Phase 3 focused on gaining input on the apps' design/usability and implementation. Discussion topics were unique to each group's purpose and expertise. ***Appendix A*** provides additional details on the multistakeholder working groups.

The multistakeholder group meetings were generally held biweekly starting in late March/early April 2020 to accommodate stakeholder recruitment. Each stakeholder group met three times (once per phase) between April and early December. The clinicians/leadership and other health professionals/clinicians groups were split, and two meeting times were offered per phase.

These groups worked in parallel as they moved through three phases of investigation, each taking about 2 months:

- ***Phase 1—Understanding the Problem***. During this phase, the stakeholders were oriented to the eCP project and the purpose of the groups. Discussions focused on the issues and challenges of patients who have CKD and clinicians managing their care and services. The groups also discussed opportunities for

improvement and value of the eCP apps. A summary of the issues, challenges, opportunities, and value was captured and relayed to the app developer.

- ***Phase 2—Requirement Gathering and Feedback***. During this phase, the stakeholder groups reviewed the NIDDK materials updated by the app developer (e.g., NIDDK use case, personas,[1] IG) and provided feedback. Information needs and data elements were discussed from different stakeholder perspectives. A summary of these discussions was shared with the app developer for their consideration in refining the apps and related documentation.
- ***Phase 3—Input on the App Design/Usability and Implementation***. During this phase, the stakeholder groups discussed workflow from different perspectives; provided feedback on app wireframes, including the technical standards/infrastructure; and completed usability testing. Stakeholders provided qualitative feedback on the apps through direct observation and discussion. A summary of workflow considerations, comments on the wireframes, and findings from the sessions were shared with the future app developer. The groups also discussed implementation of the apps and considerations for the developer and prototype testing team to consider.

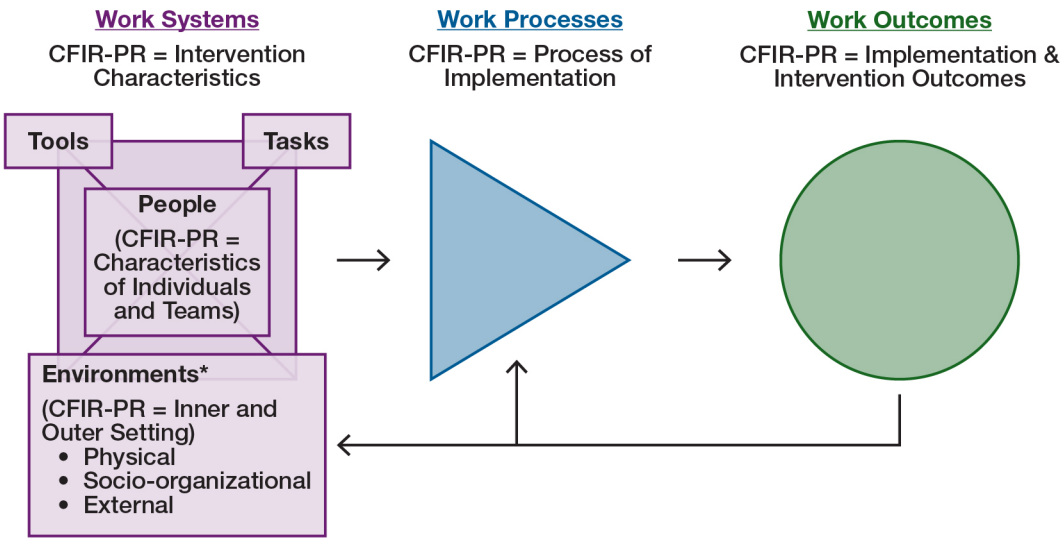
Each group met once per phase at a minimum. A health informatics researcher led the discussion and was assisted by a notetaker. Four individual semistructured interviews were conducted with those who could not attend focus group meetings. Additional stakeholder group meetings or email discussions were used as needed to elicit input while minimizing participant burden. An overview of each discussion topic was created and organized by phase and stakeholder group. These discussion questions addressed concepts related to opportunities/needs, barriers/issues, requirements for workflow and data, usability, and feedback on the apps' design.

After each meeting, transcripts were uploaded to Dedoose, web-based qualitative data analysis software. A preliminary codebook was developed using the work system elements from the Systems Engineering Initiative for Patient Safety (SEIPS) model. Researchers ensured consistency by double coding and reviewing 10 percent of the transcripts, as well as meeting weekly throughout the coding process. New codes were created as recurring themes emerged. Preliminary findings were presented to stakeholders after each phase as a means of member checking.

Use of the SEIPS Model within the CFIR-PR

A sociotechnical systems approach was applied using the SEIPS model to understand the user experience of the stakeholder working groups while interacting with wireframes of the eCP apps. The SEIPS model considers the patient journey, which may involve several encounters with different stakeholders (ranging from caregivers to clinicians) distributed across different care settings.[24] Within the patient journey, the work system consists of five interacting elements: (1) person, (2) tasks, (3) tools and technologies, (4) physical environment, and (5) organization. ***Figure 3*** shows how the SEIPS constructs map to the CFIR-PR.

Figure 3. Systems Engineering Initiative for Patient Safety Model Mapped to the CFIR-PR



CFIR-PR = Consolidated Framework for Implementation Research Process Redesign

Clinician and Patient Usability Testing Observations

Using a semistructured interview protocol, usability testing was conducted similarly with clinicians and patients. Participants were first offered a short training video that briefly described the purpose of the project and the expectations of usability testing, and provided screenshots showing the apps' major features and navigational tools. Participants were also asked to test and confirm their access to the apps in advance to avoid delays during the testing session.

Clinicians with varying specialties were enlisted for usability testing. Prior to testing, each clinician gave their comfort level with technology and with eCPs on a five-point Likert scale, with larger values indicating more experience and higher comfort levels. The "Patricia Noelle" persona was created and loaded prior to the app demo. Usability data on whether clinicians could navigate to each page and view all the available information were recorded. Clinicians also answered four qualitative questions for each page: (1) Are the data displayed helpful? If so, what is helpful? If not, why not? (2) Are there any extraneous data displayed? (3) What data are missing? (4) Is this information clinically relevant and does it add value to the encounter or treatment?

After the tester had completed their review of each page, they were asked to rate the four questions using the Likert scale and answer three additional questions: (1) How would you incorporate the eCP app into your daily workflow? (2) Is the current display appealing? (3) Are there any other comments or thoughts about the eCP app?

As with the clinician testing, each participant rated their comfort with technology and care planning apps before beginning the app review. Patients also answered two preliminary questions about their care coordination: (1) What do you like about the existing care coordination among clinicians? (2) What else would help support the coordination of your care?

For the demo, each patient's own data were loaded into the app. For the patient's privacy, their screen was not shared, and they were instead instructed to talk through their actions. For each of the five pages, the same usability data on whether patients could navigate to each page and view all the available information were recorded. Patients were also asked similar qualitative questions on each page: (1) Is the information helpful? If so, what is helpful? If not, why not? (2) Are there any data here that you do not find helpful? (3) What other information would you like to see here? (4) Does this information make sense to you?

The patients were asked to rate the same four statements using the Likert scale. They were also asked five additional qualitative questions: (1) Thinking about the words used in the apps, including the labels, headings, and acronyms, is the language understandable? If not, which words should be changed? (2) How could we change the app to make it more likely for you to use it? (3) Do you feel that the eCP app could help you in managing your care? If so, how? (4) Is there anything else that could make managing your care easier? (5) Is there anything else that could make a difference in care coordination for people who help you at home?

OHSU Issues and Resolution Documentation

Developing and deploying the eCP apps involved some significant hurdles, despite the containerized nature of the solution, because the developer had not had the opportunity to test it against a production environment. As such, several substantial issues were encountered that required evaluation and resolution in order to achieve a satisfactory implementation.

A core team of implementers recorded, discussed, and resolved the issues discovered. They used a combination of an online collaboration platform, GitHub, as well as a shared spreadsheet to document progress, leave reminders about the next tasks to be completed, and make requests for further enhancements that might be on the product roadmap.

EHR Integration Details: Data Element Crosswalk

To evaluate the discrepancies between the specifications documented in the eCP IG and the U.S. Core specifications and how the eCP apps were integrated during implementation at OHSU, the RTI team created a data element crosswalk. This inventory also included differences in the IG from those in the native Epic FHIR API at OHSU. The team recorded information available about Epic's next release.

Clinician, Health IT, and Patient Post-Prototype Testing Semistructured Interviews

After the prototype testing phases of the project, key stakeholders from three groups (clinicians/leadership, IT staff, and patients/caregivers) were enrolled in groups of one to three to answer questions developed at the beginning of the project for Office of Management and Budget approval. See ***Appendix A*** for questions used to guide the interviews. A total of six clinicians, four health IT staff, and three patients were interviewed. Participants were sorted into interviews by group and availability. The seven interviews each lasted between 30 and 60 minutes and were conducted using Zoom. During the interviews, participants had the option of reviewing static slides demonstrating the eCP apps for the Patricia Noelle persona before answering the interview questions. Live notetaking was supplemented by an audio recording and a live transcription to ensure accuracy.

Log Files

Several approaches to capture data and metrics on the use and stability of the MCC-API system were considered during the system deployment process. Ultimately, the team decided to meet this need by capturing and processing MCC-API log files through Splunk. In this round of testing, the team was able to successfully validate that this system could be used to retrieve and search/analyze MCC-API log file data related to the clinician and patient app usability testing sessions.

3.3.2 Data Collection

Discussions from each of the qualitative data sources—including the multistakeholder working group sessions, usability testing during the prototype testing process, and followup interviews with key stakeholders at the end of the prototype testing period—were recorded, and detailed notes were documented for analysis.

4. Evaluation Analysis, Synthesis, and Results

Details on the overall approach to analysis across all evaluation and the synthesis from this analysis are presented as follows. Results from the analysis are also included.

4.1 Analysis and Synthesis

Analysis and synthesis across all inputs were largely qualitative and managed using Dedoose. More details are outlined as follows.

4.1.1 Multistakeholder Working Group Sessions

A qualitative thematic analysis was conducted across groups, and notes from each group were analyzed deductively using Dedoose. Each text was imported into Dedoose and tagged with a descriptor for the given multistakeholder group (patients/caregivers, clinicians/leadership, IT staff). Using a preexisting codebook, a researcher coded sections of

text and compiled them as excerpts. A second researcher reviewed the excerpts and their codes for quality assurance. A total of 183 code instances were mapped to 108 unique excerpts. The total app count for each code was also included to briefly indicate the relative frequency of each topic.

4.1.2 Usability Testing

Qualitative responses to the usability testing questions were first grouped by app page. When comments overlapped on a single page, they were grouped together into a single recommendation (e.g., the comments "How was the lab ordering determined? Could use better organization, standard ordering from elsewhere in Epic" and "ordering of labs is unusual, should be ordered/grouped by system" were grouped as "align lab ordering with Epic standards"). The number of unique clinicians behind a single recommendation was captured to aid in prioritization. Last, each recommendation was classified as "within reach" or as a "stretch goal."

4.2 Evaluation Results

The eCP apps were successfully designed, developed, implemented, and evaluated at OHSU. The following sections provide the results for each of the evaluation questions across all evaluation inputs.

4.2.1 Design (EQ1)

Development of the eCP apps focused on UCD with multistakeholder input collected through small focus groups. Participants included patients and their caregivers, clinicians, and the health IT staff from the implementation sites. Early multistakeholder input was relayed to the design team and focused on the display of information, information included in the apps, and how the apps facilitate care coordination. Feedback from these sessions included topics such as challenges related to COVID-19, information sharing and care coordination, and ways patients engage with the app. More specifically, stakeholders noted that patient preferences and input into their care plan will be important factors in the success of the apps. They also noted that a single source of truth with a single owner would be most useful and that it is important for information to be presented in a meaningful way. They also cautioned that sharing information in an app may be limited due to lack of interoperability and EHR capabilities and that to be successful, the apps must fit easily into the clinical workflow.

Chronic Kidney Disease Case Study

As a followup to the multistakeholder sessions and to stimulate the prototype testing design process, the team held detailed discussions with OHSU clinicians on the current state of data flow and how the eCP apps will ameliorate data access challenges. The following summary and diagrams describe the current and future states of data workflow as described

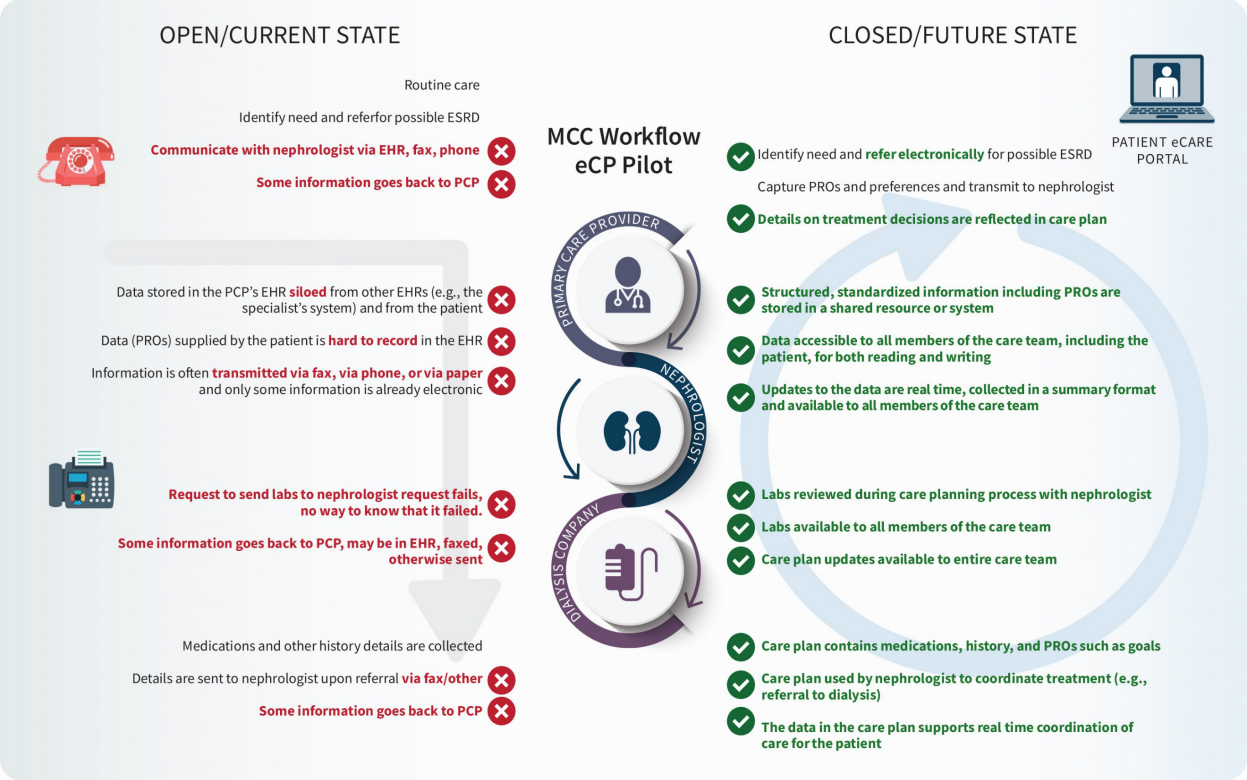
by a nephrologist at OHSU.

When a patient is diagnosed with end-stage renal disease, their PCP will start dialysis education and hand a larger part of the patient's care to the nephrologist. The nephrologist's role increases as the disease progresses. The nephrologist supports the patient in deciding about dialysis treatment. Some patient choices require surgery for dialysis access, which involves a separate surgical team and occurs 8 weeks before dialysis can begin. Other clinicians who could be involved include dietitians and social workers.

Dialysis companies often use third-party laboratories, which will fax the dialysis center results that the dialysis center manually enters into its medical record. The patient's nephrologist faxes an order to the dialysis center, receives the results via fax, and manually enters them into OHSU's EHR, which runs on software from Epic Systems, a private U.S.-based company. The nephrologist also manually reconciles medication lists from the dialysis center with the OHSU EHR, an important activity to mitigate safety implications. ***Figure 4*** depicts the flow of patient data.

In discussions with the OHSU nephrologists, the team mapped the possible data flow using fully interoperable eCP apps (depicted in Figure 4).

Figure 4. Nephrology Data Flow with eCare Plan



eCP = electronic care plan; EHR = electronic health record; ESRD = end-stage renal disease; MCC = multiple chronic conditions; PCP = primary care provider; PRO = patient-reported outcome

The key barrier here is in moving the data collected at the dialysis center (for example) to the nephrologist's EHR system (or similar) to facilitate true care coordination.

Patient feedback focused on the app's capabilities and information display. Patients preferred to text with clinicians and recommended that patient preferences such as religious affiliation or advance care plans should be included. Patients indicated that consent should be granular to allow them to confirm how much of their information is shared with which clinicians because a one-size consent does not fit everyone or every situation. Having information displayed in a way that is easy to interpret was highlighted. For example, using colors to signify whether results were normal and having the option for patients to drill down to view more information related to their care was recommended.

Clinicians discussed having the right information at the right time for the right audience. Stakeholders noted how a lot of care planning happens in the notes within the EHR. Specifically, in the outpatient setting, the problem list is used to develop a care plan. Consequently, the care team is unable to see when updates were last completed. The need for considerations around the number of contributors and processes for reviewing and accepting information written to the care plan was discussed. Desired apps and add-ons included tools to monitor blood glucose, track hospitalizations and discharges, calculate readmission risk, and flag kidney value increase. Clinicians recommended that the add-ons should be integrated, web based, or accessed through handheld devices. The sharing of information across health systems remains a huge a point of concern and frustration for clinicians and patients. Groups noted that the organization of information within the eCP apps is important, and clinicians should be able to filter and sort patient information to find what they need without a substantial number of clicks. There was a persistent desire for care plans to follow the patients and clinicians.

Health IT stakeholder feedback focused primarily on usability and information sharing and display. Participants in these groups indicated that the personas and use cases reviewed seemed reasonable, but they did not feel comfortable commenting on clinical flows. With respect to information display, they recommended indicating the source of the data (i.e., Are the data patient or clinician generated?) and noted that identifying the clinicians on the care team is an important piece of information. This list could be generated by the patient and include caregivers in the family and could indicate that provenance is important when coordinating care across primary care and specialist clinicians. Participants provided the following recommendations related to app functionality: information generated by entry in the apps should be written back to the source system, provenance should be included in the apps' data, the apps should allow concurrent users and data to be entered concurrently, and data transfer should be an on-demand pull request. A big consideration noted is how data are shared, specifically, the source of truth and how each clinician is updated.

4.2.2 Development (EQ2)

During development and implementation of the interoperable and publicly shareable MCC care coordination tool, site-specific and EHR issues were identified, as were challenges and considerations related to gaps in readiness related to HL7 standards and the IG specifically. Considerations related to the EHRs included current functionality limitations, including the EHRs' inability to support SMART on FHIR launch sequence and limitations around information stored. Goals are not typically stored in the EHR. Consequently, a FHIR repository may be required for information not written back to the patient record. Security, authentication, and information access could be restricted by the EHR capabilities and implementation. Clinicians located throughout different healthcare systems with different EHRs will typically need to manually retrieve patient information. On many occasions, the clinician is responsible for integrating information across multiple EHRs, and the lack of functionality to write back to the EHR does not improve this workflow.

Stakeholders expressed a desire for care plans to allow standard data transfer between clinicians; however, standard data transfer is hindered because care plans are highly customized and nonstandard. Participants noted how some EHRs capture social determinants of health (SDOH) data, but others do not. SDOH tracked by long-term care facilities may differ from SDOH data captured elsewhere. Other concerns related to data standards include how clinicians are unable to change mapping on records. Consequently, EHR mapping may be too granular or may lack granularity. Terminologies are currently not sufficient to support all data in the care plan. Terminologies used include Intelligent Medical Objects, RxNorm, LOINC, and SNOMED. Observation profile supports LOINC only, and at times, SNOMED terms are more robust.

Challenges related to HL7 standards versus standards used in the real world included a lack of translation software to translate clinical implementation sites that are on DSTU 2 or 3 to apps built in R4. Although demonstrated through Connectathons, there is limited implementation and a lack of ability to implement R4 apps that cross care sites. Very few clinical sites are currently fully or exclusively using R4, and this situation is likely to persist for a few years. The HL7 MCC eCP Draft IG[25] describes specifications for exchanging care plan data, including specific data elements and data format. However, health data in the real world may be using different data elements and data formats. Specific challenges related to the MCC eCP IG specifications and the data available for exchange in the site EHR include the fact that care plans have many resource types not yet supported by EHRs, yet they are expressed in an IG.

4.2.3 Implementation (EQ3)

Results from the implementation are presented according to the CFIR-PR, as discussed earlier, and organized by relevant constructs, as follows.

Intervention Characteristics

Intervention characteristics reflect the varied approaches or features of the intervention being implemented into a particular organization or organizations, including core components (the elements that are essential and indispensable to the intervention itself). These components are considered and assessed prior to implementation, and they influence adoption decisions.[26] In this section, findings on the key intervention components in the study, considering factors like adaptability, feasibility, relative advantage, and evidence strength, are presented.

Adaptability is the degree to which the intervention itself can be modified to better fit a site's needs. The back end of the apps has a moderate degree of adaptability: institutions with ample health IT resources can extend the native FHIR API's abilities to capture otherwise inaccessible data in the EHR. Institutions without those resources are not required to implement an extensive build. The front end of the apps is less adaptable in its current state. This was widely seen as a key area for possible improvements because clinicians, patients, and caregivers who tested the apps requested more customizability.

Feasibility refers to the extent to which an intervention can be applied in each setting. At the time of implementation, the native FHIR API reported the ability to provide a variety of data elements; however, the way in which these data were returned caused errors in the apps that required a translation layer between the native API and the app. As an example, when the app requested the list of medications for many patients, the response from the native FHIR API was a long list of errors that prevented the display of active medications. The errors were found to be caused by the native FHIR API's handling of discontinued medications. Several features of the apps would not have been feasible without the addition of this translation layer, provided by custom middleware, that allowed for additional functionality such as suppression and transformation of the data being exchanged. Without this middleware solution, the apps as conceived would not be feasible, and future similar projects should expect that some similar middleware will likely be required to ensure proper functioning.

Clinicians and patients were keenly aware of the relative advantage a consolidated eCP could have over existing solutions. Many clinicians mentioned the burden of having to search through multiple sources for relevant patient information. Many patients have experienced difficulties during transitions of care as a result of missing or inaccurate health data. It should be noted that the main pain points arise for patients who move among various care settings; for patients who receive care in very few settings from a limited number of clinicians, existing tools (EHRs, MyChart) are often sufficient for their needs.

The stakeholders' belief in the strength of the evidence that the intervention will achieve the intended outcome is a nuanced but important consideration. Broadly, clinicians and patients agree on the need for accessible data to support shared decision making. Historically,

however, both groups have experienced failed attempts at delivering those data, including to some degree with the eCP apps, leaving them skeptical of new interventions. This is a serious hurdle to widespread uptake of an eCP that is not easily replicated in a research environment. In a real-world setting, stakeholders will use an eCP only if they believe it will improve the quality of care they give or receive. In a research setting such as this, stakeholders must believe that their participation in the intervention will improve future care plan iterations. That belief was widely held, and stakeholders from each group worked to test and improve the eCP.

Outer and Inner Settings

The outer and inner settings of an implementation environment are key factors that influence success of an intervention's implementation.[27]

Outer setting refers to elements external to an organization that may influence implementation and/or related outcomes, such as external policy and incentives or disincentives, regulatory guidelines, and so on. The 21st Century Cures Act, and the USCDI in particular, can be seen as a backdrop to the eCP and similar efforts, such as the HL7 FHIR accelerators. The Cures Act seeks to standardize the types and transfer of patient data, establishing fines of up to $1 million for health IT developers who create barriers to the transfer of electronic health information. The possibility of future legislation extending that responsibility to providers is a key motivating factor in the development of tools for safely sharing health information, like the eCare Plan. Further, the Federal Government's clear priority of data standardization and interoperability assures forward-looking institutions that interoperability efforts can have long-term value.

An organization's inner setting refers to tangible and intangible characteristics or features through which the implementation process will proceed. OHSU, as a research health university, possesses several characteristics favorable for implementation. Health IT staff, in addition to having extensive experience with existing IT tools, have the resources and endorsement to implement new systems. Clinicians are familiar with the testing process and hold valuable informal knowledge on previous interventions, thus requiring minimal training to effectively participate in prototype testing. Finally, administrators understand the interrelated needs of the care delivery and research arms of the institution and are thus able to efficiently allocate human capital. Inner setting characteristics also varied during the development and implementation process. The level of access to information was initially low, as app developers and the OHSU team had relatively infrequent direct communication. Exploring and utilizing more rapid forms of communication improved the flow of information, and app development accelerated.

Characteristics of Individuals and Teams

In ***Table 5***, the roles, focused skills/competencies, and cross-cutting skills/competencies are identified for each phase of the project. This table helps demonstrate some of the characteristics of the broader team for future implementers.

Table 5. Relevant Phases, Roles, Skills, and Competencies

Phase of Project	Roles	Skills/Competencies
Development	▪ Knowledge engineers ▪ Software developers	▪ Health/clinical informatics ▪ Health IT
Design	▪ Users/advocates ▪ UI/UX designers and developers	▪ User-centered perspective ▪ Usability and design skills
Build	▪ EHR integrators ▪ System integrators ▪ Technical users	▪ Site-specific adaptation ▪ Technical testing
Implementation	▪ Patients, caregivers ▪ Clinicians	▪ MCC management ▪ Patient advocacy ▪ Behavioral science
Evaluation	▪ Query developers ▪ System analysts ▪ Statisticians ▪ Study designers	▪ System/product evaluation ▪ Project management ▪ Implementation science ▪ Qualitative research/ methods

EHR = electronic health record; MCC = multiple chronic conditions; UI/UX = user interface/user experience

Process of Implementation

We assessed clinician and patient comfort with technology before the usability tests. We assessed the ease, complexity, and level of awkwardness of the eCP apps and how frequently clinicians and patients might use the apps if they became available after the usability tests. Testing sessions ranged from 33 to 51 minutes, with a median time of 45 minutes. As shown in ***Tables 6*** and ***7***, most of the nine clinicians enlisted for usability testing were generally comfortable with technology (mean = 4.0) but less comfortable with eCP apps (mean = 2.9). The seven patients who performed the usability tests were somewhat comfortable using technology (mean = 3.5) and slightly more comfortable using the eCP apps (mean = 3.8). Clinicians and patients agreed that the eCP apps were easy to use (means = 4.1 and 4.2, respectively) and disagreed that the eCP apps were completed (means = 2.4 and 1.5, respectively) or cumbersome/awkward (means = 2.4 and 2.0, respectively). Clinicians indicated they would use the eCP apps somewhat more frequently than patients would (means = 3.6 and 3.0, respectively).

Table 6. Clinician Perceptions of the eCare Plan Apps Before and After the Usability Tests

Statement	Range	Median	Mean
Before Usability Testing			
I am comfortable using technology.	2.5–5.0	4.0	4.0
I am comfortable using eCPs.	1.0–5.0	3.0	2.9
After Usability Testing			
I would frequently use the eCP app.	2.0–5.0	3.8	3.6
The eCP app is easy to use.	2.0–5.0	4.5	4.1
The eCP app is complex.	1.0–4.0	2.0	2.4
I felt the app was cumbersome/ awkward to use.	1.0–4.0	2.0	2.4

eCP = electronic care plan

Likert scale: 1–5 with 1 [strongly disagree], 2 [disagree], 3 [neutral], 4 [agree], and 5 [strongly agree]

Table 7. Patient Perceptions of the eCare Plan Apps Before and After the Usability Tests

Statement	Range	Median	Mean
Before Usability Testing			
I am comfortable using technology.	2.0–5.0	3.5	3.5
I am comfortable using eCPs.	3.0–5.0	4.0	3.8
After Usability Testing			
I would frequently use the eCP app.	2.0–4.0	3.0	3.0
The eCP app is easy to use.	3.0–5.0	4.0	4.2
The eCP app is complex.	1.0–2.0	1.5	1.5
I felt the app was cumbersome/awkward to use.	2.0–3.0	2.0	2.0

eCP = electronic care plan

Likert scale: 1–5 with 1 [strongly disagree], 2 [disagree], 3 [neutral], 4 [agree], and 5 [strongly agree]

4.2.4 Outcomes (EQ4)

The following two subsections report outcomes by measures of implementation and intervention outcomes.

Measures of Implementation

Acceptability

Acceptability is a key attribute of the implementation process that demonstrates that it was carried out well and can be replicated, scaled, and sustained. In other words, what were clinicians' and patients' overall opinions about the acceptability of the eCP apps? Some of the key common themes related to site acceptability were system performance, perceived value (e.g., whether use of the apps is compelling given that the data also exist in the EHR but may be more time consuming to locate), clinician engagement, and patient engagement.

To increase patient acceptability, patients and patient advocates noted the importance of making the data relevant to the patients' needs. For instance, allowing the patient the ability to contribute information that can be received by the clinician was noted as important for increasing acceptability and use of the apps.

Reach and usage

Reach, which refers to how many users were successfully engaged in use of the apps, and usage, which is the extent that those users engaged with the app, are both important outcome measures. Reach is a short-term outcome of implementation effectiveness and helps evaluators assess the potential impact of scaling a model to various settings and populations. A total of 9 clinicians and 11 patients participated in the usability testing. As shown in ***Table 8***, most of the clinicians (78 percent) and patients (71 percent of those with known race) were White. More than half of the clinicians were male (56 percent), and most of the patients were female (73 percent). All the clinicians were between 41 and 50 years of age. Among the patients with ages known, most were 61 or older (67 percent). As expected, all the clinicians hold a postgraduate degree (100 percent). Less expected, all the patients whose education level was known had a postgraduate degree. One-fifth of the patients' preferred language was not English.

In terms of setting, of the 9 clinicians involved in prototype testing, 2 were nephrologists seeing patients in the clinic and in the dialysis center. Seven clinicians were general practice or gerontologists working across long-term, post-acute care, outpatient, and inpatient settings. These clinicians reported limitations on information sharing that make care coordination more challenging.

In terms of usage, all participants engaged with the apps somewhat equally by group based on the planned usability testing, which was guided by a protocol. For the purposes of this prototype testing, only very limited data on log file errors were tracked, and those issues were addressed to fully support usability testing.

Appropriateness (usability)

Clinicians requested common data sorting features, such as filtering by source, time stamp, and new changes, to quickly parse a patient's health information. Clinicians also saw value in being able to quickly flag or highlight important information for followup during an appointment.

Though technically challenging, offering patients the ability to edit or request edits to certain data classes was identified as a method of increasing patient uptake. Similarly, the ability to collect patient-reported outcome measures (PROMs), message providers, and integrate health data (e.g., home blood pressure readings) to examine change over time could benefit overall care coordination.

As with any app to be used by a broad population, design choices must be made to maximize accessibility. Complicated medical language should be presented in layperson's terms or link to relevant educational materials. Graphs with colored ranges are a clear way of contextualizing trends over time, but these ranges should be editable to reflect the situation of each individual patient. Last, building in similarities to existing technologies, such as an EHR system for clinicians or popular portals for patients, can lessen the learning curve for a new app.

Table 8. Characteristics of Clinician and Patient eCare Plan App Testers

Characteristic	Clinicians (n=9)	Patients (n=11)
Race		
Black or African American	0 (0%)	1 (9%)
Hispanic or Latino	0 (0%)	0 (0%)
Native Hawaiian or Other Pacific Islander	0 (0%)	1 (9%)
White	7 (78%)	5 (46%)
Other	2 (22%)	0 (0%)
Unknown	0 (0%)	4 (36%)
Gender		
Female	4 (44%)	8 (73%)
Male	5 (56%)	2 (18%)
Unknown	0 (0%)	1 (9%)
Age		
40 or younger	0 (0%)	1 (9%)
41–50	9 (100%)	1 (9%)
51–60	0 (0%)	0 (0%)
61 or older	0 (0%)	4 (36%)
Unknown	0 (0%)	5 (46%)
Education		
Less than high school degree	0 (0%)	0 (0%)
High school degree	0 (0%)	0 (0%)
College degree	0 (0%)	0 (0%)
Postgraduate degree	9 (100%)	4 (36%)
Unknown	0 (0%)	7 (64%)
Preferred Language		
English	0 (0%)	9 (36%)
Other	0 (0%)	2 (18%)

Adoption

Adoption refers to an organization's intent, decision, or effort to install or integrate an intervention by blending or combining the intervention with existing structures, processes, or services. In this section, the goal is to address key factors associated with the adoption of the eCare plan apps as described during final stakeholder interviews.

Successful adoption of the intervention among sites would be most successful if the intervention was perceived to add value to or build on their existing efforts in addressing care management for MCC for patients in ways that they may not have done, or known how to do, without the apps. During prototype testing, participants characterized this added value as saving time, being easy to use, and providing valuable information not easily summarized elsewhere, as one clinician noted:

> "Must have value added—saves time, saves clicks, allows you to see things that are more encompassing rather than hunting and pecking for data. If it feels like more work, it will have low adoption." —Clinician

Fidelity

Fidelity refers to the extent to which the intervention was implemented as intended. In the OHSU Issues and Resolution Documentation, which was the most commonly used tool when communicating between the RTI team and the OHSU team, 12 issues remained unresolved, with 4 of those being identified as issues unable to be resolved due to external constraints (i.e., limitations imposed by the EHR). The others appeared to be issues that had been resolved but were never documented as such. The two most common types of issues were display issues (e.g., data not appearing on screen despite being available) and protocol errors (e.g., information not passing properly despite a standards-accurate request).

These issues were despite initial crosswalk work, which identified several additional requirements in the IG that are still not included in USCDI. For example, for the data element Goals, additional requirements for the following elements in ***Table 9*** were included in the eCP IG but not yet specified in USCDI.

Table 9. Data Element Crosswalk Results, Goal Example

Data Element in IG but Not in USCDI	Supported by Native FHIR API
Goal.measure (Required) Bound to its relevant goal target value set	
Goal.expressedBy (Must Support)	X
Goal.addresses (Must Support)	X
Goal.outcomeReference (Must Support)	
Goal.extension:goal-acceptance (Must Support)	
Goal.extension:reasonRejected (Must Support)	
Goal.extension:goal-relationship (Must Support)	

API = application programming interface; FHIR = Fast Healthcare Interoperability Resources; IG = implementation guide; USCDI = U.S. Core Data for Interoperability

Additionally, the Goal.lifecycleStatus values returned by the native FHIR API of the EHR system provider are one of these strings (not coded concepts): active, complete, or canceled. The IG has a required binding to the GoalLifecycleStatus ValueSet. In the ValueSet, the code is "completed," not "complete." This mismatch results in a syntactical issue when the semantic detail is more or less the same.

Intervention Outcomes

This section summarizes app testing and utilization of the apps from patient and clinician perspectives and the performance of the apps themselves.

Utilization and experience

Utilization relies on the perceived value, satisfaction, and usability of any new technology by clinicians and patients. As noted previously, clinicians and patients reported being somewhat comfortable using the eCP apps after the demonstration. Most agreed or strongly agreed that the eCP app was easy to use, and most disagreed that the app was complex or cumbersome/awkward to use. Following the demonstration, most were neutral on whether or not they would frequently use the apps if they were available.

Performance

During the usability testing sessions, there was only one session during which the participant encountered a possible app or data exchange error. During this session, the Health Concerns tab in the patient app was blank. To assess the cause of the error, the team used Splunk to search MCC-API log file data for errors and exceptions on the date in question and for instances of the FHIR resource (Condition) that would have been populated into the Health Concerns tab. The search turned up no errors or exceptions and retrieved hundreds of Condition resources across all times during the day that the reported error occurred. This indicates that not only was the MCC-API system not breaking, but it was also finding and returning Condition resources to the apps that, in theory, would have been displayed on the Health Concerns page. This is the expected behavior. By ruling out an error in the MCC-API system, the team concluded that the error was most likely within the patient app itself. However, Splunk cannot integrate information from the patient and clinician apps directly because those run entirely within client browsers, and log file data from client browsers are unavailable to Splunk for processing. As such, to integrate client-side log file data into Splunk for future prototype testing, the team will need to establish a robust mechanism for the patient and clinician apps to report user actions and any errors that may occur within them back to the MCC-API system on the server, which can then be written to log files that Splunk can access.

5. Conclusion

Prototype testing of the eCP apps was successful in that the apps were integrated into the local environment, rolled out in production, able to exchange relevant data, and able to be used in small-scale prototype testing for overall usability. The scope of the prototype testing was somewhat limited (9 clinicians and 11 patients), but the ability to test with clinicians working with MCC patients, across care settings, and in a robust test environment added a lot of value to the overall results. Specifically, work is already underway (e.g., USCDI V 3.0 and FHIR R5) to improve interoperability in general, to bring along organizations that don't yet use FHIR (e.g., PointClickCare), better exchange with HIEs once they are FHIR ready (e.g., eHealth Exchange), better options for data reconciliation (e.g., CareEverywhere), and patient-mediated health information exchange (e.g., App store apps that can connect to any FHIR endpoint). Additionally, working with robust test patient data, then with actual patients and their data, added an important layer of validity and relevance to the work.

There was no single central barrier to integration/implementation, prototype testing, and evaluation of the eCP apps; rather, many factors reduced the scope and effectiveness of the prototype testing. Technical limitations, such as gaps in technical documentation, insufficient detail provided by a standard, varying stages of implementation and adherence to the standard in clinical settings (or execution to the standard), and other procedural technical issues (e.g., security review, pushing updates) were factors. These challenges interacted with insufficient agreed-upon infrastructure to move the relevant data, limited support for the workflows to collect the data and the additional effort required to map concepts to retain semantic value, and prevented the implementation of several features of the apps. Use of the CFIR-PR helped identify and describe the key constructs that conspired to contribute to and detract from successful implementation.

5.1 Factors

Following is a list of clear and specific factors to consider in the execution of similar work:

- Do not assume access to technology is available or equal for users.
  - For patients and clinicians, access to the apps via their local "system"—laptop, smartphone, tablet, or flip phone—may be wide ranging and can inhibit or limit usability.
- Do what you can to address barriers to adoption or access throughout all phases of the work.
  - Anticipate issues with access to the patient portal if required for testing and provide sufficient support for in-clinic interaction at a desktop or a laptop if needed.
- Do not assume that the quality of data in the EHR will be sufficient.
  - EHR data have limitations. It takes time during the early testing phases to review real patient data and look for addressable issues with data quality,

such as preferred gender not conveying or data presentation, like an individual's weight over time rather than normed weight over time, that may affect impressions of quality.

- Note that providing solutions for large EHR vendor systems leaves a lot of practices out of the equation.
  - A large academic medical center has greater access to tools and resources than a local dialysis center has.
- Remember that usability is a real challenge and is crucial to equitable access.
  - Patients living with MCC include people with disabilities and limited access to transportation, housing, and food. Providing a solution that requires specific abilities; access to technology, electricity, and internet service; and the skills to connect to a patient portal is self-selecting the group of users who might be able to use the system.
- Provide solutions that will directly affect problems users have (e.g., provide a single view of information that is otherwise in disparate sources).
  - When clinicians spend at least 16 minutes using the EHR for each patient visit,[28] bringing relevant information into a single view, or an organized app can provide important context and efficiency.
- For patients living with MCC, ensure that you have caregivers in your user community.
  - A significant proportion of patients living with MCC receive a significant amount of support and care from a caregiver, yet this role is not well supported in the context of information access or sharing for care coordination.
- Remember that errors in omission often have a detrimental impact on trust.
- Note that writing data back to the EHR is possible, but it is not easy, and one of the biggest barriers is where to store the data and how to make them actionable.

5.2 Limitations

Working with the OHSU team was synergistic, and although OHSU represents a wide variety of clinicians and serves patients with diverse backgrounds, the environment in the OHSU system was limited to a single EHR and a single health IT policy and resource base. As such, it would be expected that a different health system would offer different challenges and opportunities than those experienced with this project.

Each EHR system comes with a set of digital tools for development, management of the system, integration options, and sharing data. Even with clear specifications, differences in FHIR API behavior and in specification information on the vendor system side are expected. Additionally, there are often cultural differences at the vendor system level or the health system level, regarding support of USCDI requirements and interpretation of the standards.

Less-well-established FHIR functionality, such as writing data back to the EHR, is also managed differently by vendor systems and health systems. Part of the reason for this is

the clarity of the specification (or lack thereof) for implementation, though USCDI has helped push this forward. Even where this functionality is available, other considerations often come into play when determining how and where to write data back. Navigating this is complex within healthcare organizations and is influenced by the legal, security, clinical, and customer environment. With so much emphasis on PROMs, this issue is likely to change significantly in the years ahead. Ultimately, FHIR brings a lot of promise to interoperability while true plug and play still seems a long way off.

The creation and maintenance of novel EHR solutions requires a specific skill set. Although most healthcare institutions likely have at least components of the skills needed to implement a given solution, they often lack resources to create and maintain all desirable solutions. As a result, institutions must prioritize which solutions can reasonably be maintained and often do so based on potential to reuse and effort to sustain the solution.

5.3 Key Lessons Learned (EQ5)

Important lessons learned from this work are outlined for each phase of the work.

5.3.1 Design

Although working with users from the outset is an optimal approach to the development of patient- and clinician-facing apps like these, often the first iteration does not involve a truly UCD process. Although prior to this project the clinician-facing app design was informed by wireframe testing with clinicians, the late addition of the patient app and ensuing time constraints limited UCD processes in development of the patient app. Furthermore, this project evolved at a time when the FHIR standard was gaining traction, and early iterations of the design were based on use of the less flexible C-CDA (Consolidated-Clinical Document Architecture) standards. As the work evolved toward FHIR, some of the focus landed on the FHIR resource list. This fueled drivers and constraints for development. Stakeholders from the broader standards community (e.g., HL7) come from industry and academic circles, and FHIR resources develop along the lines that allow for different use cases in different workflows. Along the way, changes are proposed, discussed, and eventually balloted by member organizations in work groups where the typical end user is not often well represented where a determination is made about whether a change will be implemented.

More ideally, long-term UCD work involves taking the fundamental goals of a program and moving through a series of user interviews or brainstorming sessions to transform those goals into a set of requirements for app development that calls on specific FHIR resources. When users are engaged early and often, the end product is more well accepted and perceived to be more useful. Employing UCD best practices more consistently in the design process and placing more weight on user design requests would have facilitated development driven by patient care and needs, instead of the design process being driven to such a degree by the available health data standards.

Outcomes, especially patient-centered outcomes, should drive development as well. If evidence suggests that outcomes can be improved with certain features, it is imperative to translate them into practice. This should apply not only to well-defined health outcomes, but also to health outcomes that reflect patient perception, including patient-reported outcomes, patient experience, and goals.

Building and implementing tools that are designed to improve patient care must demonstrate impact to incentivize their use. In some cases, the incentives are clearer, such as in the pharmaceutical industry, but digital tools—tools focused on the availability and flow of information—often must be marketed to healthcare organizations without the benefit of such clear incentives. This can lead to a chicken-or-egg situation in which the design of effective digital tools does not occur because of poor support from healthcare organizations, and support and interoperability does not improve because of relative lack of proof of the effectiveness of such tools.

5.3.2 Development

As new standards evolve, early versions of the specification—in this case an IG—are designed in a sandbox environment that does not reflect the reality of real-world data. Because IGs are an integral part of the development of interoperability standards wherein they define and standardize the flow of data, it is common practice for the development of FHIR IGs to occur in and often stay limited to a sandbox, or simulated, environment. This prototype testing provided an opportunity to test the eCare plan FHIR IG in a real-world environment to improve future versions of the IG.

Data flow in real-world environments presents challenges that cannot easily be replicated in a sandbox, such as data mismatch or availability issues, or policy and governance issues. During the prototype testing, this team demonstrated interoperability gaps in which the apps were unable to access (for some data elements) and pass data back into the OHSU Epic environment (for all data elements), despite the FHIR IG specifications for data flow. One of the challenges was occasional mismatch between the IG-defined standard terminology for the data elements in the apps and terminology used in the Epic implementation. A data element crosswalk was used to fully understand and, in some cases, resolve these discrepancies. Additionally, in a real-world setting, EHRs do not currently allow for apps to easily write data into the patient record as discrete data elements. These discoveries from real-world deployment have generated feedback on the MCC FHIR IG that goes far beyond Connectathon testing.

Using a containerization approach to deployment was reasonable, but it is possible that a modern cloud-based solution would be more favorable and represent a more persistent interoperable solution. Because the containerization process allows for the packaging of an app to be deployed within a network, usually on a virtual machine, the entire process must be contained within an organization’s firewall. The packaging allows for the solution to be

updated cleanly as a package that prevents issues with missing or corrupted libraries. One downside is that changes or updates must be performed by the customer, who is often not that familiar with what is inside the container and what impact it might have on the practice environment. Cloud-based solutions would allow for a more instant update to all clients from the source developer as soon as the browser refreshes. Such a model would leave the solution much less prone to bugs or problems introduced through an update. However, cloud-based solutions do require data to be sent over the internet for processing, which can be problematic from a security and risk standpoint, may be susceptible to network outages, and are possibly more vulnerable to security breaches as the attack surface has expanded.

Including clinicians in the design and development phases is crucial. There is no substitute for having someone with clinical expertise who also has the ability to speak technically in the earlier development and design phases of the work. This early involvement could substantially reduce the amount of work and time required to implement the solution and be more successful overall with adoption.

5.3.3 Implementation

In the early stages of EHR integration, there can be a long period of trial and error to navigate the expected behavior of the FHIR API versus the actual behavior. Implementation of a FHIR switchboard that provided control back to the implementation site made even limited test environment prototype testing possible.

Reaching a shared understanding of a goal of the work and a vision for its execution requires the development of good examples that resonate with the team. For this work, iterating on a robust persona with supporting detailed scenarios resulted in strong testing details for a viable test patient. Once the vision for these was established, it was relatively easy for the team to develop test patient profiles that optimized the data being presented in the apps. Robust testing in the test environment to optimize the test patient profiles and effectively push data to as many data elements as possible was a helpful initial step. This was followed up with testing in the production environment of patient information with varying levels of complexity. Clinicians could spot, and often address, key issues with real-world data that were not easily observable with test data. In retrospect, only 9 clinicians tested, and from that, 42 separate topics from 235 qualitative responses were identified, which speaks to the usefulness of the persona.

5.3.4 Evaluation

Defining the goals and the shape of the evaluation at the outset is crucial, and establishing methods and measures for tracking each component is the key to a successful evaluation. Consistency with task leadership from the start of the project is important for the development and implementation of the evaluation plan. Incorporating data capture in the design phases is an essential path toward collecting the relevant data. Defining early what

data must be captured, how they will be captured, plans to analyze and report out, and incorporating tests of this data collection into the overall testing plan will help ensure that the relevant data are available for analysis.

Evaluation plans must also flex and adapt to changing circumstances; delivery of the app for prototype testing may directly affect the actual scope of the prototype testing, which has a direct effect on the evaluation. While this prototype testing was not able to optimize quantitative data collection on use of the apps, future work will benefit the most from mixed-methods approaches for these complex interventions, partly because so much of the work is still people and process oriented and also because these tools quickly become distributed resources creating their own "data footprints."

5.3.5 Maintenance and Sustainability

To extend app functionality beyond the native FHIR API, a piece of FHIR middleware was developed. This middleware served this instance of implementation, and the apps and the middleware are interdependent for either to be successfully used. This middleware component can be resource-intensive to build, requiring time from IT and interoperability specialists. These specialists can be hard to identify and may have much competition for their time, but when the work is accomplished, the FHIR middleware can be adapted to serve other projects, increasing utility and potential sustainability beyond a single project period. This process is also a way to establish or extend capacity for development of this type in a health system.

As a standalone resource, this solution is not generally sustainable and scalable for the health system or the eCP apps beyond this implementation, yet it is still fundamentally important to provide the full functionality required for the apps. Despite these limitations, this workaround supported progress on many fronts, including testing and refining the data exchange standards and studying the crucial components of a digital care coordination solution through focused user-centered data gathering.

Another challenge to ongoing maintenance and sustainability is the fact that there is a necessary but often complex separation between research development teams and production EHR development teams. This "firewall" can really increase the friction to iterate; to co-develop; and to rapidly launch, update, or fix apps that require real-world testing to optimize. Successful demonstration projects help reduce this friction and create a more collaborative, supportive environment to reach the goals of UCD.

Feedback from stakeholders at every stage of the project was resoundingly clear. Patients and their clinicians want better support to elicit and capture PROMs, especially goals. Ideally, they would like to be able to track and update those goals over time; to discuss, modify, and set targets for those goals; and to see how those goals impact outcomes—especially outcomes the patient is hoping to achieve. The vision for the eCP sets out to do

just this, and prototype testing of this first iteration suggests that the team is on the right trajectory.

5.4 Recommendations for Future Development

Coordination during any future phases of this work will benefit from the lessons learned here. Important areas of coordination to ensure success include these:

- Increasing accountability and collaboration between the implementation and evaluation teams.
  - Assembling the right team can be challenging with these implementations; it requires identifying people with the right technical skills for development, those with informatics and implementation expertise, and a variety of vendor system analysts. The next, more crucial step is bringing these teams together, developing a shared vision of the solution, and then creating the tasks and timeline to march toward implementation. Reassessing the vision for the solution, progress toward goals, and needed adjustments requires expertise and experience from development through evaluation.
- Generating a preliminary evaluation framework before the design work is completed to allow for a partially test-driven development environment.
  - With these complex standards-based implementations, there are so many potential surprises between what the specification states, what the documentation suggests, and what the real-world data exchange will actually support. For example, the documentation provided for medication status did not indicate that only active medications would be supplied by the API unless other statuses were explicitly requested. This mismatch also often occurs when the specification is vague or only describes what an API **should or may support**, rather than the actual expected behavior (e.g., **shall support**).
- Meeting frequently with the design team as the work progresses to allow several iterations of the components of the apps.
  - Early during Phase 2 prototype testing involving real patient data, it was found that users could not connect to the app. Rapid, iterative design work discovered and implemented the solution: user-specific invitations that activated the correct security privileges.
- Establishing a mechanism for the apps to report user actions and any errors that may occur back to the MCC-API system on the server (or similar), which can then be written to log files that can be accessed and analyzed using Splunk.
  - While this is a general principle that most implementations would ideally follow, when working with multiple emerging tools—in this case FHIR and the USCDI requirements—it is imperative. Broad sociotechnical frameworks help track the myriad factors that affect these projects and planning early (e.g., application components needed to capture app usage data), helps guarantee the ability to conduct a robust evaluation, which in turn helps address issues of sustainability.
- Using an agile process to incorporate easy-to-implement user interface/user experience modifications that can significantly contribute to better usability.

  - Developing more modular solutions that allow for iterative design changes will be pivotal to improving adoption and use, and crucial for sustainability of these solutions. As with any new tool, these solutions have developed with focus on the limits and capabilities afforded by the standards and the back-end approach to realize the goals of the apps. Front-end focus then becomes limited by decisions made on the back end. Deconstructing this and focusing on achieving a more modular approach would support iteration, especially to address user interface and user experience issues, throughout the testing process.

- Designing with real-world data and actual technical readiness in mind. Assessing site technical readiness for interoperability in each technical environment is essential to successful implementation.
  - For example, the EHR systems used at an LTPAC site may be able to share read-only data with an external app through SMART on FHIR and may not yet have the FHIR API capabilities to allow patient-reported data to be written into their system.
- Accounting for IT governance, which includes the security review and approval process, as well as management of the release environment for both testing and production within the health system.
  - Other groups that might be engaged in the governance process might include an Informatics Governance Group, a Research Data Governance Group, and/or a Committee on the Use of Health Information. Working directly with patients often requires additional levels of review and approval.
- Using containerized solutions facilitates local installations, yet without complete documentation can obscure the functions of the system. It is important that the IG contain good documentation on initial setup of the system and environment. There remains a need to facilitate FHIR requests and responses (typically through localized middleware).
  - While containerized solutions help approximate a continuous release environment in which updates to the system are easily made and propagated, a cloud-based environment for app delivery would be a more ideal approach. This would require support at the local level for additional security review. Exchange of information between source systems and the apps would use communication encryption and security approaches approved and implemented by each participating site.
- Managing user authentication using existing approaches (e.g., OAUTH2) requires sites to grant access and handle authentication.
  - In the case of an external data store approach, additional consent to allow sharing of these data would be required and would need to be handled or managed potentially electronically.
- Using recommended CDS Hooks tools to more effectively integrate the app into local workflows.
  - Although CDS Hooks services may be available in most EHR systems, site experience with and use of these services can vary. Use of CDS Hooks might require some additional design considerations, which should be addressed early in the design phases of the project.

- Planning robust testing is crucial to optimizing feasibility and usability. This includes thinking through each testing environment from the sandbox development environment to the health system production environment.
  - To optimize opportunities to identify and address bugs (and related fixes) during sandbox or prototype testing, leveraging a reporting system (e.g., REDCap for reporting + Jira for ticket creation) that is shared by the entire project team can keep things on track.
- Providing robust testing data in the IG helps optimize ability to test all components of the solution.
  - For MCC, this might mean creating user profiles for testing that explore multiple relevant use cases and cover a wide range of data elements.
- Interoperability beyond a single health system is still challenging; in order to optimize the potential to incorporate data from other systems, it is crucial to explore the policy and technical challenges to doing so in advance of implementation.
  - Some vendor systems provide internal health information exchange (HIE) capabilities (e.g., CareEverywhere for Epic systems). These may require an additional reconciliation (or adjudication) step on the part of clinical users. HIEs are also working on FHIR readiness of the data they convey. Individual sites, especially specialty sites, are also working on providing FHIR API endpoints. Both TEFCA (Trusted Exchange Framework and Common Agreement) and USCDI are drivers of this adoption.

5.4.1 Goals in Care Coordination

This work highlighted some key issues around capturing and exchanging goal information. While the capture of goals for care coordination is a concept that has been central in the care coordination conversation for some time, and several initiatives are tackling it from different perspectives, more work still needs to be done. Capturing high-quality patient-centered goals (1) requires clinical workflows that support goals that are specific and measurable and (2) involves patient–clinician agreement. Additionally, the electronic capture of patient-centered goals requires data standards that support the characteristics of high-quality goals and interoperability tools that facilitate the exchange of those goals. As a part of the MCC IG, the MCC FHIR Goal resource builds on the U.S. Core Goal resource to capture features of high-quality goals, including measurable targets, milestone goals, and goal achievement status. However, interpretation and support of the goal resource based on USCDI has been mixed.

5.4.2 Interoperability

The goals of interoperability continue to face policy and logistical roadblocks. Even interoperability among and within health systems remains incompletely developed. To enable advanced interoperability at this time, middleware is needed to serve as a bridge between systems. Implementers should be aware of the likely roadblocks to be encountered when using middleware to support greater interoperability.

Glossary

Following is a list of key terms and their definitions applicable to this report. Some terms include references to online resources with more information. Links to these online resources can be found in the References section.

application (app): a program or group of programs designed for end users; typically, software that a user downloads, installs, and manages

caregiver: individuals who provide help to another person in need; some are family members, and others are paid[29]

clinical decision support (CDS): provides clinicians, staff, patients, and other individuals with knowledge and person-specific information, intelligently filtered or presented at appropriate times, to enhance health and healthcare[30]

code: as part of the C4 model[31] for visualizing software architecture, items that comprise a component

component: as part of the C4 model[31] for visualizing software architecture, elements of an individual container in the given project scope

container: as part of the C4 model[31] for visualizing software architecture, high-level building blocks of the software system in the given project scope

context: as part of the C4 model[31] for visualizing software architecture, a software system in the given project scope

eCare plan: IT-enabled tools that support seamless care coordination, communication, and collaboration among members of the care team (patients, caregivers, and clinicians) to address the full spectrum of a patient's needs across all settings and over time[12]

Epic™: electronic health record developer and system

Epic Hyperspace: an application client that is presented to users of most areas of Epic

Fast Healthcare Interoperability Resources (FHIR): a standard for exchanging healthcare information electronically[32]

Fast Healthcare Interoperability Resources (FHIR) façade: an architectural pattern for implementing FHIR capabilities in a standards-compliant way, in the absence of that support from existing or installed electronic health record systems; can also be described as a switchboard, wrapper, or similar, intended to supply the necessary FHIR responses to support a FHIR application; works with site-specific adapters to achieve this

Glossary (continued)

feature: a set of related requirements that allow the user to satisfy a business objective or need

function: specification of behavior between outputs and inputs

Health Level Seven International (HL7): a nonprofit, ANSI-accredited standards-developing organization founded in 1987, dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery, and evaluation of health services[33]

middleware: software that exists to enable effective communication between two other pieces of software

MyChart: Epic-specific electronic health record patient portal

patient population testing: a method of testing a software system using a synthetic set of patient population data to verify that the system behaves as expected

patient-reported outcome measure (PROM): a tool used to measure patient-reported health status and quality of life[34]

prototype testing period: the time during which the applications are available within live clinic workflows and data are collected to track applications' use

requirement: a condition or capability needed by a user to solve a problem or achieve an objective

sandbox: a test environment that isolates untested code changes and outright experimentation from the production environment or repository in the context of software development, including web development and revision control

service: centrally managed software that provides some logic or functionality to end users, which a user accesses (via application programming interface, website, etc.)

shareability: the extent to which anything might be made ready for sharing. For this document, application artifacts and supporting materials such as implementation guides and lessons learned are made available to other organizations interested in implementing the applications in different settings. This can be accomplished by posting to a repository that explicitly allows and/or supports sharing.

shared decision making (SDM): a model of patient-centered care that enables and encourages people to play a role in the medical decisions that affect their health

Glossary (continued)

[software] system: a series of components working together to deliver services

Splunk: commercial software that facilitates the capture, monitoring, and analysis of server-side log file data by monitoring target log files for changes and processing those changes when they occur

stewardship: the job of supervising or taking care of something, such as an organization or property

Substitutable Medical Applications, Reusable Technologies (SMART): an open, standards-based[35] technology platform that enables innovators to create apps that seamlessly and securely run across the healthcare system; originally developed in 2010 and now an HL7 standard

tip sheet: a document providing guidance for an end user to interact with a software system

United States Core Data for Interoperability (USCDI): a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange[36]

U.S. Core Implementation Guide: based on FHIR version R4[21] and defines the minimum conformance requirements for accessing patient data[37]

U.S. Med Implementation Guide: based on the FHIR version 4.0.1[21] specification and promotes consistent implementation of the pharmacy FHIR resources in U.S. Realm Electronic Health Record Systems to provide patient and clinician access to patient medications[38]

user experience (UX): how a user interacts with and experiences a specific page on a website or screen within an application

user interface (UI): the software designed to allow a user to interact with an application; also the point of human–computer interaction and communication in a device

version: a unique state of computer software

wireframe: layout of a web page that demonstrates what interface elements will exist on key pages

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Appendix A: Protocols

A.1 Semistructured Post Prototype Testing Interview Questions by Key Stakeholder

A.1.1 Healthcare Staff Guided Interview Questions

1. Can you confirm your role and title?
2. What do you think about the provider-facing and the patient-facing e-care plan apps?
3. How useful was the training provided for the provider-facing e-care plan app?
4. How might the provider-facing e-care app fit into your daily workflow if it was available? At what point in the visit (e.g., before the visit, after the visit)?
5. How might using the apps influence your communication and coordination with patients? With other providers?
6. What are the barriers and facilitators to implementing/using the e-care plan apps? Are these barriers/facilitators the same for patients and providers?
7. Do you think the information in the provider-facing e-care plan app (drawn from the EHR) is accurate?
8. What, if any, information is missing from the provider-facing e-care plan app to make it useful for care coordination and shared decision-making?
9. Are there any burdens for you and/or your staff associated with the provider-facing e-care plan app that should be addressed?
10. How do the e-care plan apps influence your ability to collect and share patient data across healthcare settings?
11. How do the e-care plan apps support improved coordination of members of the patient's healthcare team?
12. Are there any other factors to consider around implementation and use of the e-care plan apps that we have not discussed?
13. If you were to give advice to another organization implementing the e-care plan apps, what would you tell them?
14. Is there anything else you would like to share about your experiences implementing and using the e-care plan apps?
15. What impact do you believe an app like this could have on patient outcomes?
16. What are your thoughts on the feasibility and value of the following potential additions:
    a. Consolidated list of all future appointments
    b. In-app direct messaging (either patient to provider or provider to provider)
    c. Patient goal capturing and tracking
    d. Medication schedule

e. Ability to add or modify personal information

f. Links to educational materials (e.g., videos on care coordination or acronym explanations for lab work)

A.1.2 Health IT Guided Interview Questions

1. Can you confirm your role and title?
2. Can you confirm your role in the implementation of both the provider-facing and the patient-facing e-care plan app?
3. Overall, how was the process of implementing and accessing the e-care plan apps?
4. What were the organizational barriers and facilitators you encountered when integrating the e-care plan apps into the health information technology (IT) system?
5. Are there any technical barriers (i.e., how the apps interact with the clinic's EHR) that hinder or prevent use of the e-care plan app?
6. Were there any issues with the data that were collected or the transmission of data through the e-care plan apps?
7. Did you use the implementation guides when implementing either the provider-facing or the patient-facing e-care plan apps?
8. If used, how useful were the implementation guides when implementing the e-care plan apps?
9. How did you navigate security concerns when implementing the e-care plan apps?
10. Is there anything else you would like to share about your experiences implementing the apps?
11. If you were to give advice to another organization implementing the e-care plan apps what would you tell them?
12. Is there anything else you'd like to share about the implementation guides or the e-care plan apps?
13. What has been your experience with the performance of the e-care plan apps in the EHR?
14. How sustainable would you consider the implementation of the e-care plan apps? What are the barriers to sustainability?

A.1.3 Patient Guided Interview Questions

1. What types of healthcare providers provide you with care?
2. Can you describe how you would use the patient-facing e-care plan app if it were available?
3. Did you find the patient-facing app easy to understand? Any suggestions for changes and/or improvement?
4. What barriers would you foresee if you were using the patient-facing app?
5. Would you suggest that other patients use it if it were available?

6. What advice would you give to another patient using the patient-facing e-care plan app?
7. Is there anything else you would like to share about your experiences using the patient-facing e-care plan app?
8. How do you think an app like this could affect your health?
9. How do you think an app like this would impact communication with your provider(s)?
    a. Consolidated list of all future appointments
    b. In-app direct messaging (either patient : provider or provider : provider)
    c. Patient goal capturing and tracking
    d. Medication schedule
    e. Ability to add or modify personal information
    f. Links to educational materials (e.g., videos on care coordination or acronym explanations for lab work)

Appendix B: Training Materials

B.1 eCare Plan Tip Sheet for Providers

eCare Plan Tip Sheet for Providers

This application is used for many care facilities to share Care plans

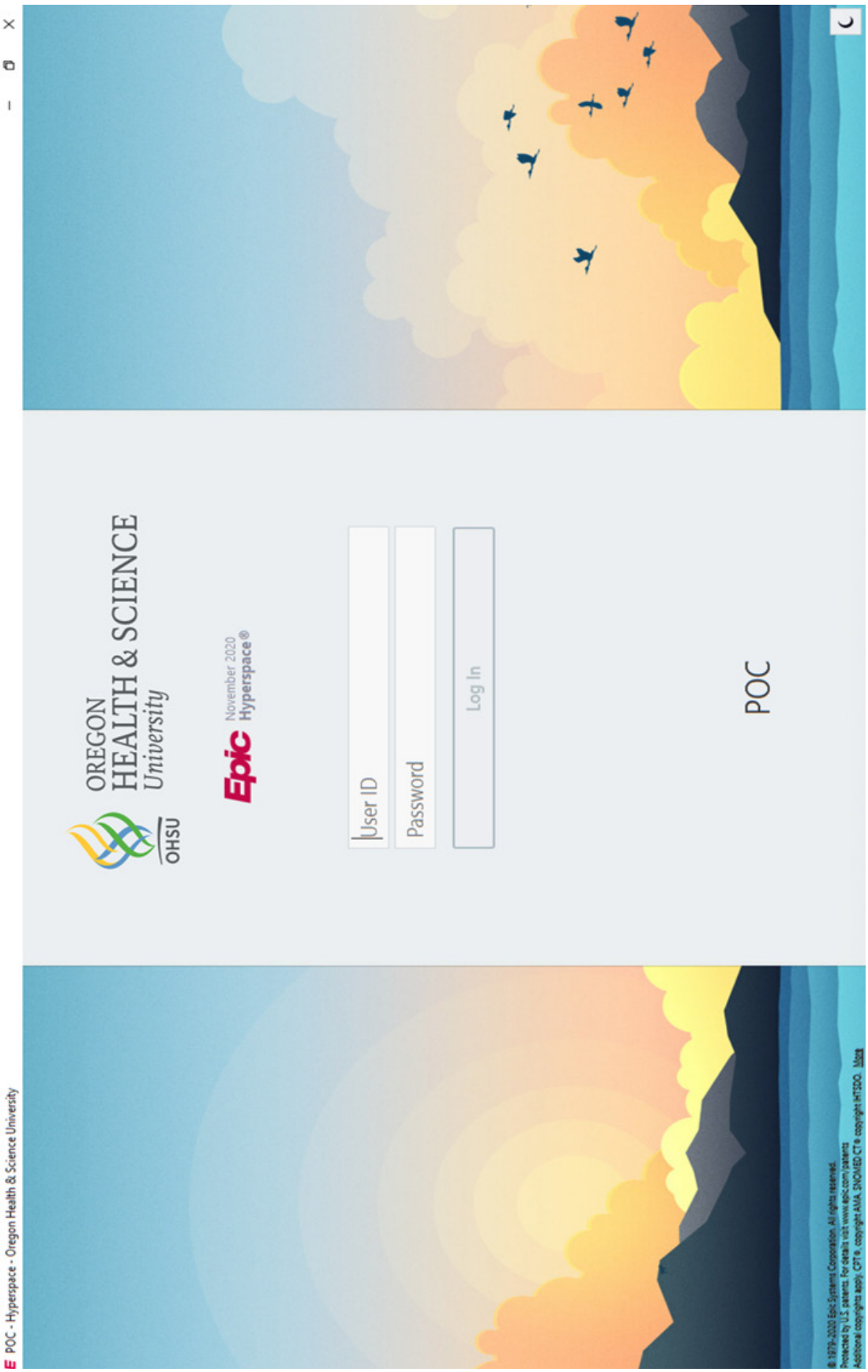
Goal:

Our goal for the electronic care (eCare) plan application (app) is to improve care coordination for people with multiple chronic conditions (MCC). The eCare plan app will serve an important role in allowing clinicians to view relevant information electronically and enable individuals to access their personal health information directly so that both clinical and nonclinical needs are addressed through shared-decision making.

The Ask: We are asking for clinicians to assess the e-care plan app's usefulness for patients with chronic kidney disease and at least one other chronic condition, and provide feedback on whether the app facilitates standardized data collection and data sharing across clinical and community settings and systems.

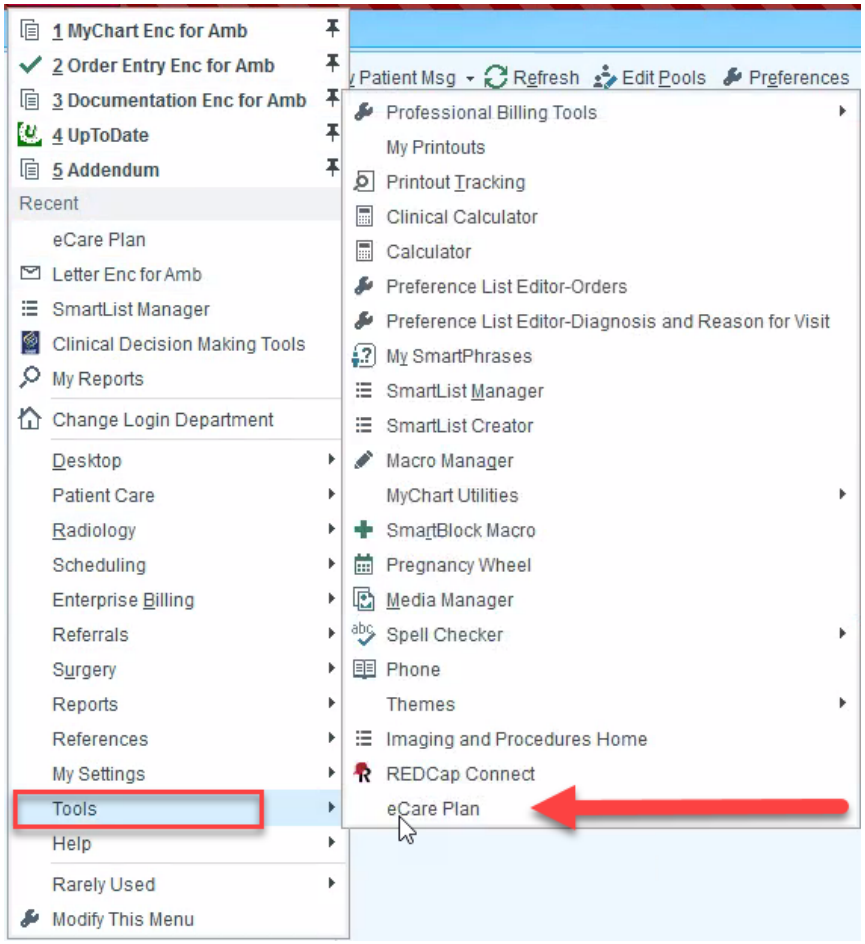
Step 1:

Log into **Epic POC**


POC - Hyperspace - Oregon Health & Science University
OREGON
HEALTH & SCIENCE
University
OHSU
Epic
November 2020
Hyperspace®
User ID
Password
Log In
POC

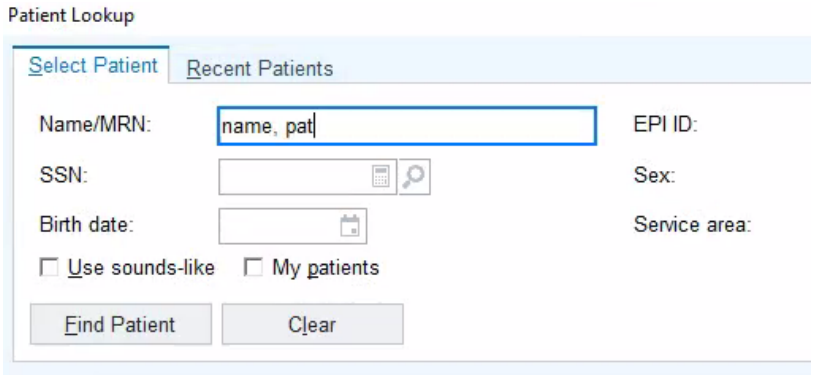
How to access the eCare Plan

From the Epic Drop Down arrow, select tools and then select eCare Plan



Then you will select the patient from the patient look up window.

Enter: Patricia Noelle



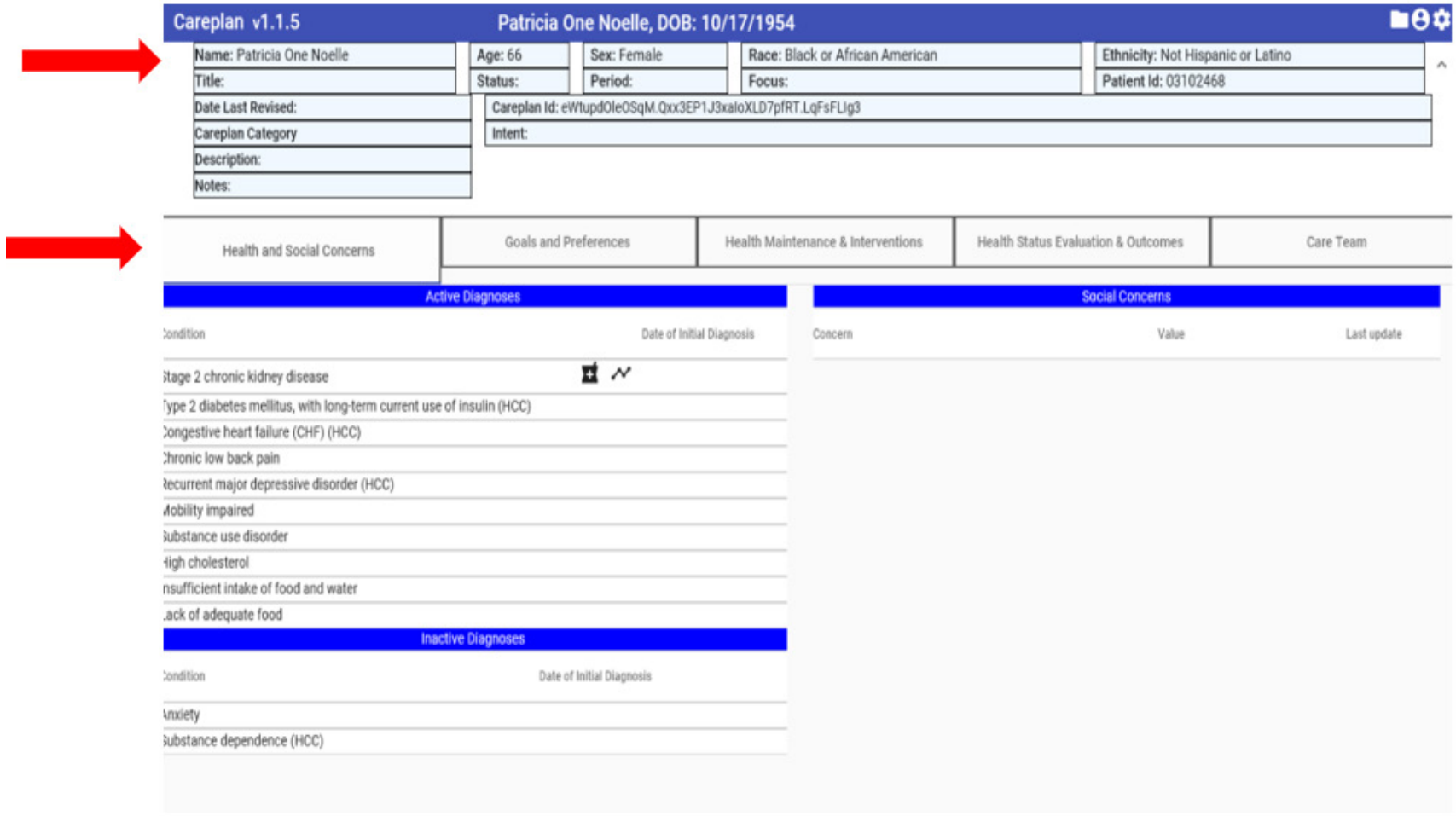
The application will then launch into a separate browser for use.

Background on Patient: Patricia Noelle is a retired schoolteacher. Her husband passed away a few years ago, and she currently lives with her daughter, Rose. Patricia has had multiple chronic conditions for the past 10 years. She feels nervous and overwhelmed managing her MCCs. This also impacts her depression. Patricia relies on Rose to drive her to the doctor and thereby can only schedule appointments when Rose is not working. Patricia has trouble walking more than half block because of her back pain and heart failure. Patricia recently received a smart phone from her daughter. She is nervous about using technology. So far, she uses it mainly to text with her daughter and peruse Pinterest for recipes

Scenario 1: Patricia Noelle's scheduled visit with her Primary Care Provider, Dr. John Carlson. Patricia is concerned about her weight, which is up 5 pounds, and her increased shortness of breath that comes on with minimal activity. Reviewing her diet and activity goals, she notes the pandemic has worsened her anxiety and caused her to eat more comfort food.

Navigating the eCare Plan App

The application will launch to the screen below, displaying a panel with patient information at the top. Below the patient banner are several tabs that will display different patient information. Upon launching the app, the Health and Social Concerns tab will be selected.

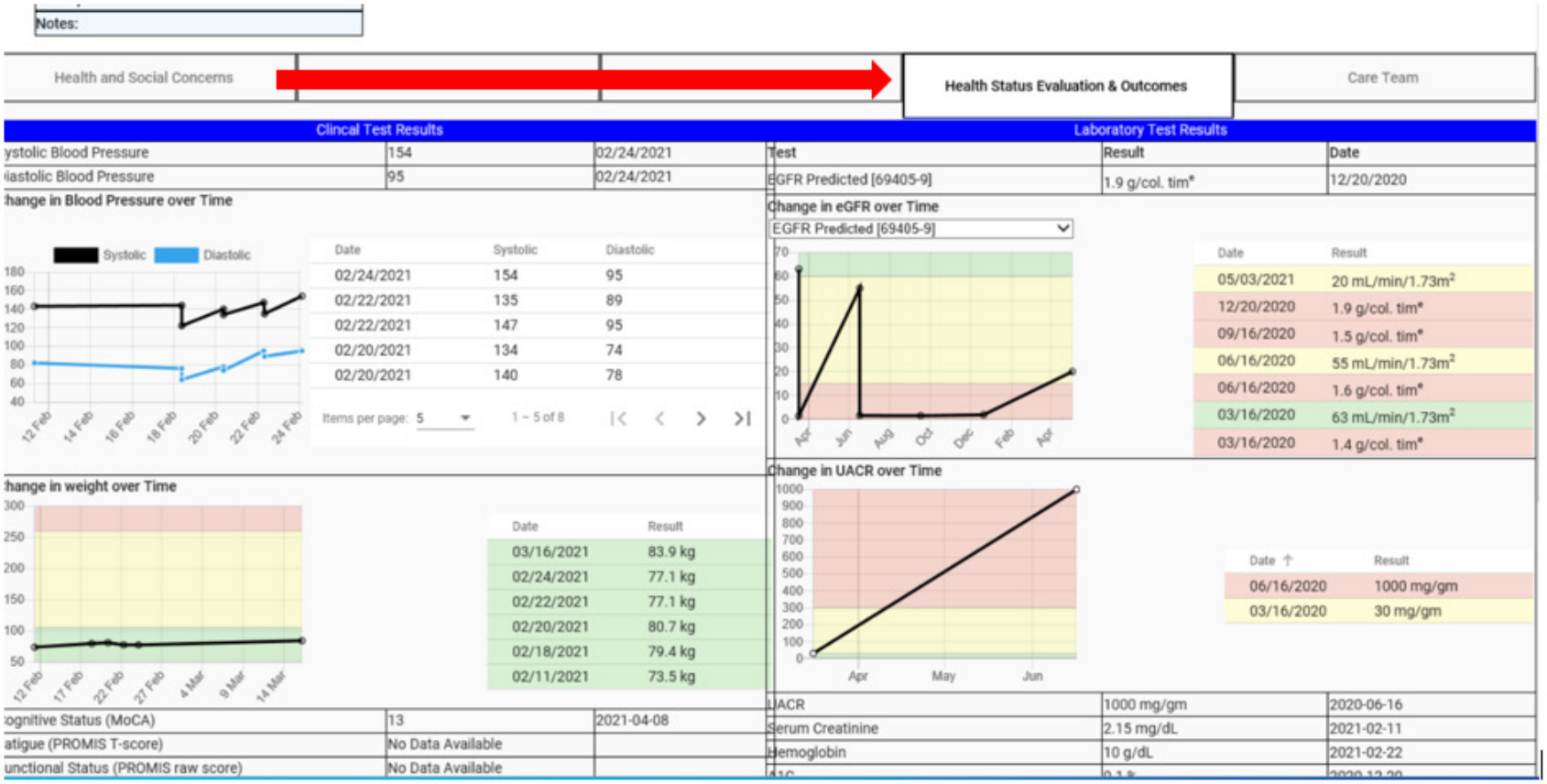


Health and Social Concerns tab displays:

- Active Diagnoses
- Inactive Diagnoses
- Social Concerns

Choose to display different tabs by clicking on the headers.

1. Navigate to the Health Status & Outcomes Tab
    a. On this page review the lab values, the vital values, and trends available with the patient



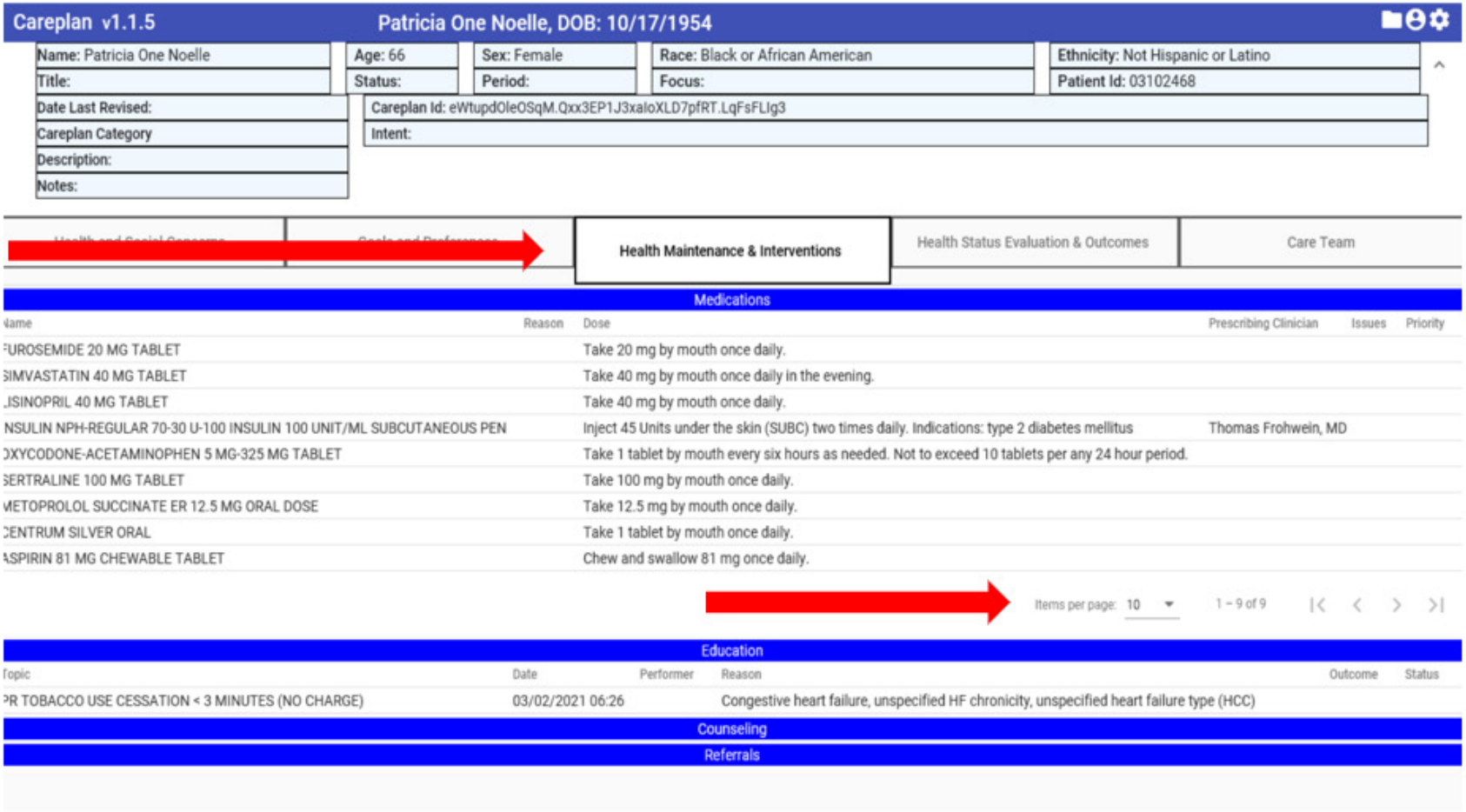
Health Status Evaluation & Outcomes tab displays:

- Clinical Test Results
- Laboratory Test Results
- Change in BP over time
- Change in weight over time
- Change in eGFR over time

- Change in UACR over time

Pause to review and answer questions

2. Select the Health Maintenance & Interventions tab
    a. On this page review medications and update as needed.

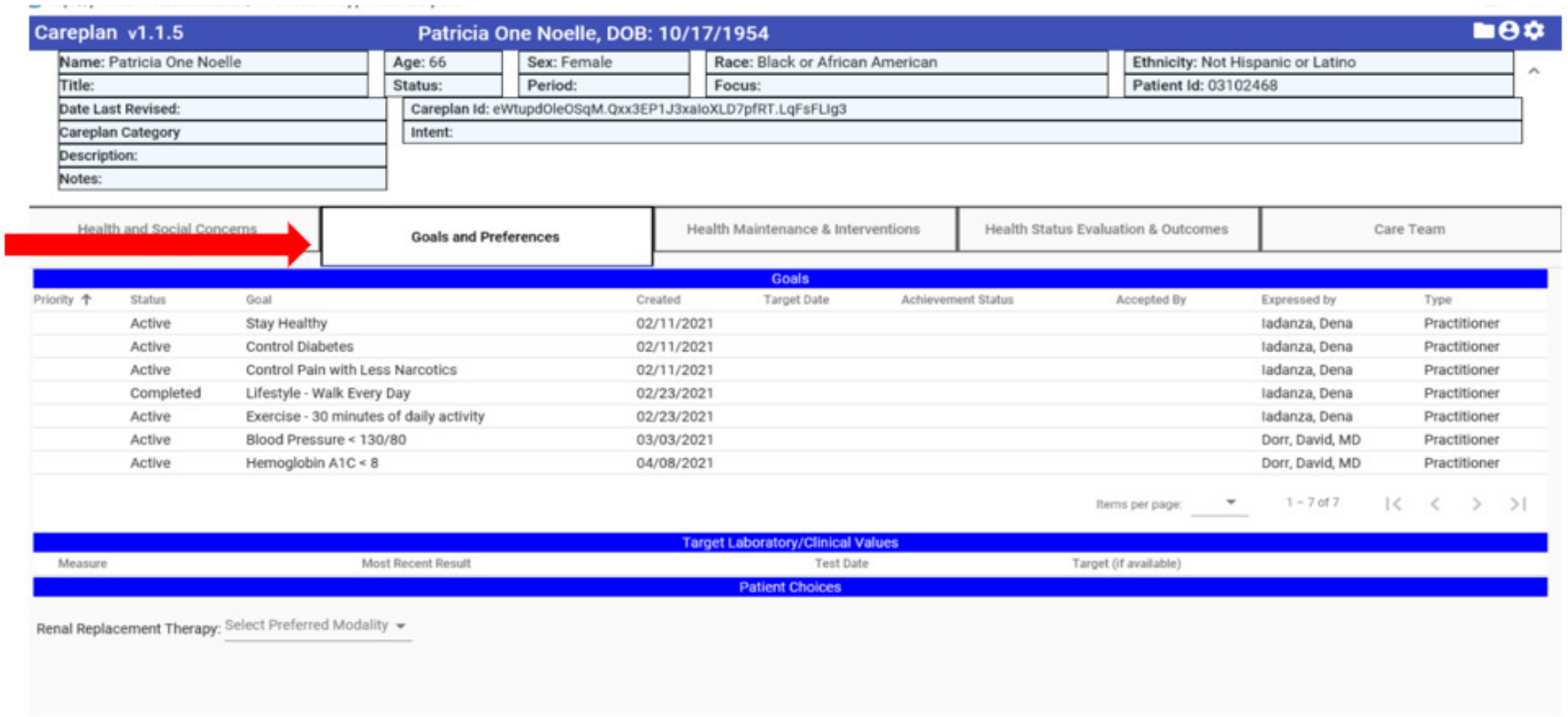


Health Maintenance & Interventions tab displays:

- Medications
  - Not all medications will automatically display. Select items per page, or click the arrows for complete list of medications
- Education
- Counseling
- Referrals

Pause to review and answer questions

3. From any screen select the Goals and Preferences tab.
   a. Review and discuss goals. Update as needed.

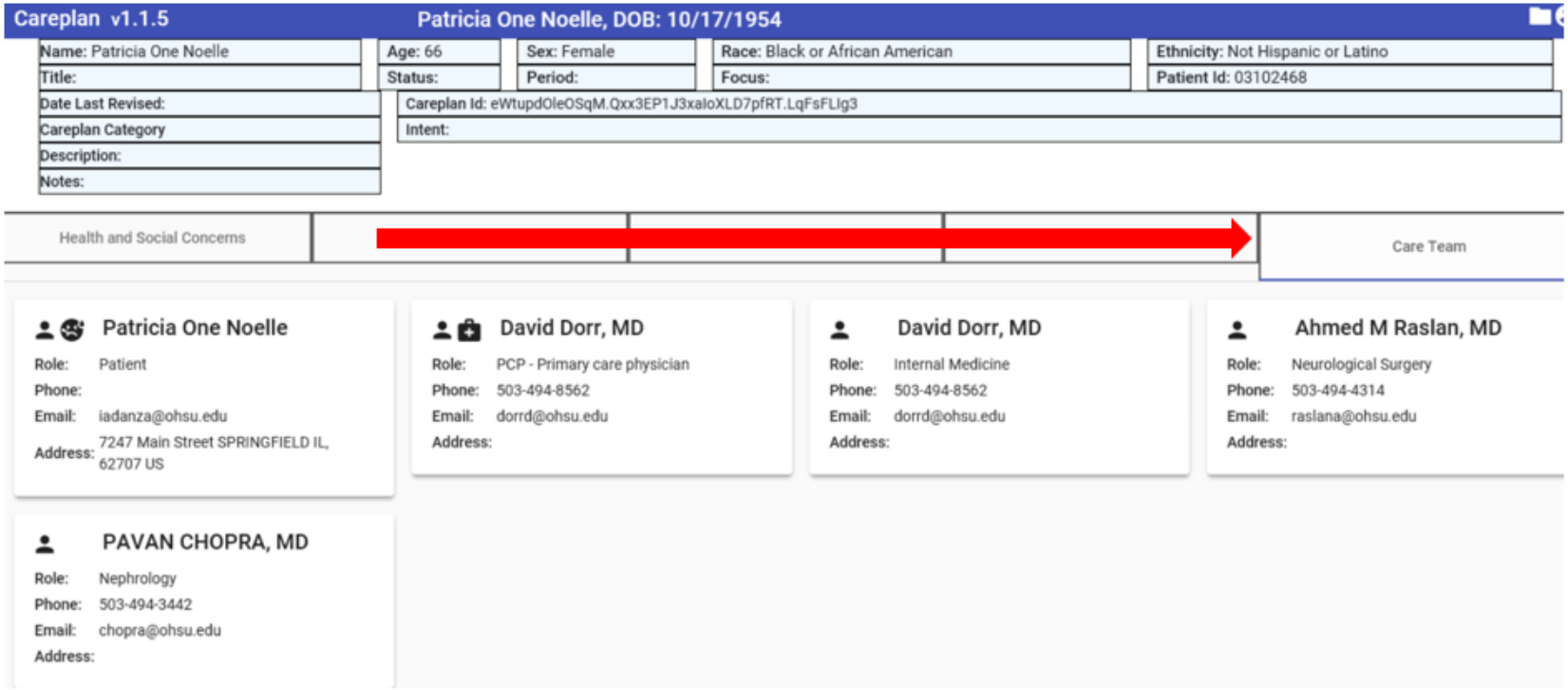


Goals and Preferences tab displays:

- Goals (set by provider)
- Target Labs/Clinical Values
- Patient Choices (patient goals)

Pause to review and answer questions

4. From any screen select the Care Team tab.
    a. Review care team (look for dietician and/or counselor)



Care Team tab displays:

- Provider information

Pause to review and answer questions

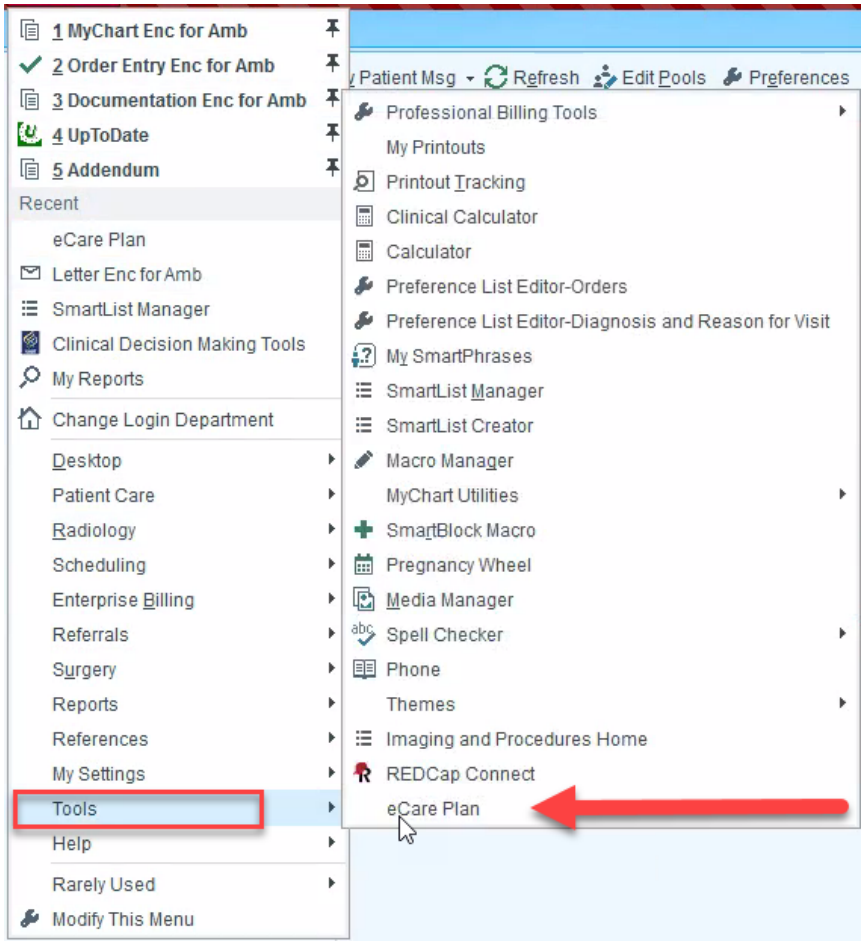
Step 2:

Log out of Epic POC and loin into Epic PROD


Production - Hyperspace - Oregon Health & Science University
Epic
HYPERSPACE® November 2020
User ID:
Password:
Log In
Exit
© 1999-2020 Epic Systems Corporation. All rights reserved.
Protected by U.S. patents. For details visit www.epic.com/patents
Additional copyrights apply. CPT®. copyright AMA. SNOMED CT® copyright IHTSDO. More

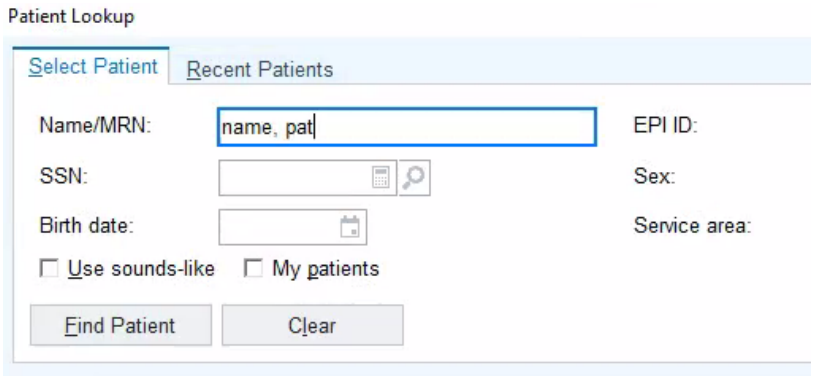
Access the eCare Plan

From the Epic Drop Down arrow, select tools and then select eCare Plan



Then you will select the patient from the patient look up window.

Select a patient you think will be appropriate – someone with multiple chronic conditions, perhaps with Chronic Kidney Disease



The application will then launch into a separate browser for use.

<<<< Second set of questions here>>>>

B.2 eCare Plan Tip Sheet for Patients

eCare Plan Tip Sheet for Patient App

This application is used for many care facilities to share Care plans

Goal:

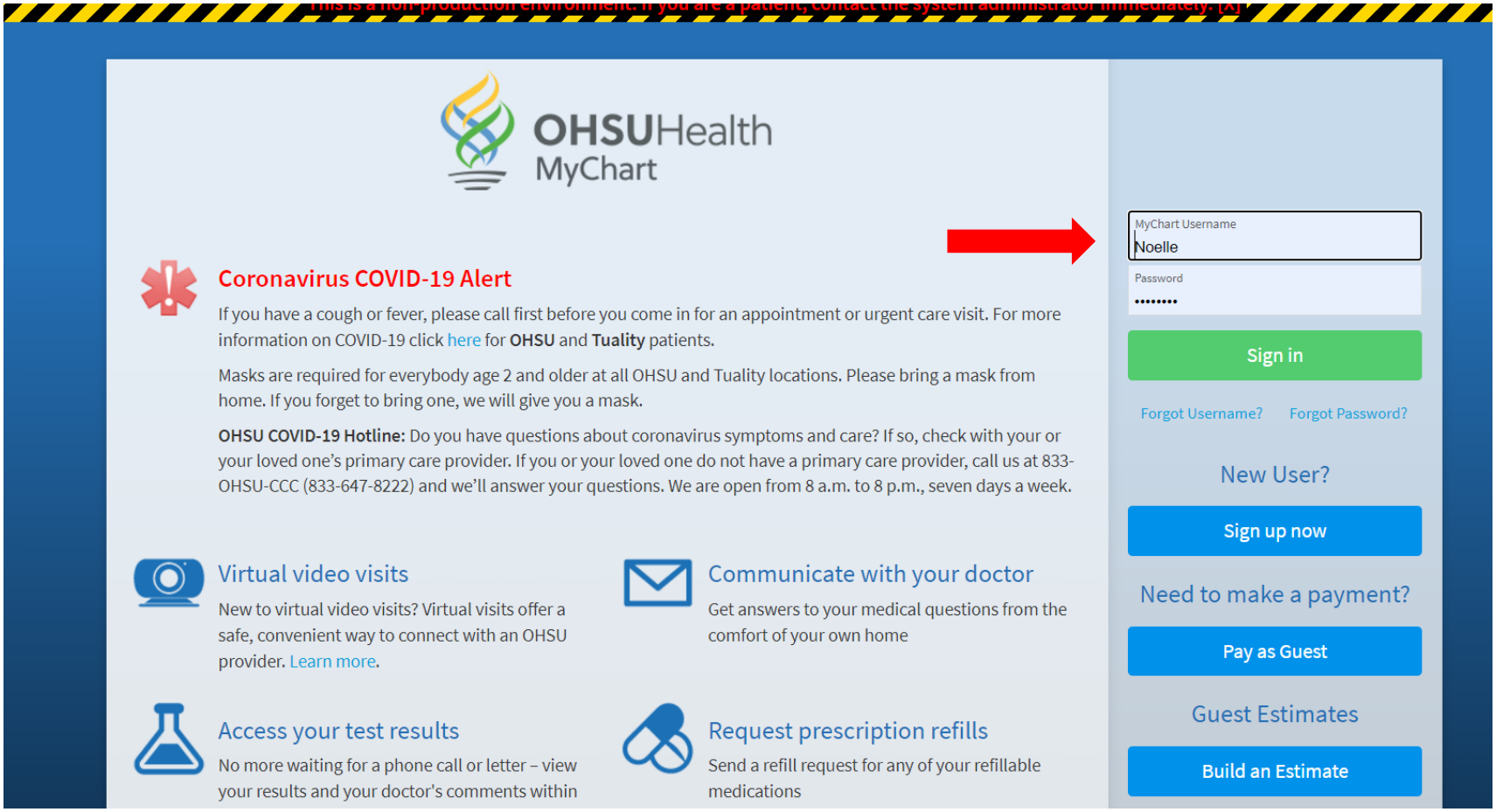
Our goal for the electronic care (eCare) plan application (app) is to improve care coordination for people with multiple chronic conditions (MCC). The eCare plan app will serve an important role in allowing clinicians to view relevant information electronically and enable individuals to access their personal health information directly so that both clinical and nonclinical needs are addressed through shared-decision making.

The Ask: We are asking for clinicians to assess the e-care plan app's usefulness for patients with chronic kidney disease and at least one other chronic condition, and provide feedback on whether the app facilitates standardized data collection and data sharing across clinical and community settings and systems. You will be looking at and becoming familiar with the patient facing application on this form.

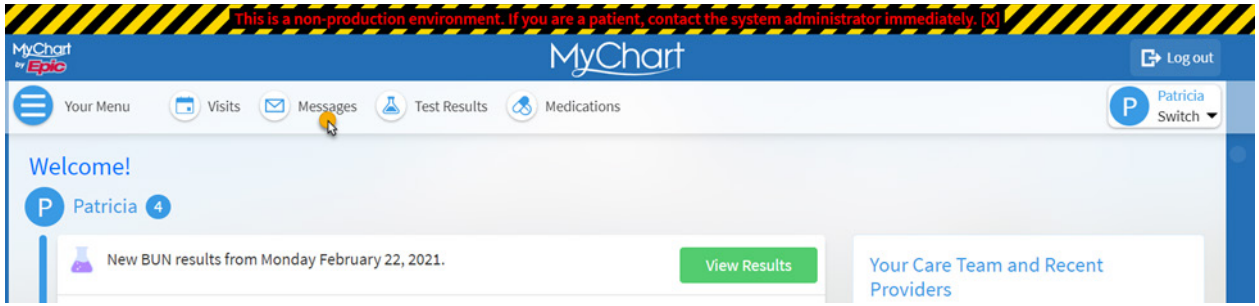
Step 1:

Go to the MyChart POC site (must be on VPN) and log in using the following credentials:

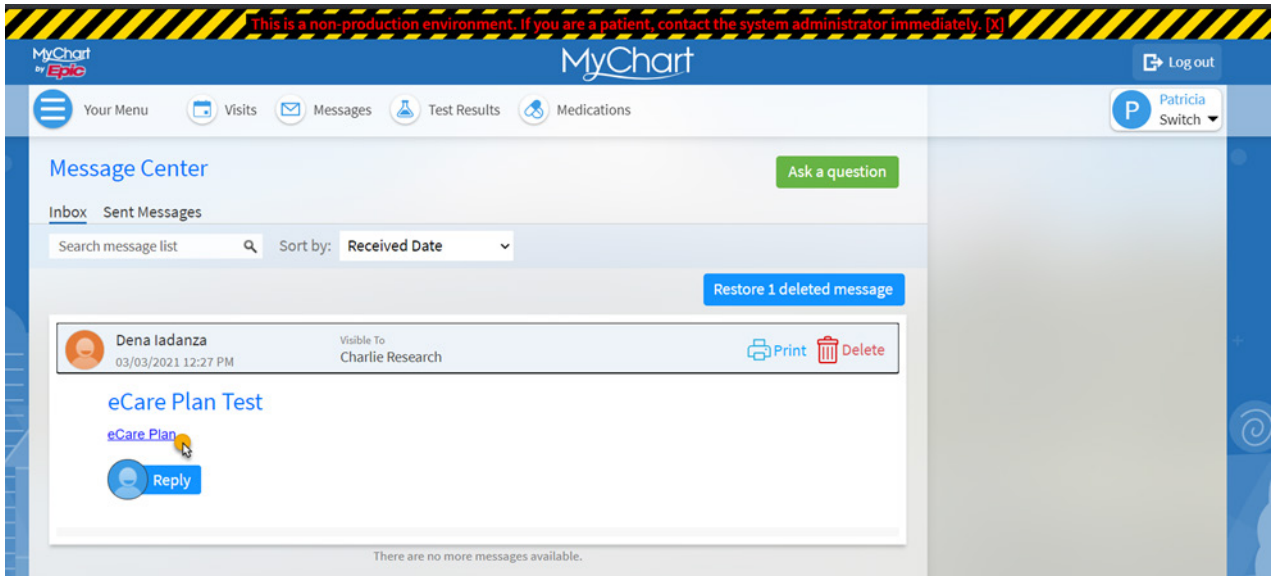
- User Name: Noelle
- Password: mychart1



Navigate to **Messages**:



Select the Hyperlink in the eCare Plan Test message:

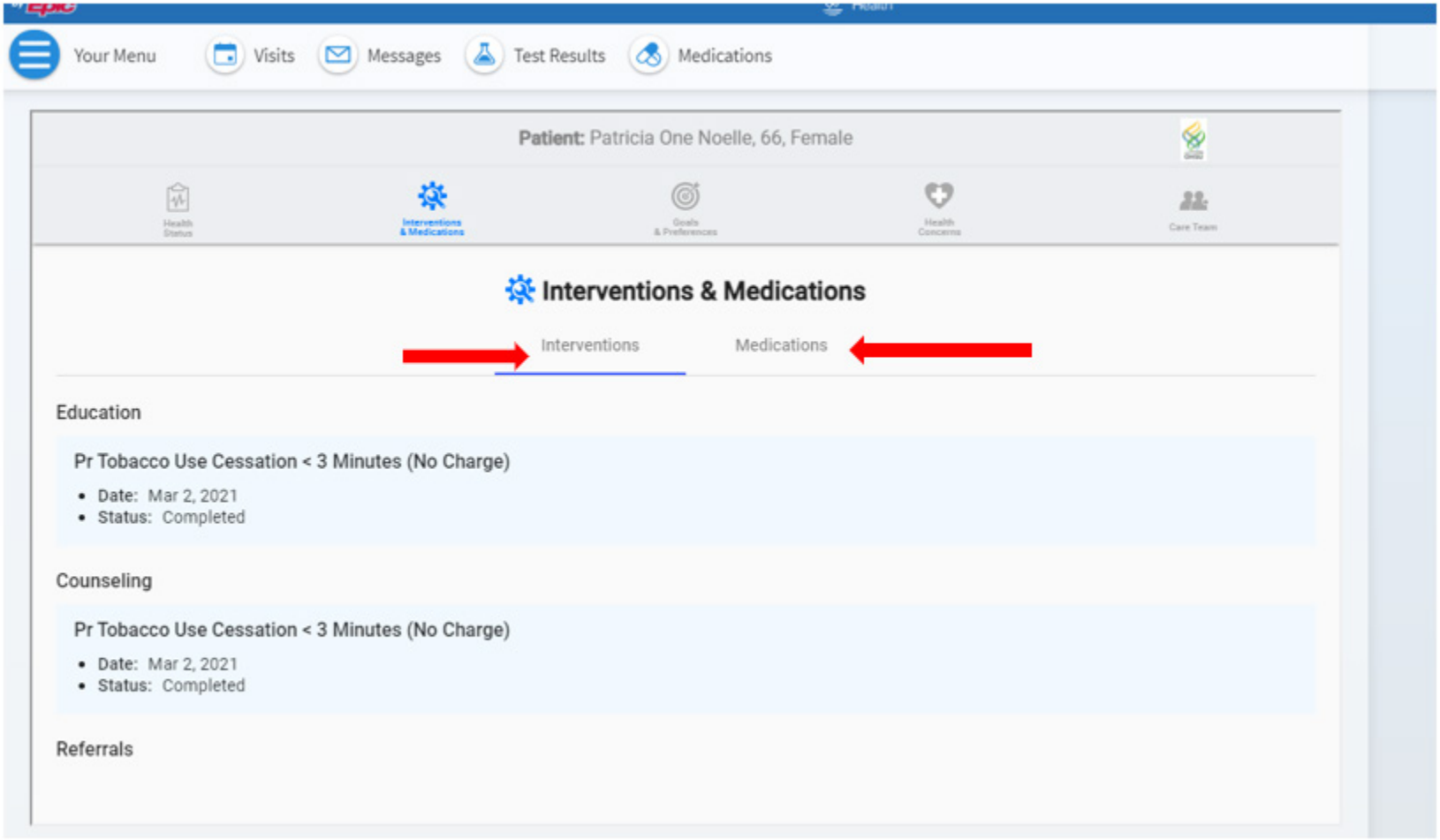


You should be redirected to the eCare Plan app

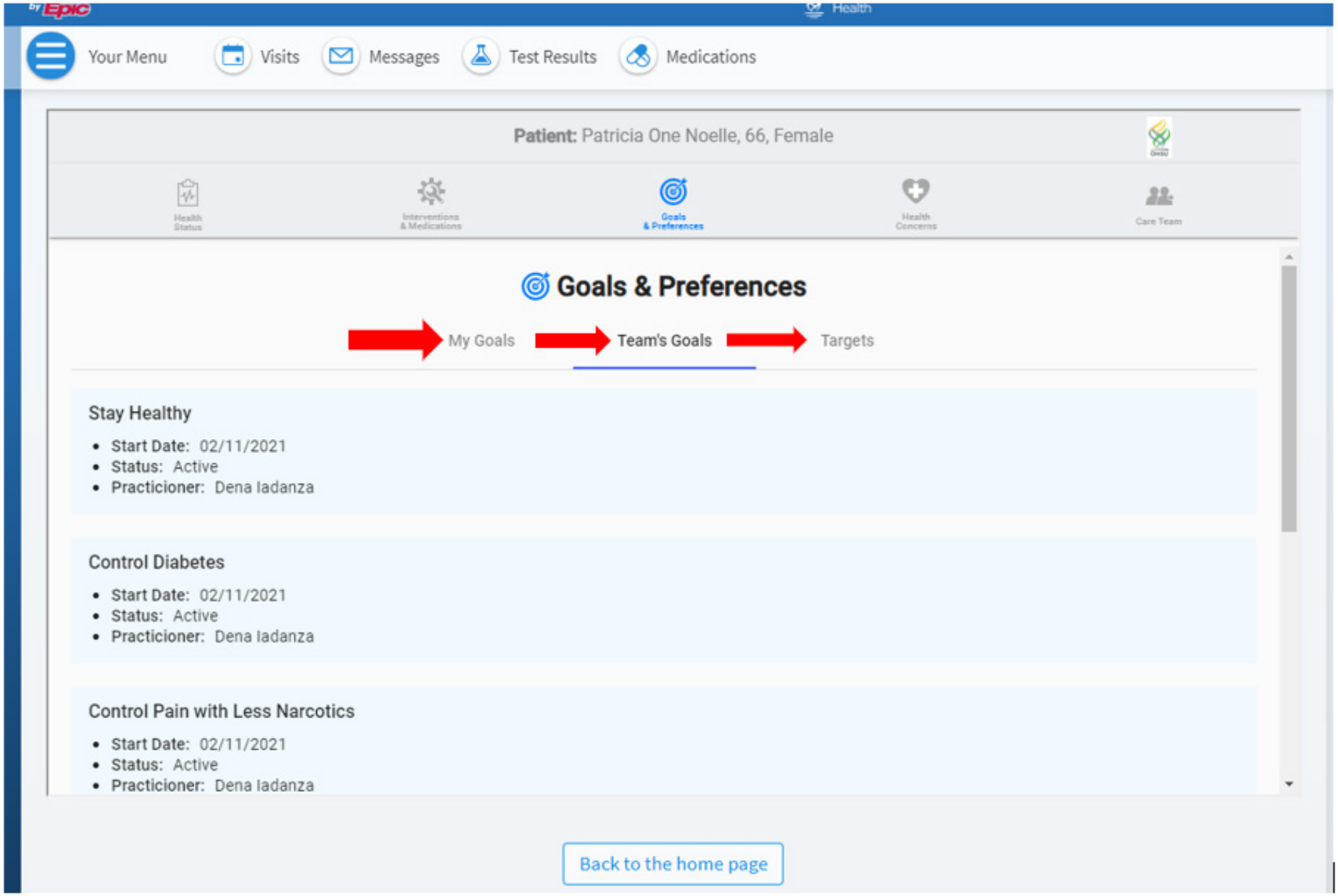
Navigating the eCare Plan App

The application will launch to the screen below, with the patient's name at the top. There is a banner of icons and titles under the patient's name that will allow you to launch to different pages. Upon entering the app, the Health Status tab will be selected. Use the side bar to scroll up and down through the graphs. Under the graphs are tabs for Vital Signs and Lab Results. Click on those for additional clinical information on the patient.

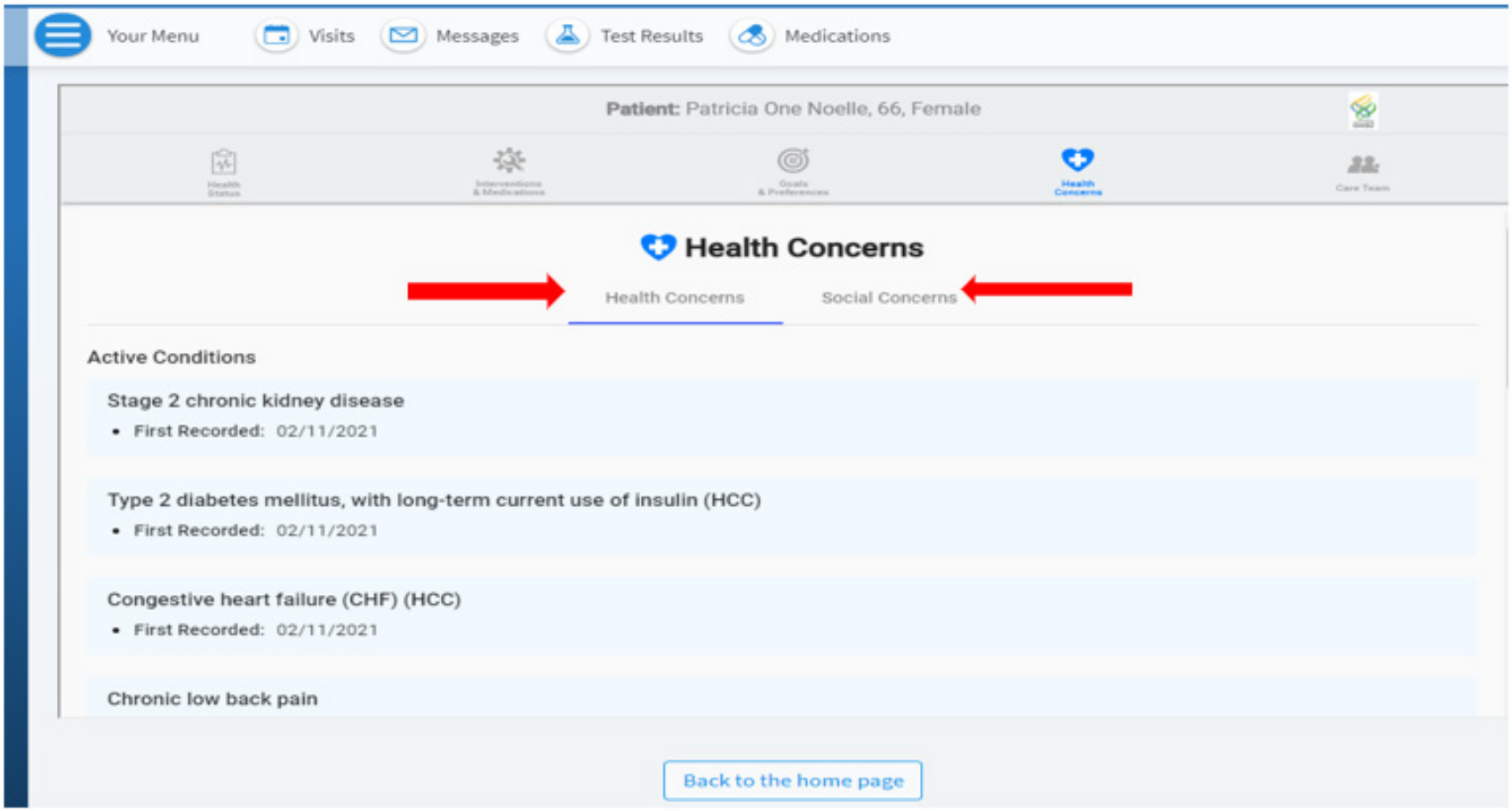
Navigate through the tabs on the top of the screen, under the patient's name. The Interventions and Mediations tab will pull up Interventions including: education, counseling, and referrals. Clicking over to the Medications tab will display current medications.



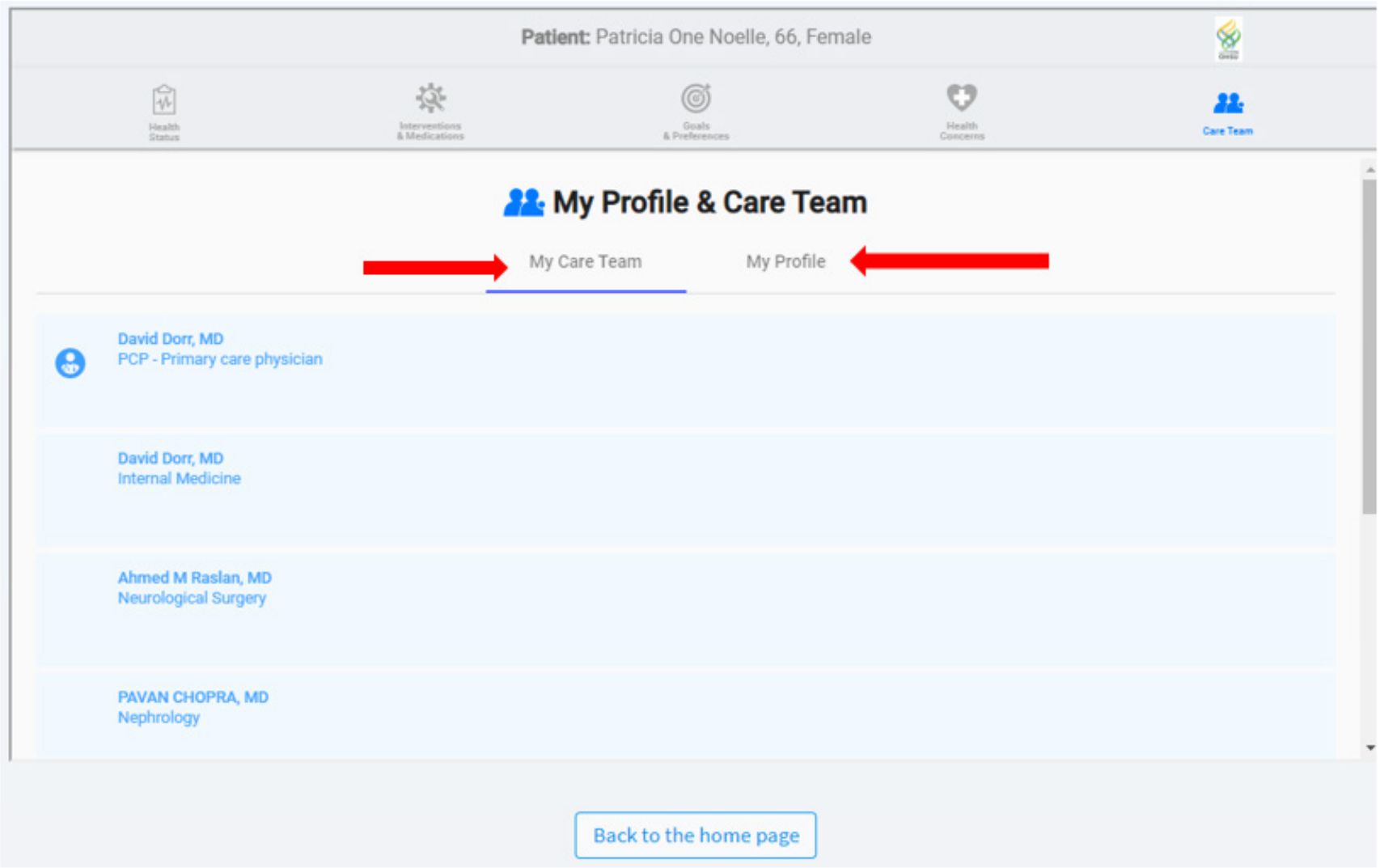
The Goals and Preferences tab has sections for the Patients Goals, Team Goals, and Targets. Click through to see each one.



The Health Concerns tab contains information both on Health Concerns and Social Concerns.



The Care Team tab contains information on the Care Team and Patient in the My Profile tab.



The *Back to home page* tab at the bottom of the app will navigate you completely out of the app, back to the MyChart home page for the patient.

When inviting real patients

When we are ready to start testing with real patient (not quite yet), we will ask you to identify patients that would be good candidates for the app (multiple chronic conditions with CKD) that would also be willing to sit with you through the testing and training. The steps for inviting real patients to the app are below:

1. When you have identified a patient that would be a good candidate for the eCare plan app, invite them by sending them a message in MyChart. Use the smart phrase (**.ecare**) to populate the message. There will be a link embedded in the message that will navigate patients to the patient app.
    - You will need to add your own signature/name and subject phase to the email.
2. Send MyChart message
3. Patient will login into Mychart
4. Help patient open the link and begin basic navigation together of the app.

B.3 eCare One Page Information for Providers and Clinic Staff

Implementation of an Electronic Care (e-Care) Plan for People with Multiple Chronic Conditions
Information for Providers & Clinic Staff

Prototype testing Description:

The e-care and prototype testing will test two e-care plan apps (a patient-facing and provider-facing app) with a goal of improving care coordination for people with multiple chronic conditions (MCC).

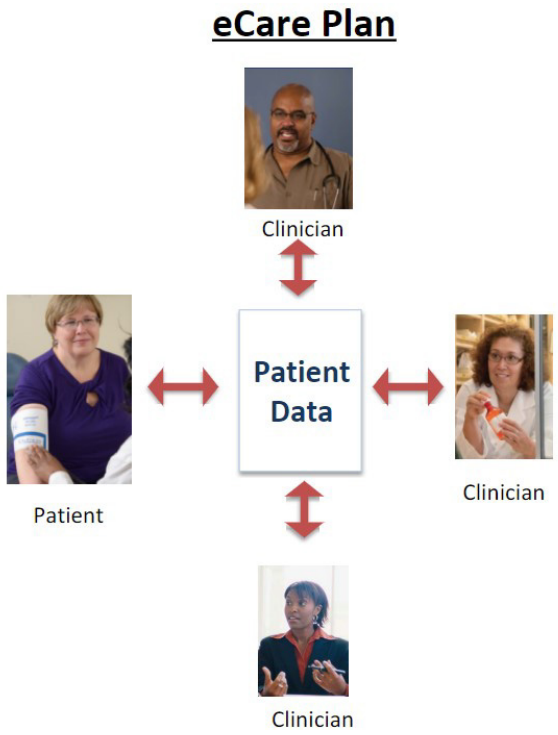
It is funded by the Agency for Healthcare Research and Quality (AHRQ) who has partnered with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). RTI International, a nonprofit research institute, has been hired by AHRQ to assess the usefulness of the e-care plan apps.

Both the provider-facing and patient-facing applications will make patient-centered data available across care and research settings for people with chronic kidney disease (CKD) and multiple chronic conditions (MCC).

Goal of the Prototype testing:

The prototype testing is working to answer the following questions:

- What are the barriers and facilitators to implementing the e-care plan app from an organizational and technical perspective?
- What are the barriers and facilitators to using the e-care plan apps within and across organizations?
- How does the e-care plan app influence data collection and sharing across settings?
- What are the intra- and interorganizational social and technical factors to consider when implementing and using the app?



Participating Sites:

The sites participating in this project are:

- OHSU Internal Medicine
- OHSU Hillsboro Medical Center
- OHSU Family Medicine South Waterfront
- OHSU Nephrology and Hypertension Clinic
- **Holladay Park Plaza* (will be the first site to prototype testing the e-care plan apps)*
- Mirabella

Prototype testing Timeline (TBD):

An initial soft launch of the two e-care plan apps will launch at Holladay Park Plaza in April-May 2021. The full launch, which will include your clinic site, will occur in June through November 2021.

Prototype Testing Site Responsibilities

- Test both apps in the clinic setting.
- Designate prototype testing site champion(s) and super user(s).
- Train clinic staff on how to use the apps.
- Recruit patients to walkthrough the patient-facing app.
- Attend training and prototype testing meetings as appropriate.
- Provide feedback on the apps.

Patient Involvement

Each site will recruit 3-4 patients with chronic kidney disease and multiple chronic conditions to use the patient-facing app.

Additional Questions or Technical Support

If you're encountering an issue with either of the e-care plan apps, please log your issue here. If you have additional questions or need immediate assistance, please reach out to Matthew Storer (storer@ohsu.edu).

B.4 eCare One Page Information for Patients and Caregivers

Implementation of an Electronic Care (e-Care) Plan for People with Multiple Chronic Conditions
Information for Patients & Caregivers

What is the e-care plan app prototype testing?

This prototype testing is testing test two electronic care (e-care) plan applications (apps) – one app is for providers and one app is for patients.

Who is the Agency for Healthcare Research and Quality (AHRQ)?

AHRQ is a federal agency under the U.S. Department of Health and Human Services who is working to improve healthcare quality, safety, accessibility, and affordable.

This prototype testing is being funded by the Agency for Healthcare Research and Quality (AHRQ) who has partnered with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). RTI International is a nonprofit research institute who has been hired by AHRQ to assess the e care plan app's usefulness.

What is the goal of the e-care plan app prototype testing?

We want to make it easier for you! The goal of this prototype testing is to improve care coordination for people with multiple chronic conditions - making it simpler for those patients with multiple providers to share information.

How long will the e-care plan app be available to me?

The patient-facing e-care plan app will be available for you to use from June through November 2021 (TBD).

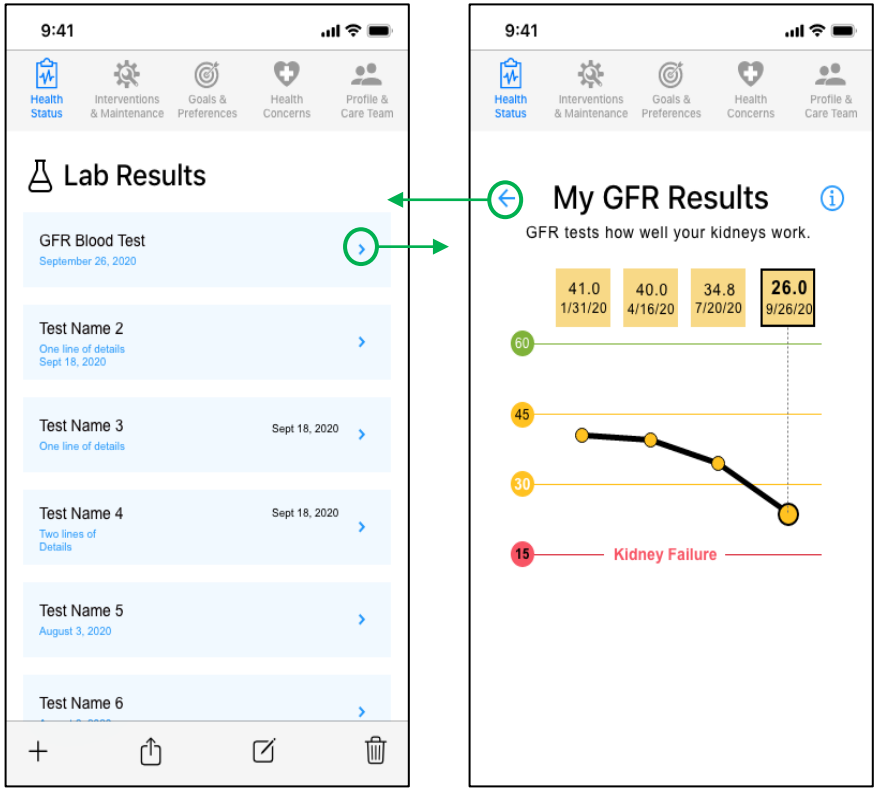
What are the benefits to using the patient-facing e-care plan app?

By using the e-care plan app, your healthcare information becomes:

- ✓ Easily accessible
- ✓ Centralized
- ✓ Trackable over time
- ✓ Sharable with your provider

Who is the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)?

NIDDK is a federal agency under the U.S. National Institutes of Health who is working to improve knowledge and create treatments for chronic diseases.



When will I use the e-care plan app?

Your provider or other clinic staff member will walk you through using app. You will not be responsible for entering information outside of your appointments.

Who is my data shared with?

Only your healthcare providers will have access to your healthcare data. AHRQ, NIDDK, and RTI International **WILL NOT** receive or collect your healthcare data.

B.5 Provider Training Video

Provider Training Video Link

B.6 Patient Training Video

Patient Training Video Link

Appendix C: Acronyms and Abbreviations

AHRQ	Agency for Healthcare Research and Quality
API	application programming interface
CDS	clinical decision support
CFIR-PR	Consolidated Framework for Implementation Research Process Redesign
COVID-19	coronavirus disease 2019
eCare	electronic care
eCP	electronic care plan
EHR	electronic health record
EQ	evaluation question
FHIR	Fast Healthcare Interoperability Resources
HL7	Health Level Seven
IG	implementation guide
IT	information technology
LOINC	Logical Observation Identifiers Names and Codes
MCC	multiple chronic conditions
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
OHSU	Oregon Health & Science University
PCOR	patient-centered outcomes research
PCP	primary care provider
PFA	Patient and Family Advisors
PROM	patient-reported outcome measure
SDOH	social determinants of health
SEIPS	Systems Engineering Initiative for Patient Safety
SMART	Substitutable Medical Applications, Reusable Technologies
UCD	user-centered design
UI	user interface
USCDI	United States Core Data for Interoperability
UX	user experience