Empowered Patients, Informed Research: A pilot project for radiotherapy data sharing using the Opal patient portal

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Introduction

- **Use of AI in medicine & medical physics is accelerating**
  - Outcome modelling
  - Image analysis
  - Detection and Diagnosis
  - etc.

- **AI algorithms require large amounts of real-world data**

Introduction: Data Challenges in Healthcare

Clinicians/Researchers:

Want access to complete patient data

Patients:

Want access to their own data
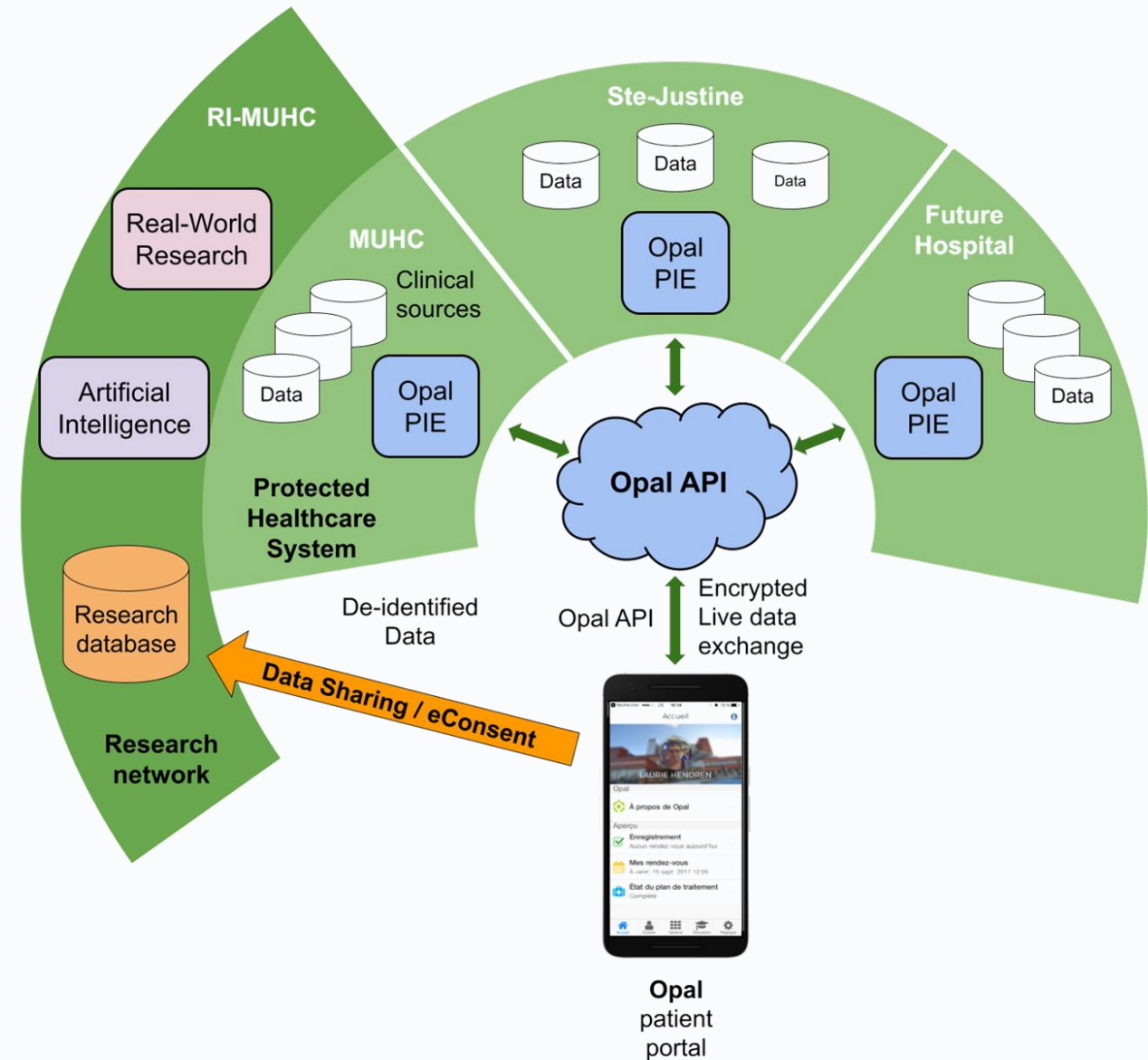
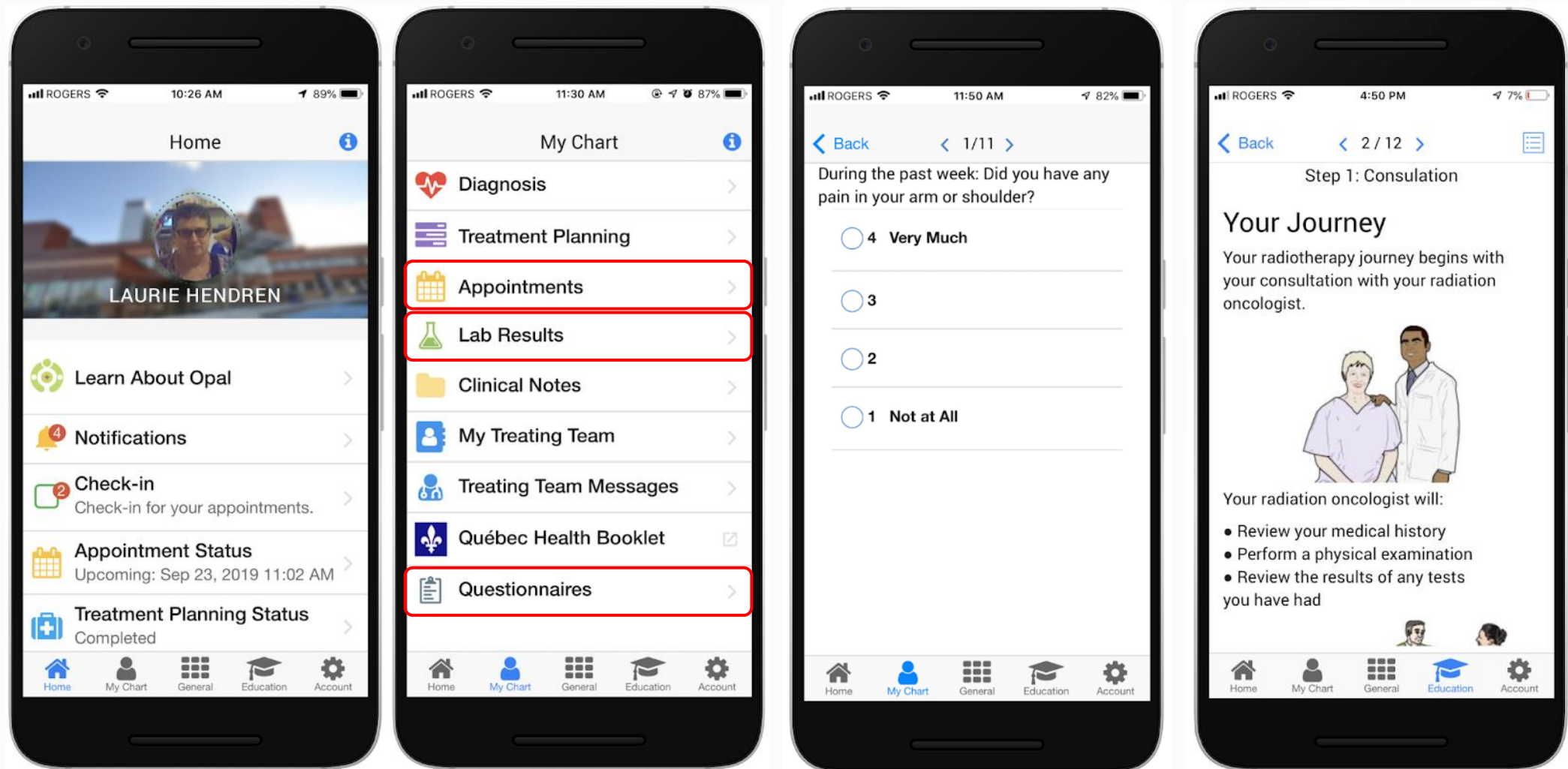Want to participate in research

The Problem:

Data are technically challenging to access: legally protected and spread across multiple institutions

Introduction

- **Overarching Goal:** To develop a **data sharing infrastructure** for healthcare within the Opal patient portal.
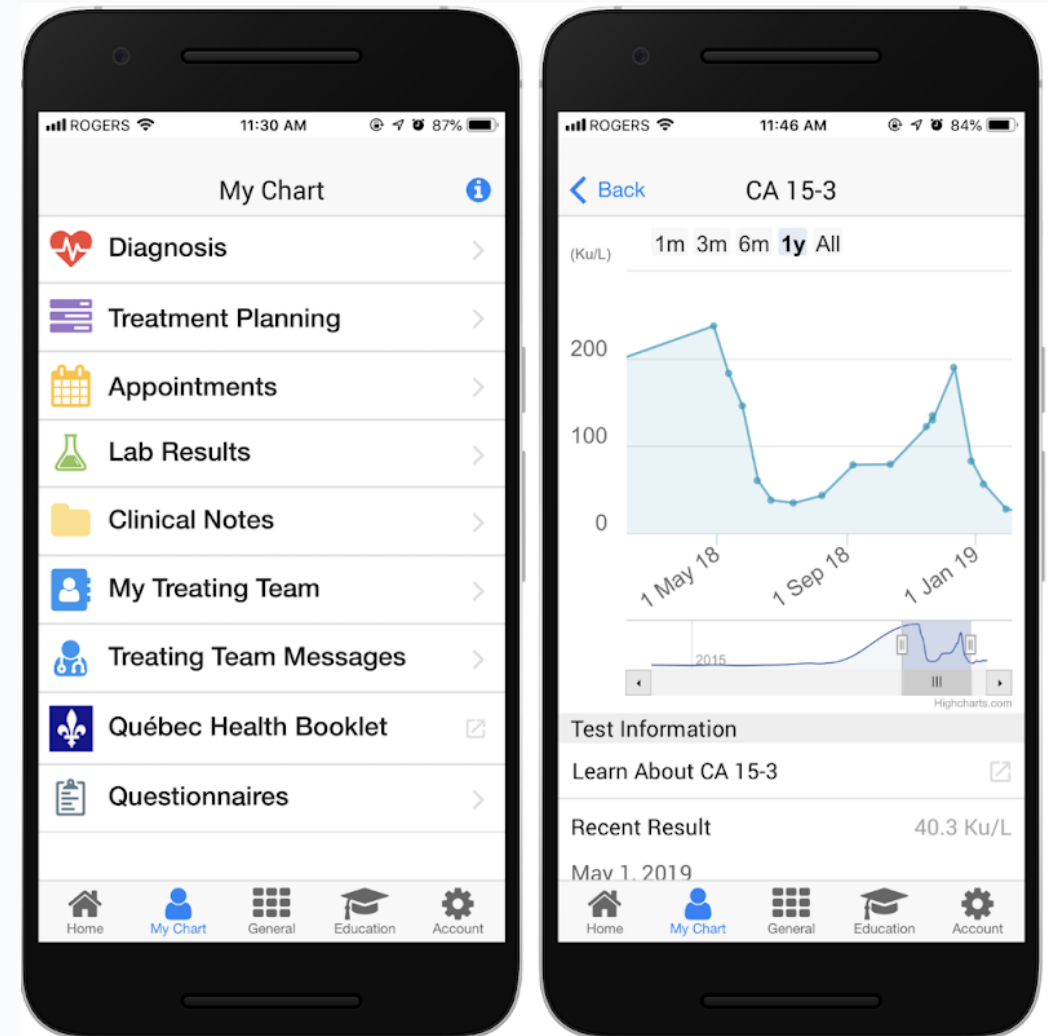
Introduction: Opal Patient Portal

Introduction: Opal Patient Portal

- **Currently in Opal:**
  - Access to some patient data
  - E.g. blood tests, clinical notes, etc.

- **Not in Opal:**
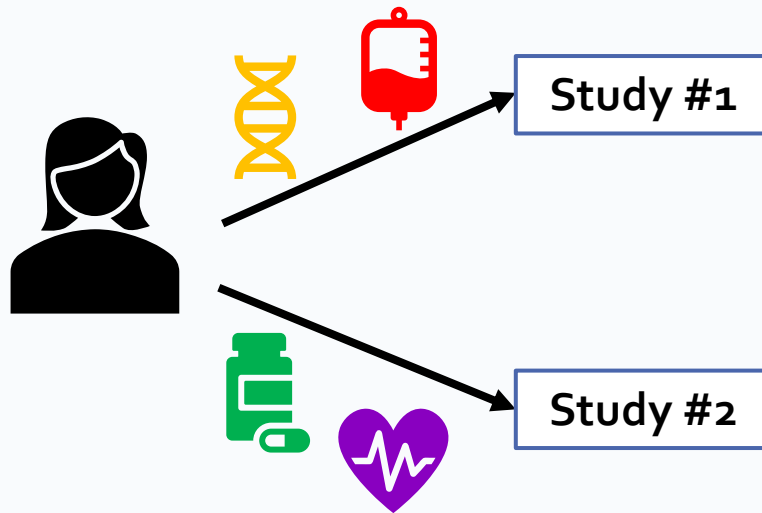 - Radiotherapy
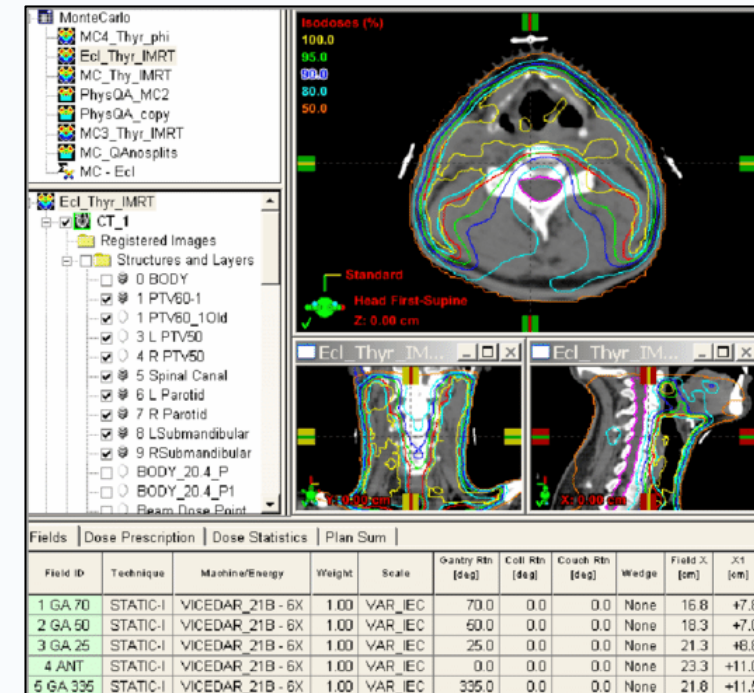 - Why is this important?

Better informed = reduced anxiety

Objectives

- Add 2 new modules to Opal

1) Research

2) Radiotherapy

GENERAL DESIGN METHODS

Participatory Stakeholder Co-Design

- **Key Stakeholders**
  - Patients
  - Clinicians
  - Researchers
  - Software Developers

- **Advantages**
  - Acceptable to patients
  - Technologically feasible

Technical Design

- **Coding Languages**
  - SQL
  - HTML
  - JavaScript
    - AngularJS
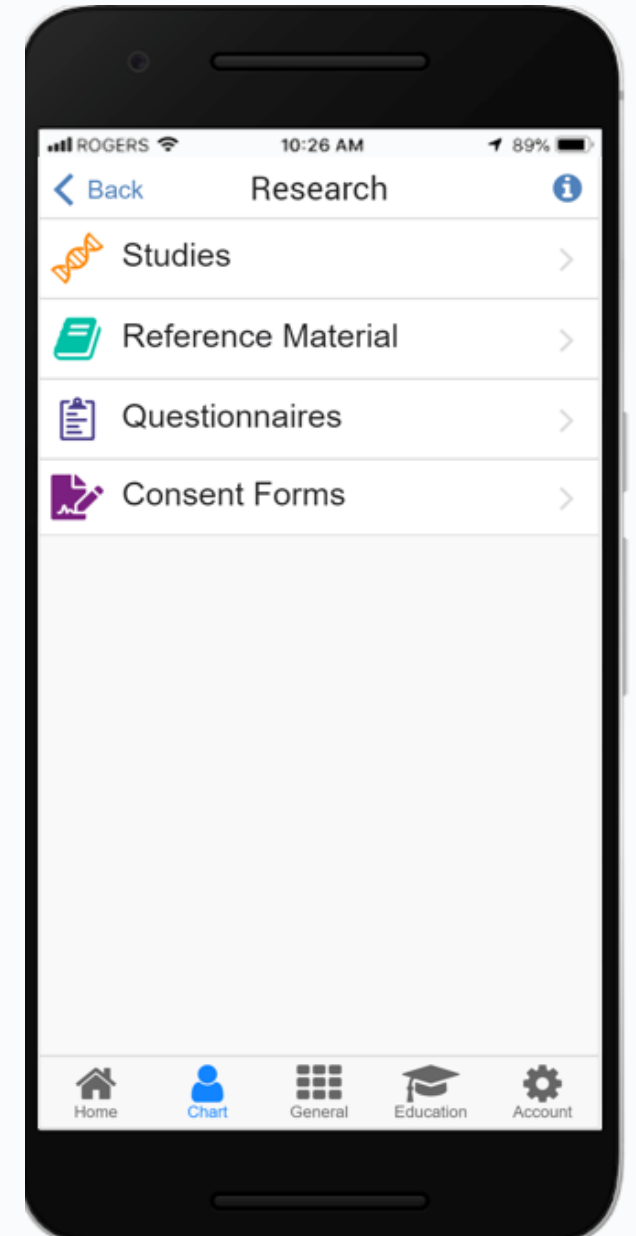   - NodeJS

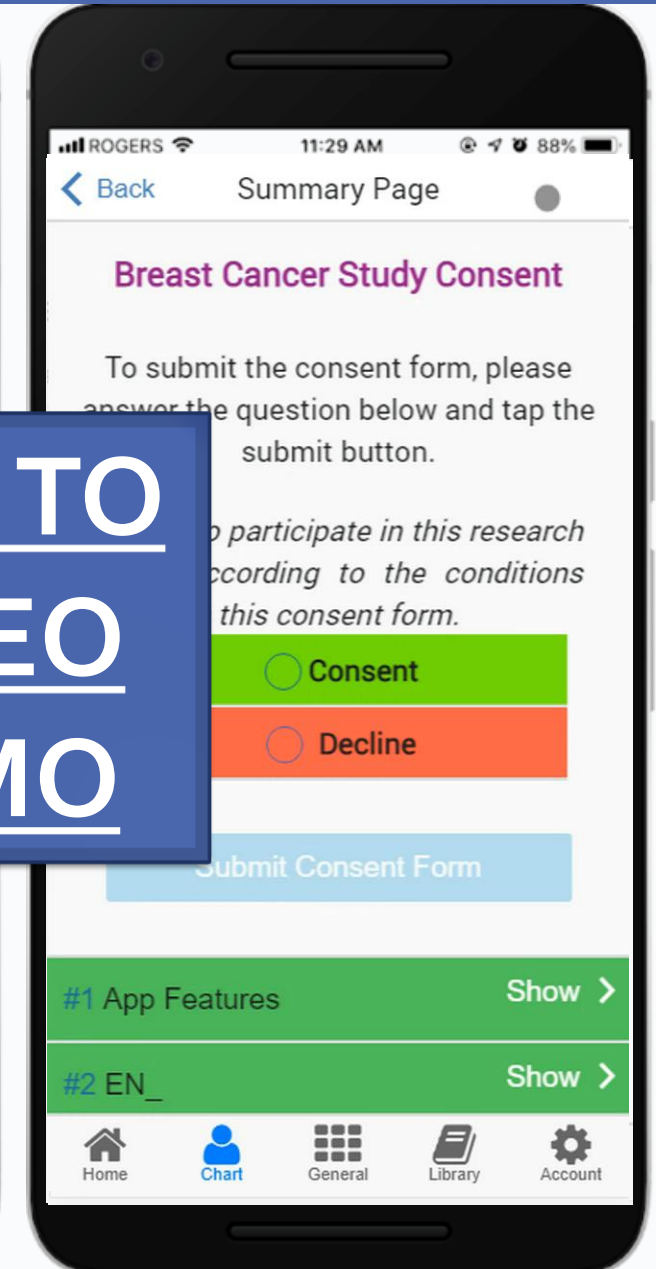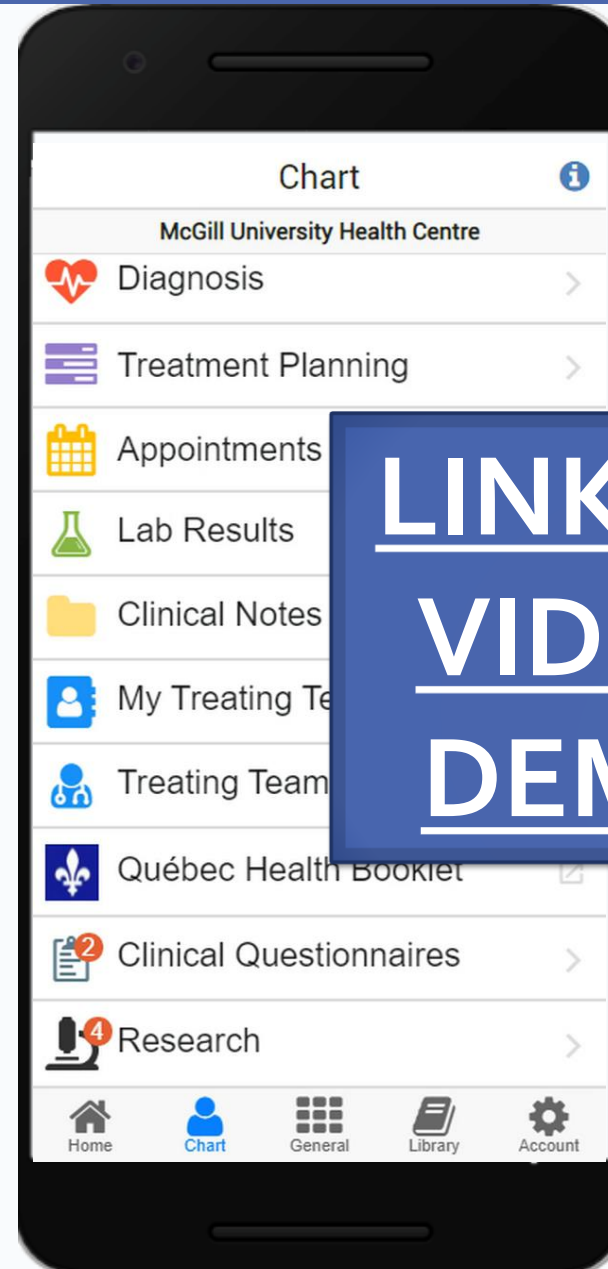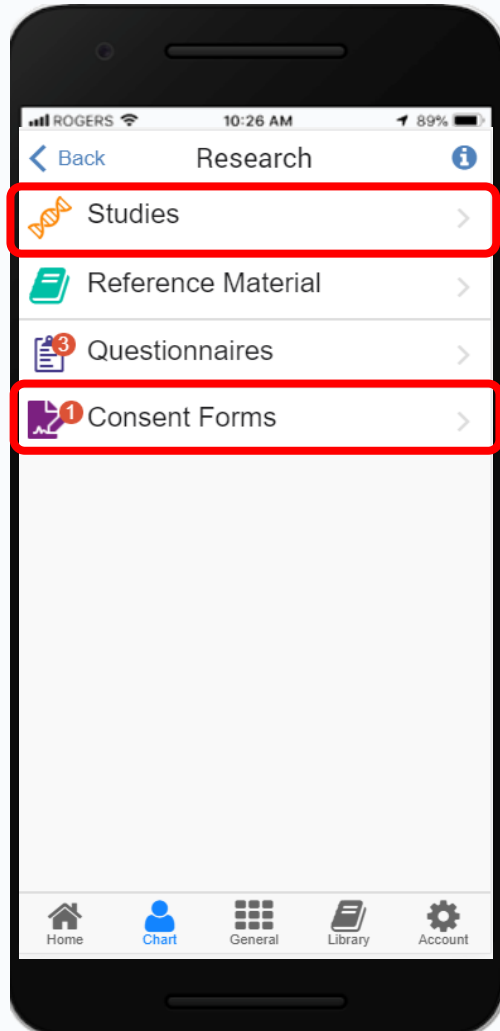# OBJECTIVE #1 – RESEARCH MENU

Methods – Design

Design goal: allow patients to sign up for and participate in research studies through the app

Features

- Studies
- Consent Forms
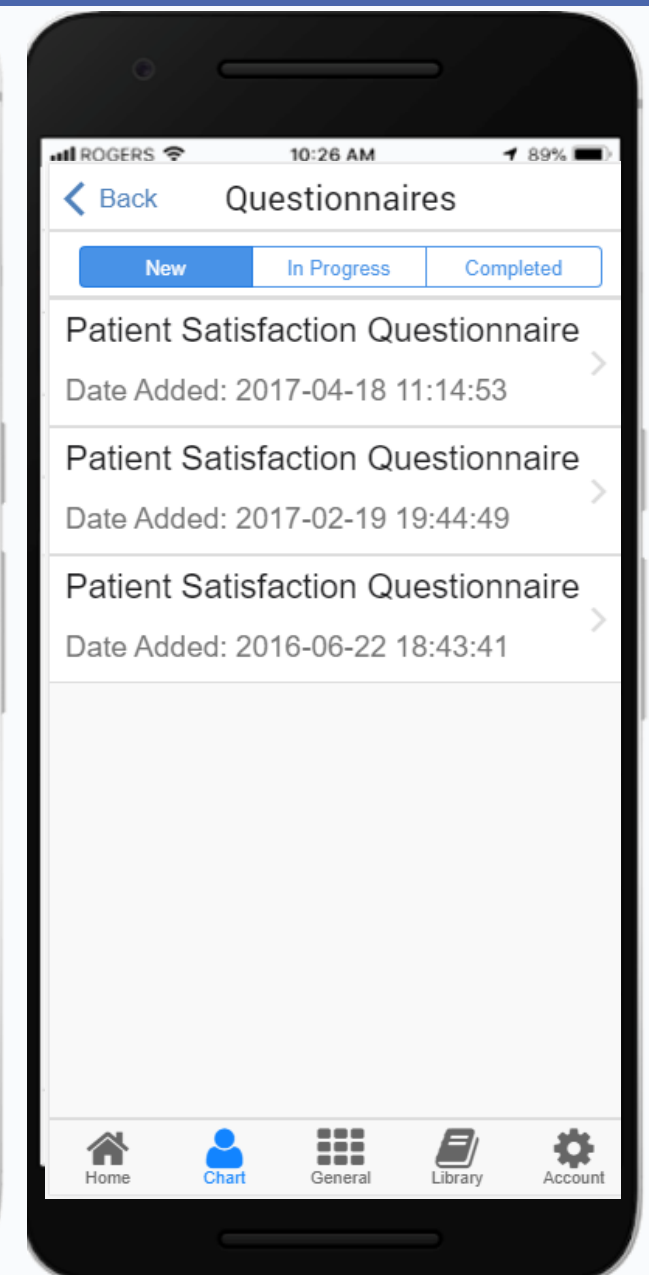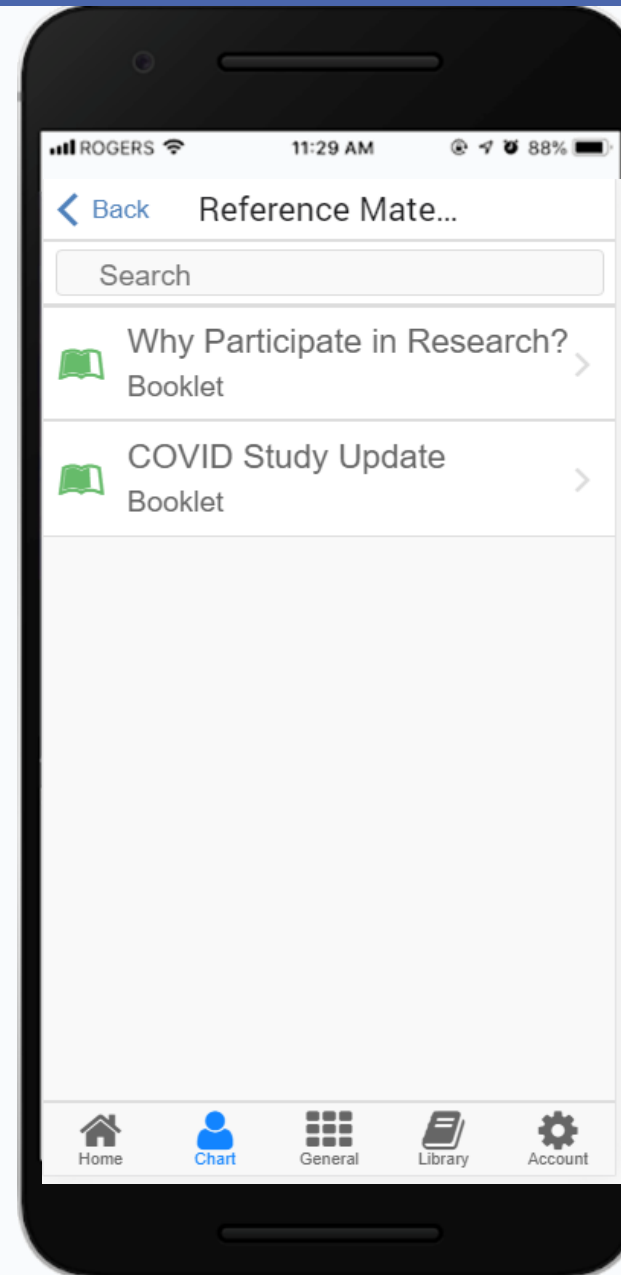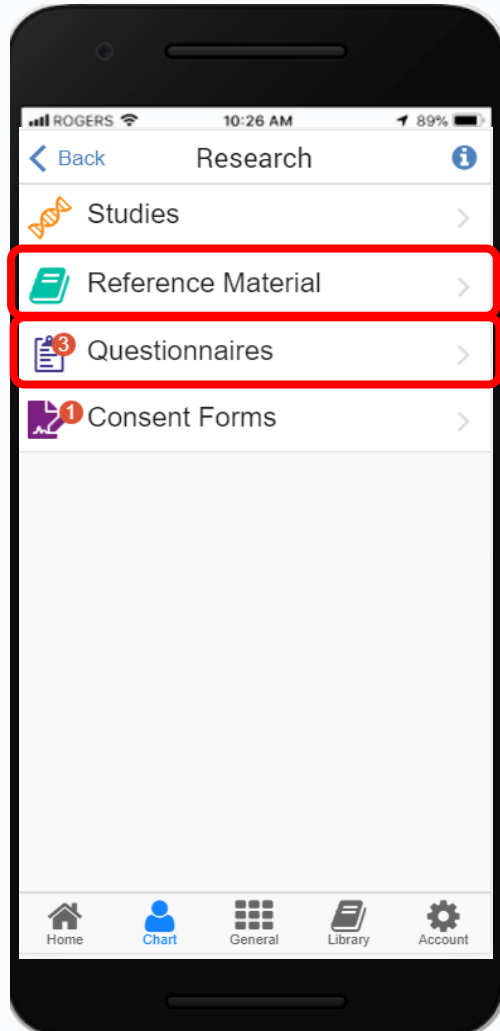- Research Questionnaires
- Reference Material

Results - Studies

Results - Research

OBJECTIVE #2 – RADIOTHERAPY MENU

Methods - Design

DICOM File

Treatment Planning System

My Design

Informative Page

- # fractions, beam energy, etc.

3D Page

- Body + Beams

Methods – Personalized Text

DICOM RT PLAN
- Particle type
- Beam Energy
- Patient position
- Dose
- # fractions
- Etc …

→

Example Text
You will be treated with **PARTICLE_TYPE** beams, PARTICLE_DESCRIPTION. The beams will have an energy of **BEAM_ENERGY** PARTICLE_UNIT. The energy determines how far the radiation penetrates in your body.

Methods – Body Visualization

DICOM RT STRUCT
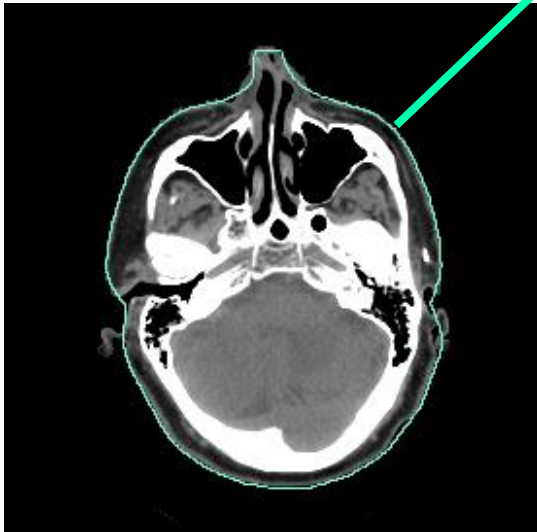
Body Contour Data:

[104.003725, -69.854828562500003, -122.5, 105.95684900000001, -69.854828562500003, -122.5, 107.90997299999999, -69.854828562500003, -122.5, 108.88653499999999, -69.824310999999994, -122.5,

- 3D Modelling with surface triangulation

vertices   edges   faces   surfaces

Results – Radiotherapy

Results – Personalized Text

Your Radiotherapy Plan

On this page you will find details about your radiotherapy treatment plan, which has been carefully put together for you based on your CT scan and your specific disease characteristics. The treatment will be repeated over **16** sessions.

- ✚ 🛏 Set-Up on the Treatment Table
- ✚ 🔊 Radiation Beams
- ✚ 🫁 Breathing Techniques
- ✚ 💊 Radiation Dose

🛏 Set-Up on the Treatment Table

The radiation treatment itself will only last a couple of minutes, however, the entire session may take 10-30 minutes. The majority of this time is spent making adjustments to ensure that you are set up exactly as you were during your CT simulation. This is important because the radiation is delivered very precisely based on your CT scan.

On the treatment table, you will lie on your **back with your head towards the machine**.

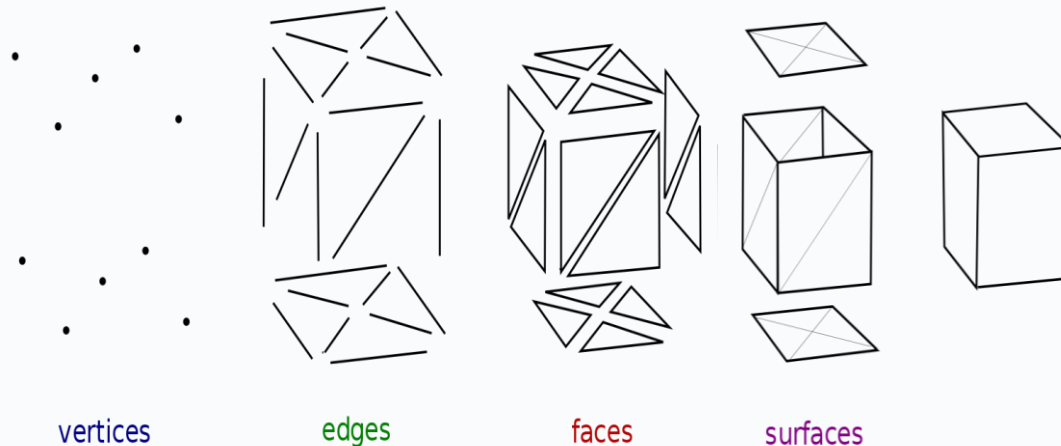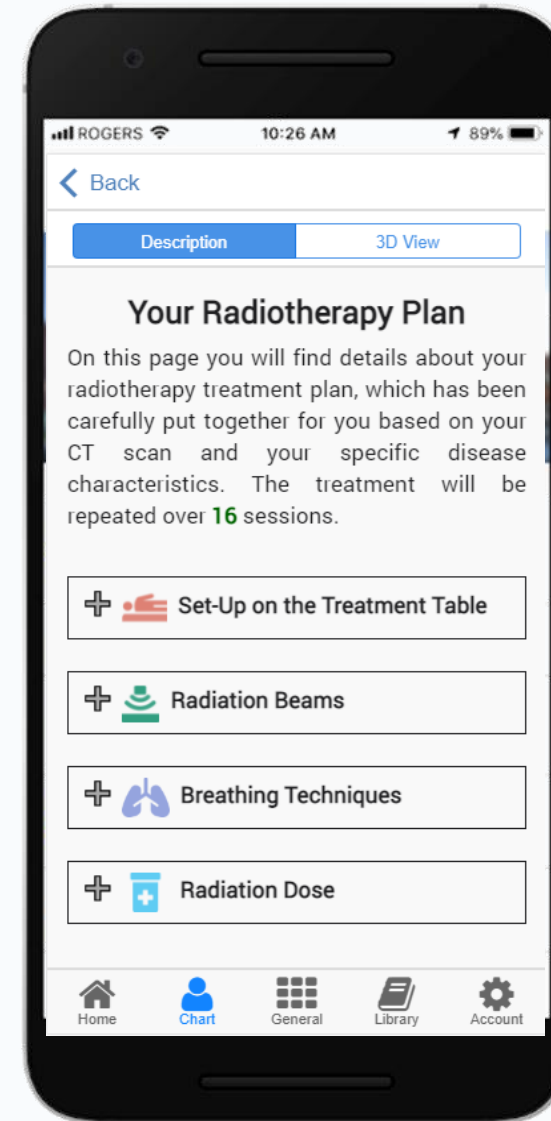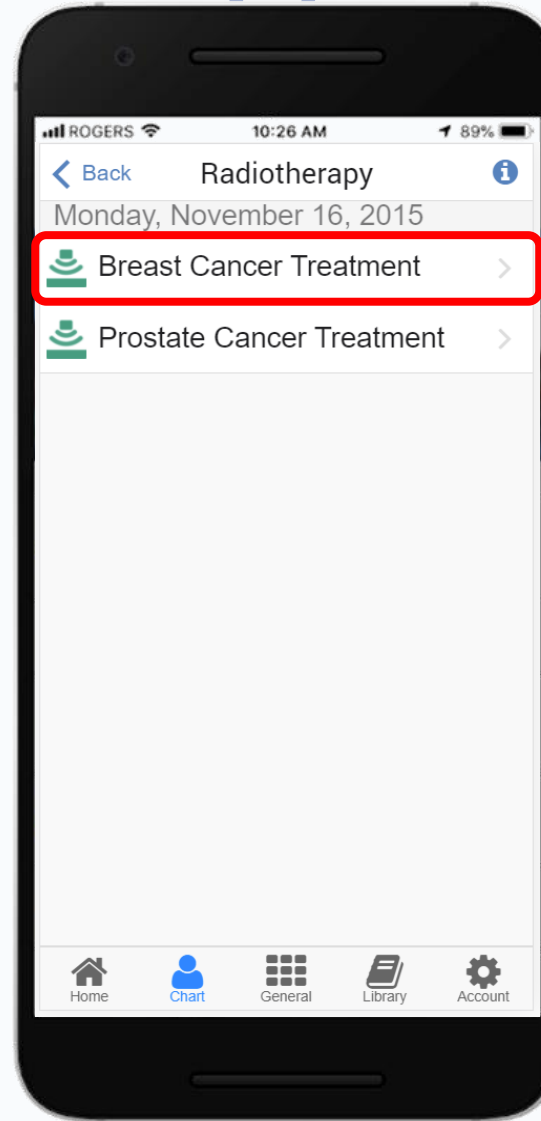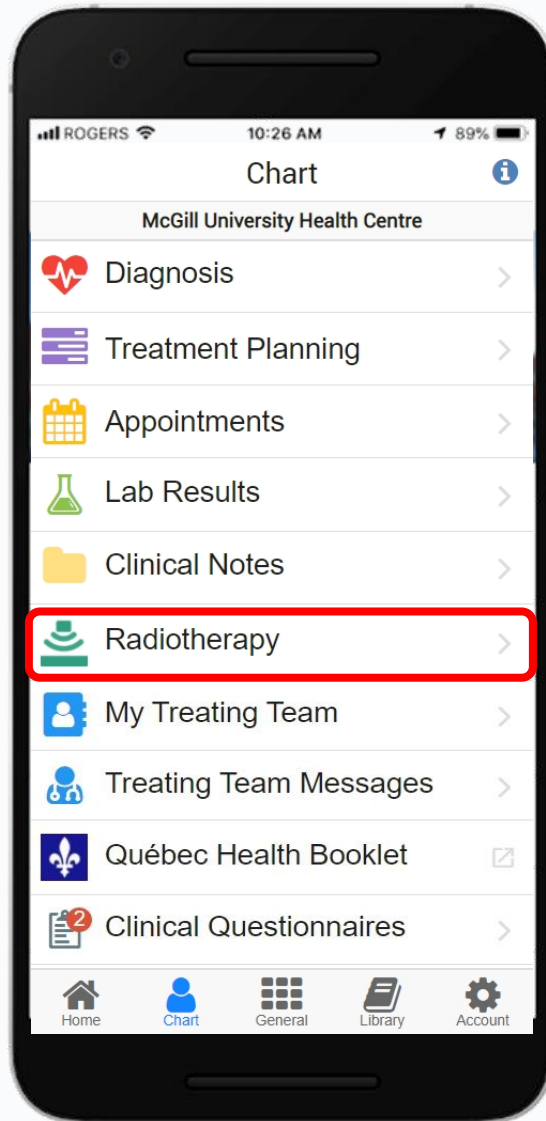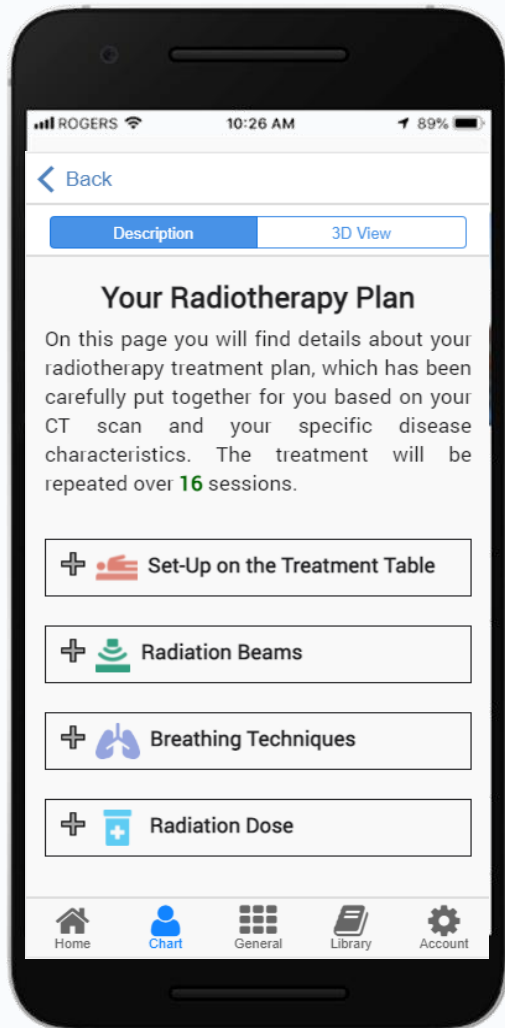For breast treatment, you will typically need to hold your arms above your head so that they are not in contact with the radiation. This may be uncomfortable or painful for some

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🔊 Radiation Beams

Once positioned, your treatment will begin. The machine will rotate around you to deliver **2** beams of radiation at different angles. You can visualize these beams on the next page.

tumour / tumour receiving radiation / healthy cells
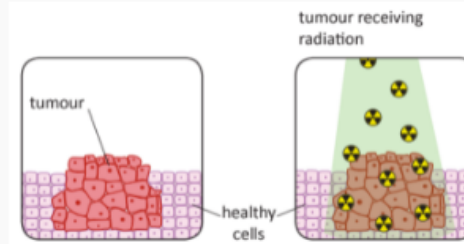
You will be treated with **photon** beams, which are beams of high energy x-rays and the most common type of radiotherapy.

The beams will have an energy value of **6 MV** (Mega-volts). The energy determines how far the radiation penetrates in your body. Higher energies can travel further inside the body and are used for deeper tumours. Typical photon beam energies range from 4 MV to 25 MV.

The widths of the beams delivered are chosen so that they are just large


💊 Radiation Dose

The prescribed radiation dose to the targeted tumour is **40 Gy** (Gray). This number indicates the amount of radiation energy to be deposited in this area.

You will not receive the full dose at once. Rather, it will be split up into **16** "fractions" (sessions). There are many reasons for splitting up treatment into smaller fractions. Mostly, it maximizes the chances of killing the tumour cells while also leaving your healthy cells enough time to repair in between sessions.

The radiation beam type, energy, angle and shape are all chosen so that the tumour receives this prescribed dose, while the surrounding healthy tissues and organs receive the least amount of radiation possible. Our goal is first to effectively remove the tumour, but also to reduce the side effects you may experience.

Results –
3D Visualization
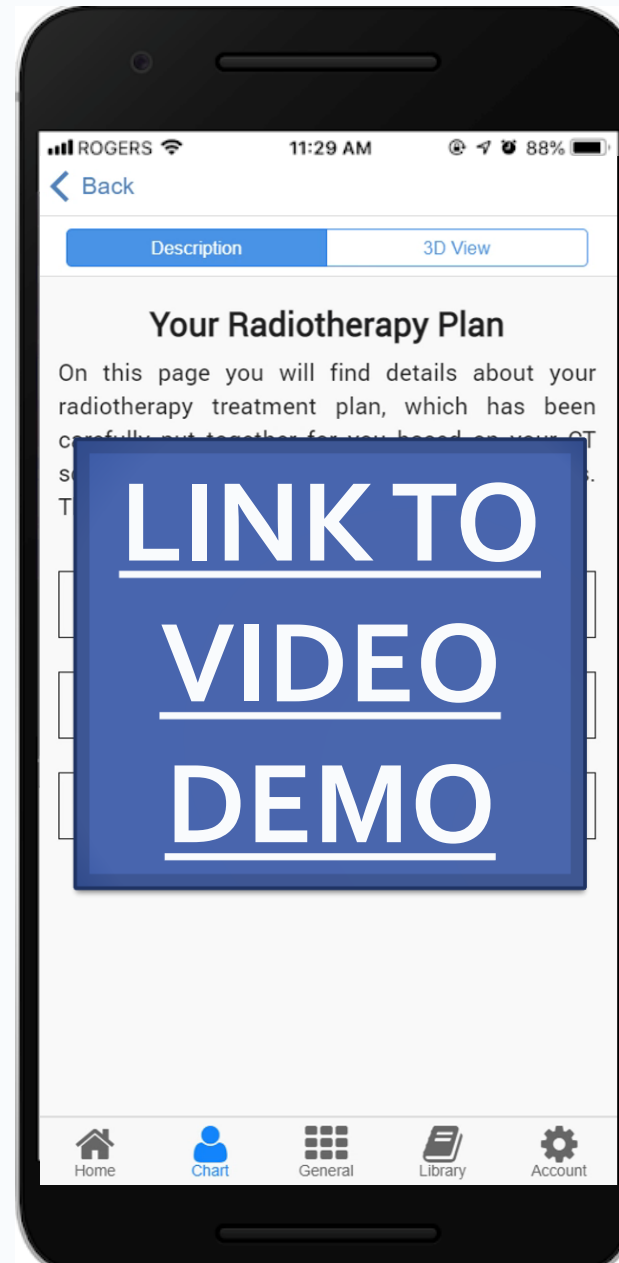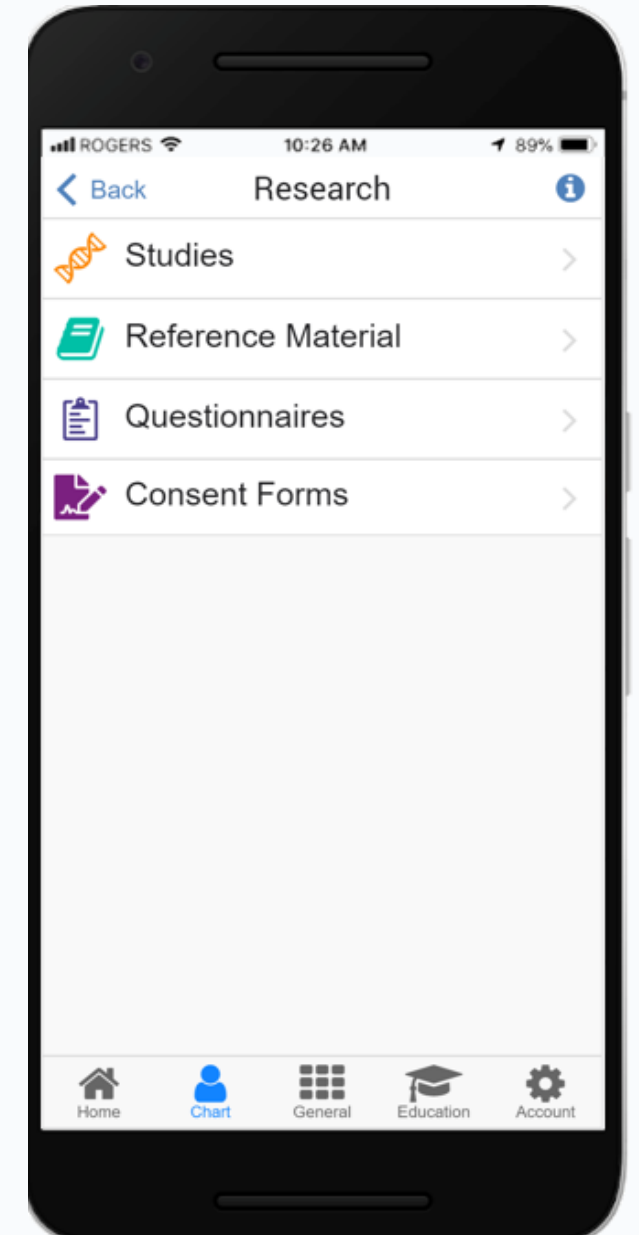
DISCUSSION – PATIENT FOCUS GROUP

Patient Focus Group

Data Sharing
- Initially hesitant about sharing their data
- How to build trust:
    1) Security
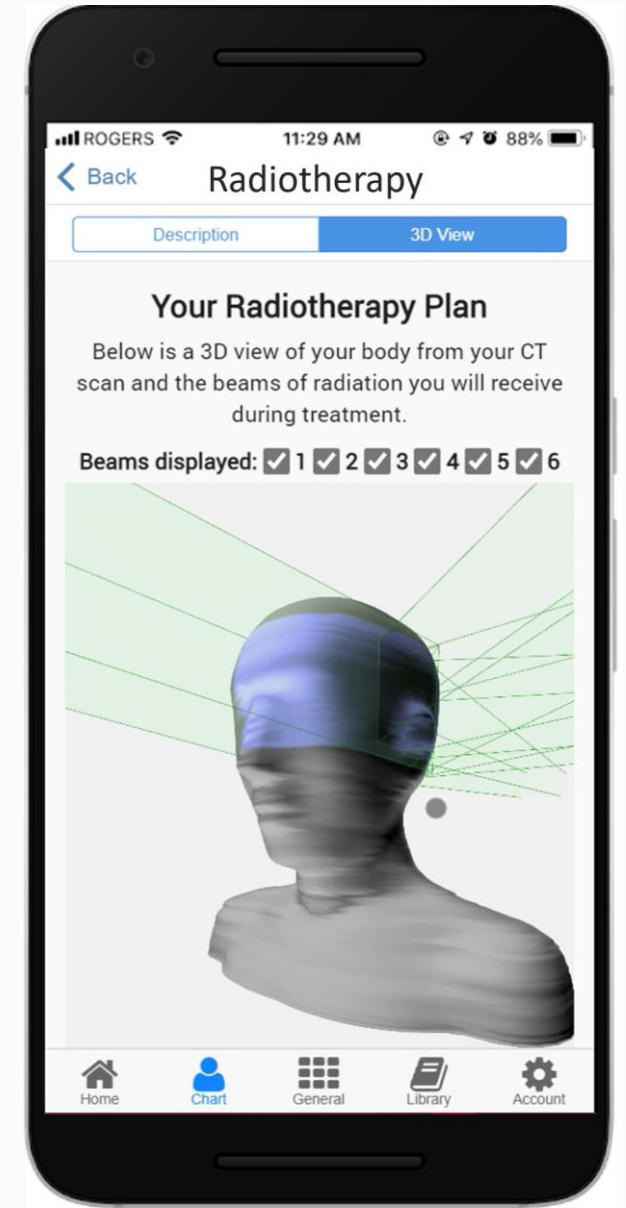   2) Transparency
    3) Engagement

Research menu
- Felt the design met their needs
- ***Pre-established trust with Opal***

Patient Focus Group

Radiotherapy Menu

- Patients wish they had this when they went through treatment

- Would help patients be better prepared and less anxious by taking away unknowns

- After seeing it, would be happy to share with researchers

CONCLUSIONS

Conclusions & Future Work

- Built Research and Radiotherapy menus into the Opal patient portal

- Very positive patient feedback!

- In the future, implement full data donation platform

- **Take home message:** Prioritizing patient education and access to data fosters an important sense of trust between the patient and researcher.
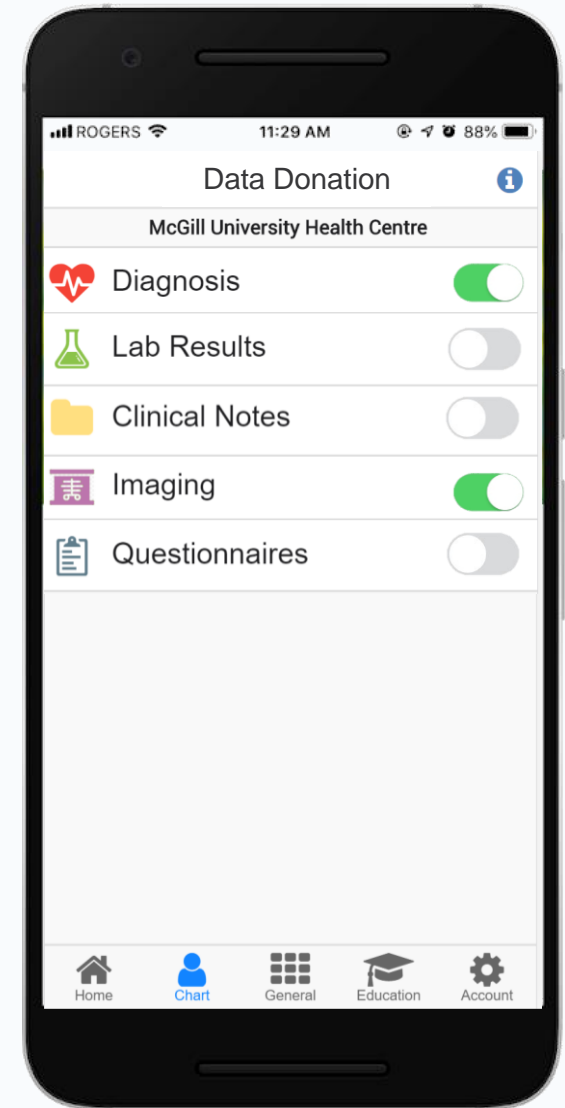
Acknowledgements

- Dr. John Kildea
- PARTAGE Team
- Opal Development Team
- NICE ROKS Team

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THANK YOU