

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

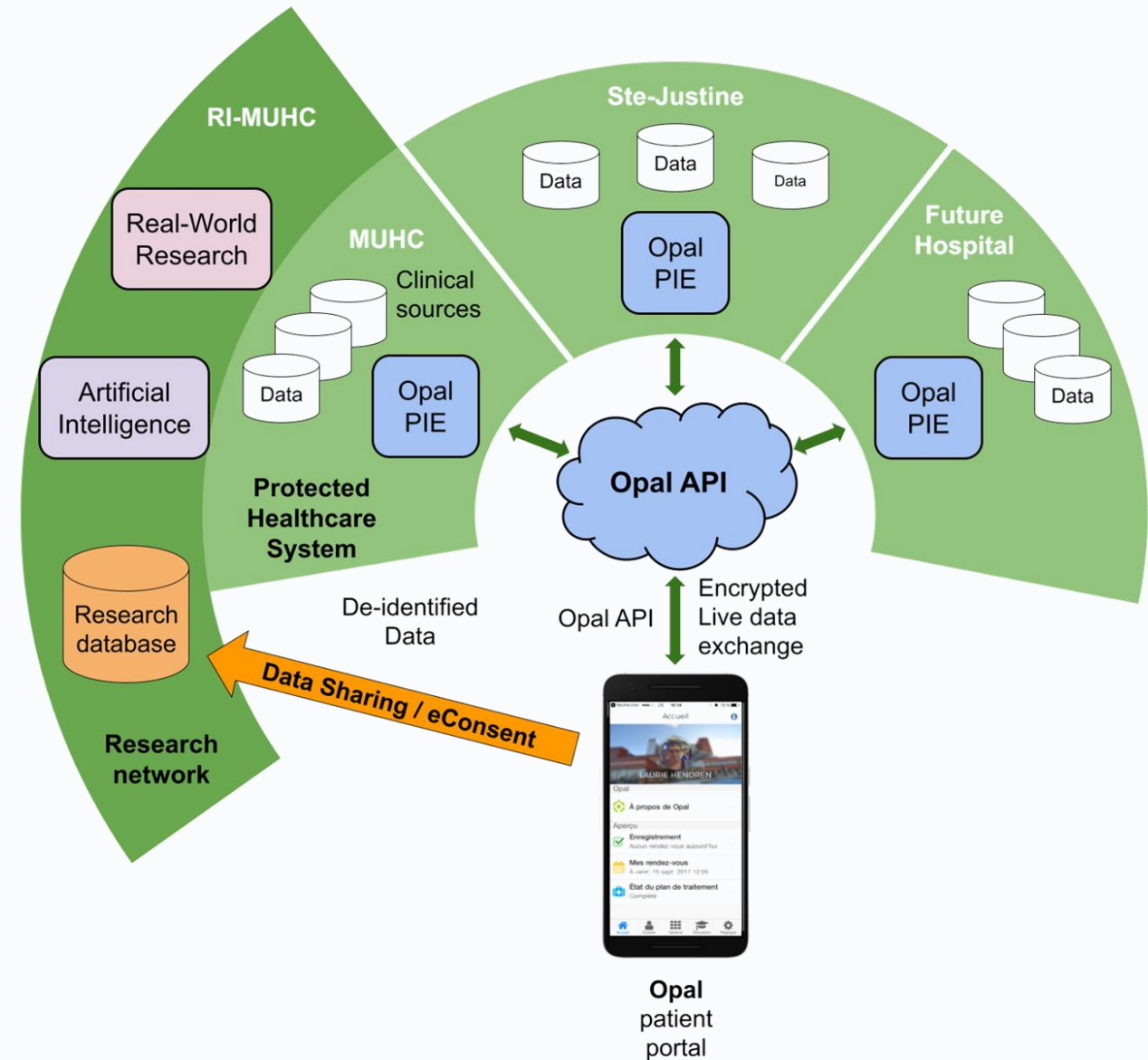
The Problem:



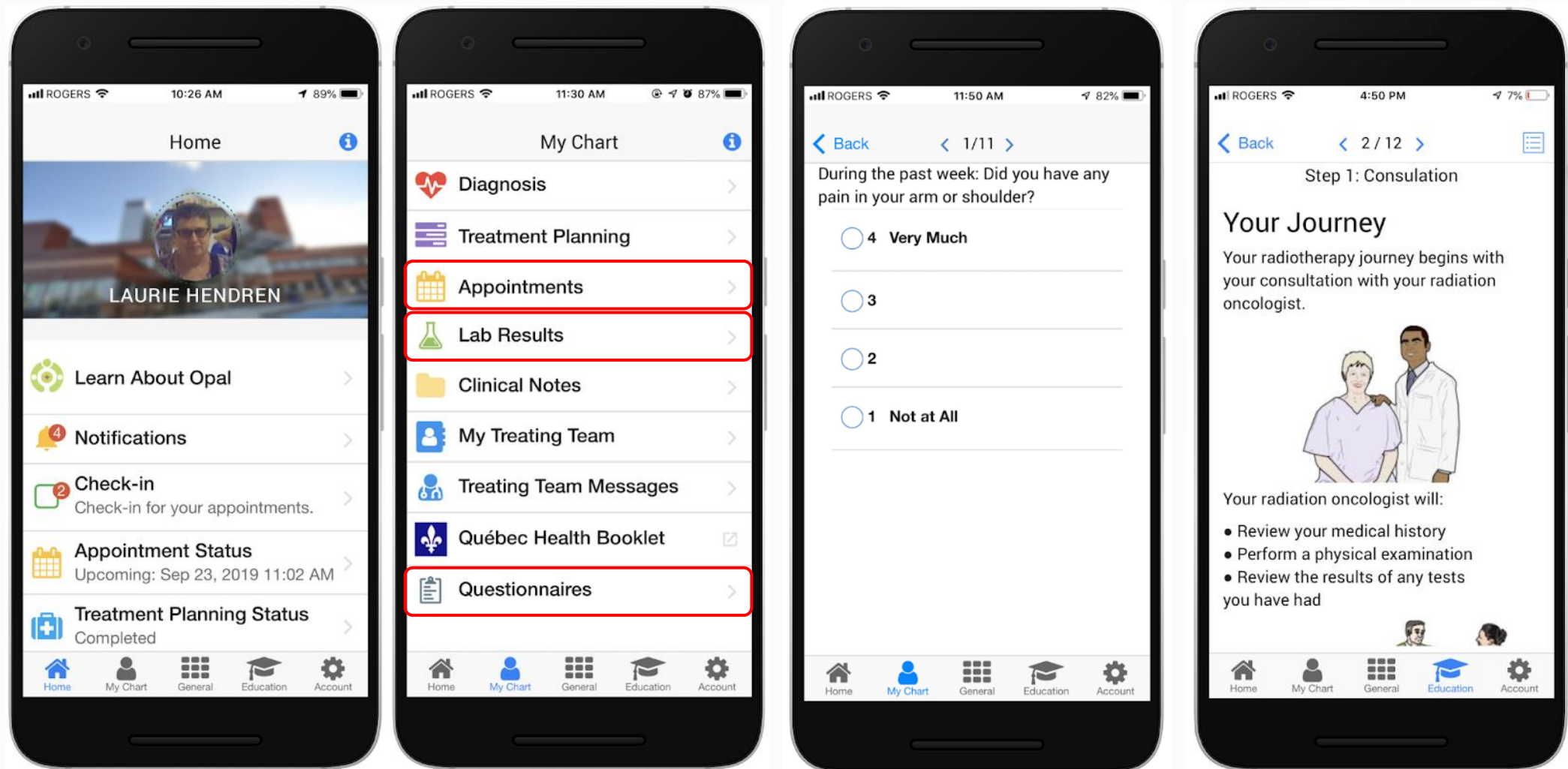
Data are technically challenging to access: legally protected and spread across multiple institutions

Introduction

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



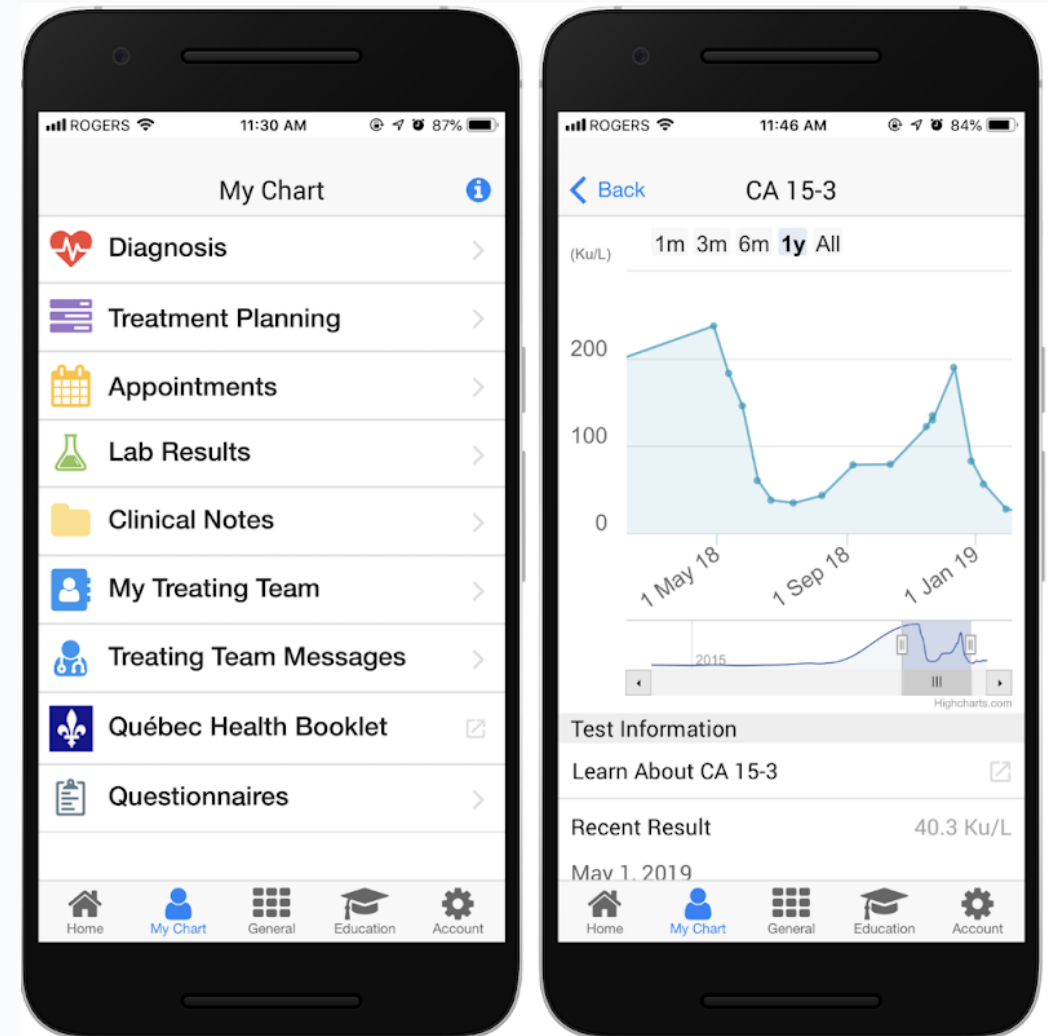
Introduction: Opal Patient Portal



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?

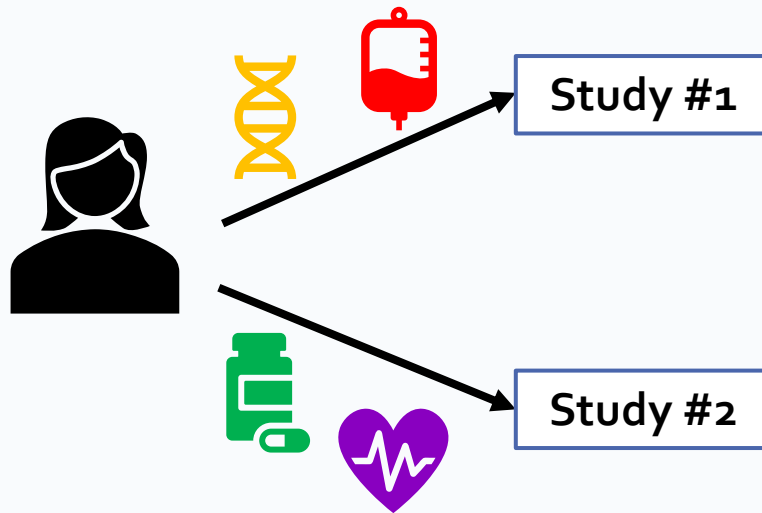
Better informed = reduced anxiety



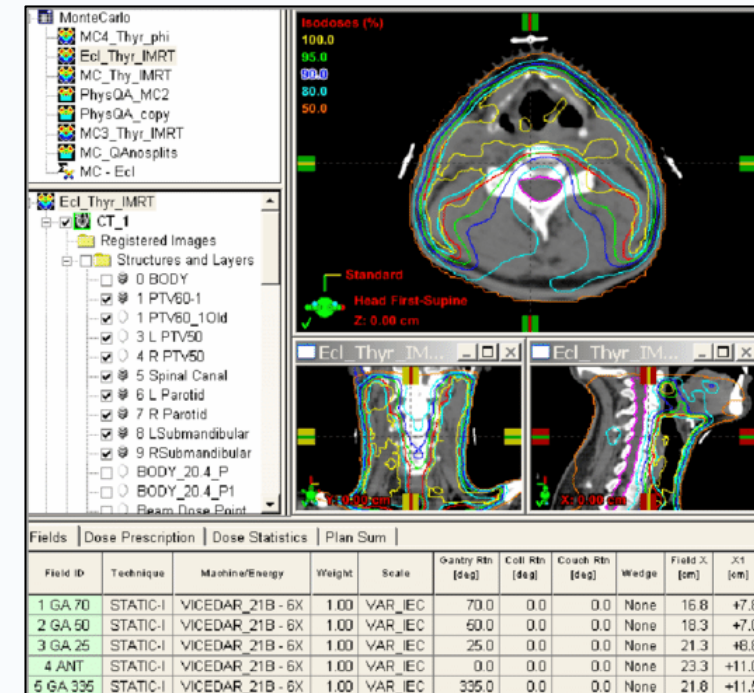
Objectives

- 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



JS



HTML



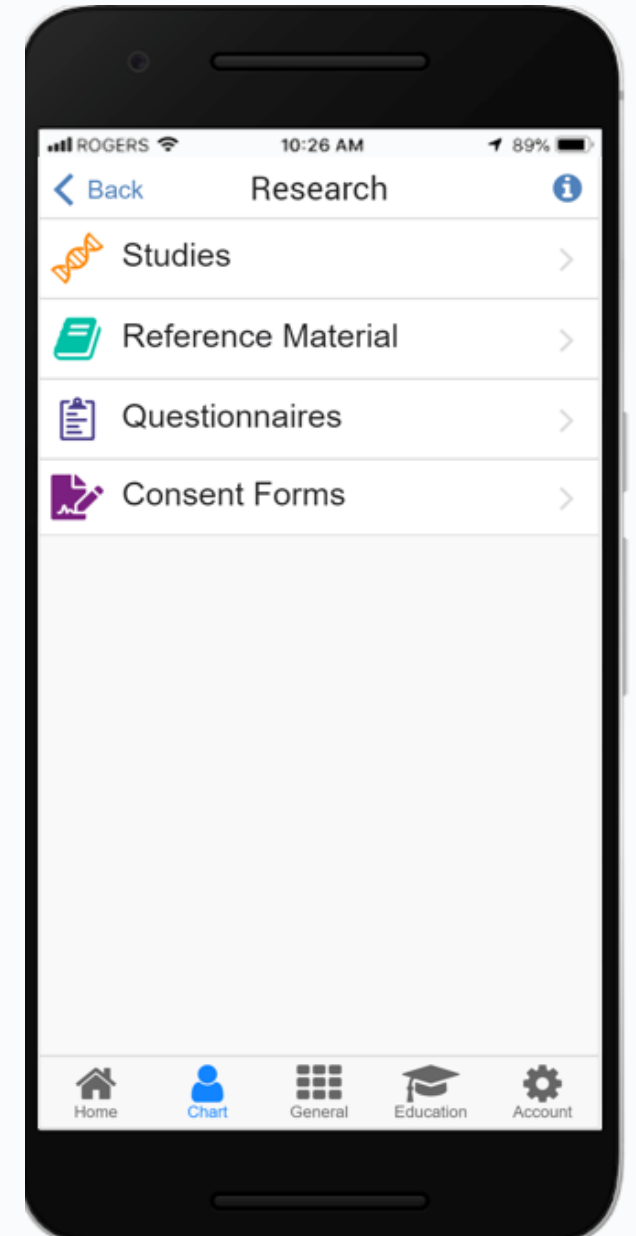
OBJECTIVE #1 – RESEARCH MENU

Methods – Design

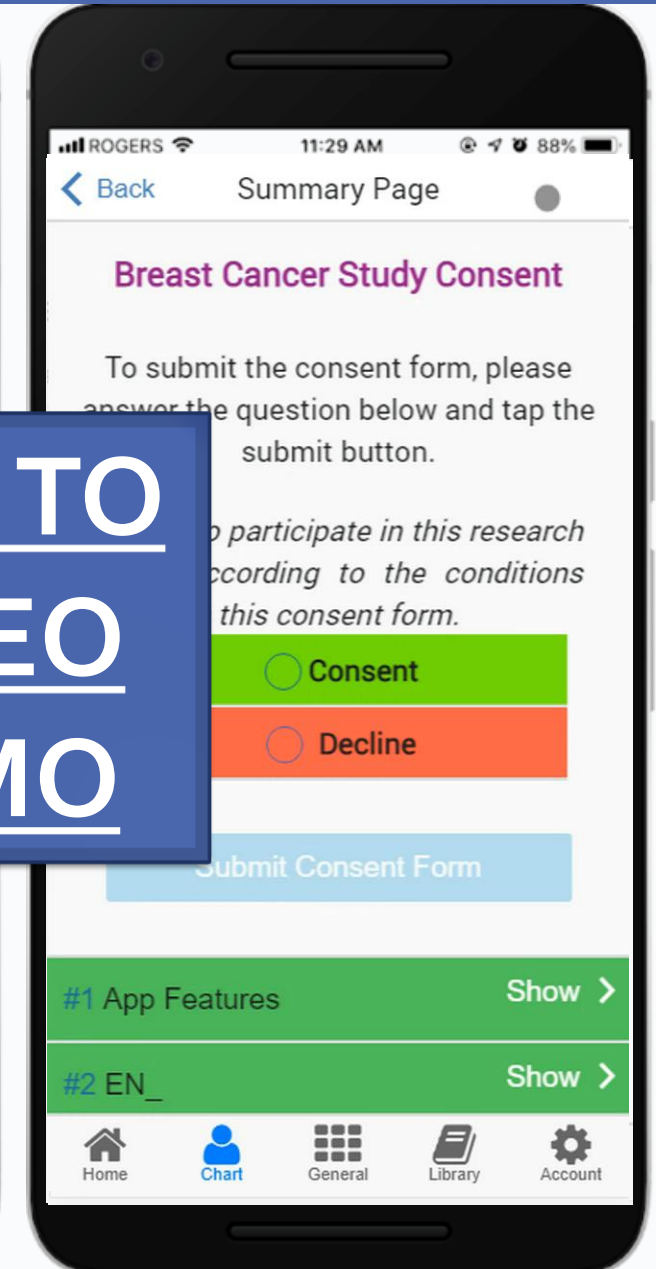
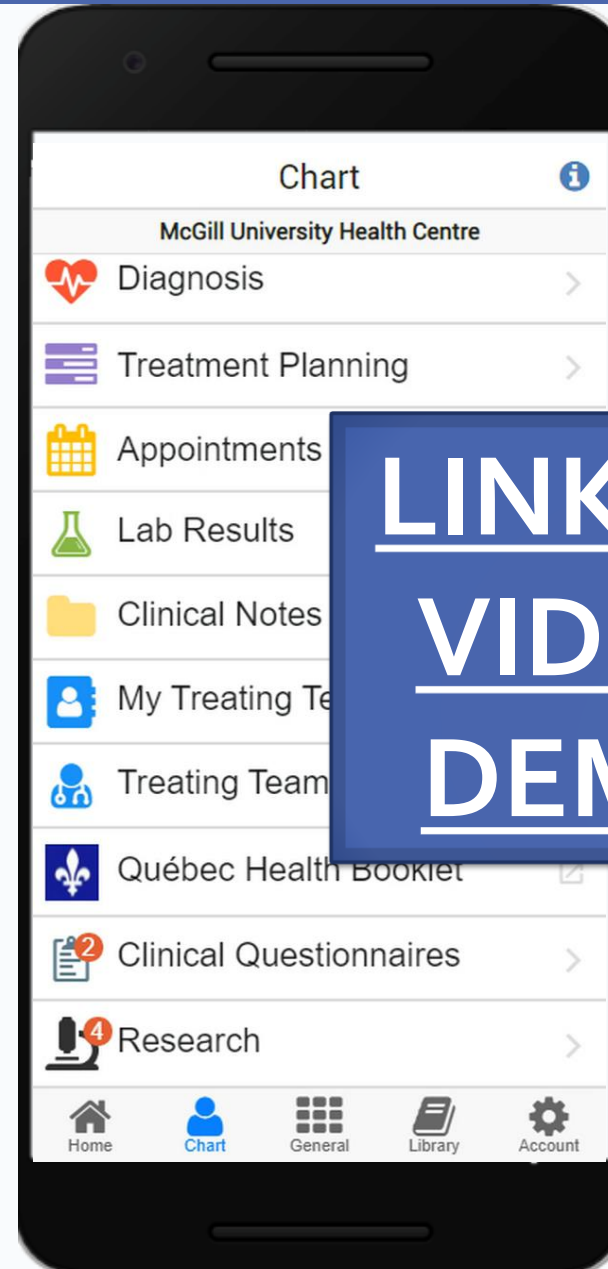
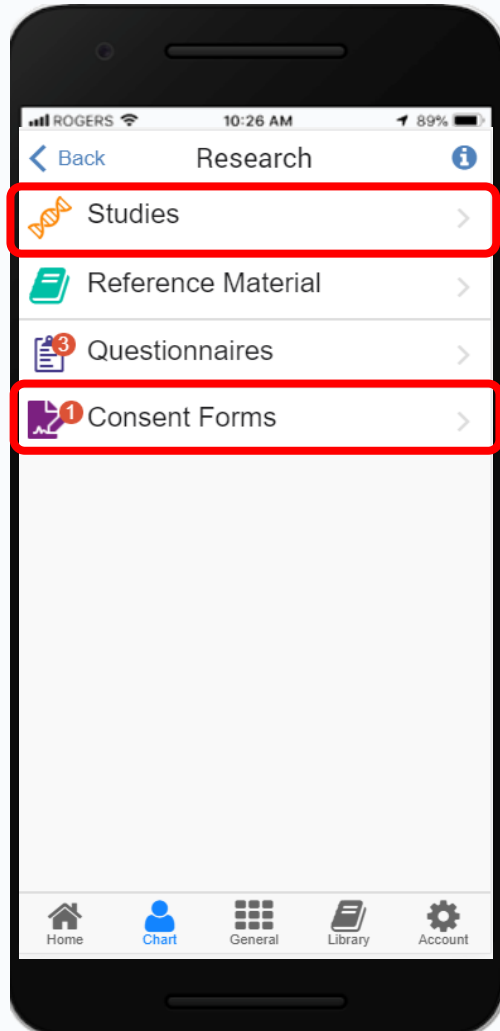
Design goal: allow patients to sign up for and participate in research studies through the app

Features

- Studies
- Consent Forms
- Research Questionnaires
- Reference Material

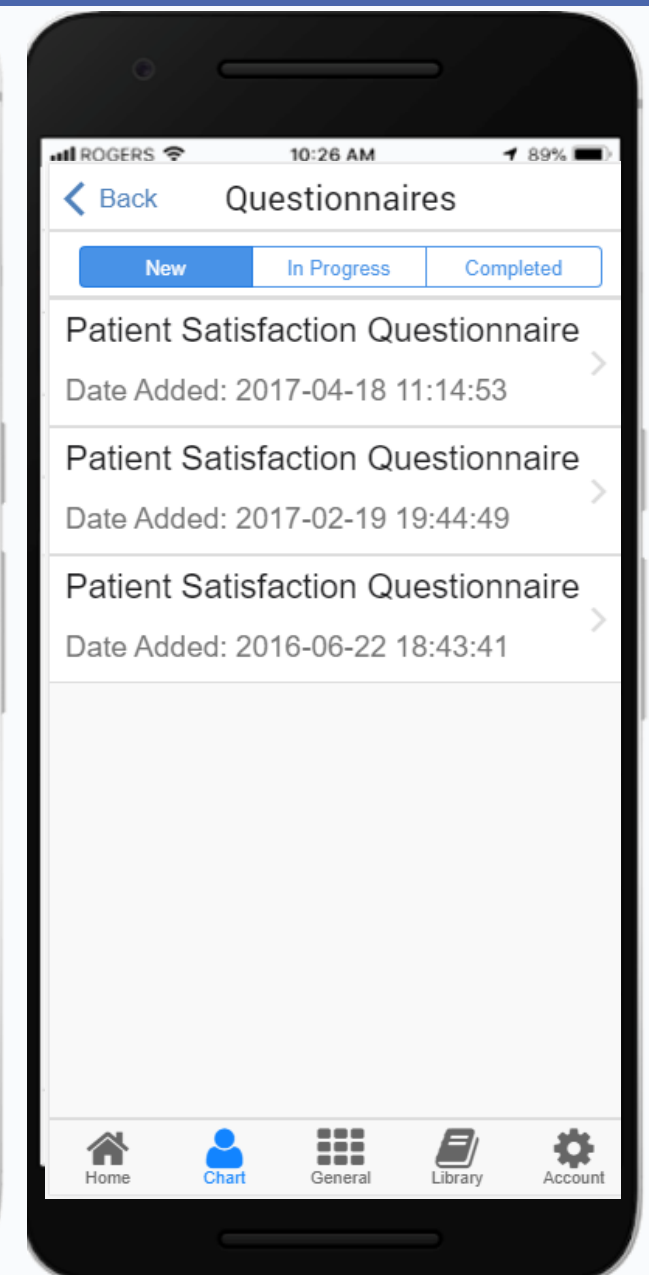
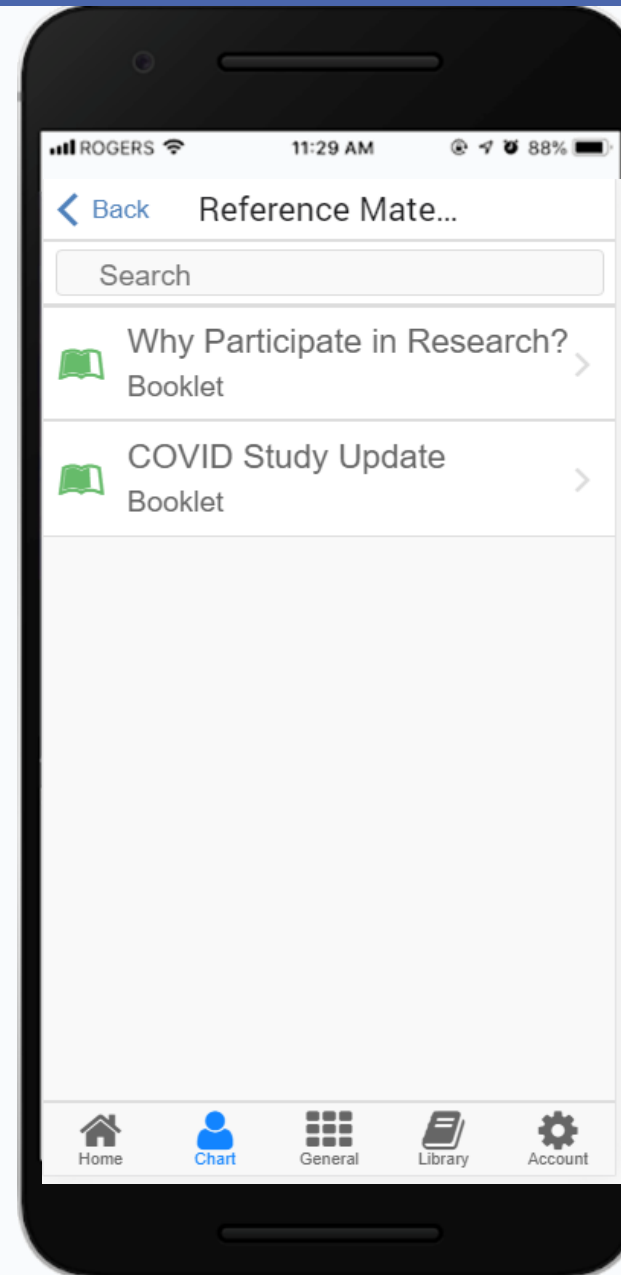
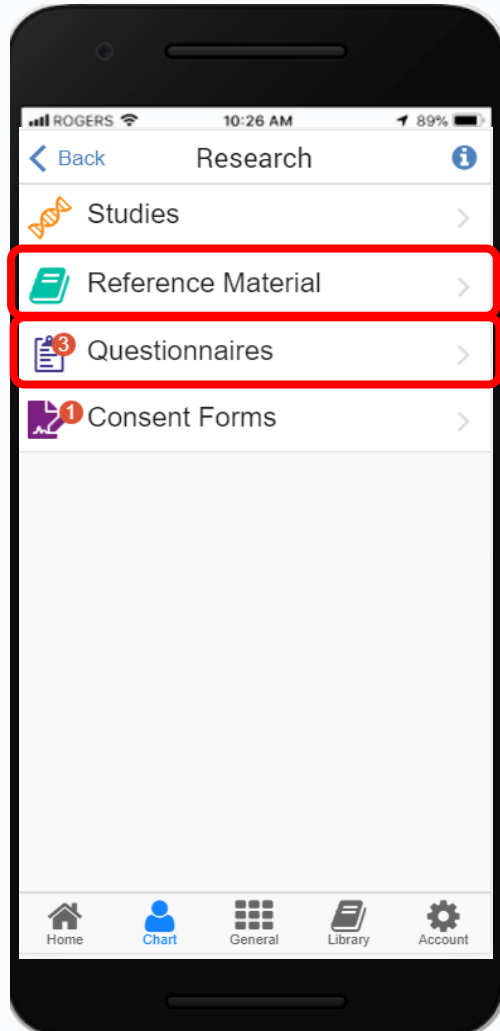


Results - Studies



[LINK TO VIDEO DEMO](#)

Results - Research



OBJECTIVE #2 – RADIOTHERAPY MENU

Methods - Design

DICOM File

Name	Value	Tag	VM	VR
RT Plan Storage				
Instance Creation Date	20110922	(0008, 0012)	1	DA
Instance Creation Time	161411	(0008, 0013)	1	TM
SOP Class UID	RT Plan Storage	(0008, 0016)	1	UI
SOP Instance UID	1.2.246.352.71.5.2088656855.377401.20110920153647	(0008, 0018)	1	UI
Study Date	20110920	(0008, 0020)	1	DA
Study Time	091908	(0008, 0030)	1	TM
Accession Number		(0008, 0050)	1	SH
Modality	RTPLAN	(0008, 0060)	1	CS
Manufacturer	VARIAN Medical Systems	(0008, 0070)	1	LO
Institution Name	CCSEO at KGH	(0008, 0080)	1	LO
Referring Physician's Name		(0008, 0090)	1	PN
Station Name	BUR1-0185	(0008, 1010)	1	SH
Institutional Department Name	RADIATION ONCOLO	(0008, 1040)	1	LO
Operators' Name	rtrow	(0008, 1070)	1	PN
Manufacturer's Model Name	ARIA 8.1 - External Beam Planning	(0008, 1090)	1	LO
Patient's Name	RANDO^PROSTATE	(0010, 0010)	1	PN
Patient ID	TEST PHYS PROSTATE	(0010, 0020)	1	LO
Patient's Birth Date		(0010, 0030)	1	DA
Patient's Sex		(0010, 0040)	1	CS
Software Version(s)	OS 8.1.20	(0018, 1020)	1	LO
Study Instance UID	1.2.840.113619.2.55.3.671756986.106.1316467036.460	(0020, 000d)	1	UI
Series Instance UID	1.2.246.352.71.2.2088656855.723251.20110920153632	(0020, 000e)	1	UI
Study ID	1447	(0020, 0010)	1	SH
Series Number	4	(0020, 0011)	1	IS
RT Plan Label	PROS	(300a, 0002)	1	SH
RT Plan Name	PROS	(300a, 0003)	1	LO
RT Plan Date	20110922	(300a, 0006)	1	DA
RT Plan Time	161342	(300a, 0007)	1	TM
RT Plan Geometry	PATIENT	(300a, 000c)	1	CS
Dose Reference Sequence				
Dose Reference 1				
Dose Reference Number	1	(300a, 0012)	1	IS
Dose Reference UID	1.2.246.352.72.11.2088656855.250418.20110920153745	(300a, 0013)	1	UI
Dose Reference Structure Type	SITE	(300a, 0014)	1	CS
Dose Reference Description	PROS	(300a, 0016)	1	LO
Dose Reference Type	TARGET	(300a, 0020)	1	CS
Target Prescription Dose	46.0	(300a, 0026)	1	DS
Private Creator	Varian Medical Systems VISION 3267	(3267, 0010)	1	OB
Private tag data	PROS	(3267, 1000)	1	OB
Dose Reference 2				
Tolerance Table Sequence				
Tolerance Table 1				
Fraction Group Sequence		(300a, 0070)	1	SQ
Fraction Group 1				
Fraction Group Number	1	(300a, 0071)	1	IS

My Design

Informative Page

- # fractions, beam energy, etc.

3D Page

- Body + Beams

Treatment Planning System

The screenshot displays a Treatment Planning System (TPS) interface. On the left, a tree view shows the plan structure, including 'MC4_Thyr_phi', 'Ecl_Thyr_IMRT', 'MC_Thyr_IMRT', 'PhysQA_MC2', 'PhysQA_copy', 'MC3_Thyr_IMRT', 'MC_QAnosplits', and 'MC - Ecl'. The main window shows a 3D axial view of a patient's head and neck with various colored contours. A status bar at the top right indicates '100.0', '95.0', '90.0', '80.0', and '50.0'. Below the main view, there are two smaller 3D views labeled 'Ecl_Thyr IM...' and 'Ecl_Thyr IM...'. At the bottom, a table titled 'Fields | Dose Prescription | Dose Statistics | Plan Sum' provides detailed information about the treatment plan.

Field ID	Technique	Machine/Energy	Weight	Scale	Gantry Rtn [deg]	Coll Rtn [deg]	Coach Rtn [deg]	Wedge	Field X [cm]	X1 [cm]
1 GA 70	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	70.0	0.0	0.0	None	16.8	+7.8
2 GA 50	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	50.0	0.0	0.0	None	18.3	+7.0
3 GA 25	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	25.0	0.0	0.0	None	21.3	+6.8
4 ANT	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	0.0	0.0	0.0	None	23.3	+11.0
5 GA 335	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	335.0	0.0	0.0	None	21.8	+11.5
6 GA 317	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	317.0	0.0	0.0	None	18.8	+10.8
7 GA 285	STATIC-I	VICEDAR_21B - 6X	1.00	VAR_IJC	285.0	0.0	0.0	None	15.8	+8.0

Introduction

Objective

Methods

Results

Discussion

Methods – Personalized Text

DICOM RT PLAN

- Particle type
- Beam Energy
- Patient position
- Dose
- # fractions
- Etc ...



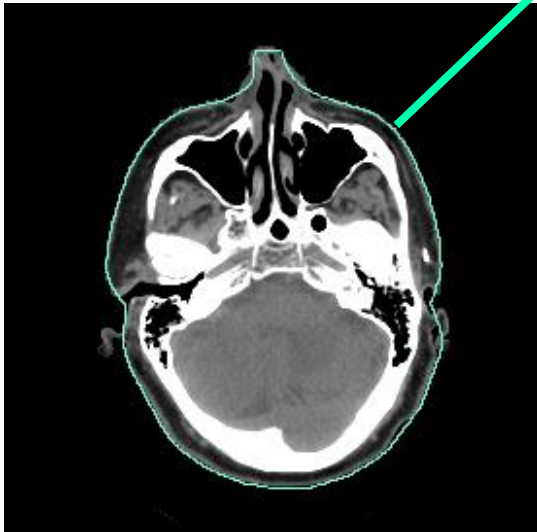
Example Text

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

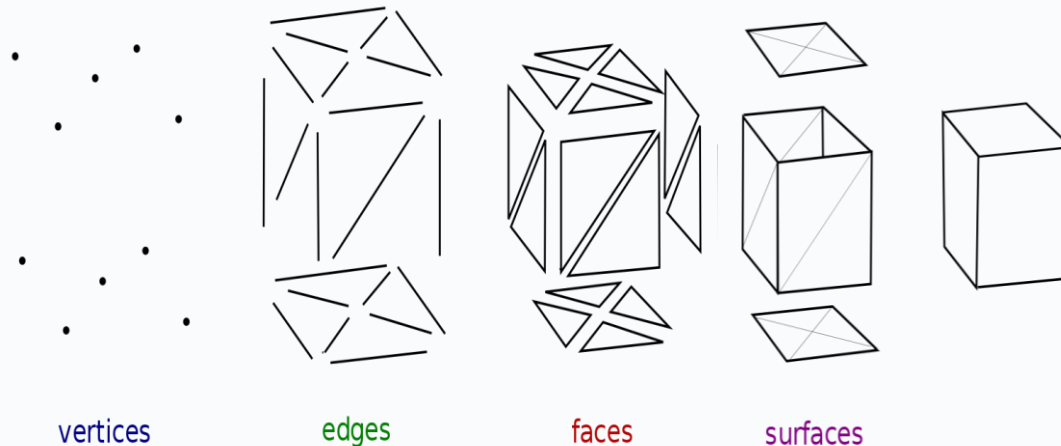
DICOM RT STRUCT



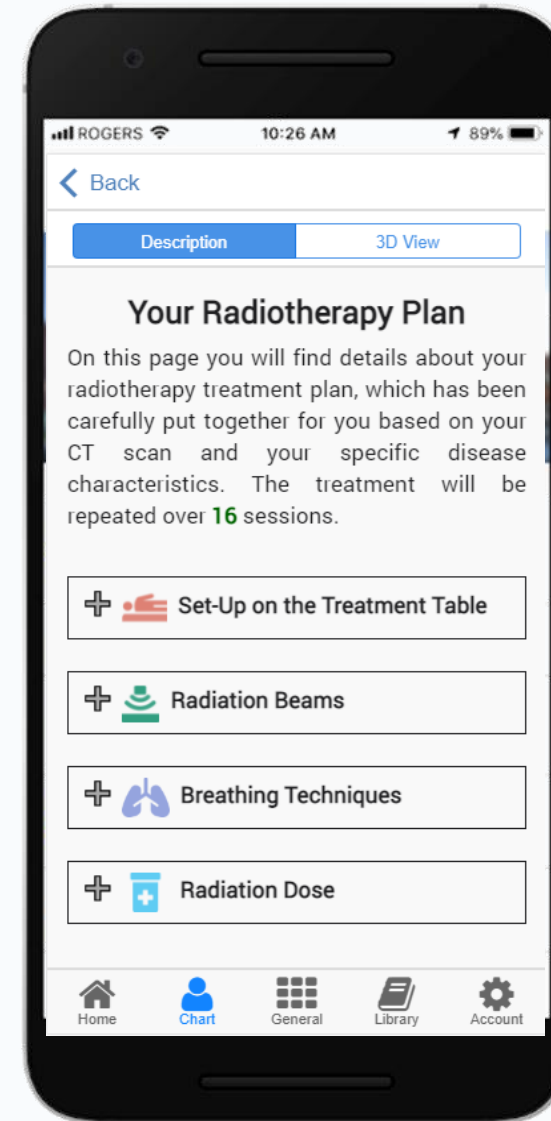
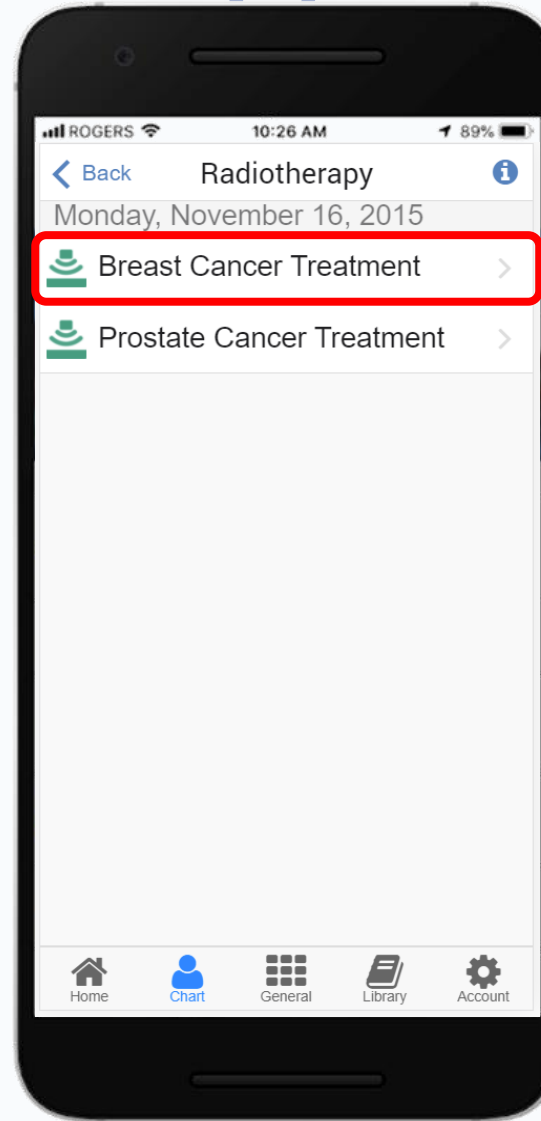
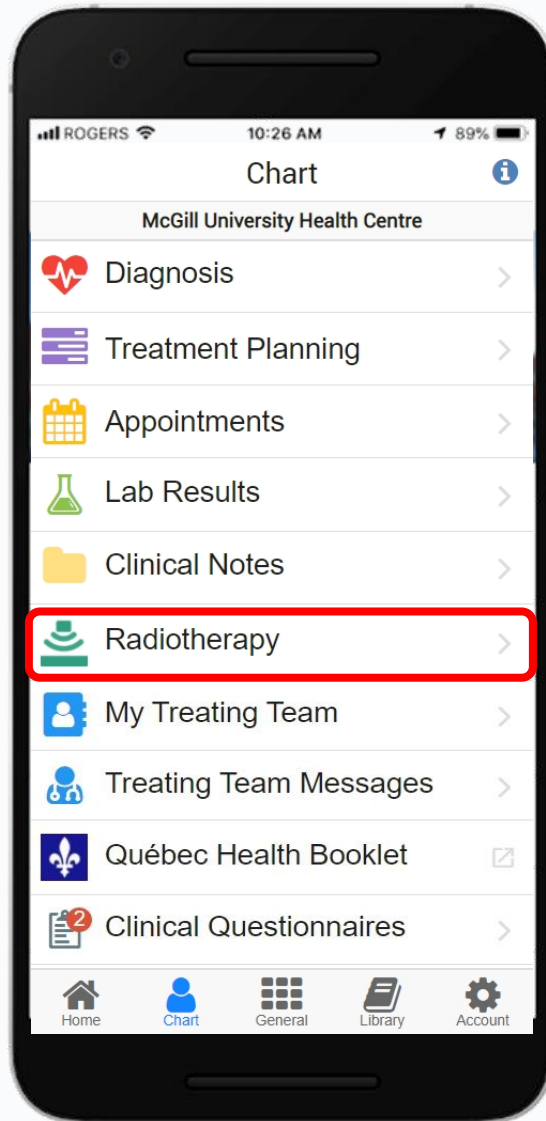
Body Contour Data:

```
[104.003725, -69.854828562500003, -122.5, 105.956849000000001, -69.854828562500003, -122.5, 107.909972999999999, -69.854828562500003, -122.5, 108.886534999999999, -69.8243109999999994, -122.5,
```

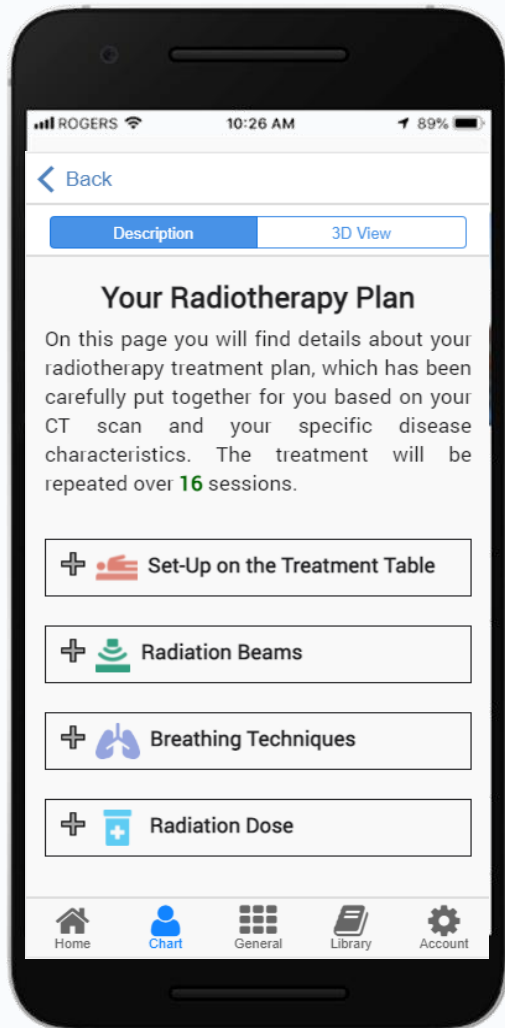
- 3D Modelling with surface triangulation



Results – Radiotherapy



Results – Personalized Text



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.

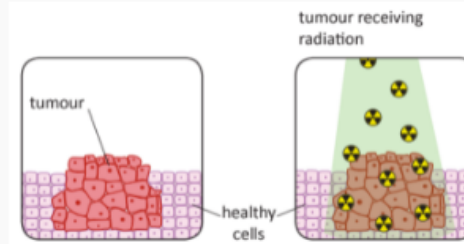


On the treatment table, you will lie on your **back with your head towards the machine**.

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

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.



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

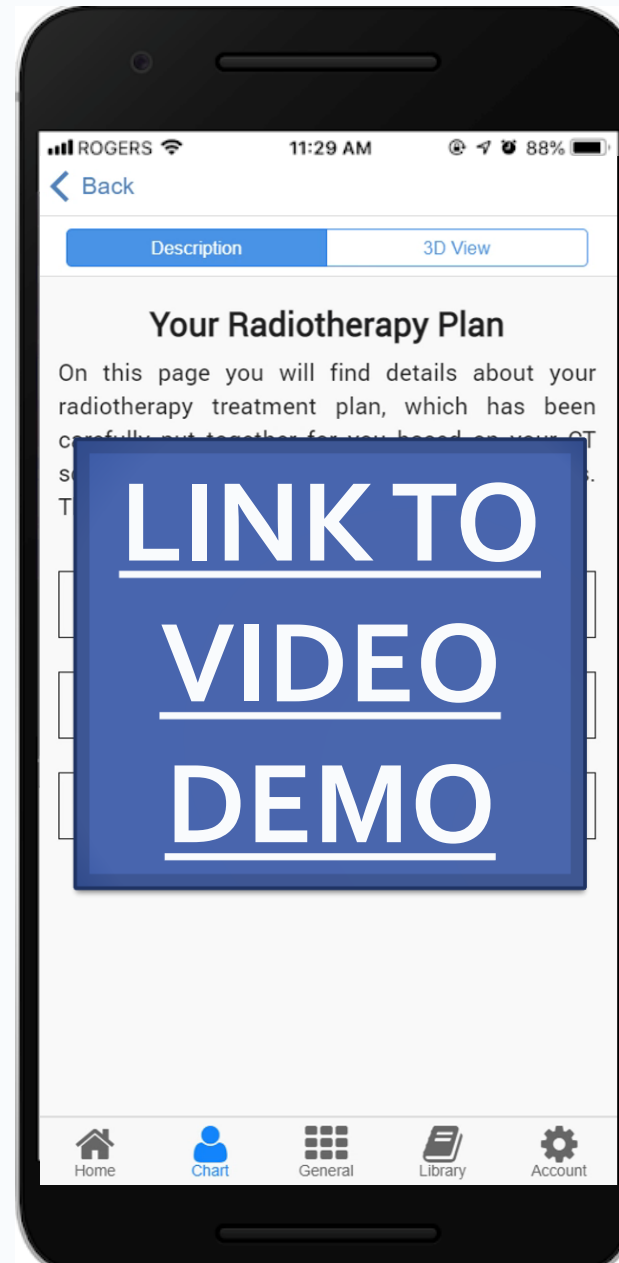
Radiation Dose

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

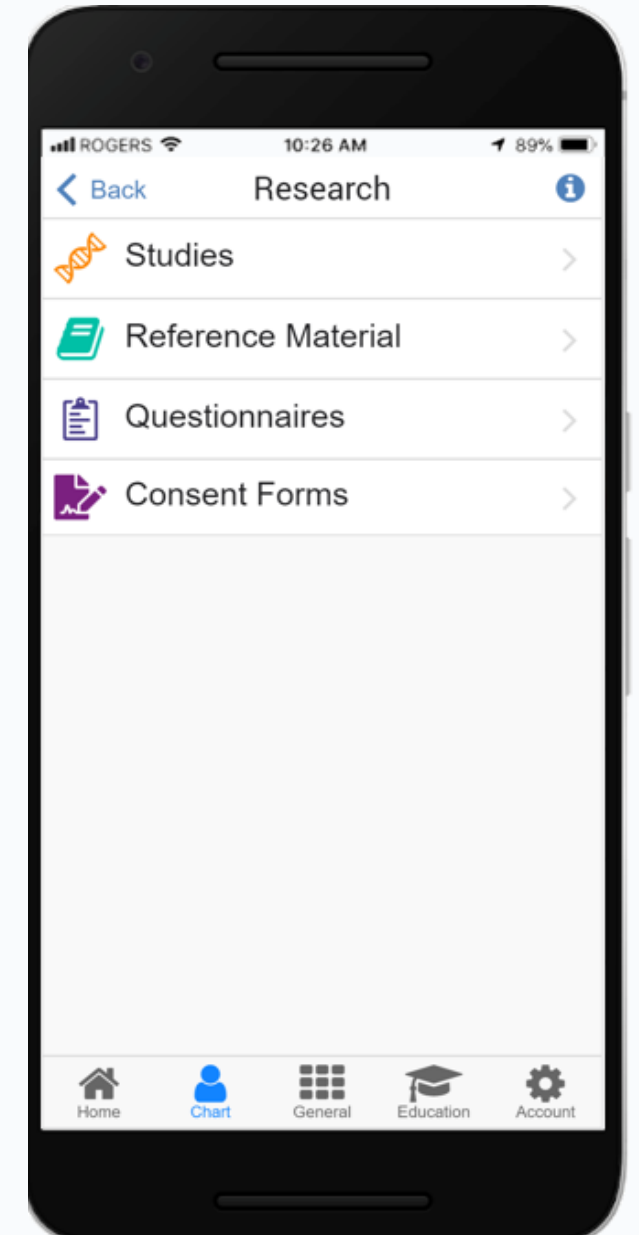
Patient Focus Group

Data Sharing

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

Research menu

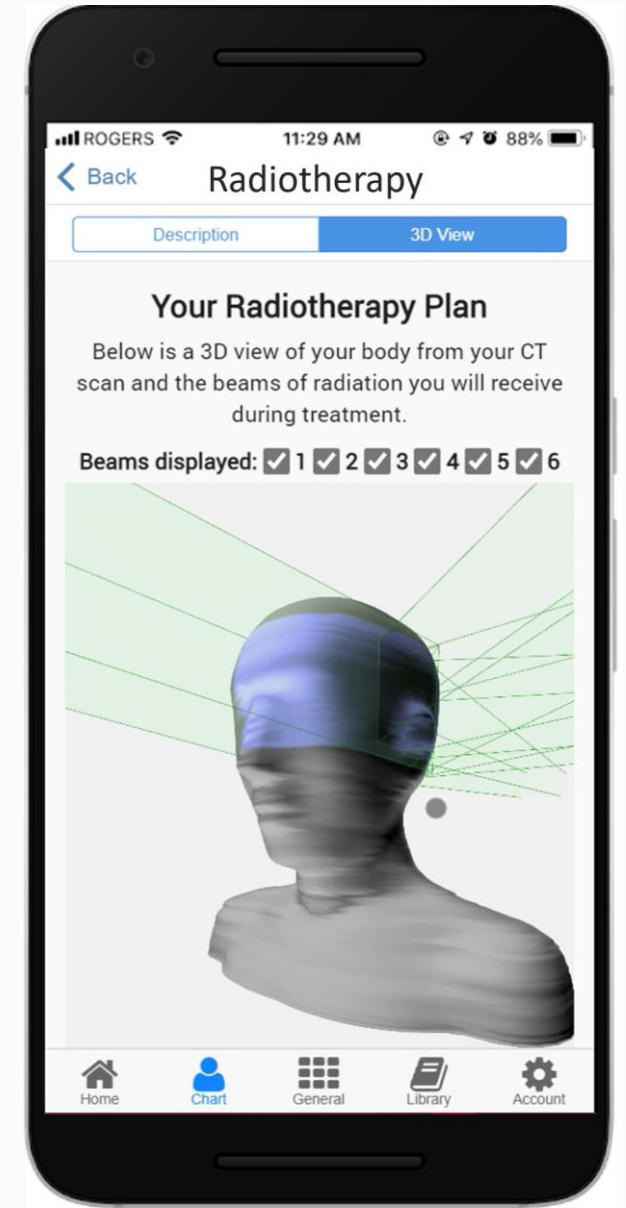
- Felt the design met their needs
- ***Pre-established trust with Opal***



Patient Focus Group

Radiotherapy Menu

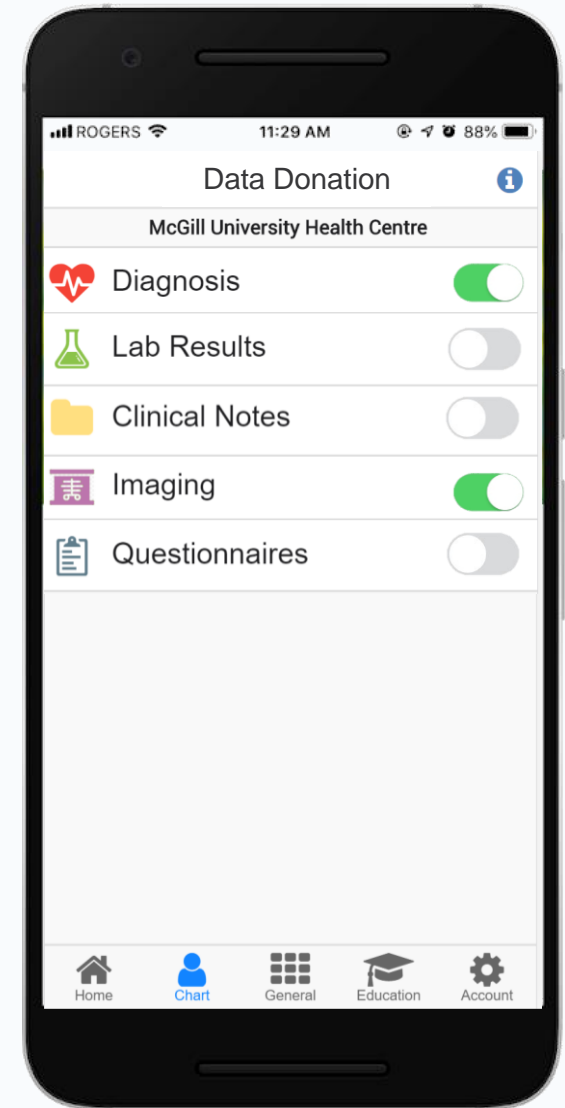
- Patients wish they had this when they went through treatment
- Would help patients be better prepared and less anxious by taking away unknowns
- After seeing it, would be happy to share with researchers



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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McGill University
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THANK YOU
