Patient-controlled data to facilitate the care pathway and quality control

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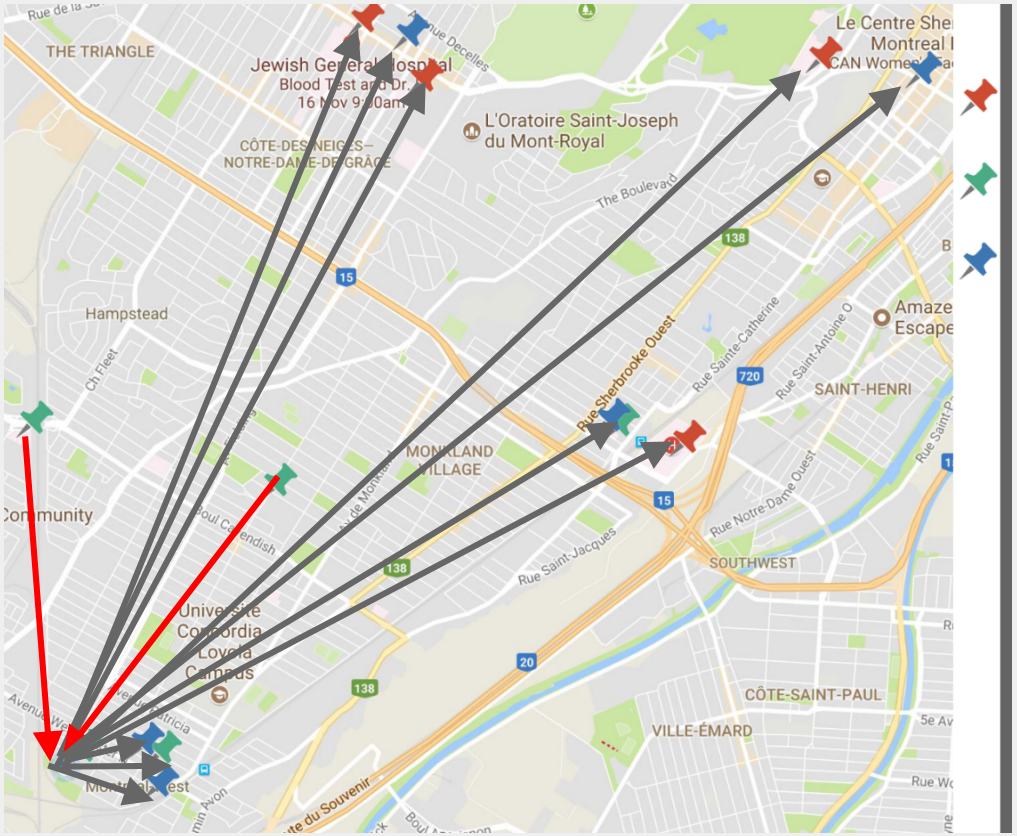
Professor, FRSC, CRC

Computer Science

McGill University

Please contact me at: **hendren@cs.mcgill.ca**

My treatment network - 36 sq. km. in Montreal



- **4 hospitals**
- **5 public clinics**
- **5 private clinics**

http://www.breastcancer.org/tips/managing_records

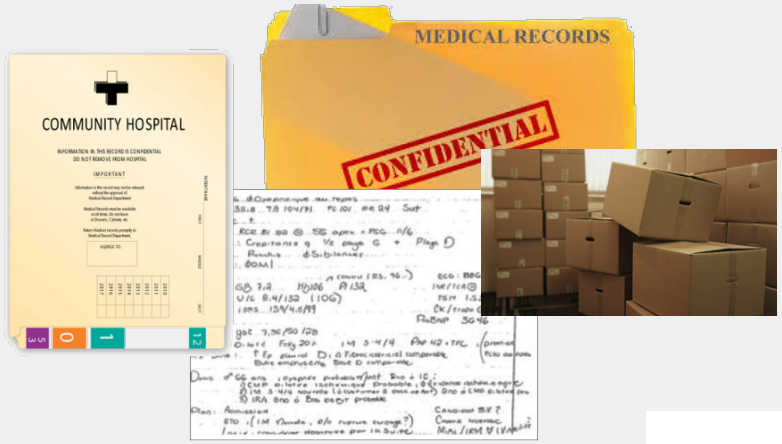
BREASTCANCER.ORG
REAL. ANSWERS.

Because your medical history is spread out among your entire medical team, it's a good idea for you to ***keep your own complete, updated records so you can play an active, informed role in your care****. Knowing your medical history* ***allows you to share accurate information*** *with a new doctor, a nutritionist, a complementary medicine practitioner, or a personal trainer. In this way, you ensure that you continue to receive the best care possible.*

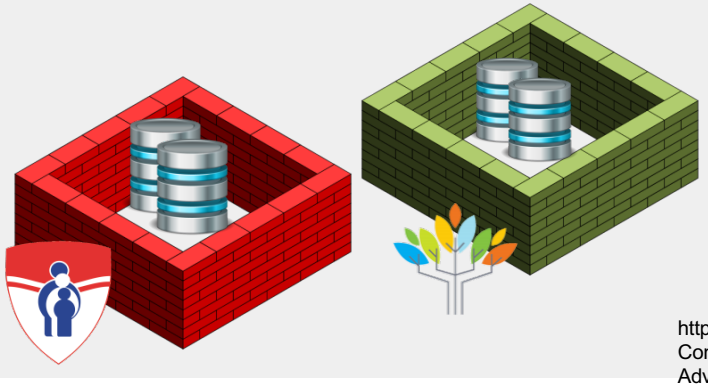
Current Status

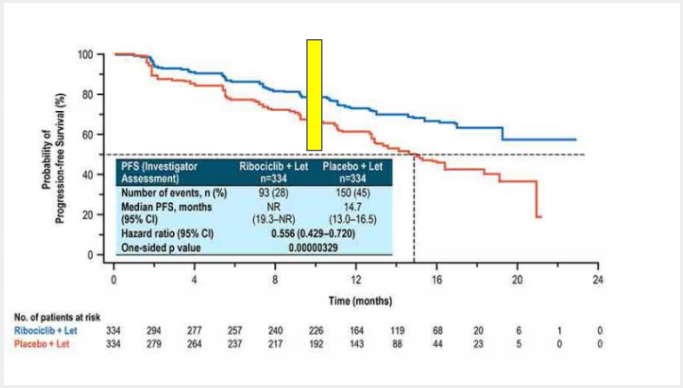
My experience, where is my data currently stored and how is it shared?

Where is my data stored?



DOSSIER SANTÉ QUÉBEC

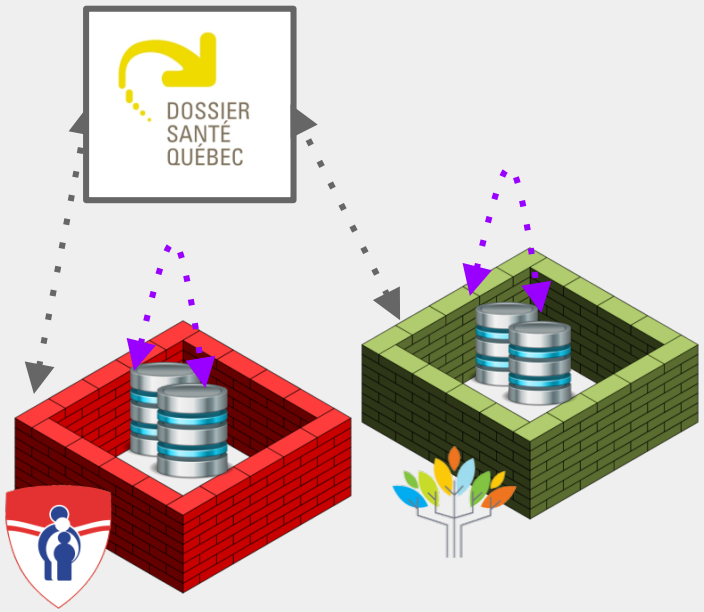




http://www.esmo.org/Conferences/Past-Conferences/ESMO-2016-Congress/Press-Media/Ribociclib-Improves-Progression-free-Survival-in-Advanced-Breast-Cancer

How is my data currently shared?

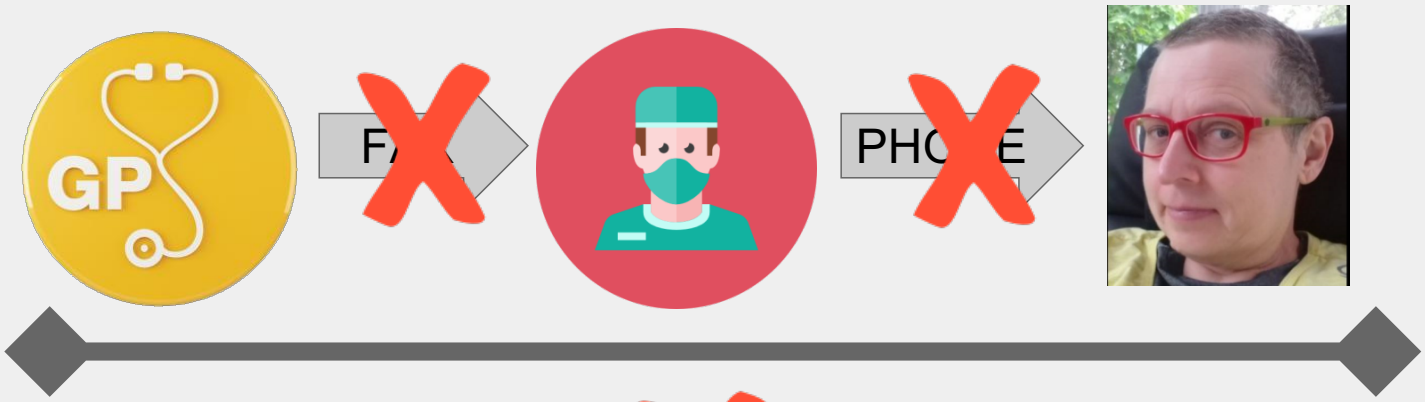
CANADA POST / POSTES CANADA



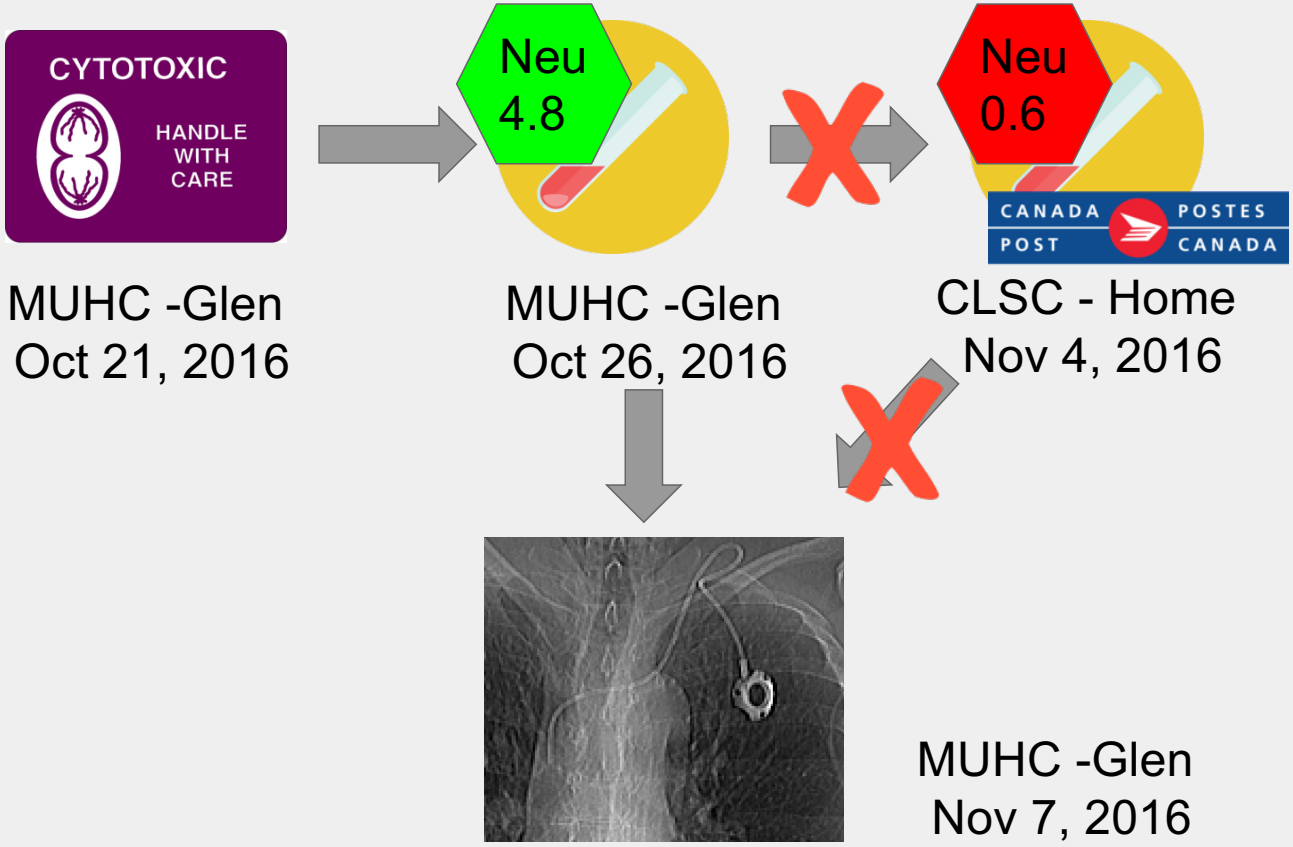
What can go wrong?

Based on personal experience ….

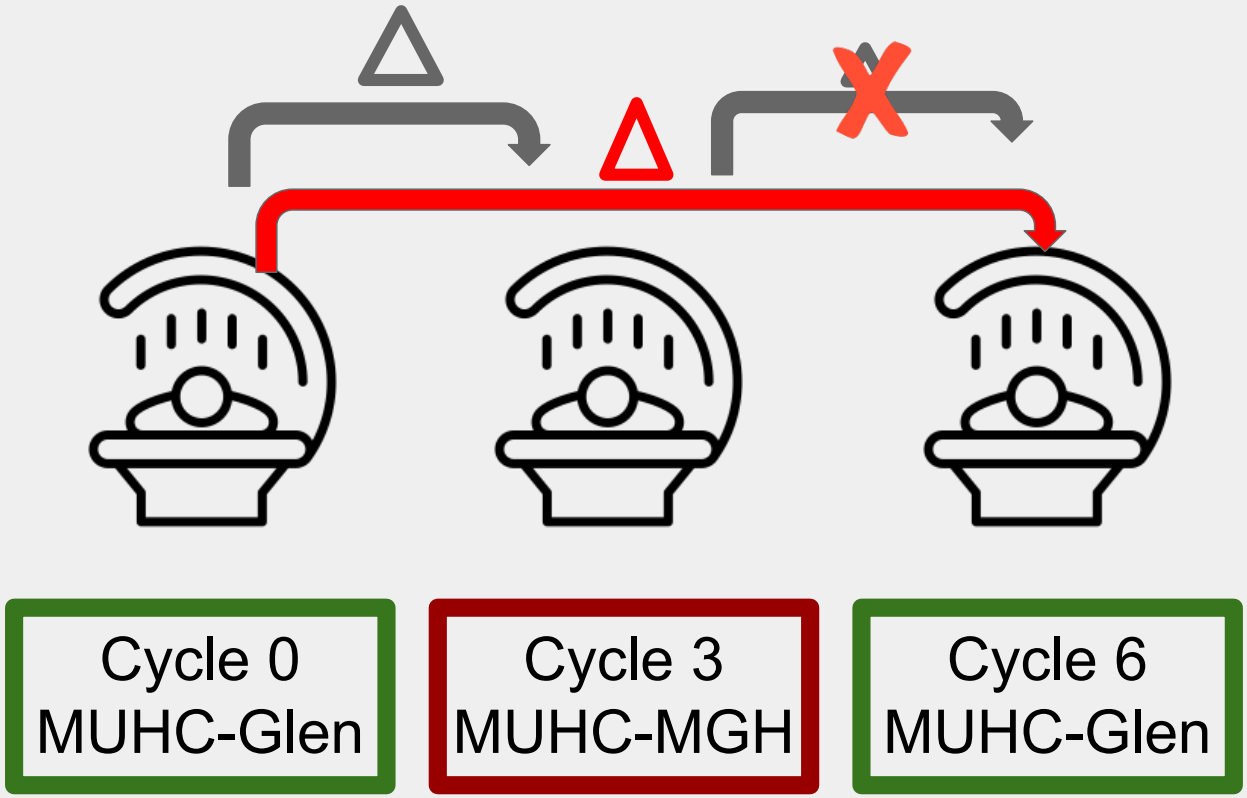
Delays in my diagnosis and treatment



Clinicians missing data, using out-of-date data.



Another example of using the wrong data ....



Unreasonable burden on me to provide data

Just go and pick-up the film, CD and reports from your mammograms and ultrasound, and take them with you to the surgeon.

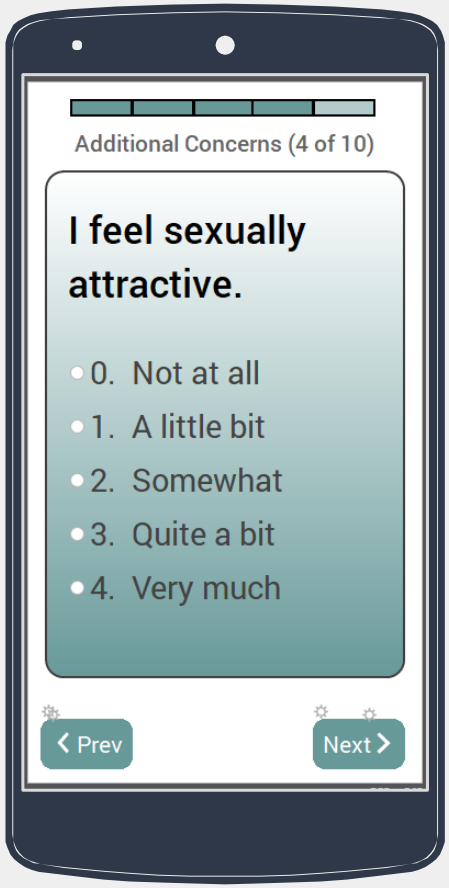
Just get your list of medications from the pharmacist.

Waste of time repeatedly giving my history

What is your age?
How much do you weigh?
When were you diagnosed?
What has happened since your last annual exam?
What are your medications?

Annoying PRO questions

- Lack of ability to give feedback about a question.
- No access to my previous answers
- Lack of feedback about results of study.

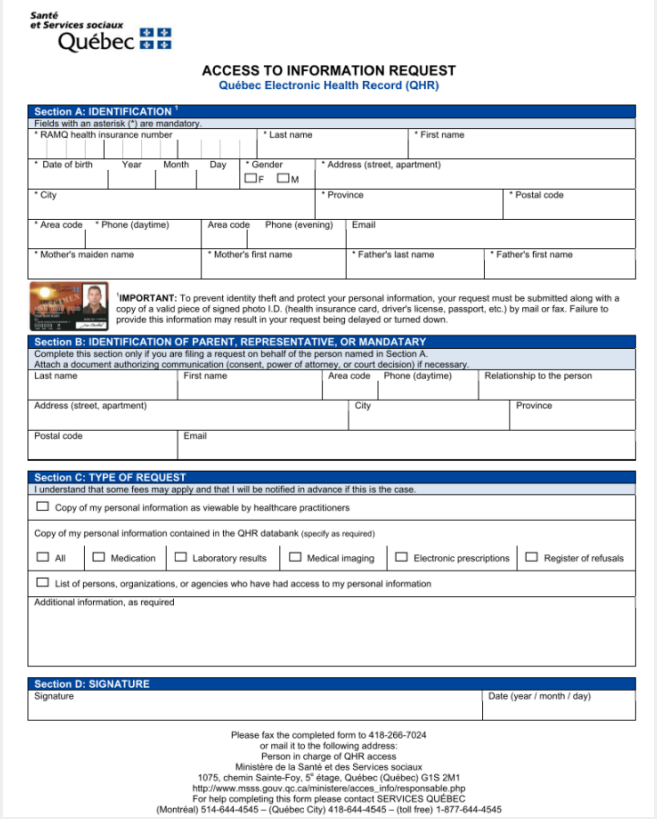


Patient-stored data

My current options as a patient ….

Getting my data …. (not so easy)

- Ask politely for a copy
- Ask more firmly for a copy
- Ask a different person
- Say that I need a copy for my GP/oncologist
- Fill out a form (pay a fee) and wait



Santé et Services sociaux Québec

ACCESS TO INFORMATION REQUEST
Québec Electronic Health Record (QHR)

Section A: IDENTIFICATION [1]
Fields with an asterisk (*) are mandatory.

* RAMQ health insurance number		* Last name	* First name
* Date of birth (Year / Month / Day)	* Gender ☐F ☐M	* Address (street, apartment)	
* City	* Province		* Postal code
* Area code * Phone (daytime)	Area code Phone (evening)	Email	
* Mother's maiden name	* Mother's first name	* Father's last name	* Father's first name

[1] **IMPORTANT:** To prevent identity theft and protect your personal information, your request must be submitted along with a copy of a valid piece of signed photo I.D. (health insurance card, driver's license, passport, etc.) by mail or fax. Failure to provide this information may result in your request being delayed or turned down.

Section B: IDENTIFICATION OF PARENT, REPRESENTATIVE, OR MANDATARY
Complete this section only if you are filing a request on behalf of the person named in Section A.
Attach a document authorizing communication (consent, power of attorney, or court decision) if necessary.

Last name	First name	Area code Phone (daytime)	Relationship to the person
Address (street, apartment)	City		Province
Postal code	Email		

Section C: TYPE OF REQUEST
I understand that some fees may apply and that I will be notified in advance if this is the case.

☐ Copy of my personal information as viewable by healthcare practitioners

Copy of my personal information contained in the QHR databank (specify as required)

☐ All ☐ Medication ☐ Laboratory results ☐ Medical imaging ☐ Electronic prescriptions ☐ Register of refusals

☐ List of persons, organizations, or agencies who have had access to my personal information

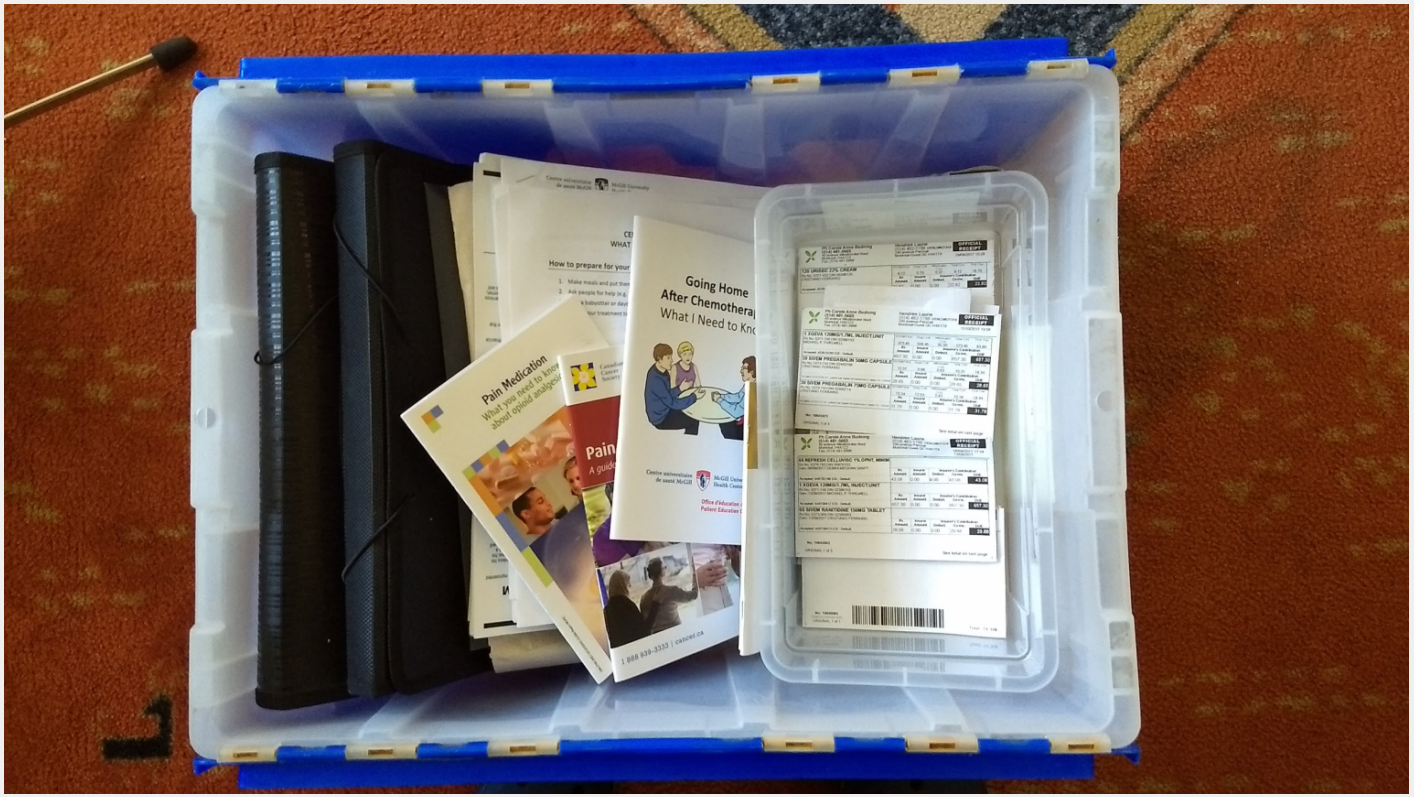
Additional information, as required

Section D: SIGNATURE

Signature	Date (year / month / day)

Please fax the completed form to 418-266-7024
or mail it to the following address:
Person in charge of QHR access
Ministère de la Santé et des Services sociaux
1075, chemin Sainte-Foy, 5e étage, Québec (Québec) G1S 2M1
http://www.msss.gouv.qc.ca/ministere/acces_info/responsable.php
For help completing this form please contact SERVICES QUÉBEC
(Montréal) 514-644-4545 – (Québec City) 418-644-4545 – (toll free) 1-877-644-4545

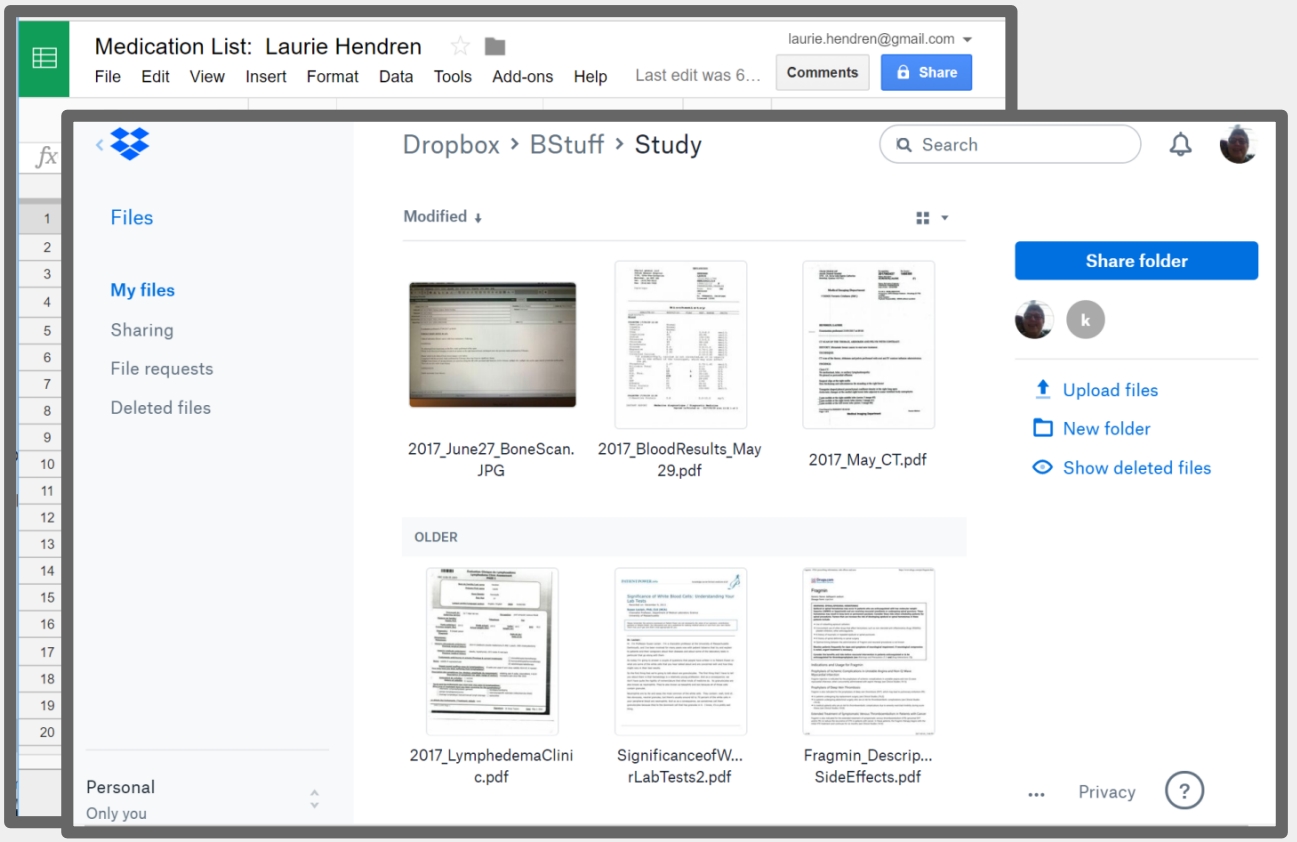
Storing my data …. first solution



A better solution ....

Google Docs

Dropbox

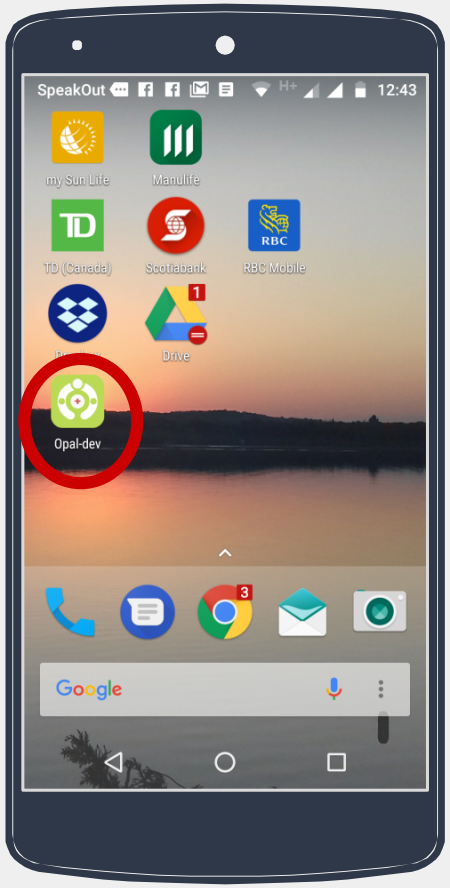


Patient-controlled data

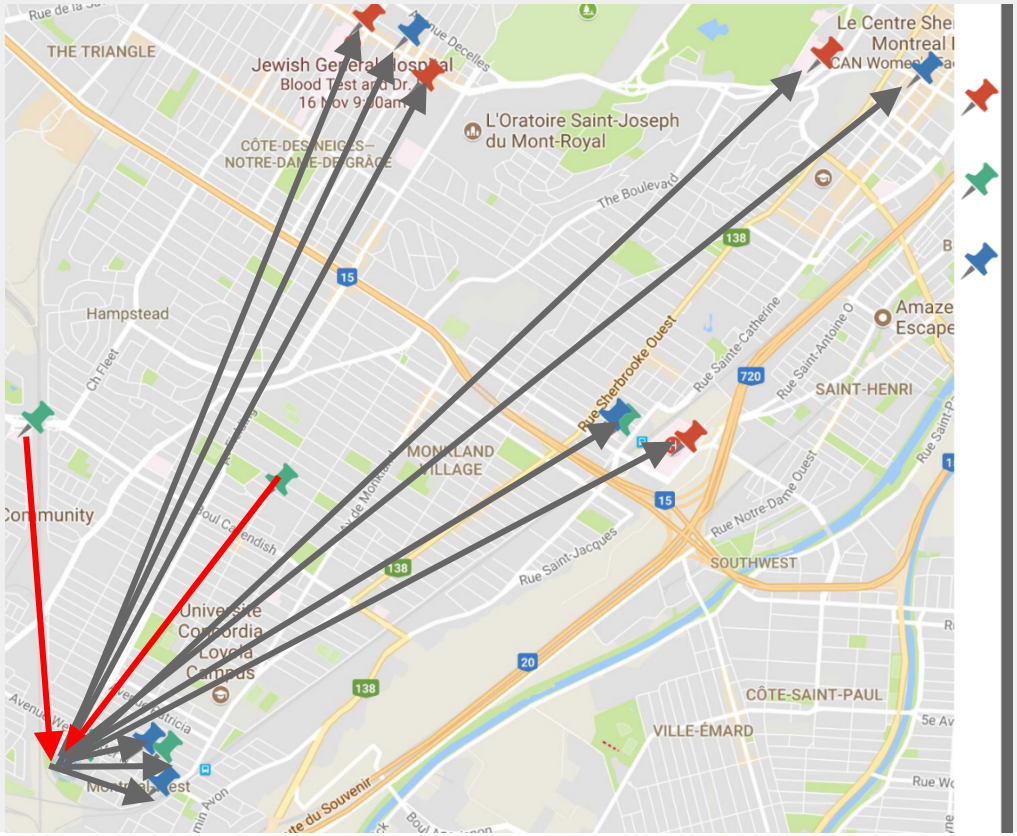
Thinking outside of the box ….

Where is my important non-health data?

- Current data and notifications provided automatically to me.
- Available via my e-devices.



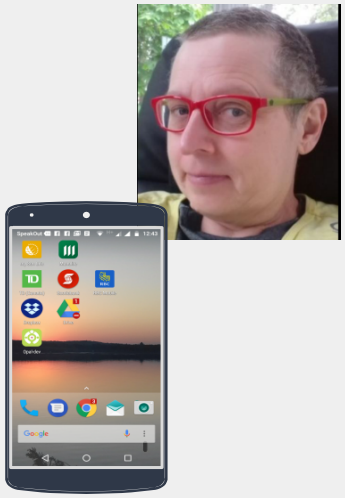
What is the common element in my health network?



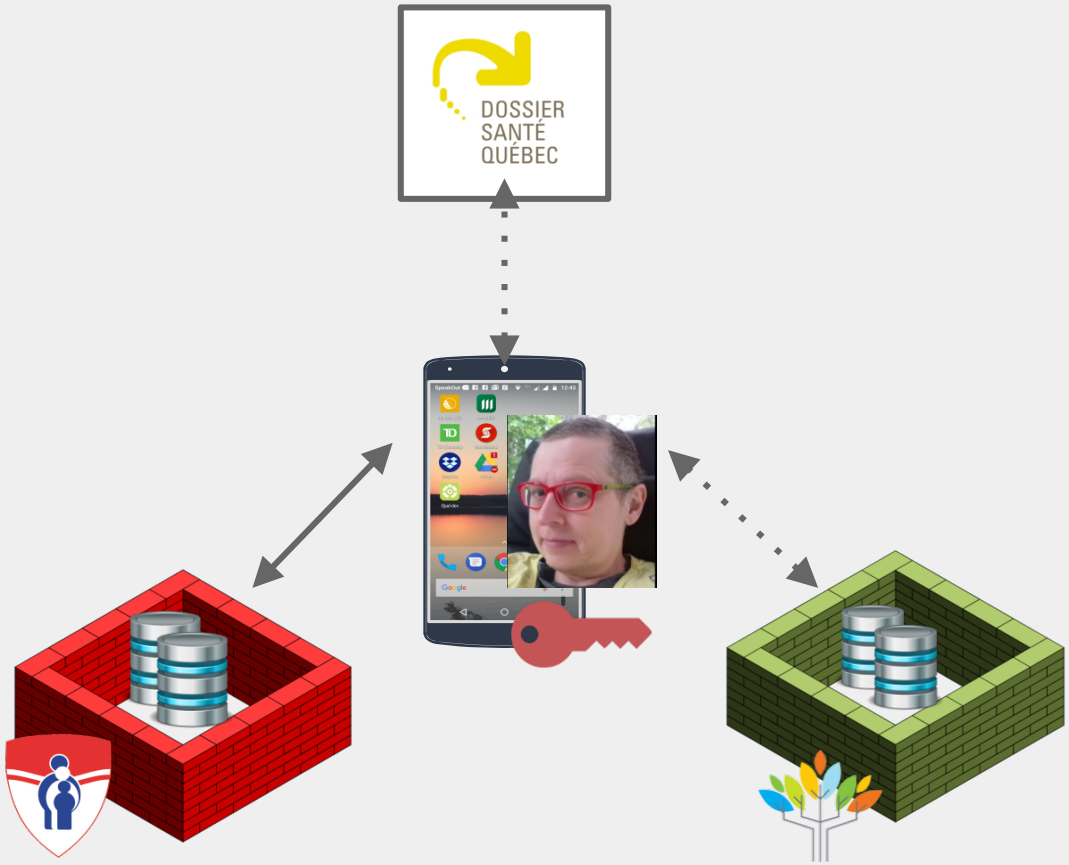
4 hospitals

5 public clinics

5 private clinics

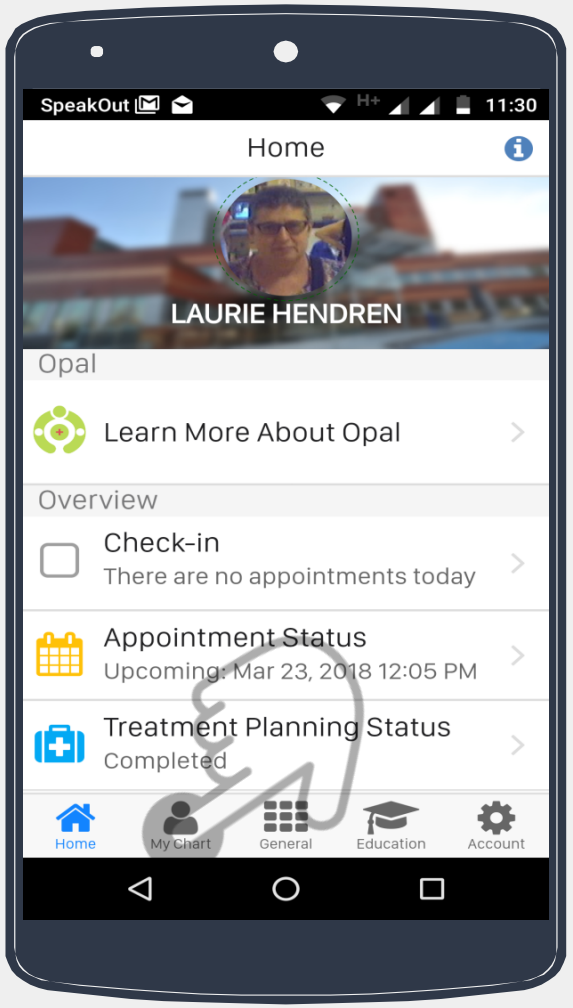


Rethinking patient-controlled data - Opal



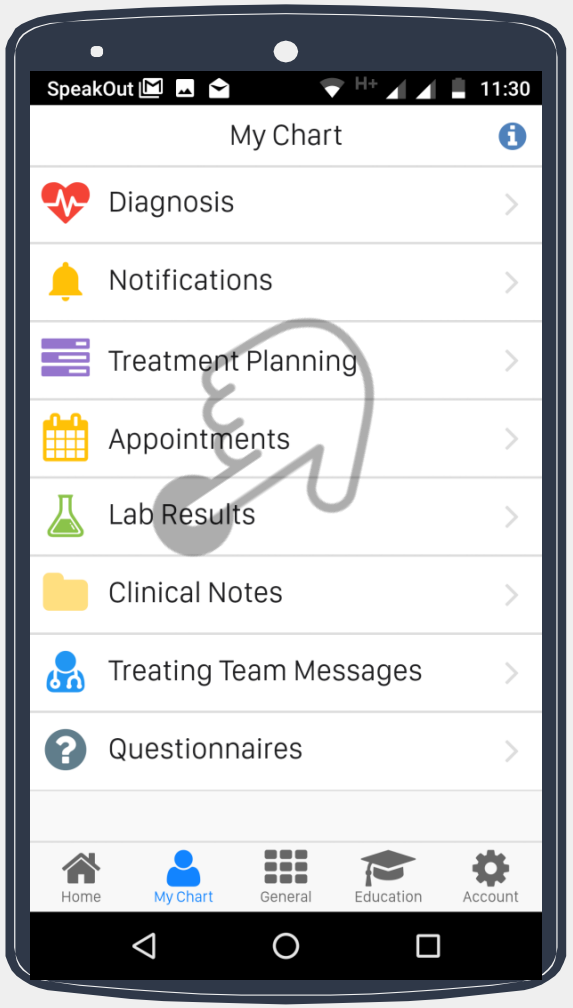
Opal - a patient app

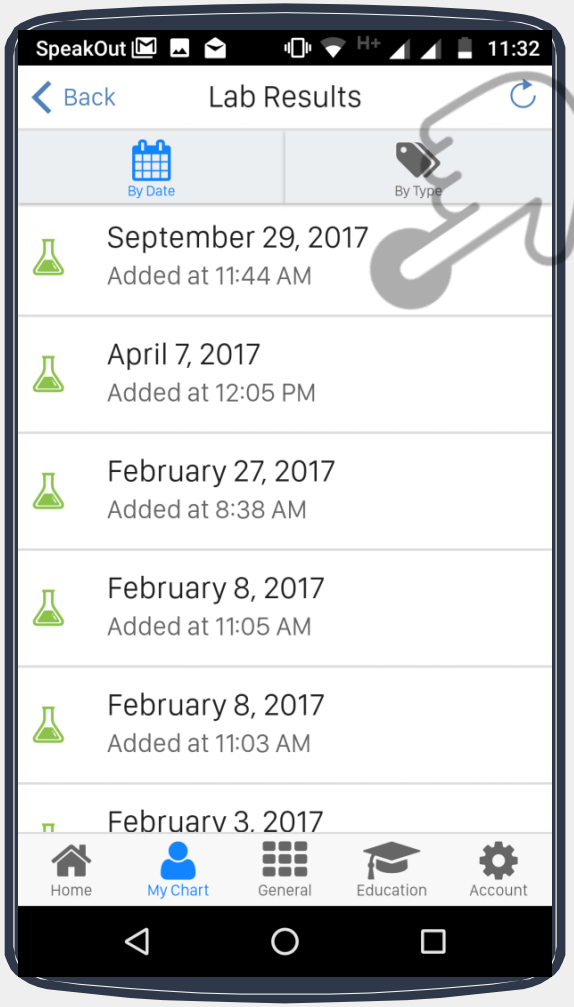
- Team co-led by Laurie Hendren, Tarek Hijal (Radiation Oncology) and John Kildea (Medical Physics)
- Patient-centric approach to provide many kinds of data.



Opal - My Chart

- All sorts of data that is specific to the patient.
- Three important categories are:
  - Lab Results
  - Clinical Notes
  - Questionnaires

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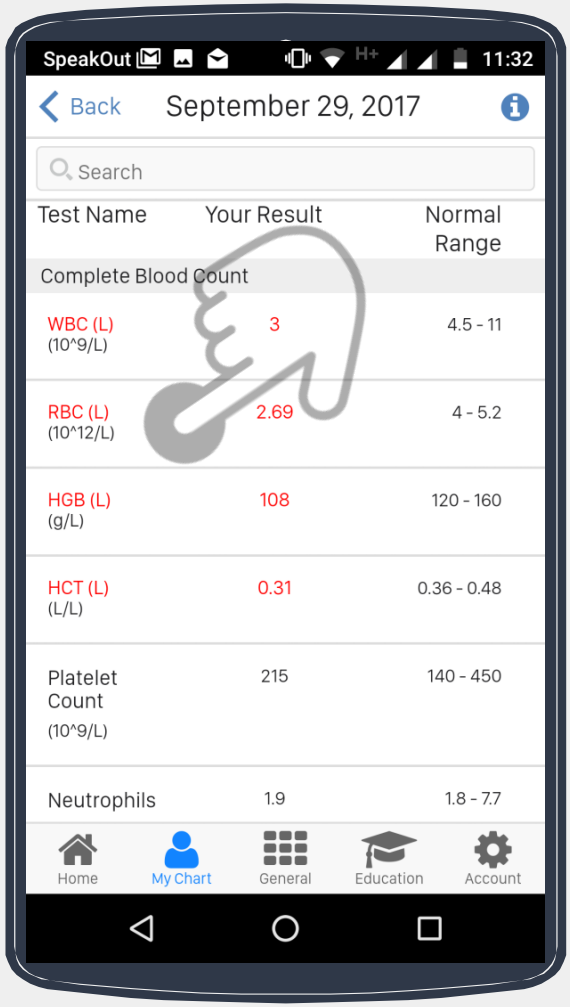
Lab Results
By Date
By Type
September 29, 2017
Added at 11:44 AM
April 7, 2017
Added at 12:05 PM
February 27, 2017
Added at 8:38 AM
February 8, 2017
Added at 11:05 AM
February 8, 2017
Added at 11:03 AM
February 3, 2017
Home
My Chart
General
Education
Account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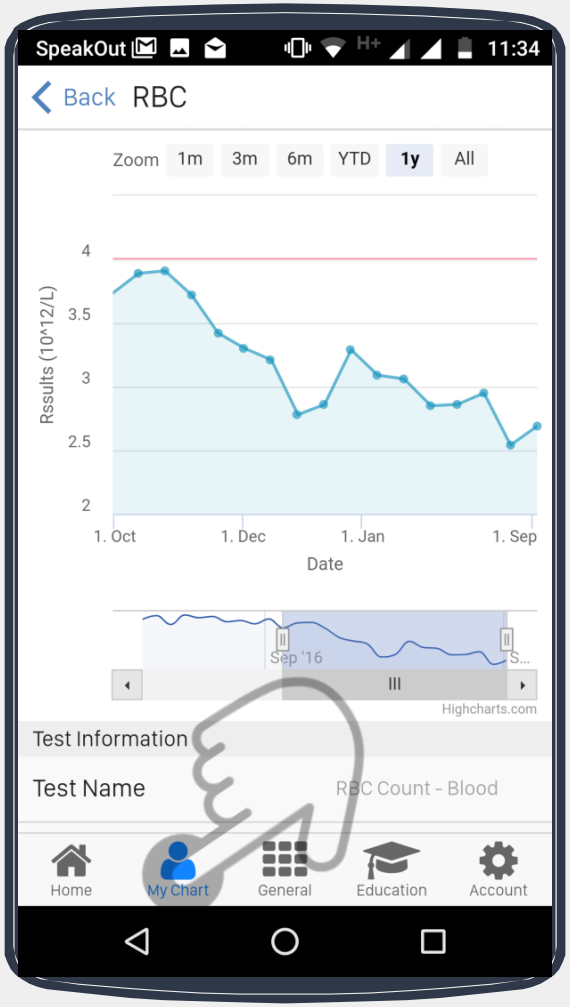
September 29, 2017
Search
Test Name
Your Result
Normal Range
Complete Blood Count
WBC (L) (10^9/L)
3
4.5 - 11
RBC (L) (10^12/L)
2.69
4 - 5.2
HGB (L) (g/L)
108
120 - 160
HCT (L) (L/L)
0.31
0.36 - 0.48
Platelet Count (10^9/L)
215
140 - 450
Neutrophils
1.9
1.8 - 7.7
Home
My Chart
General
Education
Account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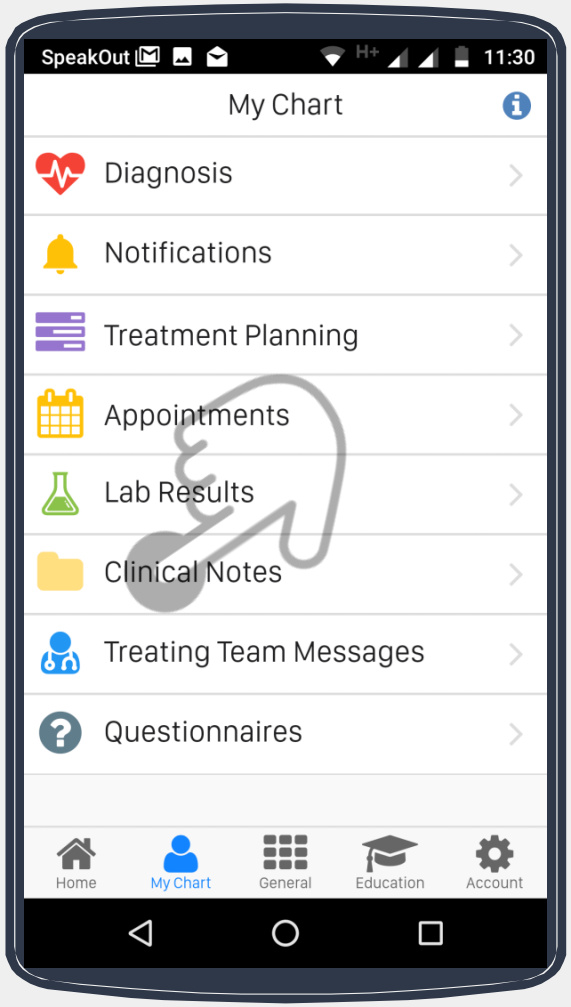
RBC
Zoom
1m
3m
6m
YTD
1y
All
Rssults (10^12/L)
4
3.5
3
2.5
2
1. Oct
1. Dec
1. Jan
1. Sep
Date
Sep '16
Highcharts.com
Test Information
Test Name
RBC Count - Blood
Home
My Chart
General
Education
Account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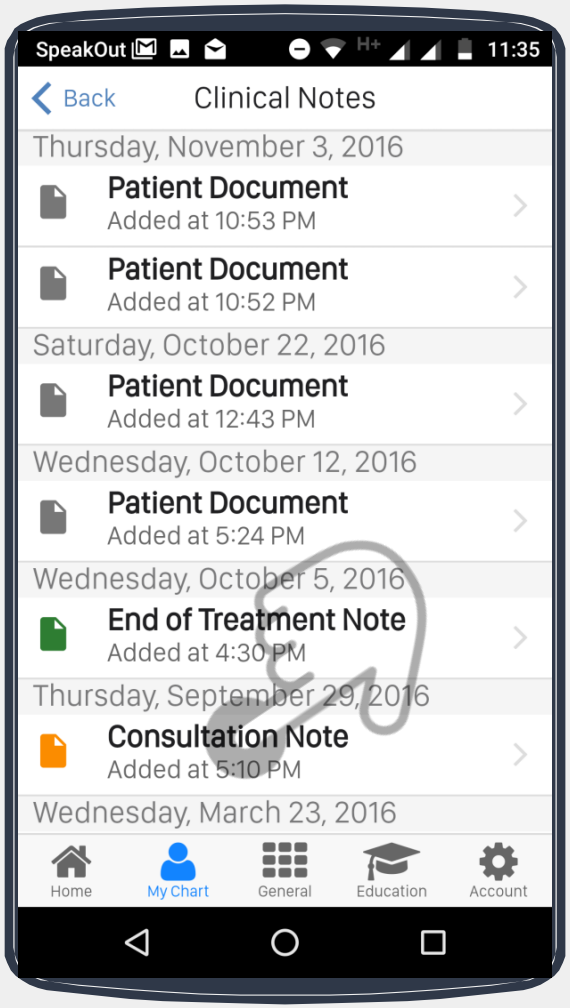
My Chart
Diagnosis
Notifications
Treatment Planning
Appointments
Lab Results
Clinical Notes
Treating Team Messages
Questionnaires
Home
My Chart
General
Education
Account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Clinical Notes
Thursday, November 3, 2016
Patient Document
Added at 10:53 PM
Patient Document
Added at 10:52 PM
Saturday, October 22, 2016
Patient Document
Added at 12:43 PM
Wednesday, October 12, 2016
Patient Document
Added at 5:24 PM
Wednesday, October 5, 2016
End of Treatment Note
Added at 4:30 PM
Thursday, September 29, 2016
Consultation Note
Added at 5:10 PM
Wednesday, March 23, 2016
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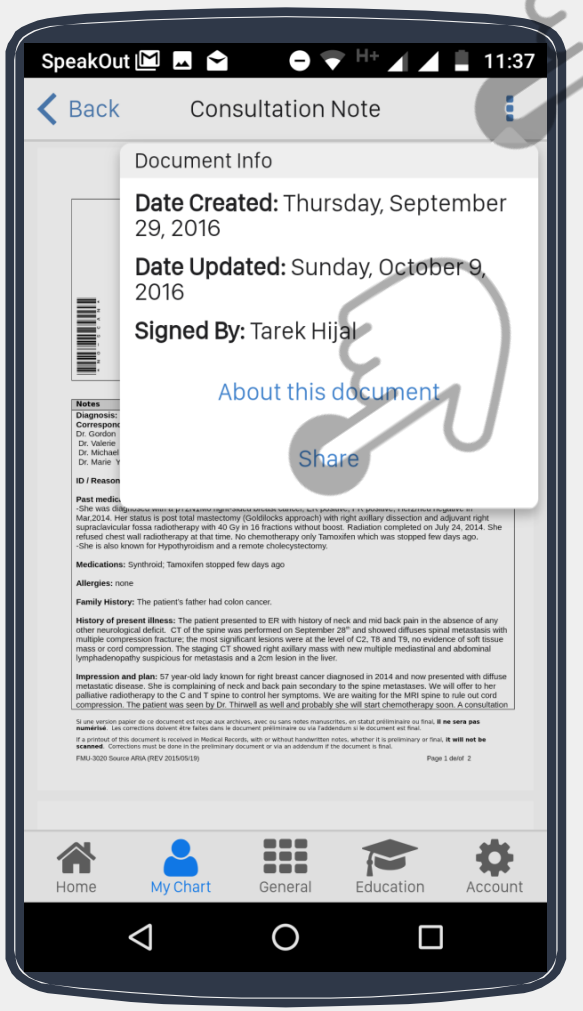
My Chart
General
Education
Account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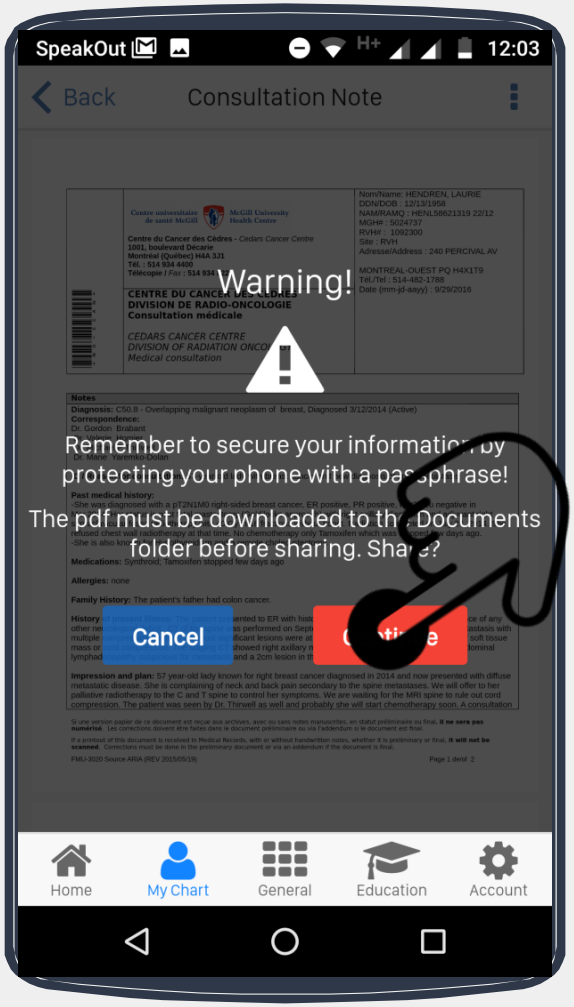
11:37
Back
Consultation Note
Document Info
Date Created: Thursday, September 29, 2016
Date Updated: Sunday, October 9, 2016
Signed By: Tarek Hijal
About this document
Share
Home
My Chart
General
Education
Account


SpeakOut
12:03
Back
Consultation Note
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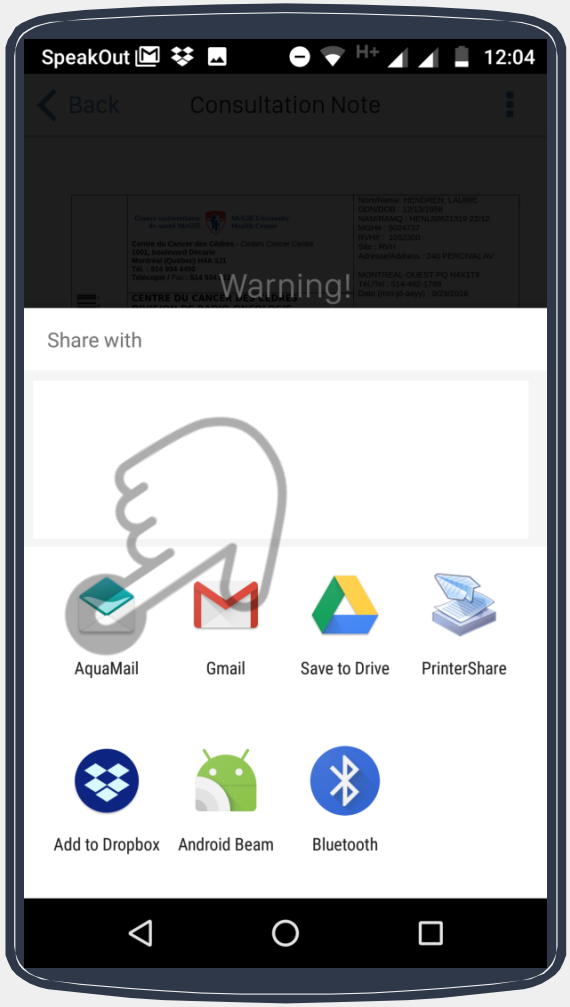
Remember to secure your information by protecting your phone with a passphrase!
The pdf must be downloaded to the Documents folder before sharing. Share?
Cancel
Home
My Chart
General
Education
Account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12:04
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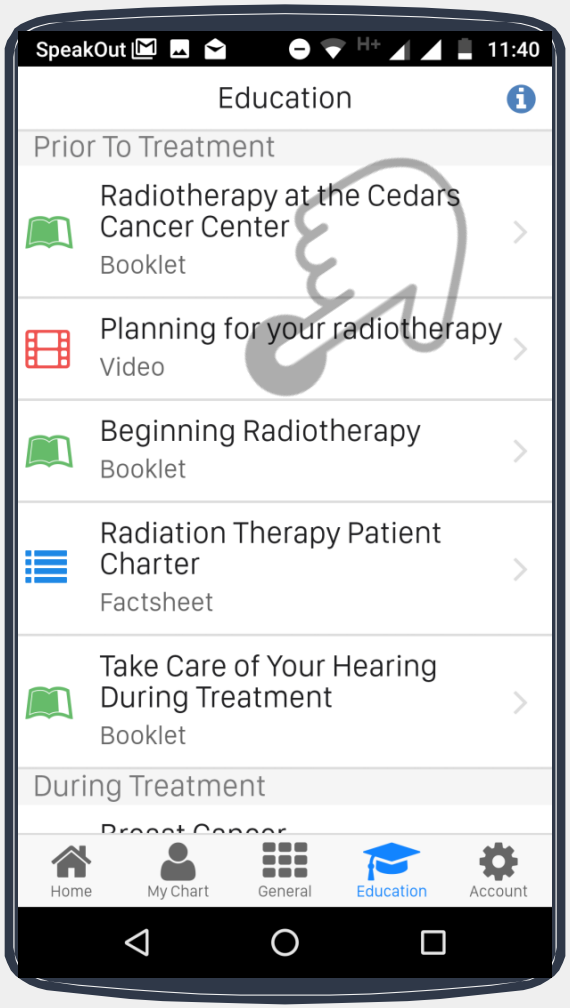
Consultation Note
Warning!
Share with
AquaMail
Gmail
Save to Drive
PrinterShare
Add to Dropbox
Android Beam
Bluetooth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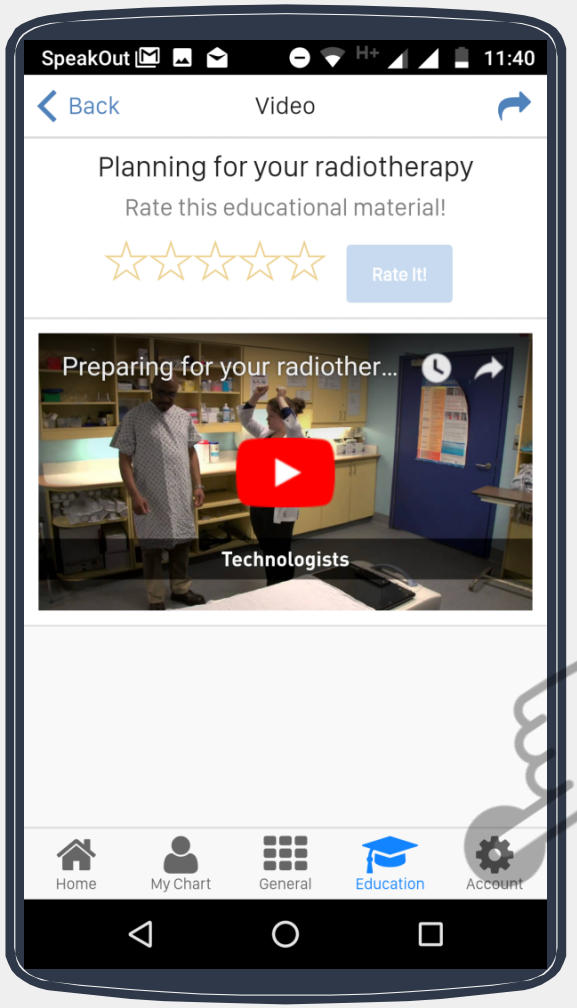
Education
Prior To Treatment
Radiotherapy at the Cedars Cancer Center
Booklet
Planning for your radiotherapy
Video
Beginning Radiotherapy
Booklet
Radiation Therapy Patient Charter
Factsheet
Take Care of Your Hearing During Treatment
Booklet
During Treatment
Home
My Chart
General
Education
Account


SpeakOut
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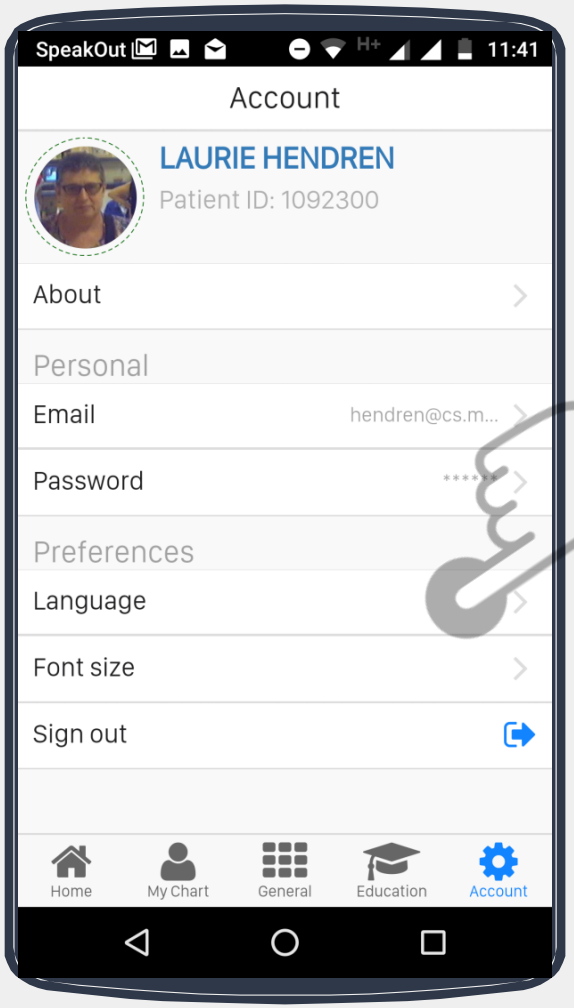
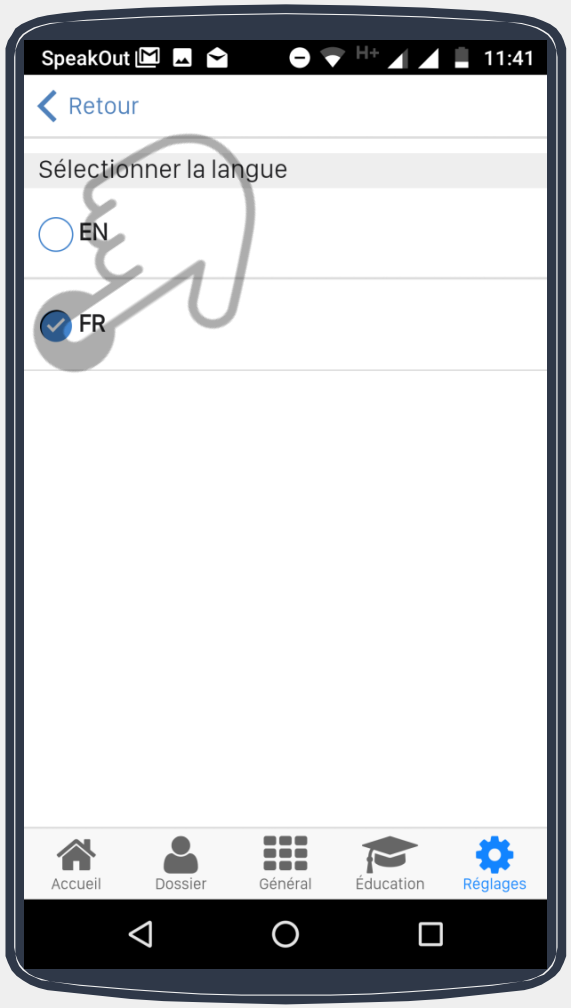
Video
Planning for your radiotherapy
Rate this educational material!
Rate It!
Preparing for your radiother...
Technologists
Home
My Chart
General
Education
Account


SpeakOut
11:41
Account
LAURIE HENDREN
Patient ID: 1092300
About
Personal
Email
hendren@cs.m...
Password
Preferences
Language
Font size
Sign out
Home
My Chart
General
Education
Account


SpeakOut
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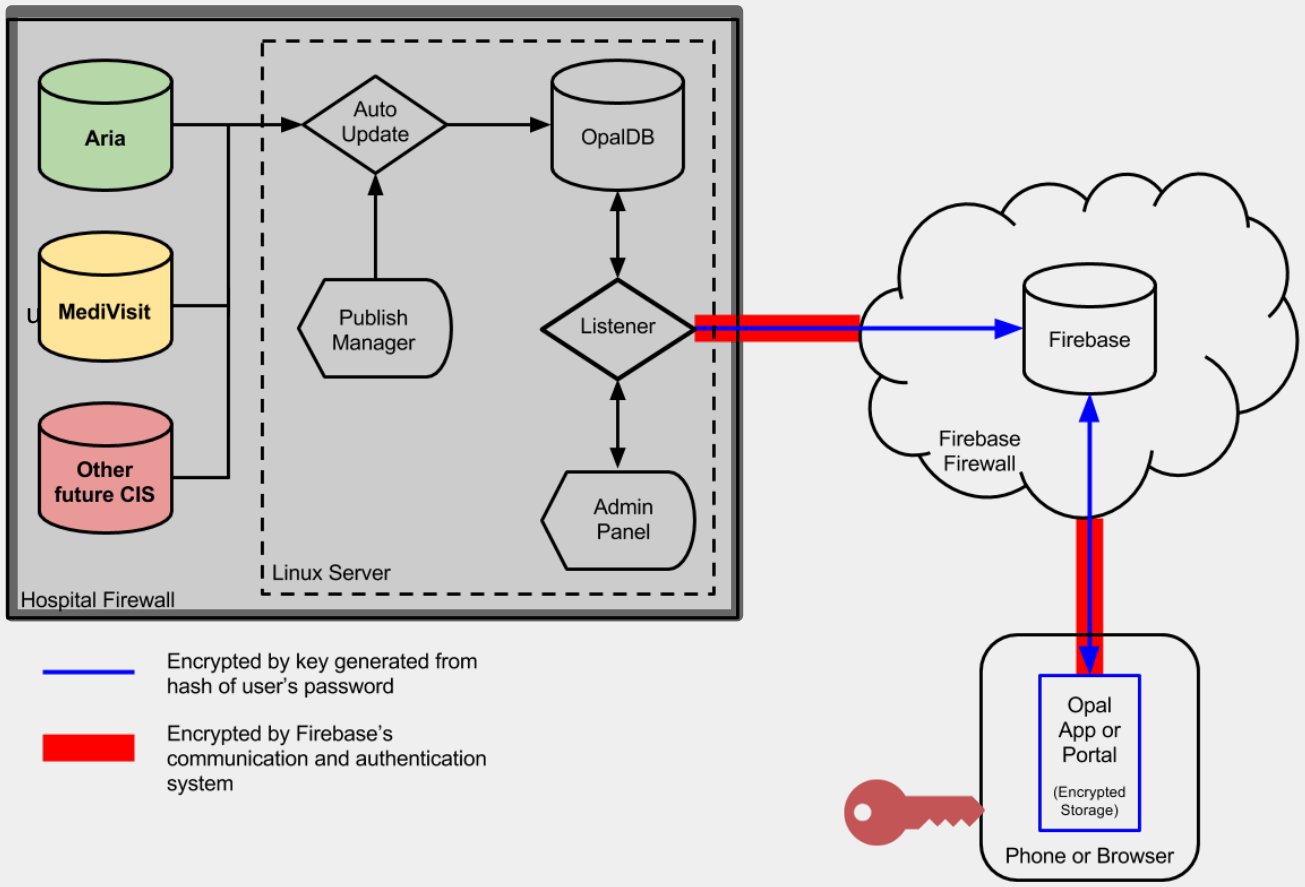
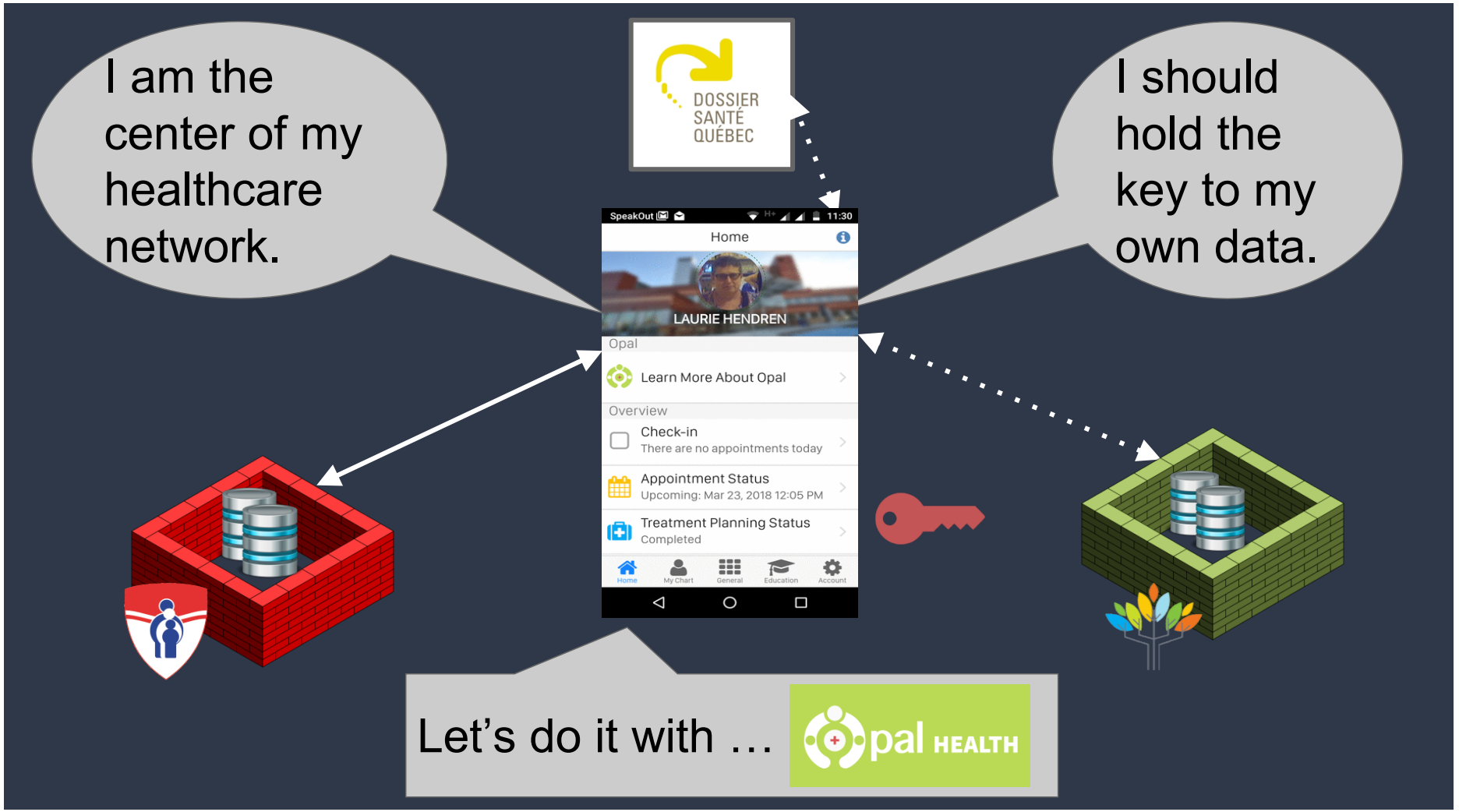
Retour
Sélectionner la langue
EN
FR
Accueil
Dossier
Général
Éducation
Réglages

How it works ...


Aria
MediVisit
Other future CIS
Auto Update
OpalDB
Publish Manager
Listener
Admin Panel
Linux Server
Hospital Firewall
Firebase
Firebase Firewall
Opal App or Portal
(Encrypted Storage)
Phone or Browser
Encrypted by key generated from hash of user's password
Encrypted by Firebase's communication and authentication system


I am the center of my healthcare network.
DOSSIER SANTÉ QUÉBEC
I should hold the key to my own data.
SpeakOut
11:30
Home
LAURIE HENDREN
Opal
Learn More About Opal
Overview
Check-in
There are no appointments today
Appointment Status
Upcoming: Mar 23, 2018 12:05 PM
Treatment Planning Status
Completed
Home
My Chart
General
Education
Account
Let's do it with …
pal HEALTH

THANKS!!!!

The Opal developers, students, and patients; the MUHC Q+ initiative, MGH Corporation, MGH Foundation, Cedars Cancer Foundation, and the MUHC.

Patient focus group

McGill

FONDATION DU CANCER DES CÈDRES

CEDARS CANCER FOUNDATION

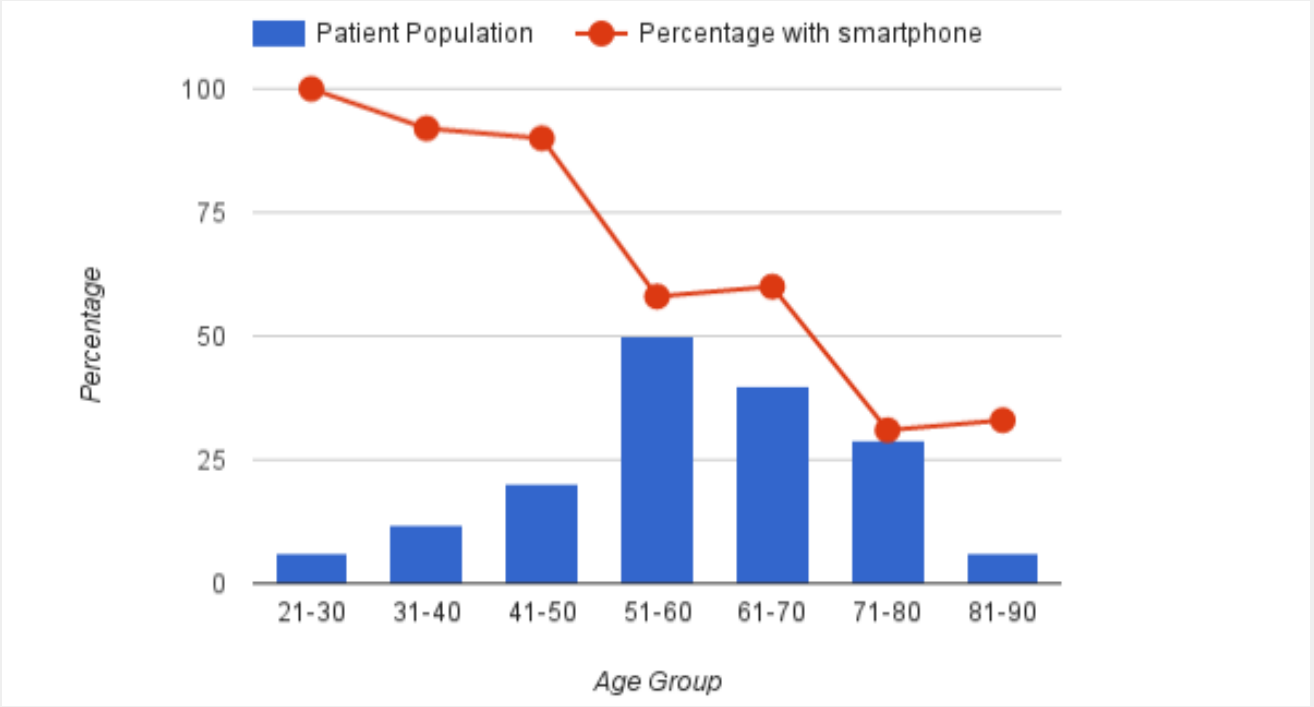
Medical Physics RESEARCH TRAINING NETWORK

NSERC CRSNG

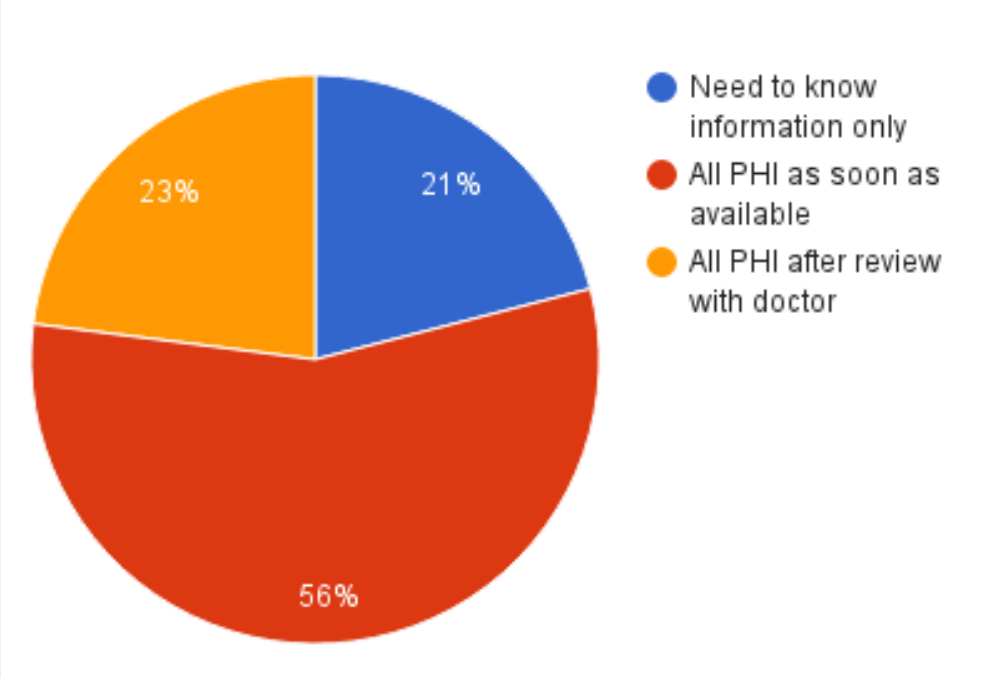
MUHC Patients' Committee

Extra Slides

Will patients use a smartphone app?

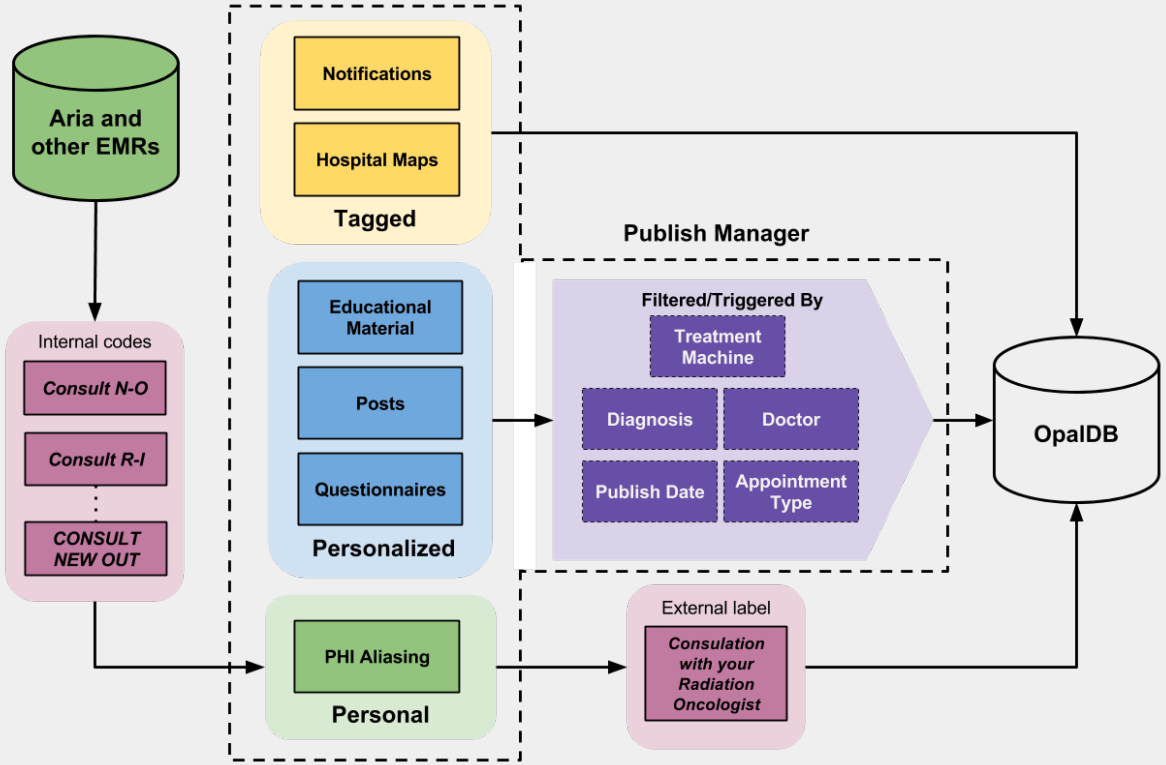
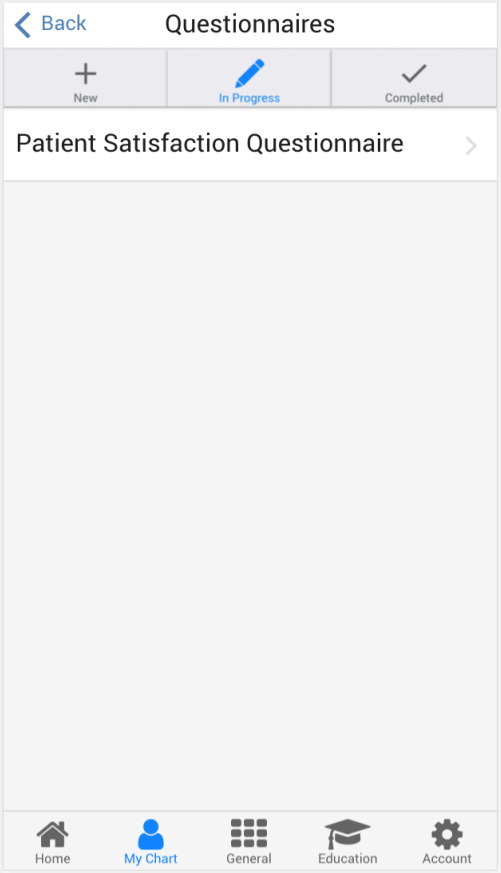
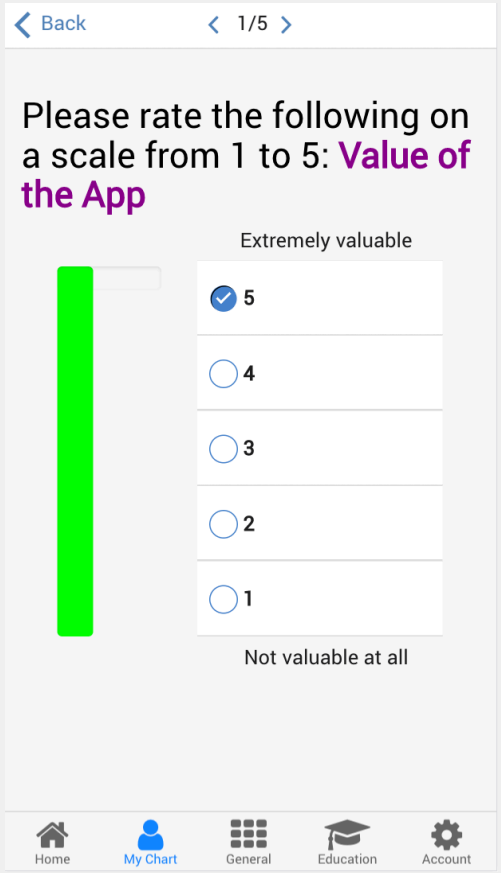
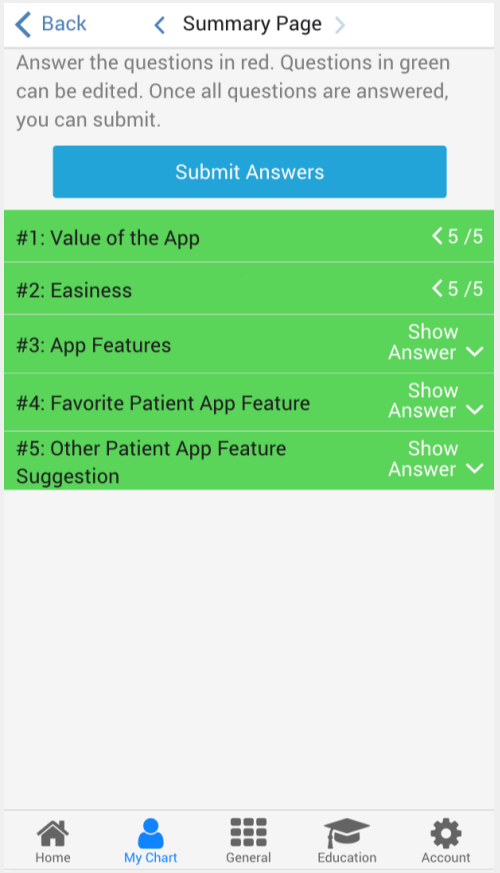


Opal - Personal Health Information Preferences



Cedars Cancer Centre waiting room survey, summer 2016 (n = 100 patients)

Opal - Publish Manager



Opal - Questionnaires