

Empowered Patients, Informed Research – A pilot project for radiotherapy data sharing using the Opal patient portal K. O'Sullivan-Steben¹, L. Galarneau¹, S. Judd², A. Laizner², T. Williams², J. Kildea¹

¹ McGill University Medical Physics Unit, ² McGill University Health Centre Research Institute

Introduction

Who needs healthcare data?

- Patients want to be informed about their care.
- Researchers and clinicians need access to complete patient data.

Results – Research Menu

Studies: Receive study invitations from researchers, which include a study description, researcher contact information and a consent form.

Results – Radiotherapy Menu

Plan Description: Personalized radiotherapy plan description based on treatment parameters. \rightarrow Accordion menus show details about patient-specific treatment set-up, beams,

Problem:

Healthcare data are difficult to access because they are spread out and legally protected.

Objective

Build a data donation platform to empower radiotherapy patients to participate in research. Specifically:

Recruit patients via a Research menu. Give patients their radiotherapy data in an educational manner.

Methodology

- Research and radiotherapy menus were built into the **Opal patient portal app** used at our centre [1].
- Participatory stakeholder co-design methodology was used to ensure an engaging design [2].

- **Reference Material:** View educational material, study updates and results from researchers.
- **Questionnaires:** Answer questionnaires for studies sent by researchers.
- **Consent Forms:** Sign electronic consent forms with Opal app password to enroll in studies.

			• •		
ROGERS 🗢	10:26 AM	1 89% 🔳	all ROGERS 🗢	10:26 AM	1 89%
	Research	0	K Back	Study	
Studies	S	>	Breast Ca	ancer Treatme	nt Study
Refere	nce Material	>	Star End	t Date: May 13, 2 Date: June 30, 20	021 021
Questio	onnaires	>	Inve Email:	stigator: John Kil	dea gill.ca
Conser			Phone N	Number: (514) 51	4-5145
			Ereas Cons	st Cancer Stud ent	У
		ĺ.		Description:	

- breathing techniques and radiation dose.
- **3D View:** Interactive 3D rendering of a patient's body and treatment beams.
 - \rightarrow Zoom, rotate and pan touch gestures.
 - \rightarrow Skin affected by radiation is highlighted.

 \rightarrow Each beam can be viewed individually.

•	
10:26 AM	내 ROGERS 축 11:29 AM @ 7 0 88% 🔲
Radiotherapy	Radiotherapy
Description 3D View	Description 3D View
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.	How is a 3D view of your body from your CT scan and the beams of radiation you will receive during treatment. Beams displayed: I I I I I I I I I I I I I I I I I I I
🕂 🛀 Set-Up on the Treatment Table	

- **Contextualizing treatment plans:**
- Treatment parameters were extracted from *DICOM-RT PLAN* files and mapped to appropriate explanatory text.

- Beam data were extracted from *DICOM*-RT PLAN files and reconstructed in 3D.
- 3) Body contour data were extracted from DICOM-RT STRUCT files and an algorithm was created to triangulate the

Fig. 1: Screenshots of the Research menu and a sample study.

Discussion & Conclusions

- Patient focus group feedback has been very positive.
- Access to explained treatment plans has the potential to reduce patient anxiety and increase willingness to share data with researchers.
- Researchers will be able to more easily recruit patients for their studies.

Fig. 2: Screenshots of a radiotherapy plan's personalized description and interactive 3D render. Demo available [3].

Acknowledgements

McGill University Health Centre Foundation

ttier-Webster Award for Innovation

- By prioritizing patient education and access to data, our platform
 - fosters an important sense of trust between the patient and
 - researcher that will empower patients to contribute to research.

References [1] Opal Med Apps. URL: <u>opalmedaps.com</u>. [2] J. Kildea *et al.* DOI: <u>10.2196/11371</u>.

[3] https://youtu.be/8PSzFf_uLKU

Research Menu Screenshots

ø		
ni Rogers 🗢	10:26 AM	1 89% 🔳
	Research	6
Studie	S	>
Refere	ence Material	>
臂 Questi	onnaires	>
Conse	nt Forms	>

		Stuc	lies		
	10:26 AM	1 89%		10:26 AM	1 89%
K Back	Studies	0	K Back	Study	
Tuesday, Apr Breast Ca Study You are inv Wednesday, Wednesday, COVID St You are par Friday, Febru	il 20, 2021 ancer Treatm ited to this stud March 17, 20 tudy rticipating in th ary 26, 2021 E Focus Grou	dy. 021 is study.	Breast Ca Star End Inves Email: Phone N	ancer Treatme t Date: May 13, 2 Date: June 30, 2 stigator: John Ki john.kildea@mo Number: (514) 51	ent Study 2021 2021 ildea cgill.ca 14-5145
	où tino otuaj.		This study effects of count. In affects the	st Cancer Stud ent Description: y aims to deter radiotherapy on particular, ra e immune syster	ermine the blood cell diotherapy n, which is

Reference Material

1 89% 🔳

Back Booklet Booklet Research Studies FAQ Rate this educational material Mate It
Back Booklet Research Studies FAQ Rate this educational material
Research Studies FAQ Rate this educational material
Rate this educational material
· · · · · · · · · · · · · · · · · · ·
ble of Contents
What is research?
Are there risks to being in a research study?
Are there benefits to being in a research study?
Who will see my records?
What is informed consent?

	INIROGERS INIROGERS <tr< th=""><th> III:30 AM III:30 A</th><th> INIROGERS < 10:26 AM 10:26</th><th> INOGERS < 11:30 AM INOGERS Back Done Question 2/2 I understand that I might be contacted at a later date to participate in self- report survey questionnaires. </th><th> INOGERS 11:30 AM 2 87% Back Summary Page Breast Cancer Study Consent To submit the consent form, please answer the question below and tap the submit button. I agree to participate in this research in the consent form of the consent form. </th></tr<>	 III:30 AM III:30 A	 INIROGERS < 10:26 AM 10:26	 INOGERS < 11:30 AM INOGERS Back Done Question 2/2 I understand that I might be contacted at a later date to participate in self- report survey questionnaires. 	 INOGERS 11:30 AM 2 87% Back Summary Page Breast Cancer Study Consent To submit the consent form, please answer the question below and tap the submit button. I agree to participate in this research in the consent form of the consent form.
Consent Forms		You are being invited to participate in a clinical trial (a type of study that involves research). Clinical trials only include participants who choose to take part. You are invited to participate in this trials because you have explain the main features of the population to which the research applies. This consent form provides you with information to help you make an informed choice. Please read this document carefully and take your time in making your \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M} \widehat{M}	 Blood Tests Radiotherapy Plan National State State	 Yes No 	study according to the conditions stated in this consent form. Consent Decline Please enter your password to confirm your consent.

Radiotherapy Menu Screenshots

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 patients, especially if you have had surgery in the area. Your treating team may suggest you practice watching TV at night with your arms over your head to prepare you.

💳 📥 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 enough to cover the targeted area. In your case, the beam is made even smaller with the use of "multileaf

- A Breathing Techniques

Breathing techniques are used for tumours that are close to the heart or likely to move significantly while breathing. During treatment, you will need to hold a deep breath. Your therapist will guide you through this process. Since your tumour moves as you breathe, holding a deep breath keeps the tumour at the same place inside the radiation beam. At this position, the tumour is also further away from your heart, which will help to protect and minimize radiation exposure to your heart.

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.

- Radiation Dose

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.

col	limators	s", sn	nall m	etal ba	ars th	nat bloc	k some
of	radiatio	on t	o ma	ke a	con	formal	beam.
					-	Multileaf	ors

<u>_uLKU</u>

