

Design and development of a novel infrastructure to securely share radiation therapy and imaging data through direct patient data sharing



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Introduction

Who needs healthcare data?

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

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:

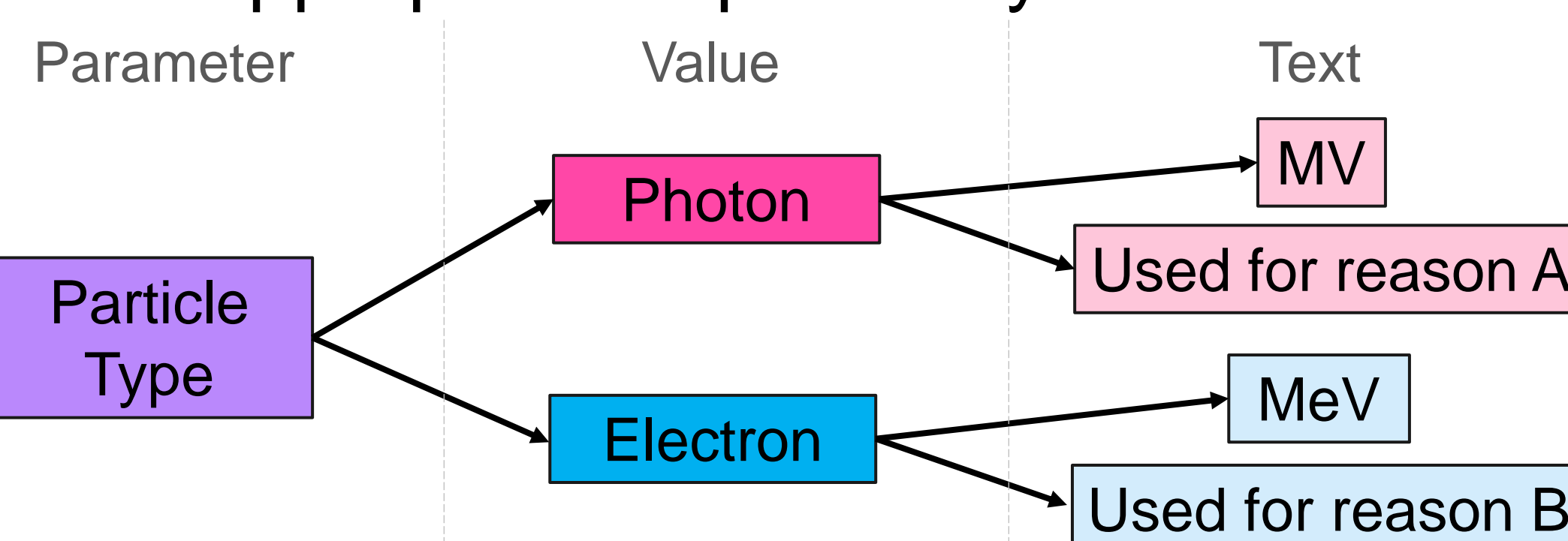
- 1) Recruit patients via a Research menu.
- 2) Give patients their radiotherapy data in an educational manner.

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].

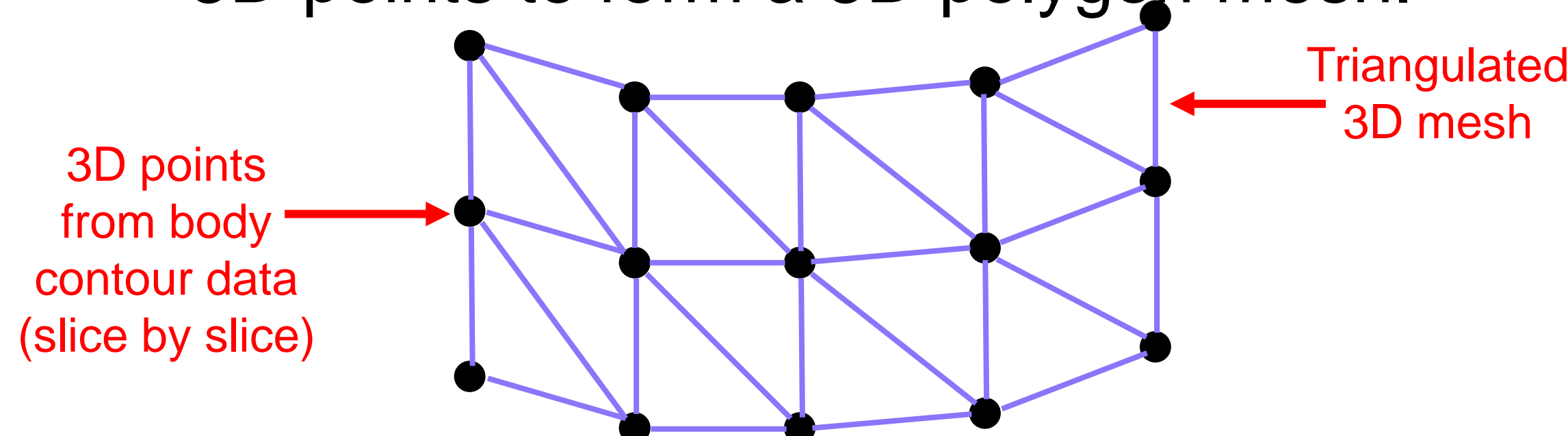
Contextualizing treatment plans:

- 1) Treatment parameters were extracted from *DICOM-RT PLAN* files and mapped to appropriate explanatory text.



- 2) 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 3D points to form a 3D polygon mesh.



Results – Research Menu

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

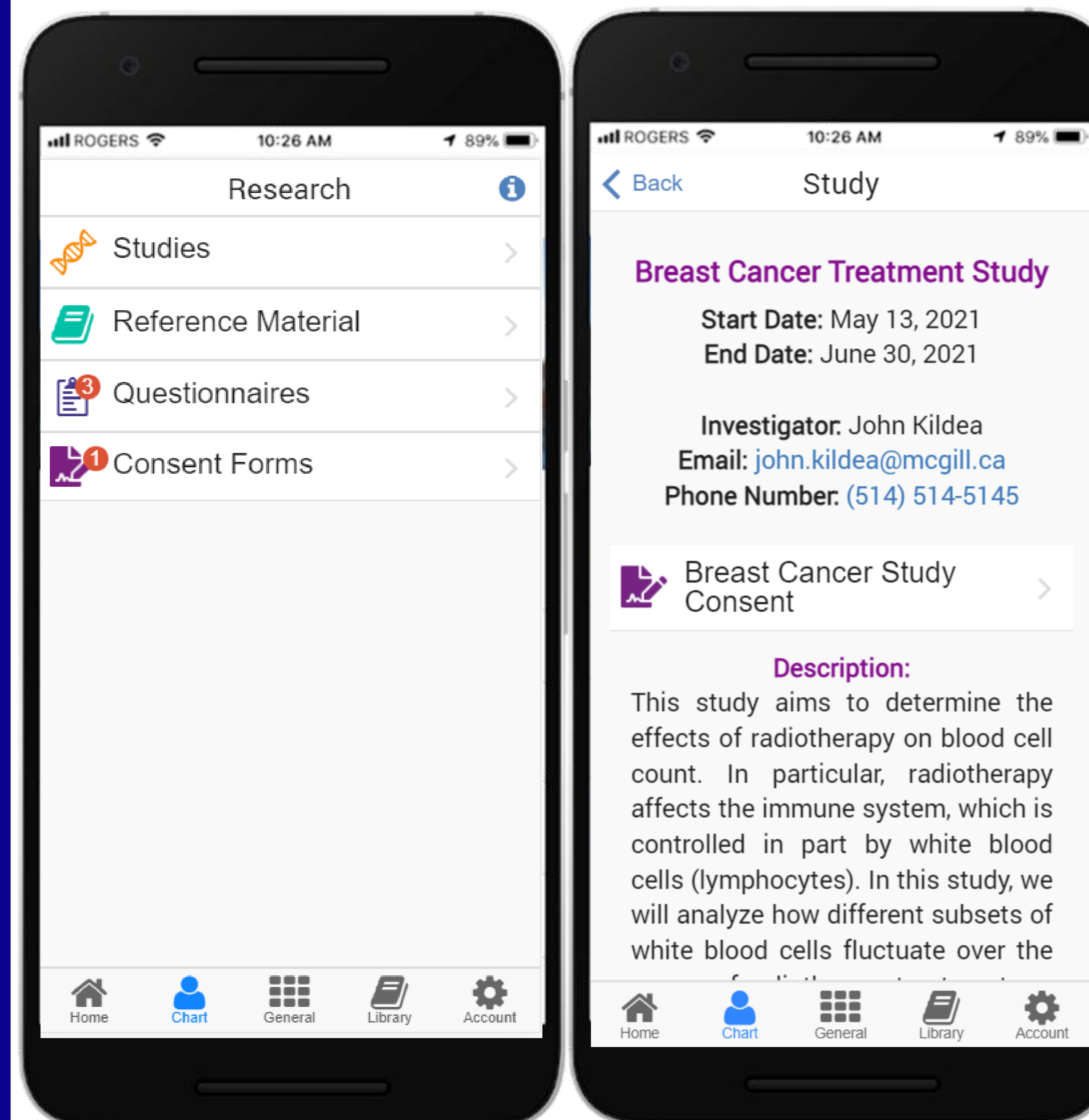


Fig. 1: Screenshots of the Research menu and a sample study.

Results – Radiotherapy Menu

- **Plan Description:** Personalized radiotherapy plan description based on treatment parameters.
 - Accordion menus show details about patient-specific treatment set-up, beams, breathing techniques and radiation dose.
- **3D View:** Interactive 3D rendering of a patient's body and treatment beams.
 - Zoom, rotate and pan touch gestures.
 - Skin affected by radiation is highlighted.
 - Each beam can be viewed individually.

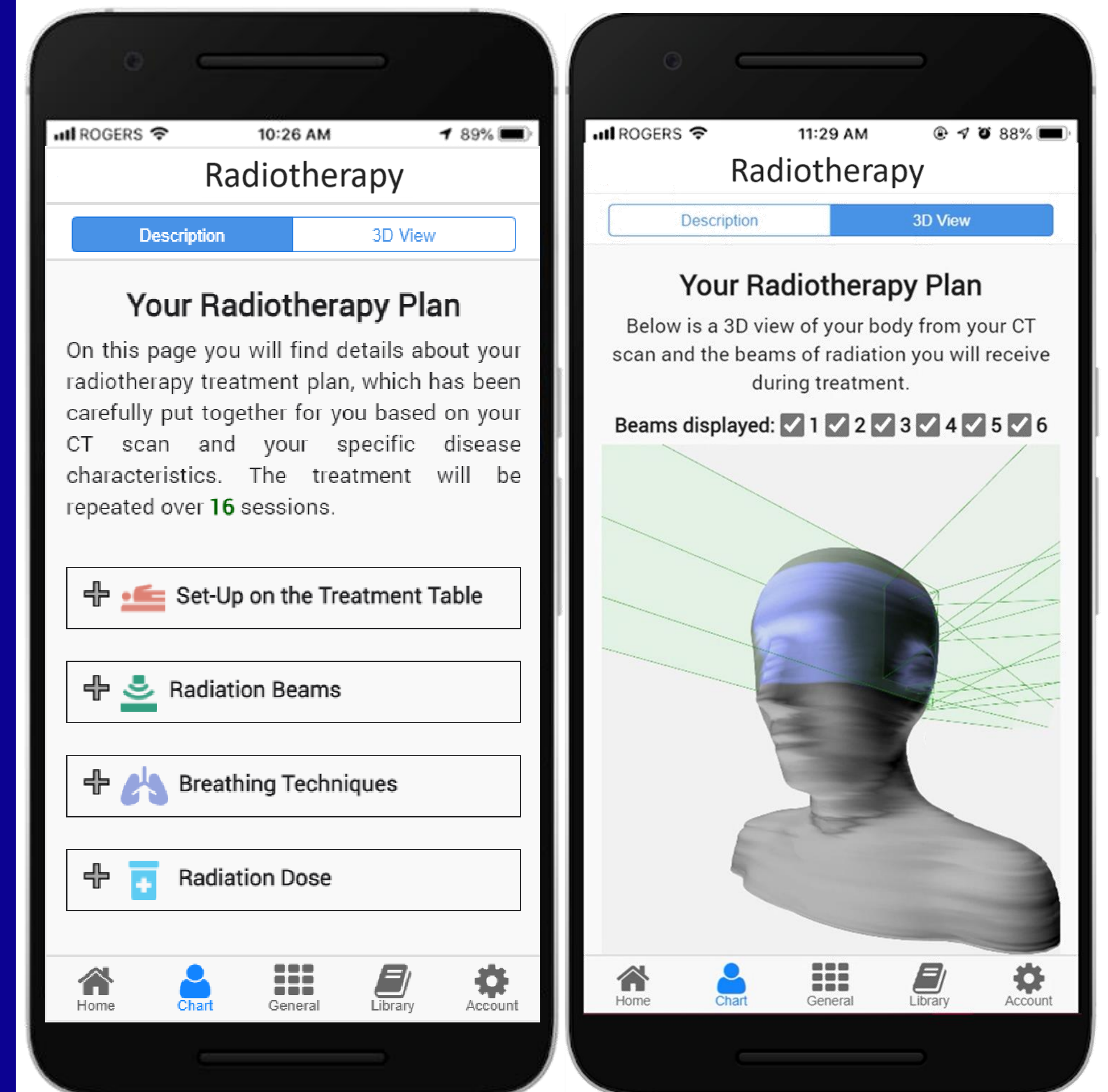


Fig. 2: Screenshots of a radiotherapy plan's personalized description and interactive 3D render.

Discussion & Conclusions

- 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.
- 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: opalmedapps.com.
 [2] J. Kildea et al. DOI: [10.2196/11371](https://doi.org/10.2196/11371)

Acknowledgements



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