

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



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Introduction

Who needs healthcare data?

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

Problem: Healthcare data is difficult to access because it is 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.

Methods

- Research and radiotherapy menus were built into the **Opal patient portal app** (opalmedaps.com) used at our centre.
- Participatory stakeholder co-design methodology was used to ensure an engaging design. ([doi:10.2196/11371](https://doi.org/10.2196/11371))
- **Contextualizing treatment plans:**
 - Treatment parameters were extracted from *DICOM-RT PLAN* files and mapped to appropriate explanatory text.
 - Body contour data were extracted from *DICOM-RT STRUCT* files and triangulated to form a 3D polygon mesh.

Results – Research Menu

Features:

- Respond to study invitations via electronic consent forms.
- Answer questionnaires for studies.
- View educational material and study updates from researchers.

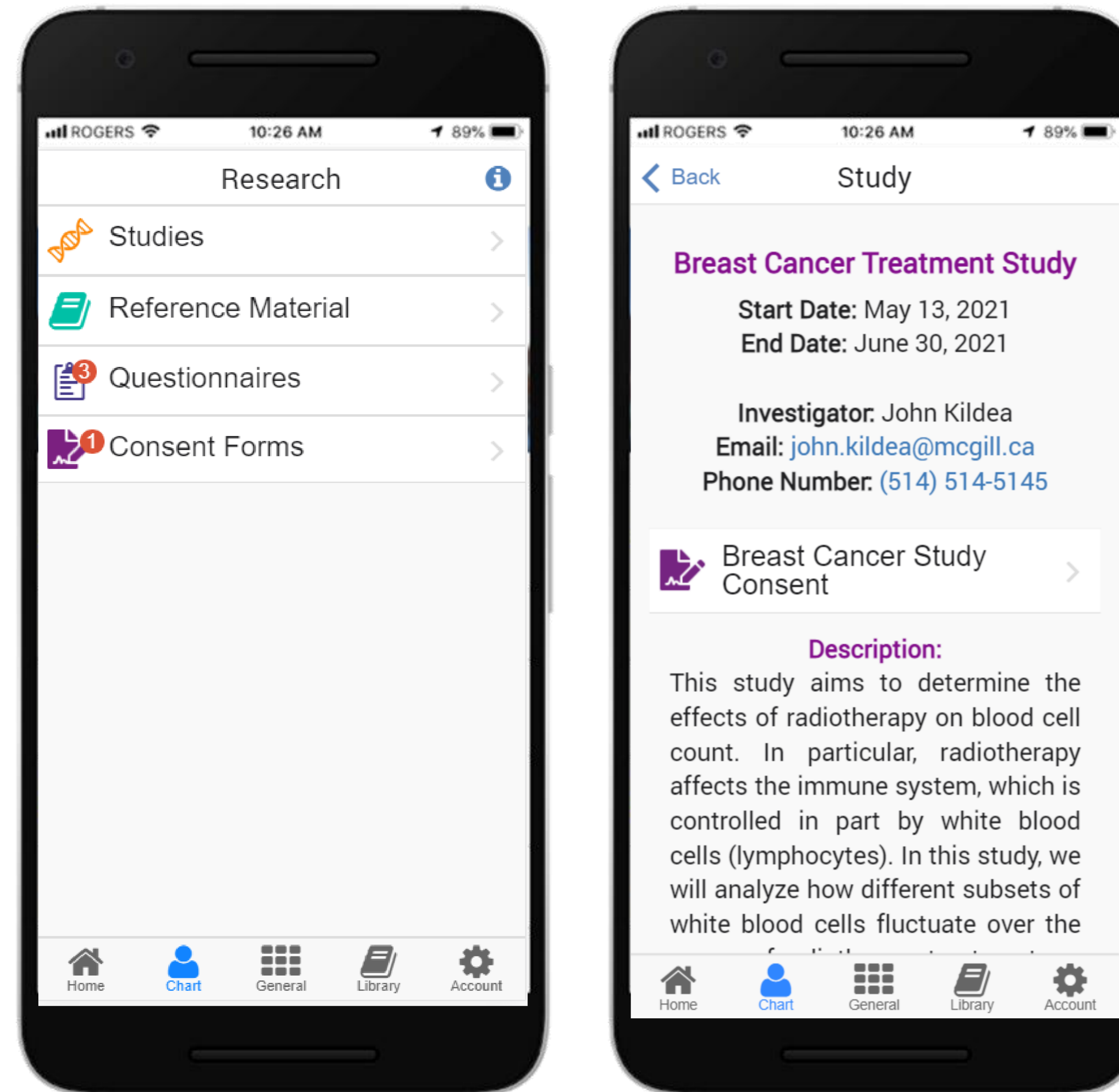


Fig. 1: Screenshots of the research menu and a sample study.

Results – Radiotherapy Menu

Features:

- Personalized plan description based on treatment parameters.
- Interactive 3D render of patient's body and treatment beams.
 - Skin affected by radiation is highlighted.
 - Each beam can be viewed individually.

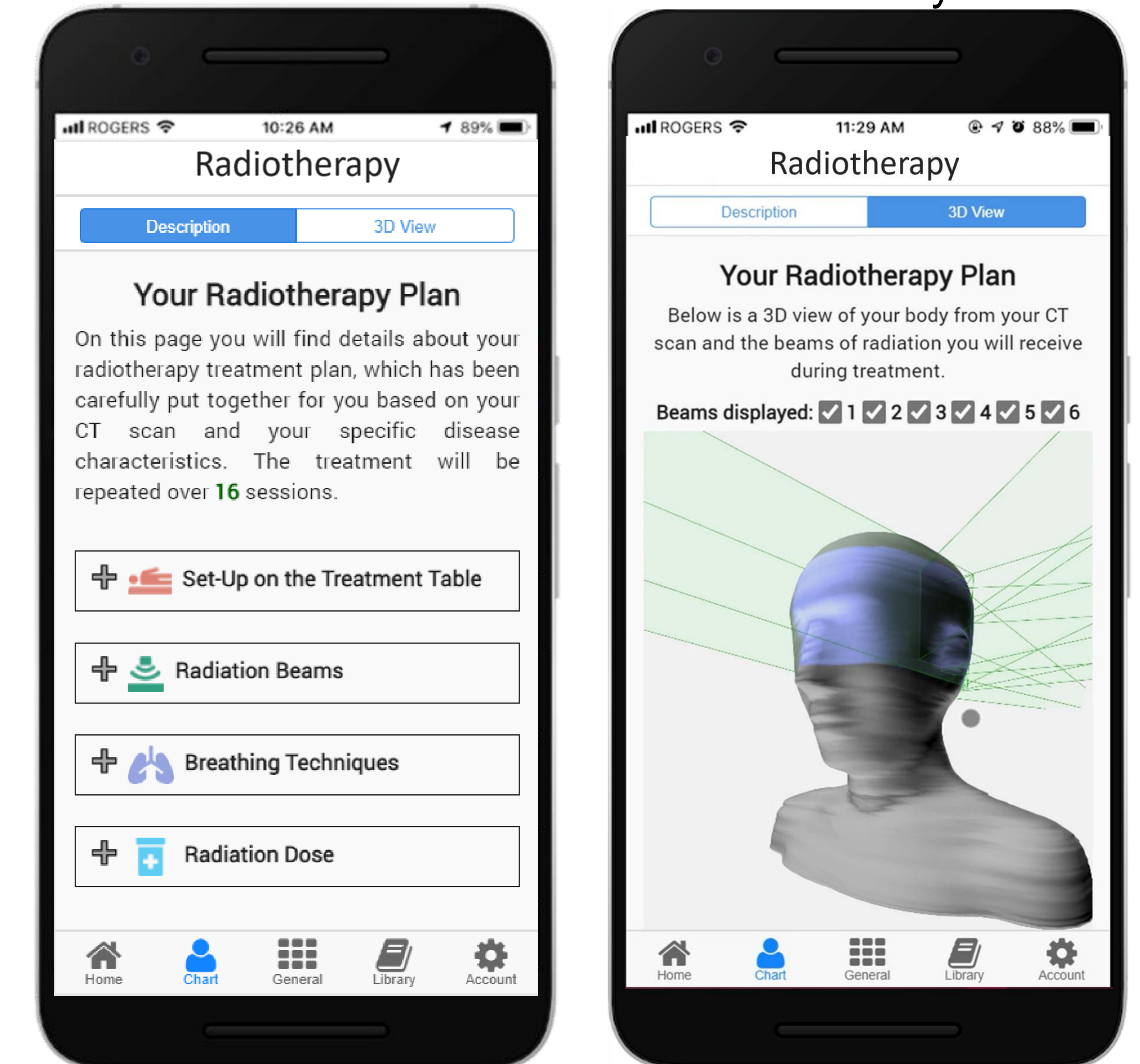


Fig. 2: Screenshots of a radiotherapy plan's personalized description and interactive 3D render.

Discussion & Conclusions

- Access to explained treatment plans will reduce patient anxiety and increase their willingness to share these data with researchers.
- Researchers will be able to more easily recruit patients for their studies.

Acknowledgements

