

# ePRO Exchange

The official newsletter of the ePRO study  
February, 2018



## Month 2

### A Brief History of ePRO

As we enter the second month of the ePRO research project, we thought it would be a good idea to give everyone a quick history of how we got to where we are today.

The ePRO tool was developed by Dr. Carolyn Steele Gray and the research team at the Bridgepoint Collaboratory, in collaboration with the Health System Performance Research Network at the University of Toronto, and the tech company QoC Health. Since September 2013, the ePRO tool has been developed through ongoing co-design workshops with healthcare providers, patients and their caregivers, at each phase. Working together, we developed the tool step-by-step to the current version we have today (see *Figure 1*).

As part of the development of a new eHealth technology, a needs assessment (Phase 1) was conducted in 2013 to understand from patients and providers what was important to them with respect to health and health service issues they've experienced, the types of information that should and could be collected to meet their needs, and any barriers to using eHealth mobile apps to collect the information. Following this, a prototype of the ePRO tool was developed (Phase 2) that was then tested with three working

groups: (1) patients and caregivers, (2) primary health care providers, and (3) experts and the research team. We next conducted a usability pilot in Phase 3 with 11 patients and 6 primary health care providers from a Family Health Team in Toronto. The aim of this step was to determine whether the ePRO tool was feasible (*continued...*)

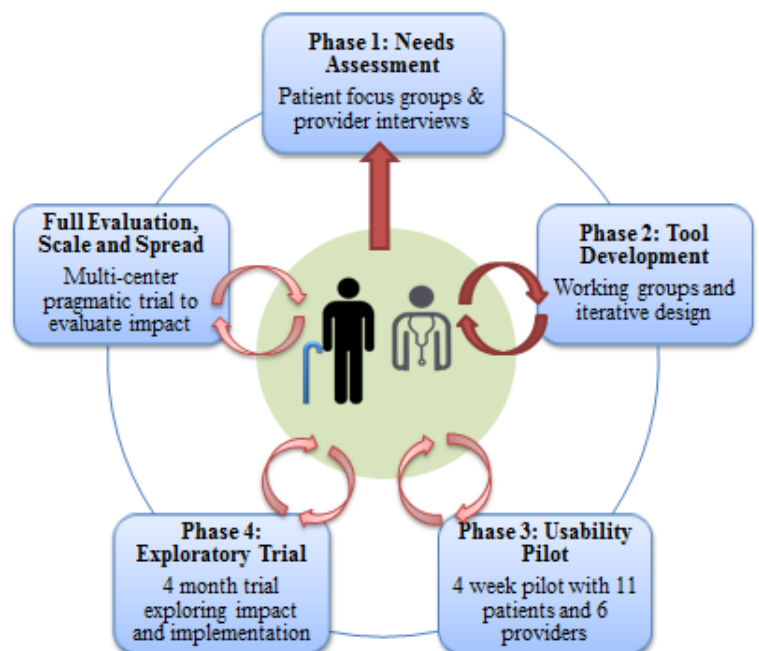


Figure 1: Development of the ePRO tool

to be used by patients with complex care needs and their primary health care providers as part of the delivery of health care services, and to see if the tool was usable from the perspective of both patient and provider. The results from this pilot phase led to another modification of the tool. Then in 2015-2016 we conducted our exploratory trial (Phase 4) of ePRO in two Family Health Teams, to get a first sense of how the tool impacted on patients and providers, and to test out our full trial methods. While we identified new ways to improve the technology, we did see some great improvements in the ability of patients to manage their health, and improved communication between patients and their providers.

This brings us to Phase 5 (happening right now). With your help, we are currently conducting

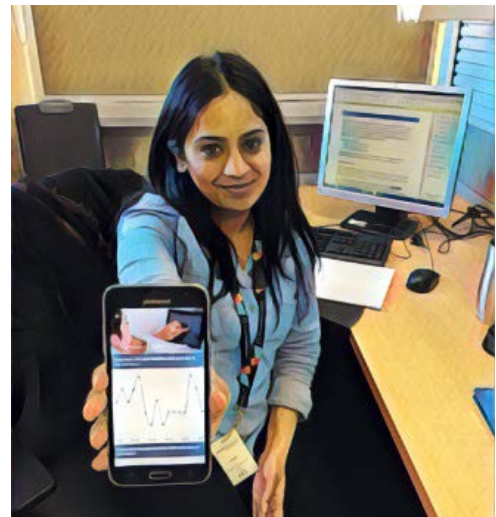
a pragmatic stepped-wedge randomized trial at 6 Family Health teams across Ontario with an embedded case study of implementation at four of the sites to address our three research questions:

1. *Does ePRO improve patient quality of life, care experience, and self-management in older adults with complex needs?*
2. *Is ePRO cost-effective for older adults with complex needs from the perspective of the health care system?*
3. *What are the most important implementation factors to effectively scale and spread ePRO in primary health care settings?*

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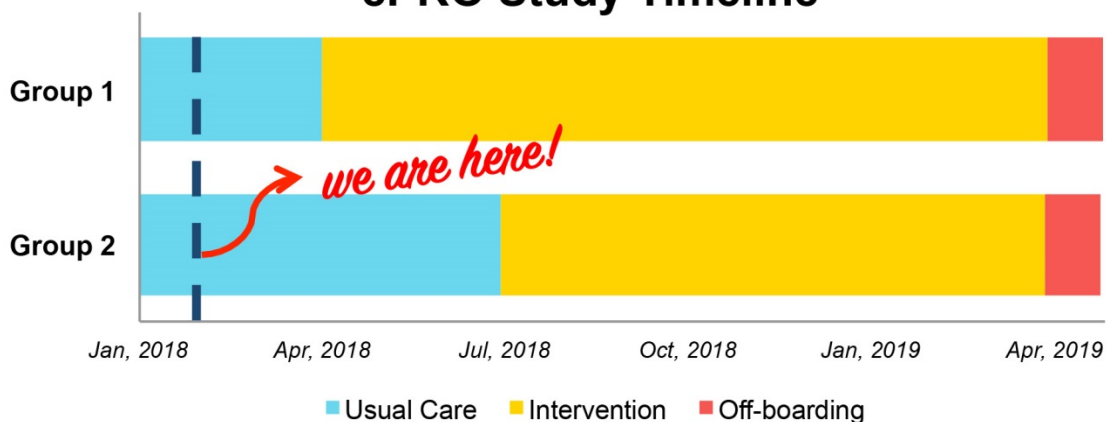
## **Welcome Jasvinei!**

Please welcome our newest Research Assistant, Jasvinei Sritharan, to the ePRO team. Here she is trying out the ePRO app on a test phone. We're excited to have Jasvinei join our team and she looks forward to getting to know our ePRO participants!



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## **ePRO Study Timeline**



## Site Randomization Results

Now for the moment we have all been waiting for – **Site Randomization**. With the assistance of randomization software (RANDOM.ORG) (which is a more advanced method of flipping a coin), we have successfully grouped 3 sites to each block. Below is a breakdown of where each Family Health Team was assigned.

**Just a recap of what this means:** The only difference between Block 1 and Block 2 is 1) the length of the control period or “business as usual” (either 3 months or 6 months long, for which you will be in your regular routine care) and 2) the length of the intervention period (either 12 or 9 months where you and your healthcare provider use the ePRO app).

Block 1	
Control	Intervention (App)
Jan 2018 – Apr 2018	• May 2018 – April 2019
Summerville Family Health Team	
Southlake Academic Family Health Team	
Georgian Bay Family Health Team	

Block 2	
Control	Intervention (App)
Jan 2018 – Jul 2018	• Aug 2018 – Apr 2019
Mount Sinai Academic Family Health Team	
Ottawa Valley Family Health Team	
Family First Health Care Centre	

**Block 1** participants will be getting the mobile phones, and training on the ePRO app beginning in April, and will start using the ePRO app this May until April 2019.

**Block 2** participants will continue usual care until July 2018, and will begin to use the app in August.

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## What's next?

1. For **Block 1** participants we are now working with your Family Health Teams to book a training and on-boarding visit for the days of *April 15 to May 1*. We look forward to seeing you soon.
2. We are excited to share with you our plan to establish a *Patient Advisory* group, whose role would extend beyond our study, and help our researchers better understand the participant experience when designing research studies. Our patient advocate, Charles Shorrocks, who will be featured in next month's newsletter, will help guide this process along with the research team. More information on how you can be involved coming soon!

**\*\*A reminder that if you have not yet completed your surveys, to please do so at your earliest convenience. Thank you!**

Talk nerdy to me: **Surveys**



***Thank you very much for completing the first set of surveys. 1 down 5 to go!***

We would also like to take a moment and share with you some of the great feedback we received from some of our participants about the surveys themselves. Some participants found it difficult to answer some questions as they felt there wasn't a response option that best described themselves. A few others found some of the questions or responses not relevant. Firstly, thank you for reaching out to us. We really do want to hear from you.

The surveys we asked you to complete (and will again over the duration of this study) are validated surveys, which means that previous research has shown these surveys are appropriately designed to measure what they were intended to measure. Some of the surveys (e.g. The Assessment of Quality of Life instrument and Patient Activation Measure) have been used by numerous researchers and scientists in various other studies. Although some of the questions may not directly apply to your personal health experience (and we recognize this as a limitation of survey research), answering the questions to the best of your ability contributes immensely to our study.

In recognition of the feedback received, we are

currently examining if we can improve the survey questions to better reflect individual lived experiences. From now on, we will include a comments page with the surveys for you to jot down any comments or for open-ended responses. Moreover, our study will be addressing the limitations of survey through observation visits, focus groups, and interviews with **you**. These interactions will allow you to speak more about your personal experiences and stories, which will allow us to get to know you better beyond check boxes on a survey.

As we move forward, our team would like to reaffirm the importance of working with you as **partners** in this study. If there is ever a question, or something you are just not sure about, we are only a phone call or email away. We always welcome your thoughts.

As a token of our appreciation, please find enclosed a \$10 Tim Hortons gift card. For those of you who completed the surveys online, you will receive your Tim Hortons gift card in the mail.



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*Thank you very much from the ePRO team. Next issue of the ePRO exchange will be March, 2018.*

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