

# ePRO Exchange

The Official newsletter of the ePRO study

March, 2018



Month 3



## What is Goal-Oriented Care?

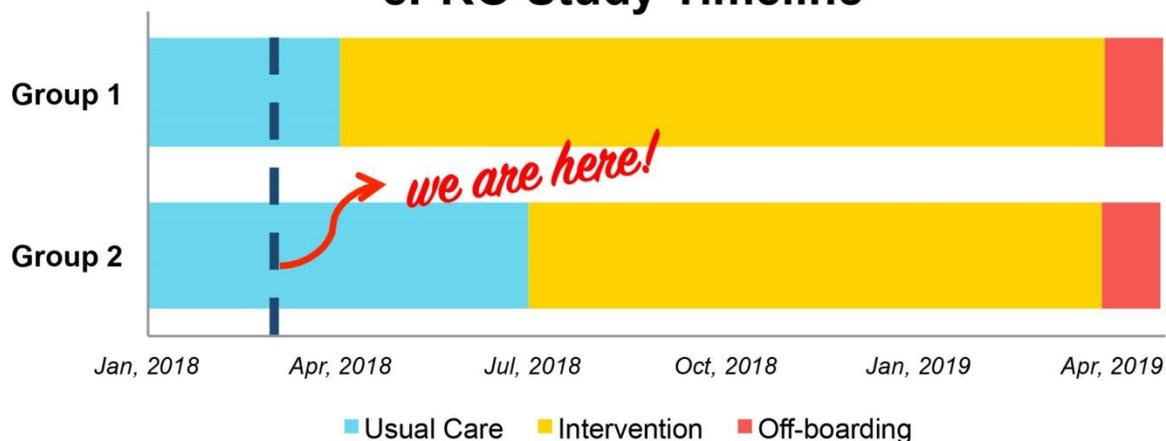
Goal-oriented care focuses on an individual's personal health goal as the motivation for care decisions. Person-centred, goal-oriented care (what ePRO is designed to support) can help individuals prioritize their competing issues and collaboratively work with their healthcare providers to develop personal care plans. Goals can go beyond just physical health symptoms, and can focus on function, social interactions and needs, personal values and beliefs. **Goal-oriented care supports care for the whole patient, not just the parts!**

Goal-oriented approaches can help patients prioritize their competing issues to help improve quality of life, while supporting

primary health care providers and clinicians with clinical decision-making. This allows for effective shared decision making, with the individuals selecting the health outcome of highest priority and the provider determining what treatment strategies are most likely to achieve that outcome.

Goal setting is a key feature of coordinated care plans that seek to support coordination and continuity of care for older adults with complex care needs. Patients and clinicians can agree on steps that can be taken to achieve these goals and monitor progress in reaching them. This approach can support improved self-management for patients.

## ePRO Study Timeline



## **What's next?**

For **Block 1** participants, we have scheduled training times with the clinicians in mid-April and will be working with your Family Health Teams to book a training and on-boarding visit with you for the days of *April 15 to May 1*. We look forward to seeing you soon. **Block 2** participants will continue usual care until July 2018, and will begin to use the app in August.

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## **Meet Carolyn**

Dr. Carolyn Steele Gray is a Scientist at the Bridgepoint Collaboratory for Research and Innovation at the Lunenfeld-Tanenbaum Research Institute and a Status Assistant Professor in the Institute for Health Policy, Management and Evaluation at the University of Toronto in Canada. Her program of work focuses on the role of technology to support patient-centred care delivery for persons with complex care needs. Carolyn is the lead Principal Investigator on the ePRO trial, working with Co-leads Dr. Ross Upshur and Dr. Walter Wodchis.

Carolyn's background in Kinesiology sparked her interest in research. Working part time in an athletic therapy clinic during her

undergraduate training, she saw the health care struggles of all kinds of clients, whether varsity athletes or older adults living in the community. Over her graduate work, and post-doctoral training she began to see the tremendous opportunity of technology to meet these needs, and enable better care delivery.

Beyond research Carolyn loves to be active and outdoors with her family; her husband Ian, her two kids Henry (age 6) and Lilian (age 2), and her two large huskies (Fen & Ada). Carolyn is an avid runner, training towards her first triathlon this year. When she can, she volunteers at her son's school and sports leagues, enjoying the opportunity to contribute back to her community in Toronto.



## **Choose Your Own Adventure**

By: Charles Shorrock

At the risk of showing my age, does anyone remember those "Choose Your Own Adventure" books from the 80's? You were the hero and got to choose different actions and then flip to the right page to see how it turned out. I loved those books.

As an adult, I've come to learn that sometimes we don't get to make all the choices and what happens can seem more like a bad dream than an adventure. In my case that dream looked like a split second of falling on some stairs. What followed was ten months of recovery, including four as an inpatient with both my legs in locked braces.

I was miserable in the hospital and from day one - I just wanted to know what I needed to do to be able to leave and know how many days would that take. It seemed like a simple question. The answer, no matter whom I asked, was frustratingly vague; the only part that was clear was that it would be weeks or months, not days.

The best part of my day, at this point, was physio at 10 AM. It seemed to be one of the few moments when someone talked to me like I was indeed a 45-year-old, fully grown man. I still couldn't get a firm answer on leaving, but at least we talked about life outside of the hospital. What did I like to do, did I have any goals that I wanted to achieve, what were my concerns? So I told him.

I had just taken up bike riding again after 30 years. I had found yoga the year before that and loved it. I was really afraid that I would not be able to do those things again. That I would be stuck with a cane and knees that were better for predicting rain than walking or running. What he said next changed everything for me because he told me the truth.

He said that I might not get all those things back.

It was still vague, but at least it was honest. He explained why and I understood then, that

it was the most accurate answer he could give. It depended on how much or little effort I put in, along with how resilient my muscles were. While I could not change some things, I was in control of others and did everything I could to push myself. That led to it being my turn to tell him something.



I was still frustrated by everyone's lack of clear language. Even in therapy, I would be told: "*I do not recommend this or that.*" One morning I seemed extra sore and stiff, he asked what I had done the day before. When I told him I tried walking outside the hospital, he was beside himself at the risk I had taken. So I explained to him that if he said *recommend*, I took it as a recommendation. Optional. If he meant for me not to do something, he would have to tell me "Charles, don't do this or that." If he did, I would not do it. After all, I wanted to go home.

I do not think he had ever had someone quite so direct before, but he understood what I was saying. He could see the benefit of clarity. He had just been burned, like many healthcare providers, by patients who did not listen or didn't understand and so ended up angry when things did not work out as they wanted.

In the end, I was really sad to leave him. Even though my outpatient therapists were just as good, it was Dennis who had seen me through those first few months. Together we had both become engaged in really co-designing my treatment in a way that left both of us feeling invested in getting the best outcome. It is an approach that changed all of my healthcare interactions in the three years since then.

I hope that as we move forward during the study, that some of you will become engaged in new ways as well. As we mentioned in the last newsletter, we hope to find ways to gain some insight into your experiences and are working on ways to do that. For now, I would love to hear anything you would like to share

with me about a healthcare provider or relationship that you have found impactful - positive or challenging. Send them to me at [Charles@charleshorrock.ca](mailto:Charles@charleshorrock.ca) and maybe we can gather some of the lessons learnt in a future article.



### Talk nerdy to me: **Case Study**

Researchers from many disciplines use the case study method to observe, explore, or study a topic in greater detail, in a real-life context. Case study research is a “naturalistic” design which examines a phenomenon in its natural context as opposed to an “experimental” design where a researcher aims to control a particular variables or set of variables of interest. Considering the frequency with which innovations are now happening in healthcare settings, the case study approach is ideal to better understand complex health service interventions, policy and delivery.

In addition, case studies lend themselves to answering ‘how’, ‘what’, and ‘why’ type questions that can support the development and refinement of a theory. In our study we will be using observations, interviews, focus groups, and questionnaires to collect data surrounding the individual lived experience, which will undoubtedly produce a richer narrative of user experiences with the ePRO app. This will be our opportunity to go beyond just numbers and data points, and ask you how you used the app in your everyday life. 😊



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

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