

# UTOPIAN Clinical Research Group Meeting MINUTES

February 24, 2022  
Time: 4:00 PM – 5:00 PM EST  
Teleconference (Zoom)

## Action Items:

1. For those interested in a long COVID-19 study, please contact Dr. Andrew Pinto at, [andrew.pinto@utoronto.ca](mailto:andrew.pinto@utoronto.ca)

## Review & Approval of Minutes

- Minutes from the previous UTOPIAN Clinical Research Group (CRG) meeting were **approved**.

## Lecture Series 2: Patient-Oriented Clinical Trials in Primary Care

*Presenters: Dr. Michelle Greiver and Kathy Kastner*

### Introduction

- This presentation aims to encourage researchers to want to involve patients in their research projects and recognize the value of their contribution.

### Kathy's Message

- Kathy Kastner of [www.bestendings.com](http://www.bestendings.com) and author of 'Death kills... and other things I learned on the internet' has participated as a patient partner in many research projects in the past and continues to do so. She has been an invited speaker at the Stanford Medicine Annual Conference, presented a TED Talk called 'Exit Laughing,' and has presented her original research at various health conferences. Currently, she is a Patient & Family Advisory (PFA) on the Meta-LARC Advance Care Planning (ACP) project. Her passions include plain language and ensuring proper context.
- Kathy shares that as a patient, she's valued the insight into the protocols, processes, and limitations of research. Specific to the ACP project, while it took some time to understand how best she could contribute, the supportive environment has helped her focus on the 'do-able'

### Michelle's Message

- Patient-oriented research leads to better researchers and better projects.
- Michelle shares that this is a learning process. She has learned alongside patients how to best involve them in research and maximize their contributions.

### CIHR SPOR

- The [Canadian Institutes of Health Research Strategy for Patient-Oriented Research](https://www.cihr.gc.ca/eng/program/spor/index.html) (CIHR SPOR) aims to transform the role of patient from a passive receptive of services to a proactive partner who helps shape health research and, as a result, health care.
- SPOR believes that patient-oriented research is about engaging patients, caregivers, and families as partners in the research process to ensure that studies focus on patient-identified priorities, which ultimately leads to better patient outcomes.
- One of SPOR's primary principles is that patients need to be involved in all aspects of research to ensure questions and results are relevant, while decision-makers and clinicians need to be involved to ensure integration into policy and practice.

### Meaningful Patient Engagement

- One way to engage with patients is including them as research committee members, whereby they can contribute to planning, designing, and guiding the project as it progresses.
  - By being involved at this level, patients also become competent researchers as they become more familiar with research processes.
  - Patients have an important role in helping clinicians identify the right research question, study design, recruitment, data collection, and the analysis of findings ((i.e., ensuring the effectiveness of recruitment/data collection materials, providing context, offering a different perspective on analysis, etc.).

### Outcomes of Patient-Oriented Research

- Inclusive mechanisms and processes are created to engage with patients, as involving them in the research process is still an evolving paradigm shift.
- Respectful collaboration is established amongst patients, researchers, and health care providers, as each learns to work together with the others toward the end goals of the research project.
- The lived experience of patients is valued in informing the research process.
- Patients and researchers work together toward the common goal of timely implementation of quality research. Patients can act as advocates for change.

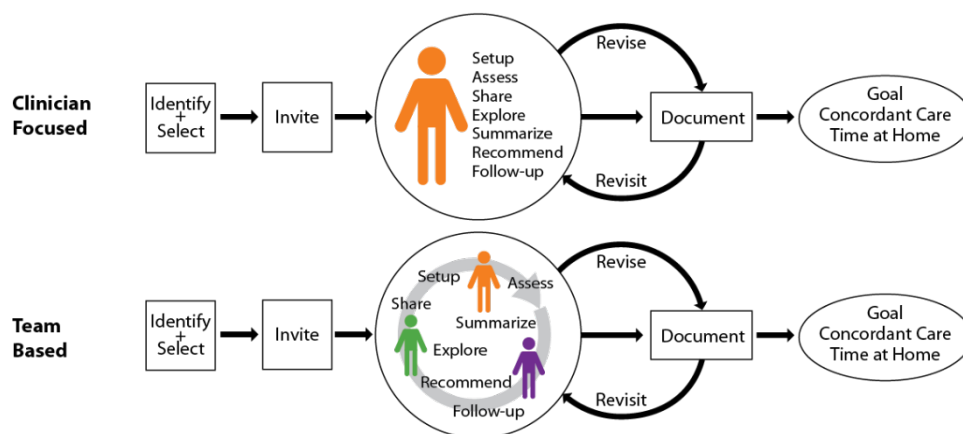
### Working with Patient and Family Advisors

- PFAs support community-based pragmatic research trials that seek to answer real-world questions that matter to patients and their families.
- It's important to find a balance between what's important and what can actually be measured.

### Meta-LARC Advance Care Planning Study

- Many patients with serious illnesses value conversations that enable them to consider what is important to them and share their preferences with their families, care partners, and health care providers.
- The Serious Illness Care Program (SICP; [www.ariadnelabs.com](http://www.ariadnelabs.com)) is designed to help clinicians initiate serious illness care conversations (SIC) at the right time and in the right way so that patients and families can make better-informed choices and plans that align with their values, with the goal of assuring well-being and quality of life in the context of serious illnesses and limited life span.
- This bi-national cluster randomized trial was funded by the Patient-Centered Outcomes Research Institute (PCORI; \$8M) and led by Principal Investigators (PIs) Drs. Annette Totten and France Légaré.
  - The study involved 7 Practice-Based Research Networks (PBRNs) in Canada and the US, 42 primary care clinics (6 per PBRN), and 1,120 patients and care partners.
  - Primary outcomes included goal concordant care and days at home.
  - This study aims to assess the comparative effectiveness of primary care team-based versus clinician-based SICP implementation and explore contextual factors influencing the implementation of the two models and how these vary across practices.
  - Clinics were randomized to clinician-focused or team-based ACP and all participating clinicians at each clinic were trained according to their clinic's randomization.
- This study aims to generate evidence that will support making ACP a routine practice in primary care, helping patients with serious illness get care that supports what is important to them and their families.

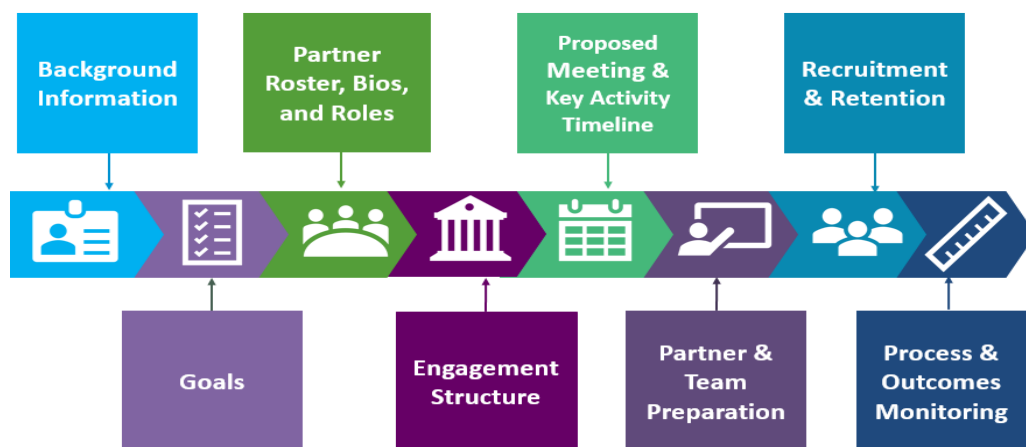
## Serious Illness Care Program



### How did PFAs influence the Meta-LARC ACP Study?

- PFAs:
  - Brought lived experience to the project team.
  - Helped researchers and clinicians understand the patient experience.
  - Described misconceptions and gaps in care that people face while undergoing ACP.
  - Built relationships and trust so patients, families, and clinicians feel more comfortable having these conversations.
- With the support of PFAs, researchers better developed:
  - Training, tools, and workflows that used respectful language and tone.
  - Materials that were provided to patients and families to prepare for initial and follow-up SIC.
  - Research outcomes that mattered to patients and families

### Building an Engagement Plan



- Building an engagement plan was a deliverable of this project and helped the team in fulfilling the objectives of a patient- and stakeholder-engaged clinical research project.
- The engagement plan is similar to a protocol in that it provides detailed plans that guide the project and can be referred to as the project progresses and evolves. The plan holds all involved parties accountable and provides a way to document the process.

- To create the engagement plan, the following steps were followed:
  1. Created an Engagement Plan Work Group that was composed of:
    - 11 PFAs (7 associated with each participating PBRN and 2 at-large in both the U.S. and Canada)
    - Institute for Patient- and Family-Centered Care representative
    - Joint Coordinating Center representatives (PI and a dedicated Engagement Manager)
    - PBRN representatives (Project Coordinators)
  2. Developed the Engagement Plan
    - Surveyed stakeholders and PFAs to identify their engagement goals.
    - Conducted a consensus discussion where participants reviewed engagement goals to determine shared goals and develop a purpose statement.
  3. Selected a Writing Team
    - Various sections of the plan were distributed among participants based on experience, areas of expertise, and volunteering.
  4. Finalized the Plan
    - Several drafts of the plan were reviewed by members of the working group and a final version was then submitted to PCORI.
  5. Ongoing Quality Improvement (QI)
    - The team engaged in ongoing QI of the engagement process by monitoring engagement goals, conducting quarterly PFA meetings and annual interviews, measuring input and impact on the project, establishing processes to support PFA recruitment and retention, and creating a supportive environment that led to a mutual understanding of roles and expectations, and meaningful and successful interactions and contributions.

## Conclusions

- Working with PFAs as core team members was extremely valuable to the overall project and led to both short- and long-term benefits.
- Research that involves PFAs contributes to the development of evidence that considers patient and care partner perspectives, leading to improved patient outcomes.

## Resources

- <https://diabetesaction.ca/patient-engagement-resources/>
- <https://ossu.ca/resources/resources-training/>
- <https://ossu.ca/for-researchers/patient-engagement-resources/>
- <https://www.pcori.org/engagement/engagement-resources>

## Discussion

[Q: Question; A: Answer; C: Comment]

- **Q:** What scares researchers and clinicians away from involving patient partners in their research.
  - **A:** A component of this is likely the fear of losing control of a project.
- **Q:** How do you know you have the 'right' patient partner?
  - **A:** It is a relationship that requires meaningful effort.
  - **A:** Many patients who may seemingly represent a population (i.e., an Indigenous patient partner) often feel that they only represent their own experiences, which are not necessarily those of the wider group or population.
  - **A:** Lived experience is important to take into account. Having experience with a particular topic, condition, or situation may make some patient partners more suitable to a project than others.

- **Q:** Did Meta-LARC co-create a new 'language,' did patients learn 'research jargon,' or did researchers adopt more accessible language when discussing the project.
  - **A:** Meta-LARC conducted a training session with PFAs prior to the launch of the study to go over the scope, structure, and protocol. There is a continued effort to maintain a safe space and atmosphere of mutual respect where questions can be asked freely by all those involved.
  - **C:** If it's not necessary to use jargon, don't use it!

## Recent Publications

- Spithoff S, Stockdale J, Rowe R, McPhail B, Persaud N. [The commercialization of patient data in Canada: ethics, privacy and policy](#). CMAJ. 2022 Jan. 194 (3) E95-E97; DOI: 10.1503/cmaj.210455
- Stephenson E, O'Neill B, Kalia S, Ji C, Crampton N, Butt D, Tu K. [Effects of the COVID-19 pandemic on anxiety and depression in primary care: A retrospective cohort study](#). Journal of Affective Disorders. 2022. Feb 6;303:216-222. doi.org/10.1016/j.jad.2022.02.004
- Ji C, Piche-Renaud P-P, Stephenson E, Apajee J, Forte M, Friedman JN, Zlotkin S, Morris S, Tu K. [Impact of the COVID-19 pandemic on routine immunization coverage in children under 2 years old in Ontario, Canada](#). Vaccine. 2022. Feb 8. doi.org/10.1016/j.vaccine.2022.02.008
- Goodarzynejad H, Meaney C, Brauer P, Greiver M, Moineddin R, Monavvari AA. [Recent trends in adult body mass index and prevalence of excess weight: Data from the Canadian Primary Care Sentinel Surveillance Network](#). Canadian Family Physician. 2022 Feb; 68 (2) 128-138; DOI: <https://doi.org/10.46747/cfp.6802128/>
- Chin C, Amri M, Greiver M, Wintemute K. [Improving health equity by screening for poverty: a survey of family physician screening behaviors and perceptions in Toronto, Canada](#). Health Equity; Feb 2022: 124-13.
- Meaney C, Escobar M, Moineddin R, Stukel TA, Kalia S, Aliarzadeh B, Chen T, O'Neill B, Greiver M. [Non-Negative Matrix Factorization Temporal Topic Models and Clinical Text Data Identify COVID-19 Pandemic Effects on Primary Healthcare and Community Health in Toronto, Canada](#). J Biomed Inform. 2022 Feb 21:104034. doi: 10.1016/j.jbi.2022.104034. Epub ahead of print. PMID: 35202844; PMCID: PMC8861144.

## New Research Ideas

- Therapeutic treatments of COVID in primary care: limited evidence
  - This initiative started when researchers learned that the federal government has purchased a large amount of Paxlovid, an antiviral oral medication for COVID-19 that was recently approved by Health Canada based on weak evidence
  - It is anticipated that COVID is going to be endemic and treating patients will largely be in community settings
  - The goal is to seek evidence on efficacy applicable to Canadian populations and to develop research capacity in primary care
  - A CIHR grant application is being prepared for this proposed project involving interprofessional teams from primary care, infectious diseases, public health