BUILDING A FRAMEWORK FOR SUPPORTING MEANINGFUL FAMILY CAREGIVER ENGAGEMENT:

LESSONS LEARNED

The Le Royal
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INTRODUCTION: FROM CO-DESIGN AND BEYOND

From its creation, this project has been directed and initiated by caregiver advisors at The Royal; their experiences and perceptions of meaningful engagement practices were the foundation of this research. Since then, every step of this process has been co-designed by a team of caregiver advisors, service providers, and researchers.

While pursuing this style of collaboration over this past year and a half, we have overcome many challenges and celebrated even more successes. To immortalize this experience, we have briefly highlighted important moments during this research and discussed reoccurring challenges. We hope our experiences can guide future researchers through the exciting adventure of co-design research.

Team Structure

As laid out in the grant proposal, co-design and collaboration were foundational for this project. To give context to this publication and our effects with collaboration, we decided to outline the structure of our team:

A caregiver advisor acted as the Principal Investigator and visionary of the project. A research coordinator was hired to work directly under the Principal Investigator to manage the project and research efforts. Two caregiver advisors with previous research experience consulted on the project based upon their expertise and connections. Additional support was gained from a team of researchers, service providers, and caregivers from local hospitals and community organizations who acted as consultants throughout the process. Additional external service providers and caregiver advisors were invited to consult during specific phases of the project to ensure the team had represented the needs of the target populations. All caregivers involved were compensated for their time accordingly.

LESSONS LEARNED

A Knowledge User as the Principal Investigator

As a Caregiver Advisor and Knowledge User, the Principal Investigator found there were several challenges to fulfilling their role.

To begin, the requirements for a Principal Investigator applicant for the Canadian Institutes of Health Research (CIHR) grant were particularly difficult. For example, the '*Gender and Health Core Competency Module for Sex and Gender in Primary Data Collection with Human Participants'* Certificate was very difficult to obtain for a layperson.

Additionally, while the role of the Principal Investigator was defined by the Strategy for Patient-Oriented Research (SPOR) grant, working as a layperson within a research institution required a certain level of knowledge of the day-to-day responsibilities and organizational procedures to complete a project.

For future projects where the Principal Investigator is a Knowledge User, we would recommend allocating a mentor or coach to assist with the CIHR grant requirements. Additionally, research institutes or health organizations interested in conducting patient-oriented research should consider developing a guide of processes and procedures for future Knowledge Users who wish to assist with research efforts.

COVID-19 Complications

This project began when COVID-19 protective orders were starting. During this period, there were some delays while organizing around the new standards. Thankfully, CIHR gave the project an additional year to spend the funds, allowing the project to compensate for this delay successfully.

The more severe complication was the requirement for social distancing. To limit all in-person contact and stop the spread of COVID-19, the project became remotely organized and all meetings were conducted via Zoom. There were some benefits to this change: we could now include team members who were living across the province to partake in weekly virtual meetings. In addition, the funds allocated to travel expenses were redistributed to other budget needs.

Due to COVID restrictions, the proposed 'Day of Collaboration' that would have brought together face-to-face a range of stakeholders to review and give input into transforming the findings from the discovery phase into knowledge products was not feasible. This task was successfully carried out via ZOOM over three separate sessions, using break out rooms and ensuring that participants received informative materials in advance of the sessions. This

collaborative model served us well and participants were given opportunities to submit additional comments post-sessions.

In summary, the Zoom alternative was effective, easy to use, and provided a wonderful platform for discussion. For future projects, we would recommend using a virtual alternative like Zoom to facilitate discussion with participants and team members.

Over-Extended Partners

While many caregiver advisors, researchers, and service providers were willing to become involved with the project, some were committed to other responsibilities which limited their involvement. Therefore, some partners could not provide insights to assist with the co-design when requested, could not answer important e-mails, or lacked the time to read the background information provided to offer educated feedback. For example, several unexpected health and family health complications arose within our core team, preventing their full engagement.

To compensate for the lack of available time and team drop off, we recruited several contacts from the Principal Investigator's network to become involved with the project to ensure we had the caregiver advisor and service provider perspectives required for a true co-design project.

Other complications in this project were the uncertainties of how the original grant applicants were expected to be involved. Their roles and contributions we not well defined during the process and, therefore, most of the grant applicants were rarely involved.

For future projects, we would recommend clearly outlining a memorandum of understanding for team members and grant applicants, which can be referred to throughout the project.

Finding Collaborative Partners

To ensure successful collaboration, finding the right collaborators was important and we relied heavily upon the Principal Investigator's connections to find partners who had valuable expertise. Often times, we found that if the Principal Investigator reached out in a personal e-mail, we would get an answer. E-mails from the research coordinator, even with the Principal Investigator CC'd, were answered far less, especially from newer collaborators to the project. From this, we believe that with the Principal Investigator having fostered a comprehensive network of contacts who were both experienced and reliable on this specific topic was key to the success of the development of useful knowledge products.

One issue we did experience, however, was a miscommunication in the original grant application. In the application, we were under the impression that a member on the team had access to certain target community, such as first nations. However, when planning our outreach strategy, it was discovered that while work had been done with first nations by this individual, there were no personalized relationships or connections that could be used to meaningfully engage the community. As such, we had to cancel our outreach plan.

For future projects, we would recommend relying upon the connections of involved caregiver advisors and, if a specific community is intended to be contacted, the engagement strategy should be arranged very early on.

Communication Preferences

During this project, we discovered that some methods of interacting, communicating, and sharing information were more effective than others. In our experience, using Monday.com was not valuable. It took time to set up and, after training everyone on the team, the site was rarely used. Instead, providing update e-mails and a google share between core team members was effective.