

## **Research Engagement Facilitator: Bridging the gap between researchers and people with lived experience**

Chalghoumi H, Forster VJ, Kowal C, Stubbs A.

### *Introduction*

Researchers and organizations are becoming increasingly aware of the need to involve patients, care partners and families in research teams, referred to throughout as people with lived experience (PWLE) to ensure innovative and impactful research. PWLE have been advocating for greater involvement for decades and the widespread use of social media and videoconferencing technology has resulted in more interactions between PWLE and researchers. Research funding agencies are also increasingly requiring the involvement of PWLE as a condition for awarding research grants in many health and social related disciplines. These partnerships are complex and require excellent communication, openness and willingness to ensure that all parties feel valued in the partnership.

Although some researchers and patients/family members foster excellent partnerships that fulfill all of these criteria, many do not for a wide variety of reasons which can substantially limit the positive impact of PWLE being involved. Therefore in this essay we suggest that research partnerships could frequently benefit by incorporating another person into the partnership, the “research engagement facilitator (REF).” We will describe the role of a REF as part of the research team as well as key qualities of a person who might fulfill this role and the potential impact on the PWLE representatives, researchers and wider research team.

### *Literature review*

A review of recent literature was curated to understand if and how similar engagement strategies have been implemented in research and practice. With little information on similar roles such as the one presented in this proposal, the literature reviewed also includes community-based providers that have identified and adopted effective strategies for engagement. This provides parallel information and insight into ways in which this can be incorporated through research.

Through a brief analysis of the literature, the barriers, reviews and experiences of engagement of PWLE had a consistent foundation of the professional team making a profound shift in approach and attitude that focuses on family strengths with consistent consideration to identifying and addressing barriers (Chrispeels & Rivero, 2001; Hamilton et al, 2021; Hornby & Lafaele, 2011; Mytton et al., 2014; Peña, 2000). This is consistent with the widely used framework developed by Joyce Epstein (1995) in looking for elements of connection and approaches to building partnerships with trauma-informed approaches that include elements of equity and anti-oppressive lenses (OACAS Library Guides, n.d.).

The professional roles that equate to promoting this engagement in community-based settings are equipped with humanistic knowledge and empathy with the ability to develop relationships (OCASI, 2016). This is consistently seen through elements that are learned and intrinsic through insights into human behaviour, the area of service/research, and highly developed case management and conflict resolution skills (Alliance for Healthier Communities, 2020). These elements of both foundation and practical experiences were used to develop and inform the job description proposed.

### *Description and proposed purpose of role*

The REF is a specialized role that serves to enhance family engagement in research and we propose that a REF would be an integral part of a research team, forming a bridge between researchers and PWLE to ensure frequent and productive communication between all members of the group. This, in turn, would help to ensure that PWLE feel valued and supported as members of the research team and would also guarantee that they have a dedicated point of contact. The REF plays an essential and active role in facilitating family engagement in research and proactively engages PWLE to participate in the research process. A key role of the REF will be ensuring that the PWLE member understands any scientific jargon or complex concepts by working with both the researchers and the PWLE to facilitate effective communication of complex concepts.

### *Needed skills/qualities/training for a REF*

We have included within this paper, a job posting (appendix 1) which summarizes the personal skills and qualities desirable in a REF. Three sub-themes emerge as characteristics needed for REFs to effectively perform their role: the ability to understand research methods, effective communication skills, and personality. These qualities go hand in hand with showing respect and inclusion for cultural sensitivity.

*Understanding research methods:* Having a strong understanding of the following domains: scientific concepts & research design, ethical and participant safety considerations, medical products development & regulation of research studies using medical products, clinical study operations (Good Clinical Practice), study and site management, and data management & informatics.

*Communication:* The ability to explain the research in lay terms and outline the expectations of both the researcher and PWLE is critical to be successful in this role. Being able to hear concerns of both researchers and PWLE and actively resolve issues as they arise. Multilingualism is an asset as conversation in native languages allows for deeper understanding.

*Personality:* Outgoing, self-confident, approachable, and empathetic with a genuine concern for the well-being of others. Acts as a leader by displaying professionalism and teamwork.

Candidates well suited for this role can come from several backgrounds including social work, nursing, clinical research, and counseling. Training sessions in relationship building, conflict resolution and research administration would enhance the candidate's skillset. If the role is within a clinical setting, certification may help with career advancement. Two organizations that provide certification include the Association of Clinical Research Professionals (ACRPnet.org) and the Society of Clinical Research Associates (SoCRA.org).

### *The impact of REFs*

Including a REF on a research team will greatly enhance the communication and working relationship between the researchers and the PWLE. By ensuring all members of the research team feel valued, research innovation and impact can be maximized. Further, researchers will also gain confidence and experience of how to personally ensure equitable and productive relationships with PWLE and will be more likely to retain participants in the study, as well as for future research studies. For some PWLE, participating in research studies may also be a source of stress and harm (Flagal, Best & Hunter, 2007) and the REF will be trained to identify when PWLE are struggling and intervene accordingly, as well as to make sure researchers do not inadvertently contribute to this harm.

### *Moving forward: Ideas for promoting the REF*

To promote REF as a profession and service, it is necessary to develop a clear and agreed-on scope of practice with the REF practitioner's roles, responsibilities, and related skills. In this paper, we propose specific responsibilities, qualifications and skills that could serve as a starting point to define this scope (Appendix 1).

The agreed-upon scope should be integrated into carefully designed training programs with evidence-oriented competencies and practical realities to ensure rigour, ethics, and professionalism in supporting researchers and PWLE. REF training programs should evaluate and monitor the outcomes for PWLE to assist in and improve these outcomes and inform future decisions. Future research could also improve REF-related services and programs by assessing the outcomes and identifying facilitators and barriers to the REF roles interventions and opportunities for the future.

Finally, to ensure the sustainability of REFs as a profession, researchers and research centers, health and community organizations, and other concerned governmental entities should implement sustainable models for funding the REF services.

### *Conclusion*

As the pace of interest for family engagement in research continues to grow, the use of a REF is a strategic opportunity to make research recruitment and retention more efficient and effective. Family members are more interconnected and empowered than ever before. Awareness of research is gradually growing as more family

members are motivated in being part of research. Beyond helping find research projects, a REF could fill an essential role in helping family members understand, and effectively engage in research. The REF could be an instrumental research team member that aids in family retention and facilitates knowledge translation.

By supporting researchers and family members in this way, REFs ultimately are THE missing link to help bridge the gap between researchers and family members.

### References

Alliance for Healthier Communities. (2020). *Mental Health and Engagement Work*. Retrieved March 1, 2022 from <https://www.allianceon.org/job-posting/Mental-Health-Outreach-and-Engagement-Worker-0>

Chrispeels, J. & Rivero, E. (2001). Engaging Latino Families for Student Success: How parent education can reshape parents' sense of place in the education of their children. *Peabody Journal of Education*, 76(2), pp. 119-169. <https://doi.org/10.2080/00220676009492741>

Epstein, J. L. (May 1995). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan*, 76(9), 701–712.

Flagel, D. C., Best, L. A., & Hunter, A. C. (2007). Perceptions of stress among students participating in psychology research: A Canadian survey. *Journal of Empirical Research on Human Research Ethics*, 2(3), 61-67. <https://journals.sagepub.com/doi/abs/10.1525/jer.2007.2.3.61>

Hamilton, C. B., Hoens, A. M., McKinnon, A. M., McQuitty, S., English, K., Hawke, L. D., & Li, L. C. (2021). Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expectations: an International Journal of Public Participation in Health Care and Health Policy*, 24(3), 863–879. <https://doi.org/10.1111/hex.13227>

Hornby, G., & Lafaele, R. (2011). Barriers to parental involvement in education: an explanatory model. *Educational Review (Birmingham)*, 63(1), 37–52. <https://doi.org/10.1080/00131911.2010.488049>

Mytton, J., Ingram, J., Manns, S., & Thomas, J. (2014). Facilitators and Barriers to Engagement in Parenting Programs: A Qualitative Systematic Review. *Health Education & Behavior*, 41(2), 127–137. <https://doi.org/10.1177/1090198113485755>

OACAS Library Guides. (n.d.). *Family engagement in child welfare: Strategies for engaging families*. Retrieved March 1, 2022, from <https://oacas.libguides.com/family-engagement/strategies>

Ontario Council of Agencies Serving Immigrants (OCASI). (2016). *Community Engagement*. Retrieved March 1, 2022, from <http://www.ocasi.org/>

Peña, D. (2000). Parent Involvement: Influencing Factors and Implications. *The Journal of Educational Research*, 94(1). <https://doi.org/10.1080/00220670009598741>

*Link to video describing the research engagement facilitator role*  
<https://www.powtoon.com/c/fk9ZZWKTsc4/1/m>

*The following job posting is meant to be used as a template for institutions wishing to hire Research Engagement Facilitators as part of their research program/framework*

# RESEARCH ENGAGEMENT FACILITATOR

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<<Insert description of Institution, Location, Program, and Project>>

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## WHAT THE ROLE IS

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The Research Engagement Facilitator (REF) is a specialized role that serves to enhance family engagement in research. As part of the research team, the REF works alongside investigators, research nurses, managers, coordinators and assistants to promote and facilitate research programs and platforms. The REF serves as a bridge between researchers and persons with lived experience (PWLE) by explaining research objectives and participant involvement using easy to understand terms and diagrams.

The REF will:

- Provide exceptional support to researchers and PWLE through various stages of the research process.
- Be paired with investigators and work seamlessly and collaboratively with them to ensure a positive experience for PWLE throughout the research process.
- Have a strong understanding of research methods including patient enrollment, informed consent process, data collection, analysis and results dissemination.
- Be available to PWLE to answer any non-clinical related questions and assist PWLE in finding answers from the appropriate internal and external resources.
- Play an essential and active role in facilitating family engagement in research and proactively engages PWLE to participate in the research process. The candidate is highly motivated to work in research and to positively support researchers and PWLE.
- Facilitate dialogue and communication between researchers and PWLE by encouraging open discourse.

## WHAT THE ROLE IS NOT

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Research administration and tasks generally fulfilled by investigators and/or research coordinators including but not limited to: grant management, research ethics applications, regulatory document preparation, patient screening, participant enrollment, data collection, analysis and manuscript preparation.

## KEY TASKS

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- Identifying PWLE interested in utilizing research engagement facilitator service

## KEY SKILLS

- RESEARCH METHODS
- COMMUNICATION
- PROBLEM SOLVING
- PROJECT MANAGEMENT

## LEVEL/SALARY RANGE

## JOB CATEGORY

## POSITION TYPE (FULL-TIME, PART-TIME, CONTRACT)

## DATE POSTED

## POSTING EXPIRES

- 
- Acting as a resource for PWLE to ensure they have access to the information and answers needed prior to and during research involvement
  - Work with research assistants/coordinators to ensure informed consent is obtained prior to the start of any research
  - Proactively reviewing and understanding research protocol in order to effectively relay intended objectives to research participants
  - Ensure all parties feel that the partnerships are productive and that their contributions are valued
  - Providing general guidance to PWLE and responding to inquiries over the phone, through email or text message
  - Following up with PWLE to ensure needs are met

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### **ACTIVELY SEEKS PWLE FEEDBACK AND SERVES TO FACILITATE RESOLUTION OF PWLE ISSUES BY:**

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- Providing a supportive and caring environment
- Talking with the PWLE to understand their concerns and obtain information to support effective and timely resolution
- Escalating issues to the Research Manager or appropriate resource, as needed
- Setting up meetings between the PWLE and Research Manager when required
- Following up with the Research Manager to ensure PWLE feedback and concerns have been adequately resolved
- Playing an active role in implementing feedback from PWLE satisfaction surveys into research processes and environment

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### **JOB REQUIREMENTS**

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- Successful completion of a University Degree or College Diploma
- Knowledge and previous experience in research, customer service or client relations role
- Strong interest and understanding of research methods
- High level of maturity and ability to demonstrate compassionate care and communication
- Demonstrated problem solving with high level of communication both written and verbal
- Ability to work independently and take initiative
- Passionate about conflict resolution and mediation
- Highly organized and understands and respects the importance of diversity and inclusion
- Considers the ethical aspects of research participation
- Previous experience as a family/patient research partner is an asset
- Being multilingual is an asset
- Certified as a Clinical Research Professional/Associate is an asset

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*This resource was created as part of the McMaster University, CanChild, and Kids Brain Health Network Family Engagement in Research Certificate of Completion Program. Copyright © 2022 Hajer Chalghoumi, Victoria Forster, Christine Kowal, Alisha Stubbs. All Rights Reserved.*