

Engaging refugees and asylum seekers as community research partners: key undertakings from the RÉAC! research project

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Abstract

Background: Evaluation of the engagement of people with lived experience of forced migration in community-based research is minimal in North America. In this commentary, we examined the participatory governance model used in the REAC! research project to involve refugees and asylum seekers as service user partners, and to assess its impact on research processes, participant experiences, and policy and practice outcomes.

Methods: A participatory advisory board structure was implemented in Québec and Ontario from 2021 to 2024. Boards included community and public service providers, funders, and refugee/asylum seeker service users. Engagement procedures were adapted from the Learning Together Patient and Public Engagement framework, including language and migration related accommodations. Data included reflective notes, ongoing communications, and end of project interviews with refugee/asylum seeker service users. A narrative analysis identified key themes.

Results: Clarifying roles, expectations, and benefits throughout the research process enabled early trust building. Inclusive communication channels, safe discussion environments, and language support strengthened participation. Over time, refugee/asylum seeker service users gained confidence, engaged in co-analysis, and co-formulated policy recommendations. Challenges included balancing their lived experience of forced migration with their professional identities and navigating time constraints.

Conclusions: Meaningful involvement of refugees and asylum seekers can enhance research relevance, empower participants, and improve cross sectoral collaborations. Participatory governance in research can strengthen health system equity and generate actionable recommendations for improving accessibility and service quality.

Background

During COVID-19, it became more important than ever for public and community-based organizations to work across sector lines in supporting the health and wellbeing of refugees and asylum seekers. Mandatory distancing pushed for new forms of cross-sectoral collaboration – especially between the community and the public sectors in Canada. From 2021 to 2024, the *REAC!* participatory research project sought to analyze these new collaborations, their success and challenges, from the perspectives of community and public service providers, as well as from the perspectives of service users – refugees and asylum seekers – in Canada's most populated provinces, Québec and Ontario.

From the onset, the *REAC!* research team projected the meaningful involvement of refugees and asylum-seekers as key community research partners who would contribute to the governance of the research. We recruited six refugee and asylum-seeker service users on our advisory board. This idea was based on the realization that accountability towards migrant service users during the pandemic was minimal, if not non-existent. Yet through their lived experience of forced migration, these service users are an invaluable source of knowledge and expertise on the services provided (Touati et al., 2025). While there is a large

Canadian literature on the importance and impacts of patient partnerships (Pomey et al., 2019), evaluation of public engagement, and especially asylum seekers or refugees, is minimal in this part of the world. Yet, just like with patient-partners, collecting their continuous feedback and regularly engaging with them are instrumental steps to improve health systems.

As the project ended and our findings get published (anon, 2025a; anon, 2025b; anon, 2025c), the present study offers critical reflections about *RÉAC!*'s model of involving advisory board members with lived experience of forced migration in the governance of the research project, the impacts it might have had on the research, its policy and practical outcomes, what these people with lived experience of forced migration might have gained in the process, and what could be improved.

Methods

In 2021, when we designed the *RÉAC!* research proposal (anon, 2023), we decided to implement a participatory governance structure, through the creation of two research advisory boards – one for Québec and one for Ontario. Community and public service providers, funders of cross-sectoral initiatives, and refugee and asylum-seeker service users were invited to participate in on these advisory boards. Each advisory board met online (Zoom) every 3-4 months. Each advisory board was responsible for (a) reviewing the research objectives and the data collection tools, (b) contributing to designing, validating and distributing the recruitment tools, (c) commenting and validating each of the research stages (selection of cross-sectoral initiatives to study in each province, etc.) employing a feedback loop approach, (d) discussing and validating the analysis plan, (e) discussing and validating the preliminary findings, and (f) co-organising and co-presenting in diverse knowledge-translation events in both Québec and Ontario.

Involving several refugee and asylum-seeker service users in these advisory boards meant designing a public engagement approach in research that was essentially inclusive, respectful, and mutually beneficial. We adapted an early version of the *Learning Together : Evaluation framework for Patient and Public Engagement (PPE) in research* approach (Centre of Excellence on Partnership with Patients and the Public, 2023) to account for language (not all service user board members could speak French or English and therefore our processes needed to account for this aspect) and migration (e.g., it could be hard for them to speak out in public and in front of policy-makers, about their problems, because they could be fearing deportation, especially asylum seekers), i.e. aspects that were specific to the *RÉAC!* research project.

Based on the PPE framework, we anticipated that two paramount components were needed for this inclusive, participatory process to truly work: 1) **establishing and maintaining trust relationships** over time, and 2) **creating a safe and inclusive discussion space**. First, we needed to instigate trust relationships between us and the refugee/asylum-seeker service users. We therefore decided to start by holding an orientation session where we would get to know each other better. We organized a fun, online ice-breaking activity where everyone could be set on an equal footing. The activity provided the

opportunity to discuss and validate researchers and service users' roles, what was expected from all parties (e.g., expected benefits for researchers and service users). We then implemented channels of communications according to the preference of our service user board members, i.e., by email for Ontario or through a *WhatsApp* group for Québec. Second, we needed to provide them with all the necessary resources (e.g., language interpretation upon needed) prior to, during, and after each meeting, to ensure that they would be able to contribute as much as they wanted to and in their preferred format. Of course, that meant that we also needed to make sure the discussion space provided was safe for them to speak into, therefore we guaranteed the compliance of every board member to two main rules. The first rule was that every board member formally accepts the advisory board meeting instructions, whereby an equitable approach ensured that (i) more weight was given to the contribution of service user members, and (ii) a respectful, culturally sensitive tone was used at all times. The second rule was to secure at least 10 minutes in each board meeting dedicated to asking service users' suggestions and comments, before moving onto other board members' contributions.

We compiled *ad hoc* reflective notes after each meeting, personal communications with several user representatives (n=2), and we approached each service user (n=6) at the end of the final workshop, to ask about their experience with the research project. Using a narrative analysis of the data collected, we draw key undertakings from the process, that we present in the next section.

Findings

Findings indicated that clarifying roles, purpose of research, and expectations was instrumental at the beginning, in order to instigate healthy conditions for collaboration. Connecting with prospective service user members was made possible through linkages with community organizations or resource persons that they already trusted. Then, the first contact (i.e., orientation sessions) was decisive to 'break the ice' and create the common ground on which we could establish trust relationships. Once this was established, frequent interactions were key, not only through group communications (we initially thought this was enough – we readjusted this aspect as we went along) but also through individual, one-on-one messaging and oral conversations. Securing an open, warm and safe space, that allowed service user board members to feel included (e.g., by providing Spanish language interpretation during online meetings), was another asset; as we witnessed refugee and asylum seekers on our advisory board gaining autonomy and sense of initiative (e.g., getting more comfortable in public speaking vs. just putting thoughts and reflections in the Zoom chat box) as the project went along. Toward the end of the project, some of them could go as far as to co-analyse the data and present their own policy and practice recommendations during meetings (e.g., to improve service accessibility and quality). This was probably one of the main achievements of the *REAC!* research – to realise that it possibly had a positive impact on refugee's and asylum seeker's empowerment process. Two of the board members with lived experience of forced migration were even eager to co-present the research findings on various occasions, and they were both invited to co-author scientific articles (including the present manuscript).

Of course, board members with lived experience of forced migration also faced several challenges. Of note, some of them also had a professional role, working in community-based organisations on topics closely related to those of the *REAC!* research. This issue was also reflected in similar studies (Oda et al., 2022): individual partners with lived experience are chosen based on one key aspect of their identity (i.e., their lived migration experience). However, other aspects and roles might emerge. In our project, their role was mostly viewed from the lens of their refugee/asylum seeker experience, which was a limitation. The benefits for the research project to also incorporate their professional role were somehow overlooked (e.g., opening more opportunities for recruitment and knowledge dissemination). In addition, professional roles might allow for bringing additional analytical insights, not only as a service user with lived migration experience, but also as someone who supports other service users. Of course, the next challenge can always be the time constraints for them – even if they get compensated for their time in research advisory boards, how much they can spend on advocacy, outreach and engagement, remains an unresolved issue.

Implications for Policy and Practice

Participatory research is widely recommended. When it comes to cross-sectoral collaboration in times of crisis, its relevance seems even more obvious, yet few scholars provide in-depth details on **how** to achieve such co-creation, and how it may be beneficial to scholars, service providers, and community partners. Such uniquely inclusive, participatory approach tackles structural barriers to the integration of underserved, marginalised people in health systems; one that can create empowerment opportunities for those who contribute to research projects' governance. It also enables them to provide impactful policy and practice recommendations to health service providers, especially to improve accessibility and quality. From a health systems' evaluation perspective, and adopting an equity lens, such contributions are invaluable.

The experience we shared in the present study provided illustrations for successful stakeholder engagement in research co-design, that could be replicated to other settings. Future research could also further investigate the concept of 'lived experience' when thinking about refugee's and asylum seeker's participation, moving beyond the migrant identity to consider all the roles they may play.

Declarations

Research ethics approval was not required for this manuscript, as it is a View from the Field; only informal interviews were carried out with research partners. The need for consent to participate and/or publish was waived by the approving ethics committee Comité d'éthique de la recherche en sciences et en santé (CERSES) at University of Montréal.

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