

COMMENTARY

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Encouraging diversity in family engagement in research: Reflections on the development of knowledge translation tools

Janet W. T. Mah^{1*} and Katie Nickerson²

Abstract

Background Family engagement in research is crucial to generating relevant, impactful, and meaningful priorities and outcomes. Although there has been increased awareness and value for patient-oriented research, most patient partners in North America are from Western, educated, industrialized, rich and democratic societies. Encouraging underserved and marginalized populations to join the partnerships is important. This project demonstrates the development of two knowledge translation tools created to encourage diversity in patient-family and researcher partnerships.

Case study Our diverse cross-Canadian team embodies the family-researcher partnership as it consists of two research personnel from non-Western origins with immigrant experiences, a parent with lived experience, and a project director. All group members have experience in the field of mental health and neurodevelopmental conditions. Four infographics were created: 3 patient-oriented ones (in English, Chinese, and Farsi) and 1 researcher-targeted one. Content for the infographics were generated to address common barriers to patient engagement identified from literature reviews, as well as key concepts discussed during the McMaster University Continuing Education Family Engagement in Research Certificate Course sponsored by CanChild & Kids Brain Health Network. Peer consultations helped to improve the infographics to be more culturally sensitive and appealing. The patient-oriented infographic presents concise bullet points about 5 main topics: (1) what is research, (2) reasons to join, (3) your role, (4) talking to researchers, and (5) how to join. The researcher-targeted infographic presents concise bullet points about 4 topics: (1) why team up with diverse patient partners, (2) ways to partner, (3) how to connect, and (4) talking to diverse partners.

Conclusion Infographics were co-designed to encourage diversity in family engagement in research. Lessons learned throughout the project include barriers encountered (e.g., team collaboration considerations, design limitations) and strategies that facilitated the project (e.g., online collaboration platforms). Future directions include translations into other languages, increased dissemination across agencies, and evaluating the effectiveness of the infographic tools.

Keywords Family engagement, Diversity, Partnerships, Patient-oriented research

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Plain English summary

Family partnership in research is important because it keeps the results relevant and useful to families. Yet, most families who partner with researchers are from rich, Western societies. This means that research does not often include a variety of people and points of view. So, it is important to build research partnerships with diverse people. For our project, we created two information posters. The posters promote diversity in partnerships between researchers, patients, and families. Our own cross-Canada research team is an example of the family-researcher partnership. We share how we created content and translated it into Chinese and Farsi. We also share what we learned during the project, what we found difficult, and what was helpful. Next, we plan to translate the posters into other languages and share them with more people. We will also test the benefit of these posters.

Background

Patient-oriented research, in which patients are engaged as active partners rather than as passive participants, is a key vision and priority among many countries across the world (e.g., Canada's Canadian Institutes for Health Research, United States' Patient-Centered Outcomes Research Institute, United Kingdom's INVOLVE) [1–3]. This is important because patients have a right to be a part of every step of the research process, and their inclusion improves research relevance, study design, and dissemination [4].

To promote patient-oriented research, the Family Engagement in Research Program brings researchers and families together in an online course that is offered through McMaster University and sponsored by CanChild & Kids Brain Health Network [5]. Course participants include a mix of researchers (e.g., graduate students, research coordinators, investigators, clinician-researchers) and families (e.g., parents, siblings, grandparents) who have an interest in child neurodevelopmental research. Over ten weeks, readings and group discussions help learners gain a better understanding of the importance of family engagement in research, how to engage families throughout the research process, barriers/facilitators to engagement, ethics surrounding engagement, and tools and resources to support and evaluate engagement.

As part of the course, participants complete a group project to create a knowledge translation (KT) tool about patient partnerships in research. There have been many knowledge translation tools developed by course participants on a variety of topics, such as websites to introduce families to research engagement, guidelines on starting and maintaining partnerships, and blogs and social media platforms to engage youth and families [6]. However, we noticed that none has addressed cultural diversity. Many research participants and partners are those from Western, educated, industrialized, rich, and democratic (WEIRD) societies [7]. Research should reflect the diversity of human society [8], so we wanted to encourage diversity in researcher-family partnerships, given the

Canadian multicultural mosaic and how families from racialized minorities are under-represented in the fields of mental health and disability [9].

Our project

Thus, we chose to develop knowledge translation tools focused on enhancing immigrant families' understanding of research and the importance of their engagement in meaningful research partnerships. At the same time, we acknowledged that we also needed to target researchers to encourage them to authentically include immigrant families in research, not simply as data points, but as partners throughout the research process. We hoped that these KT tools would enable new Canadian and under-served communities to benefit from interactions with healthcare and research professionals in order to help build a diverse, inclusive, equitable, and accessible research community. Project outcomes arising from diverse family-research partnerships would in turn result in enhanced applications to culturally-appropriate health services.

Team

Our team embodied the family-researcher partnership as it consisted of two clinical researchers, a project director in the field of mental health and neurodevelopmental conditions, and a parent with lived experience. We also demonstrated diversity in ethnic/cultural backgrounds (e.g., two members were from non-Western origins with immigrant experiences), interdisciplinary professions (e.g., psychology, medicine, editor), and geographical locations (i.e., spanning cross-Canada from British Columbia, Alberta, Nova Scotia, and Ontario).

Project development

All team members shared our cumulative experiences and perspectives related to culture, stigma, and obstacles to healthcare and research engagement. The first author conducted a literature search to explore existing knowledge about addressing barriers to research engagement and service use by racialized populations. Although

no published articles were found at the time specifically about barriers to patient engagement in research among racialized populations, we chose to focus on one article that highlighted barriers to research engagement identified from the public's view [10], and one report on barriers to service use by racialized populations [11].

We chose to develop the KT tools in the form of infographics. We thought that this format would be visually engaging, with simple text that accommodates for varying literacy and comprehension levels, and offer ease of distribution across settings. We decided to create two infographics to encourage cultural diversity in research partnerships: one targeting families from racialized groups, and one targeting researchers. The second author led the design of the infographics using Canva [12], an online design and publishing program.

Translations

Given the cultural composition of our team, we decided to translate the family infographic from English into Chinese (traditional) and Farsi. We developed the content first in English, which was then translated into the other language by someone with linguistic and cultural competence in English and Chinese or Farsi. The translations were then reviewed by independent individuals from Chinese or Iranian communities for linguistic and cultural appropriateness.

Feedback

We sought consultations from peers, course instructors, and community partners for feedback regarding design, language, and content of the four infographics developed (family resource in English, Chinese and Farsi, and researcher resource in English). Six peers, five instructors, and three community partners from various cultural, professional, and geographical backgrounds provided written feedback identifying:

- The importance of the topic and appreciation for the commitment to greater diversity in research,
- Good use of engaging visual colours, fonts, and spacing, with precise and succinct content, and
- Suggestions for minor edits in wording or content for clarity and inclusiveness.

Most of the recommendations for changes were incorporated while keeping the infographics simple and engaging.

Tool for families

For the family-focused tool (see Fig. 1 for English version; see appendix for Chinese and Farsi versions), we included basics about what research is, benefits to engaging in



Fig. 1 Infographic for Families in English

research, roles and commitment, and tips for connecting with researchers. In particular, we sought to address six barriers to research engagement identified from the public's view, which may be more representative of the underserved racialized populations whose voices may

Table 1 Infographic tool addresses barriers for family engagement in research

Identified barrier	How the infographic addresses it
lack of relevance	Add your diverse ideas
lack of impact	Research creates new services and improves current ones
lack of trust	Research is approved with safety and respect in mind
lack of legitimacy	Your diverse insights matter
lack of knowledge	No training needed You're the expert in life experience
lack of time and financial resources	Help a little or a lot Ask for help. Speak up for your needs and wants

not be captured in literature focused on patient engagement [10] – see Table 1.

Tool for researchers

The researcher-focused tool (see Fig. 2) highlights reasons to include diverse patient partners, suggested ways to partner, and tips on connecting and communicating. Furthermore, we also sought to address six common barriers to service use by racialized populations identified by the Mental Health Commission of Canada [11] – see Table 2.

Discussion

Our project demonstrates the creation of knowledge translation tools specifically aimed at encouraging patient-oriented research, particularly among diverse cultural populations. The project was developed by a multi-disciplinary team that included a family partner with lived experience. Through this collaboration, and with consideration of literature reviews and course content about key factors to consider for family engagement in research, four infographics were developed to encourage cultural diversity in family and researcher partnerships: one targeting researchers, one targeting families offered in three languages – English, Chinese, and Farsi.

Barriers encountered

We faced a few barriers during the development of this project. First, team diversity was both a strength and a challenge. Although our different professional and cultural backgrounds helped to enhance our project, it also contributed to differences in communication and working styles. For instance, lots of time (e.g., weeks for initial introduction and orientation) was needed for each team member to share their ideas and come to consensus about the project direction, content, and process. In

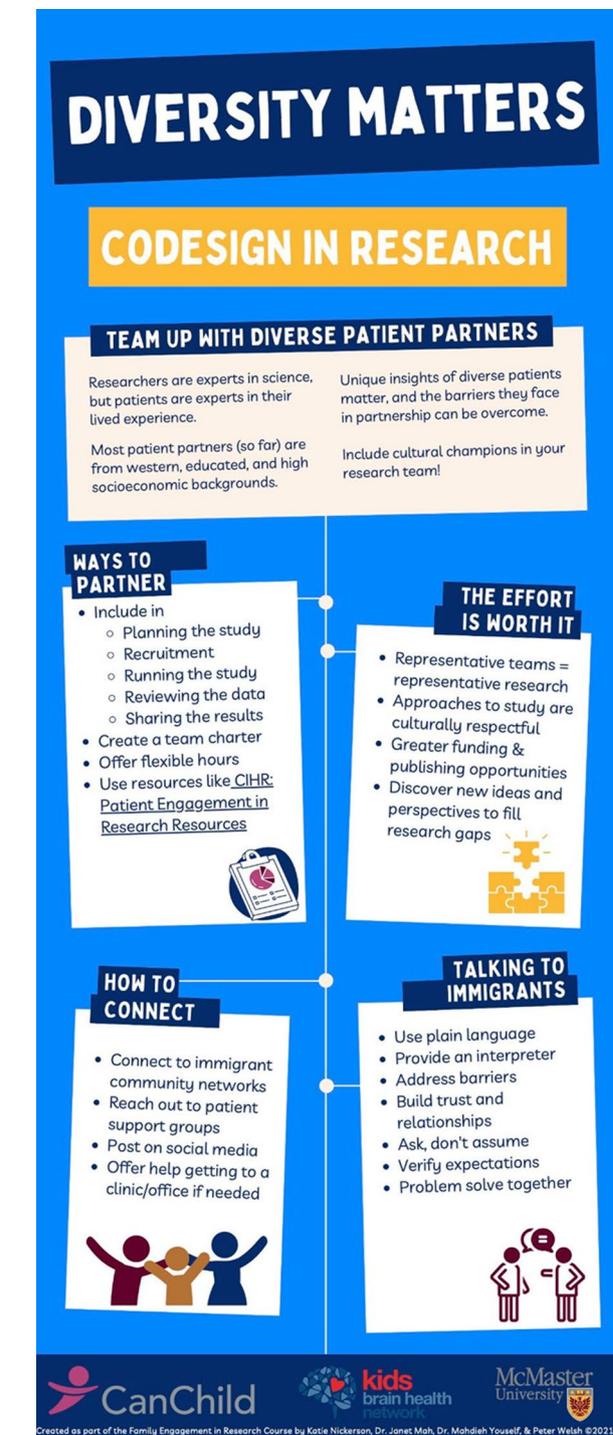


Fig. 2 Researcher Infographic

addition, because we were based in different locations across Canada, it was tricky to find common meeting times across time zones while also working around scheduling conflicts from our professional day jobs.

Infographic tool addresses barriers for the researcher to consider

Identified barrier	How the infographic addresses it
Service accessibility	Offer flexible hours Connect to community networks/support groups/social media
Patient-provider interaction	Problem solve together Include cultural champions in your research team
Circumstantial challenges	Offer help getting there. Address barriers
Language	Use plain language. Provide an interpreter
Stigma	Build trust and relationships
Fear	Verify expectations. Ask, don't assume

This was particularly important to consider for our family partner who did not have paid time to commit to this project. These are considerations that family-researcher partnerships also encounter.

Second, although infographics are advantageous for visual engagement, there are also limitations of available space for content, finding inclusive & meaningful images that are culturally sensitive, and selecting the appropriate words that would suit language and comprehension levels to accommodate English-as-a-second-language competencies. None of the team members had professional experience or training in design, and the project was unfunded, so access to design expertise and resources was also a constraint.

Lessons learned

Through this project, we learned that it's helpful to define roles and responsibilities early. In particular, identifying skills and interests of each team member can help to match up individuals with tasks and duties required. In addition, we think it may have been useful to designate an individual to be the project coordinator to keep the team accountable in following through with tasks. In a family-researcher partnership, we think having an independent project coordinator could also help bridge expectations and communication to reduce power imbalances and foster stronger alliances.

Second, we benefited from using technology for synchronous and asynchronous collaboration. For this project, we used Canva to design the infographics, as well as Google Docs and Slides for content and presentations.

These online programs allow each team member to edit the documents independently as well as simultaneously.

Finally, yet importantly, our team relied on a handy motto: GELMO, meaning "good enough, let's move on!" It was easy to go in circles when collaborating with others as we tried to respectfully consider the varied opinions and ideas, weighing the pros and cons of each. GELMO allowed us to be more efficient with our time and enhanced our effectiveness as a team.

Future directions

The developed infographics are currently posted on CanChild. We have presented our work at a provincial conference on patient-oriented research in British Columbia, Canada. There has been interest expressed from others in additional translations into other languages besides Chinese and Farsi. Further dissemination of the KT infographics can be done through research networks, community agencies, and cultural organisations. These traditional recruitment methods of advertising can also be supplemented with sampling frameworks to recruit hard-to-reach populations, such as ethnographically mapping popular venues frequented by racialized communities, and/or peer recruitment in which original participants or champions from racialized groups connect with other potential participants [13]. It would also be useful to evaluate the effectiveness of the KT tools in increasing family-researcher partnerships among culturally diverse populations before and after its dissemination.

Conclusions

Two infographics were created to encourage diversity in family engagement in research. One targeting families from immigrant backgrounds to address common barriers (in English, Chinese, and Farsi); one targeting researchers about the benefits of teaming up with diverse family partners. Lessons learned include barriers encountered (e.g., team collaboration considerations, design limitations) and strategies that facilitated the project (e.g., online collaboration platforms). These infographics can be disseminated broadly as KT tools so the voices of diverse groups can be included in family-research partnerships for more meaningful and impactful project priorities and outcomes.

Appendix

您很重要

與科研作伴

何為科學研究?

它不單是科學家們穿著實驗室工作袍、而是...

- 共同尋找問題的答案
- 共同尋找問題的答案
- 創建新的服務和改善現有的不足
- 滙合百家的成果 (如專業人士、助理、家庭等)
- 以安全和尊重作認許



您的任務

- 無需訓練
- 您可以在以下各方面學習和支援:
 - 預備科研工作
 - 帶領其他人參予
 - 執行科研工作
 - 審閱數據
 - 分享科研成果
- 作或多或少支援



參予的理由

- 加添您的想法
- 認識他人
- 學知健康的議題
- 操練英語
- 增添個人履歷
- 影響生命



與科研專業人士的對話

- 要求有翻譯人員
- 明列一個問題清單
- 問清楚如何到達研究中心參予
- 明確表達您的必需和期望



如何參予

- 查看本地和互聯網上的資訊、例如是 www.reachbc.ca
- 挑選與您相關的議題



誰是專家?

科研的專業人士是科學領域的專家、但您卻是您生活經歷上的專家。您的文化洞察力很重要。





這是為 Katie Nickerson, Dr. Janet Mah, Mahdieh Yousefi, 和 Peter Welsh 的學科「家庭參與的研究」而設。© 2021

شما مهم هستید!

در تحقیقات مشارکت کنید

تحقیق چیست؟

تحقیق تنها به معنی دانشمندی در لباس های آزمایشگاهی نیست، تحقیق...

- یافتن پاسخ هایبست با کمک یکدیگر برای سوالات
- جستجوی راه هایبست برای بهبود روند زندگی
- ایجاد خدمات جدید است و اصلاح خدمات فعلی
- توسط گروه های متنوعی انجام میشود (متخصصان، دستیاران، خانواده ها)
- ایمن، قابل اطمینان و تصویب شده است




نقش شما

- معمولاً نیاز به آموزش قبلی وجود ندارد
- میتوانید در رابطه با این موارد پیامورید و همکاری کنید:
 - طرح ریزی پژوهش
 - ترغیب دیگران به مشارکت
 - پیشبرد مراحل پژوهش
 - بازنگری داده ها
 - انتشار نتایج
- همکاری در هر ابعادی، چه زیاد و چه کم



دلایل پیوستن به یک پژوهش

- ایده های خودتان را اضافه کنید
- با دیگران ملاقات و تعامل کنید
- در مورد سلامت بیشتر بدانید
- زبان انگلیسی تمرین کنید
- سوابق خود را ارتقا، دهید
- بر زندگی دیگران تاثیر بگذارید



در هنگام گفتگو با محققان

- در صورت ملاحظید درخواست مترجم کنید
- فهرستی از سوالات خود داشته باشید
- از کمک خواستن اجتناب نکنید
- آزادانه نیازها و خواسته هایتان را بیان کنید



چگونه ملحق شویم؟

- به شبکه های محلی یا سایت ها نگاه ی بیندازید به عنوان مثال: www.reachbc.ca
- موضوعاتی را که برایتان مهم است انتخاب کنید



متخصص کیست؟

پژوهشگران، متخصص در زمینه علوم هستند، اما شما در تجربیات زندگی خودتان متخصص هستید... پیش های فرهنگی شما اهمیت دارد!





Created as part of the Family Engagement in Research Course by Katie Nickerson, Dr. Janet Mah, Dr. Mahdieh Yousefi, & Peter Welsh © 2021

Abbreviations

GELMO Good enough, let's move on!
 KT Knowledge translation
 WEIRD Western, educated, industrialized, rich and democratic

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Author contributions

All authors contributed to the conception and design of the infographic tools; JM was a major contributor in writing the manuscript; KN reviewed and revised the draft manuscript.

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Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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