

Meeting in the middle: experiences of citizenship in community-engaged psychosis research

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Abstract

Purpose – Previous research has highlighted the importance of engaging people with lived experience (PWLE) in the knowledge creation process. However, diverse approaches to engagement exist. In addition, tensions remain in community-engaged research (CER), including how to address structural inequalities in research settings. This study aims to consider how CER interacts with citizenship within and beyond the research context.

Design/methodology/approach – This study discusses the authors' experiences as a majority-PWLE of psychosis research team in Canada, including successes and challenges the authors experienced building their team and navigating research institutions. This study also reflects on the authors' pathways through citizenship, prior to and during the research process. This study discusses divergent models of CER and their applicability to the cyclical process of citizenship and community participation.

Findings – Relationships between academic and peer researchers developed organically over time. However, this study was limited by structural barriers such as pay inequality and access to funding. The authors recognize that there are barriers to full citizenship and acknowledge their resources and privilege of being well supported within their communities. Team members built on a foundation of citizenship to access participation in research. This led to opportunities to engage in community spaces, and for PWLE to participate in research as partners and leaders. This study also found that citizenship is a way of giving back, by building a sense of social responsibility.

Originality/value – Academic and peer researchers can reflect on the authors' experiences to build more inclusive research teams and communities by using a citizenship approach to research participation.

Keywords Community-engaged research, Psychosis, Lived experience, Peer research, Citizenship

Paper type Viewpoint

Introduction

Community engagement in health research has become increasingly common (Manafo *et al.*, 2018), as has the involvement of people with lived experience (PWLE) in mental health research (Sangill *et al.*, 2019). Not only can lived experience enhance the quality and relevance of research (Brett *et al.*, 2014; Domecq *et al.*, 2014), but input into the knowledge creation process is an important form of civic participation (United Nations Human Rights Council, 2019) and a means to achieve social justice and change (Faulkner, 2017; Lambert and Carr, 2018; Shimmmin *et al.*, 2017). In Canada, this is formally recognized in the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework (Canadian Institutes of Health Research, 2014). The framework outlines ways PWLE may be involved in research, including as leaders, and key outcomes such as collaboration and mutual capacity building. In recent years, SPOR has funded several major projects in the area of mental health (Breault *et al.*, 2018; Guinaudie *et al.*, 2020; Henderson *et al.*, 2018).

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Despite growing acknowledgment of the role of lived experience in mental health research, tensions remain. Engagement represents a diverse spectrum of approaches (Greenhalgh *et al.*, 2019; Happell and Roper, 2007; Vaughn *et al.*, 2018), while service user/survivor-led research unsettles the very paradigm of academic researchers engaging PWLE (Rose *et al.*, 2018). Across models, concerns have been raised about who is enabled to participate (Jones *et al.*, 2021; Shimmin *et al.*, 2017) and how power is shared (Beresford, 2002; Smith and Bailey, 2010; Vaughn *et al.*, 2018). This paper explores the topic through a citizenship lens, drawing on our own experiences as a majority-PWLE of psychosis research team in British Columbia (BC), Canada. We consider how involvement in the knowledge creation process can enhance citizenship, as well as how it can inadvertently entrench inequalities. We also present suggestions for academic and peer researchers in building access to citizenship within and beyond the research context.

Citizenship and community-engaged research

Broadly, citizenship refers to the ways membership within a polity is constituted, including through cultural and symbolic processes (Isin and Wood, 1999; Lister, 2007). In the field of mental health, authors have grounded citizenship in social and cultural connectedness (MacIntyre *et al.*, 2022; McCabe *et al.*, 2007; Ware *et al.*, 2007), the responsibilities of a “caring society” to provide services and resources (Crabtree and Chong, 2000), the ability to participate politically through voting or advocacy (Chiu and Chan, 2007; Morrow, 2004) and access to human rights (Hazelton, 2005; Prior, 2007). It has thus been summarized as “the rights, responsibilities, roles, resources, and relationships” that allow for reciprocal and valued participation in a community (Atterbury and Rowe, 2017; Ponce and Rowe, 2018; Rowe and Baranoski, 2011). Unfortunately, the small body of empirical research relating to PWLE’s experiences of citizenship reveals significant barriers to full citizenship, including stigma, incarceration, homelessness, unemployment, lack of treatment autonomy and lack of legal citizenship (Clayton *et al.*, 2020; Cogan *et al.*, 2021; Jordan *et al.*, 2022; Vervliet *et al.*, 2019). A subset of PWLE may experience conditional citizenship, dependent on the ability to successfully navigate “rigid” social norms and associated feelings of alienation (Hamer *et al.*, 2014).

In line with a participatory focus, much of the above research has adopted community-engaged methods (Cogan *et al.*, 2021; Ponce and Rowe, 2018; Rowe and Baranoski, 2011; Vervliet *et al.*, 2019), including community-based participatory research (CBPR) (Israel *et al.*, 1998). Community-engaged research (CER) represents a spectrum of approaches that involve people affected by an issue in understanding and addressing that issue (Key *et al.*, 2019); in this article, we use CER as an umbrella term inclusive of the concepts of patient and public involvement (Greenhalgh *et al.*, 2019), peer research (Roche *et al.*, 2010; Vaughn *et al.*, 2018), coproduction (Hickey *et al.*, 2018) and user/survivor-led research (Ormerod *et al.*, 2018; Taylor *et al.*, 2012).

Many authors conceptualize CER as essentially democratic. Strengthening communities and shifting power to those who have historically been reduced to “subjects” are emphasized (Faulkner, 2017; Jones *et al.*, 2014), with connections drawn to legacies of activist research in disability and HIV/AIDS research (Lambert and Carr, 2018; Shimmin *et al.*, 2017). CER can provide an avenue for civic participation by opening conversations at the community level between service users and providers (Michalak *et al.*, 2015), generating opportunities for democratic debate (Godin *et al.*, 2007) and restoring agency in the policy-making process (Pelletier *et al.*, 2011). For individuals, CER can build an inroad to engage with knowledge creation processes that otherwise appear inaccessible (Johnston *et al.*, 2021) and develop skills and opportunities (Ochocka *et al.*, 2002; Syrett, 2011). Indeed, the 2019 Special Rapporteur on the Right to Health named user-led initiatives, including research, as essential to full participation in civic society and the promotion of mental health (United Nations Human Rights Council, 2019).

However, many approaches exist to CER. Some research is spearheaded by user/survivor collectives to address community concerns (The Dream Team and University of Toronto, 2008; Wallcraft and Nettle, 2009; Walsh and Boyle, 2009; Wright *et al.*, 2004). More often, academics and service providers maintain control, including over how resources and labor are distributed, with PWLE as consultants or employees (Happell and Roper, 2007; Vaughn *et al.*, 2018). Beresford additionally distinguishes between “democratic” and “consumerist” approaches, with the latter prioritizing effective service delivery rather than empowering community members (Beresford, 2002, p. 97). Arnstein’s ladder of citizen participation (Arnstein, 1969) can be applied to research, with the lower steps, e.g. receiving therapeutic interventions and consultation constituting relatively powerless forms of participation compared to uppermost steps of partnership with and leadership by PWLE (Roper *et al.*, 2018). This echoes the premises of citizenship approaches to mental health: services cannot replace membership in a community (Rowe and Baranoski, 2011).

CER also risks embedding disparities in citizenship, when it centers those with the most preexisting access to resources and neglects those who have experienced the deepest forms of social exclusion (Jones *et al.*, 2021; Roche *et al.*, 2020; Shimmin *et al.*, 2017). Hierarchies can occur in which “professional” service users are privileged (Lakeman *et al.*, 2007, p. 15; Rose, 2018). Those who are unable to meet the demand to “re-style” themselves into “productive and better functioning citizens[s]” may be precluded from peer researcher positions (Guta *et al.*, 2013, p. 446; Roche *et al.*, 2010) – including, paradoxically, people currently experiencing psychosocial disability or difference (Jones and Shattell, 2016). Research settings may themselves erect barriers to full citizenship, with peer research often constituting a precarious and underpaid form of employment (MacKinnon *et al.*, 2021) and research institutions not designed for participation by PWLE (Flicker *et al.*, 2007; Guta *et al.*, 2010; Jones *et al.*, 2021; Smith and Bailey, 2010).

Although CER can increase access to citizenship for PWLE by strengthening community ties and promoting agency in achieving social and policy changes (Vaughn *et al.*, 2018), it may at other times reproduce familiar dynamics of exclusion, devaluation and domination (Sangill *et al.*, 2019). Attention to identity and life experience on the research team (Muhammad *et al.*, 2015) and the diverse narratives that make up a community (Brown and Jones, 2021) are essential. Therefore, we sought to analyze our experiences of citizenship as a majority-PWLE of psychosis research team.

Case example: our experiences with community-engaged research

Our work on social and cultural influences in early psychosis emerged from conversations at the BC Early Psychosis Peer Recovery Network (EPPRN). The four authors of this viewpoint are founding members of the EPPRN Research Committee. For the first year, we met regularly without any set research agenda before developing a research project together. Although some of us had already met prior to our involvement with EPPRN, we also built new and deep relationships on the Research Committee.

This viewpoint was jointly developed in a cyclical process of writing and reflection at weekly research meetings. We worked on and discussed the draft – as well as other scholarship, activism and current events, as these were pulled into the writing process – in collaborative writing sessions. During this process, we found that our perspectives both on the article we had planned to write and on CER itself evolved, resulting in an exploration of our pathways through citizenship as researchers. In this sense, the cowriting process was not only a product of research but part of it. All four authors contributed to the writing process, led by the first author. The first three authors are research assistants with lived experience at a Canadian university, while the senior author is an assistant professor there.

History of Early Psychosis Peer Recovery Network

The EPI Advanced Practice Program (EPI APP) is an overarching coordinating body for early psychosis intervention services in BC. Two of our research team members are members: one attends as an academic researcher and another attends as a person with lived experience. In 2018, a suggestion was put forward for the EPI APP to engage with youth at risk for or receiving treatment for psychosis. Our research team member with lived experience saw this as an opportunity to get involved and use both personal and professional experience as a peer leader and was keen to reach out to PWLE. This led to the development of EPPRN (formerly the EPI Alumni Council), a group of primarily youth who have come together to share experiences and hope. EPPRN is coordinated by peers and funded by a health authority. It has four subcommittees: research, peer support, advocacy and advisory, and public speaking and education. Involvement with EPPRN can be part of members' paths to full citizenship, by providing opportunities to develop a sense of active, meaningful membership in a community (e.g. research activities; advising on issues related to EPI in BC; mutual aid peer support groups; public speaking about lived experience). One goal of the Research Committee is to involve current and former EPI clients as partners in research. We maintain an open line of communication about research activities at EPPRN meetings, and EPPRN members who are not currently part of the research team are likewise invited to attend research meetings.

Meeting in the middle

Rather than coming together “top-down,” with academic researchers recruiting community members from outside academia, but also in contrast to a “bottom-up” approach where community members organize independently to conduct their own research, our team formed by “meeting in the middle.” Academic researchers and community members came together organically as a research team by developing relationships in a shared space and identifying mutual interests. At that point, we began to codevelop research questions and a study design. Briefly, we are interested in how youth experiencing early psychosis draw on a range of cultural resources to make sense of their experiences. We have several phases in our study: scoping review; survey; series of deliberative dialogues ([Plamondon, 2015](#)) with youth, their supporters, and early psychosis service providers and community leaders; and the development of a research agenda based on the first three phases.

Successes and challenges

We have encountered both successes and challenges in our work so far. One success was achieved by building a majority of PWLE of psychosis in the research team, who are fully involved in the research process at every level. This has included collaborating on research questions, grant and ethics applications, survey development, scoping review, dialogue protocol and knowledge translation activities. All peer researchers were formally hired as research technicians through the university. This moves beyond hiring PWLE as consultants, which is common in peer research ([Vaughn et al., 2018](#)).

Despite this, our team faced challenges working in a university setting. For example, a pay and status hierarchy remained between peer researchers hired and the academic researcher on the team, who received grant funding to pay peer researchers. This means that although we aspire to approach our work as partners, the academic researcher on our team effectively controls hiring and resources. Ideally, there would be equitable pay for all team members. We also struggled with funding not designed for, nor conducive to, peer-led research – for example, many grant applications require a university-affiliated researcher as Principal Investigator. While incredibly rewarding, CER is time consuming, and with the struggles of gaining substantial funding for this type of work, we are limited to weekly meetings over an extended time. This leaves peer researchers in a potentially

precarious position of relying on additional sources of income to support themselves. It is therefore important to consider that hiring peer researchers as university employees does not necessarily challenge structural inequalities (MacKinnon *et al.*, 2021), though it can be an important way for academic researchers to demonstrate respect for the time and effort invested in a partnership.

Another challenge we experienced was that team members had different skill sets and experience with research. As a result, we needed to slow down and provide opportunities for learning. However, we also saw the mutual exchange of knowledge as a success. The academic researcher was able to support the development of technical skills including writing an ethics application, using Covidence software for conducting reviews, Qualtrics survey development, best practices with a university librarian and steps to conducting dialogues. Peer researchers can transfer these technical skills to future community-led projects (Israel *et al.*, 1998). Peer researchers on the team provided deeper insight into the research topic and design of the research. By sharing experiences, all team members developed as researchers.

Relationships were also an important success. The team came together organically over an extended period, allowing us the time to develop a strong sense of trust and friendship. One way we center relationships in the team is by “checking in” on a personal level at the beginning of each meeting and sharing openly about emotions – opening ourselves to what Brown and Jones call “the generative experience of being moved” (Brown and Jones, 2021). We also share a commitment to working toward social justice. For example, early on we codeveloped a document that contained a mission statement and shared values. This extends to building relationships in the wider community, including by inviting a range of community members to participate in research meetings. Two authors are members of the BC Hearing Voices Network, and the research project has served as a “bridge” for the BCHVN to build connections with EPPRN, strengthening community networks overall. This highlights the importance of building relationships as colleagues, friends and community members, in contrast to tokenistic inclusion.

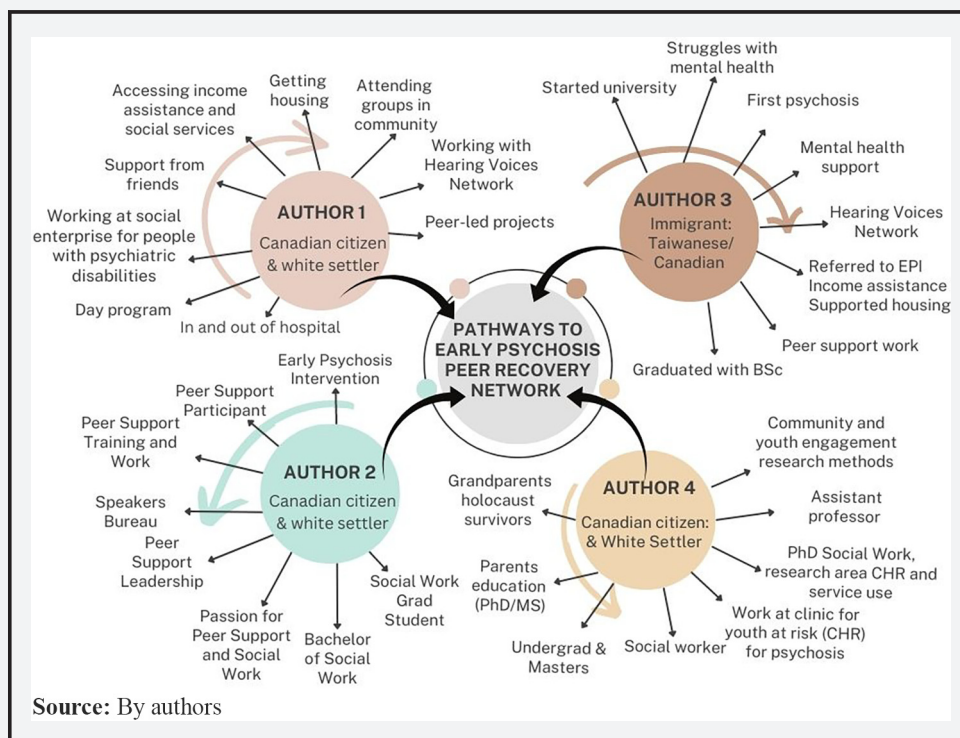
We also prioritized health and well-being. We spoke about and practiced respect for personal boundaries and were mindful of the challenges posed by chronic mental and physical health conditions. At times, we adjusted timelines depending on team members’ health needs. While this delayed some of our work, we understand that research is a process that unfolds over time.

Finally, reflecting on larger issues of access and social justice (e.g. around language barriers in dialogues, connecting with Indigenous communities, inclusiveness in surveys) has been a priority. However, we found that institutional barriers to increasing access were sometimes present – for instance, limited funds for interpretation and translation of study materials. Our team attempts to continue interrogating our relationship to this research as peer and academic researchers, such as who is and is not represented at research meetings? How can we build the relationships that are missing? Although a “researcher pipeline” (Jones *et al.*, 2021) that creates and sustains opportunities for those who have historically been excluded offers a vision of a more inclusive future, research institutions that recruit a peer workforce while leaving systemic problems unaddressed risks creating only superficial change. We next explore access to citizenship within and beyond the research context.

Pathways through citizenship in community-engaged research

Over the course of our discussions on our pathways to the EPPRN research council (Figure 1), it became clear that many factors had shaped our experience of citizenship long before the project began. While our pathways differ in some respects (for instance, in degree of formal education) and are alike in others – for instance, peer researchers felt that

Figure 1 Pathways to early psychosis peer recovery network



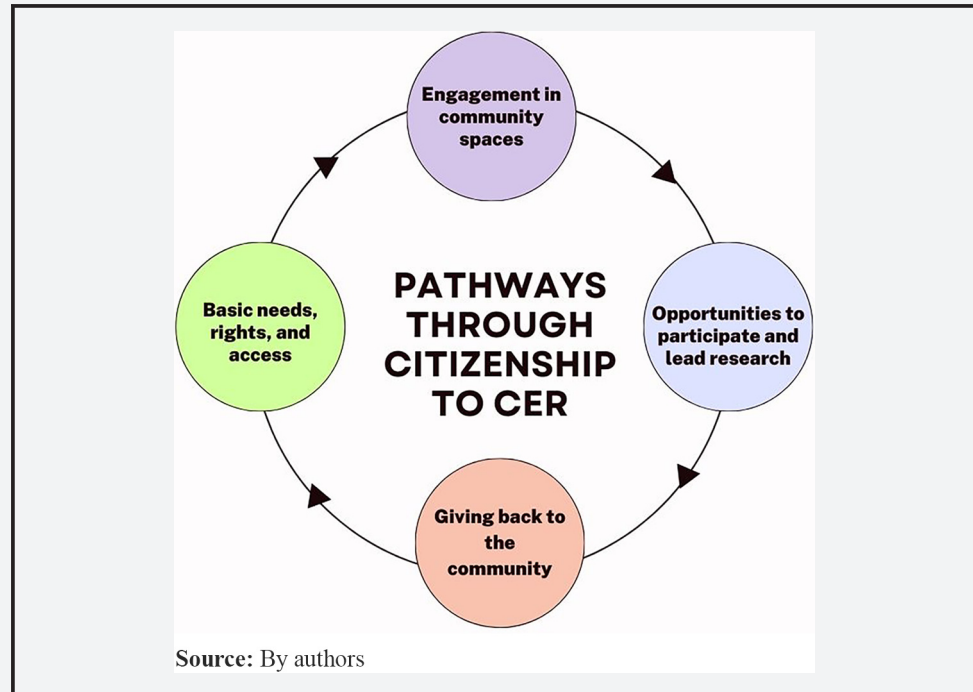
Source: By authors

being able to secure housing was an important part of our pathways, as were strong peer support networks. We therefore summarize the process of citizenship in CER in four steps: access to the fundamental “building blocks” of citizenship, including the rights and resources needed to participate in community spaces; engagement in community spaces, including spaces where PWLE, academics and service providers are present as community members; opportunities for PWLE to participate in research as partners and leaders; and finally, opportunities for peer and academic researchers to “give back” by working with communities to improve access to citizenship (see [Figure 2](#)).

Although peer researchers on our team had previously experienced both social and structural barriers to full citizenship, such as housing insecurity and detention under the [Mental Health Act \(1996\)](#), we were well-supported within our communities at the time of this project. Participation in peer support networks and projects, and eventually peer research, contributed to a gradual process of rebuilding our citizenship. However, this process was closely, and somewhat paradoxically, intertwined with access to participation itself ([Cogan et al., 2021](#)).

Barriers to full citizenship are often the same barriers PWLE face to participation generally, including in research. Participation in research requires resources, potentially including the time to participate, access to transportation, phone or internet access, childcare arrangements and more ([Bonevski et al., 2014](#); [Roche et al., 2020](#)). Lack of accommodation of cultural and linguistic differences can create communication barriers ([Brown et al., 2014](#)), while past experiences of traumatic, stigmatizing or exclusionary treatment by researchers and service providers (or in the community generally) erode trust ([Shimmin et al., 2017](#)). Participation is further complicated for those who lack certain legal rights, such as undocumented immigrants ([Campbell-Page and Shaw-Ridley, 2013](#)) and incarcerated people ([Hatton and Fisher, 2011](#)). For some PWLE, for instance in hospital or tertiary care settings, participation in research may additionally be “gatekept” by service providers

Figure 2 Pathways through citizenship to CER



based on perceptions of (in)capacity or interference with treatment (Furimsky *et al.*, 2008; Rose, 2018; Walsh and Boyle, 2009). These barriers mirror those identified as hindering full citizenship for PWLE, including social exclusion (Cogan *et al.*, 2021), disempowering relationships with services/providers (Ponce *et al.*, 2016; Vervliet *et al.*, 2019) and lack of legal citizenship or material resources (Clayton *et al.*, 2020). We feel that structural change is needed to expand opportunities for PWLE and academic researchers to “be in community.” As long as a gulf exists simply in access to necessities like shelter, it will remain difficult to come together as equal partners – or to come into contact at all. Forms of CER like CBPR and participatory action research have often attempted to challenge conditions of inequity, including in environmental justice (Balazs and Morello-Frosch, 2013), healthcare (Clements-Nolle and Bachrach, 2003), housing (The Dream Team and University of Toronto, 2008) and food security (Breckwich Vásquez *et al.*, 2007). In sociologist Randy Stoecker’s words, “Doing research’ is not, in itself, a goal” (Stoecker, 2008, p. 111).

Others have questioned whether even CER can be truly inclusive, as it may nevertheless reproduce hierarchies among community members (Egid *et al.*, 2021; Rose, 2018). The question of who “represents” a community often arises (Minkler, 2004; Minkler *et al.*, 2002; Roche *et al.*, 2010). Our own research team, although it is majority PWLE of psychosis, cannot be said to represent PWLE of psychosis *in general*, in terms of race, socioeconomic status, education or access to resources. The peer researchers also joined the project at points in our lives when we were relatively able to conform to the values of normative citizenship (Roets *et al.*, 2012) and present as employable, “functional” citizens. We have received comments (likely intended as compliments) implying both that this ability is surprising and that PWLE of psychosis who present less normatively do not have skills or knowledge to contribute. This aligns with other authors’ observations about who is (n’t) supported to engage in research (Jones and Shattell, 2016) and illustrates a dynamic of “conditional” citizenship (Hamer *et al.*, 2014) that can serve to make PWLE “governable” rather than to empower them (Guta *et al.*, 2013).

We feel that fostering spaces where PWLE, academics and service providers experience “being in community” can help to counter expectations of assimilation or control by developing mutual understanding, trust and respect as fellow community members. Establishing a relationship with a community prior to undertaking a specific project is common in certain forms of CER, notably CBPR (Israel *et al.*, 1998). However, tensions can result when academic researchers enter communities as outsiders – and are seen as abandoning them when the relationship ends (Mayan and Daum, 2016), particularly if the research has exploited the community’s resources without producing any benefit (Neufeld *et al.*, 2019; Wilson *et al.*, 2018). We suggest building intentional community spaces that bring together diverse groups of people in conversation is reminiscent of María Elena Torre’s concept of the “contact zone,” a “messy social space” where participants use their differences to work toward equity and change (Torre *et al.*, 2008, p. 25). Ideally, such spaces would not shy away from the complexities of “deep engagement” (Brown and Jones, 2021, p. 2) and would instead embrace the possibilities of both friendship and disagreement.

In our case, EPPRN served as a forum for PWLE, academics and service providers to come together – notably, however, many of our members were also connected to each other outside of the group (for instance, through past projects or personal friendships), and many of our members had connections to other peer networks or service organizations in the community. This resulted in a space with interpersonal roots. We do not suggest that academics and service providers can materialize a community with PWLE overnight; however, we believe that equitable partnerships rely on creating genuine *opportunities* for community, in all its complexity and depth.

Finally, we believe that the process of building citizenship unfolds through the process of “giving back,” or practicing social responsibility toward communities (Ponce *et al.*, 2012, p. 357). By sharing resources, skills and knowledge, we build the capacity of the communities to which we belong and increase access to citizenship for others. These acts of citizenship might occur in the research setting, in other organizations in which we are able to advocate for change (Hamer *et al.*, 2019; Nelson *et al.*, 2001) or simply in the context of human relationships (MacIntyre *et al.*, 2022; McKnight, 1987). By considering research as one of many ways in which we are connected as community members and citizens, we open ourselves to real collaboration.

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