Chapter 12
Organizational Participatory Research in North America

Paula Louise Bush, Jeannie Haggerty, Carol Repchinsky, Michael T. Wright, Christine Loignon, Vera Granikov, Ann C. Macaulay, Jean-François Pelletier, Sharon Parry, Gillian Bartlett-Esquilant, and Pierre Pluye

Brief Overview of Participatory Health Research in Canada and the United States

Participatory health research (PHR) is informed by various works in community development, education, and organizational learning to name a few (Cargo and Mercer 2008; International Collaboration for Participatory Health Research (ICPHR) 2013a). Today, a host of terms are used to refer to various forms of participatory research in health and other domains creating confusion and debate around issues such as who participates in the research process, how, and when. Indeed,

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P. L. Bush (✉) · J. Haggerty · C. Repchinsky · V. Granikov · G. Bartlett-Esquilant · P. Pluye
Department of Family Medicine, McGill University, Montreal, Quebec, Canada
e-mail: Paula.bush@mcgill.ca; jeannie.haggerty@mcgill.ca; Carol.repchinsky@bell.ca; Gillian.bartlett@mcgill.ca; pierre.pluye@mcgill.ca

M. T. Wright
Catholic University of Applied Sciences, Institute for Social Health, Berlin, Germany
e-mail: Michael.Wright@KHSB-Berlin.de

C. Loignon
Department of Family Medicine, Sherbrooke University, Longueuil, Quebec, Canada
e-mail: christine.loignon@usherbrooke.ca

A. C. Macaulay
Department of Family Medicine, McGill University, Montreal, Quebec, Canada

CIET/Participatory Research at McGill (PRAM), Montreal, Quebec, Canada
e-mail: Ann.macaulay@mcgill.ca

J.-F. Pelletier
University of Montreal Mental Health Research Institute, Montreal, Quebec, Canada
e-mail: Jean-Francois.Pelletier@yale.edu

S. Parry
Westmount YMCA, Westmount, Quebec, Canada
e-mail: sharon.parry@ymcaquebec.org

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participatory health researchers in the North American Primary Care Research Group are currently grappling with clarifying the similarities and differences in their respective engaged research. It is beyond the scope of this chapter to delve into the multiple terms used and their varying definitions; we refer the reader to such works as Margaret Cargo and Shawna Mercer's critical review (2008) and those cited in an annotated bibliography of the Oxford University Press (Bush et al. 2018). In this chapter, PHR consists of the research process outlined in 1995 by Lawrence W. Green and colleagues in their publication *Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada* (Green et al. 1995). The authors wrote:

> Participatory research seeks to link the processes of research, by which data are systematically collected and analyzed, with the purpose of taking action or affecting social change. To link the two processes, participatory research demands a high level of participation by those most directly affected by the issue being studied, usually called the community. (p. 3)

The authors explain that a community is not necessarily geographic but is "any group of individuals sharing a given interest" (p. 4). Further, they describe the complementary nature of the university researchers and the community members' expertise as well as the bilateral nature of the learning that occurs through the process:

> Collaboration takes place between some people within the community whose interests lie in changing health status or conditions of living and one or more technically trained researchers whose interests lie in developing knowledge. The collaboration allows both to participate in new activities: researchers become highly involved in the change process, and community members become involved to varying degrees at each stage of the research process. The collaborative stages include: (a) identifying the problem and formulating the research questions; (b) selecting the research methods or instruments; (c) analyzing or interpreting the results; (d) applying results; and (e) disseminating results. (pp. 3–4)

Subsequent to these guidelines, Barbara A. Israel, in Detroit, USA, led a review that outlined eight key principles of partnering with communities for research (Israel et al. 1998). In the same year, the North American Primary Care Research Group (NAPCRG) accepted as a policy statement on PHR a document produced by a task force chaired by Ann C. Macaulay "Responsible Research with Communities: Participatory Research in Primary Care," an abridged version of which was subsequently published in the *British Medical Journal* (Macaulay et al. 1999). This policy statement was amended nearly two decades later (Allen et al. 2017) attesting to the strong and continued leadership of NAPCRG for PHR.

In their critical review regarding strategies to engage research partners for translating evidence into action in community health, Salsberg et al. (2015) used the keyword "participatory research" to identify the main authors with practical expertise in this area. The top four authors identified are North American (based on their CiteSpace centrality scores for literature published between 1995 and 2009), namely, Barbara A. Israel, Meredith Minkler, Nina Wallerstein, and Ann C. Macaulay. These women have co-edited important texts on PHR methods (Israel

2013; Israel et al. 2005; Minkler and Wallerstein 2008, 2003) and co-authored critical papers on the ethics and measurement of PHR (Minkler 2004; Oetzel et al. 2015; Wallerstein 2000; Wallerstein et al. 2008; Jones et al. 2014). Moreover, they are all strong advocates for PHR in their respective jurisdictions and universities. In 1995, Barbara A. Israel established the Detroit Community-Academic Urban Research Center which has been "fostering health equity through community-based participatory research (CBPR) for more than 20 years."[1] In the Southern United States, Nina Wallerstein is the director of the Center for Participatory Research, launched in 2009, which strives to, among other things, "co-create new knowledge and translate existing knowledge to improve quality of life among New Mexico's diverse populations."[2] For her part, Meredith Minkler served on the advisory board of the Center for Collaborative Research for an Equitable California which was in operation from 2009 to 2015 when funding ended.[3] In Canada, Dr. Ann C. Macaulay is the inaugural director of Participatory Research at McGill, which was merged with CIET in 2015.[4] She has co-authored literature reviews that have helped to advance the science of PHR (Bush et al. 2017; Jagosh et al. 2012; Macaulay et al. 1999) and three editions of an annotated bibliography for PHR in public health published by the Oxford University Press (Macaulay et al. 2011, 2015; Bush et al. 2018) and is a leader for PHR among indigenous populations in Canada helping to produce, for instance, a chapter on the matter in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS).[5]

Additional noteworthy PHR work in North America includes some long-standing community-university partnerships that have developed sustainable infrastructure and have published extensively on their work. For instance, in 1986, the Vietnamese Community Health Promotion Project[6] was founded as a community-academic research unit at the University of California, San Francisco, with the mission of improving the health of Vietnamese living in the United States. In Quebec, Canada, the Kahnawake Schools Diabetes Prevention Project (KSDPP)[7] began in August 1994 with the goal of decreasing the onset of type 2 diabetes among present and future generations. One of the notable achievements of this partnership is the code of research ethics (available on the website). For its part, the Native Hawaiian Cancer Network, 'Imi Hale,[8] began in 2000 and has since leveraged considerable capacity for cancer research in Hawaii.

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[1] https://www.detroiturc.org.

[2] https://cpr.unm.edu/about/index.html.

[3] https://ccrec.ucsc.edu/.

[4] http://pram.mcgill.ca/.

[5] http://www.pre.ethics.gc.ca/eng/index/).

[6] http://www.suckhoelavang.org/sklvweb/en/.

[7] https://www.ksdpp.org/index.php.

[8] http://www.imihale.org/.

Participatory Health Research with Organizations

The preceding examples all include communities of place partnering with academic researchers and seek to improve healthy lifestyle behaviors of populations. Yet, as specified by the ICPHR, "in PHR, those engaged in the research as active partners may be patients or users of services, members of health-related interest groups or other communities of identity or place, health care or related practitioners, managers and policy-makers" (International Collaboration for Participatory Health Research (ICPHR) 2013b, p. 4). This chapter discusses PHR carried out with health practitioners and other staff working in health organizations, such as hospitals or primary care clinics, to ultimately benefit the patients for whom they care. PHR in the organizational context (compared to the community one) is a strategy for organizational change and requires that some additional aspects be considered. For instance, when conducting PHR within a health organization, its hierarchy, policies, and routines need to be known and understood by the outside researchers to enable the integration of the PHR into the organization. Together, university and organization stakeholders blend quantitative, qualitative, or mixed methods research with action, to evaluate and improve healthcare practices, services, and policies (Argyris et al. 1985; Lewin 1946; Munn-Giddings et al. 2008; Munten et al. 2010; Soh 2011; Waterman et al. 2001). In particular, organization stakeholders also develop research capacity and increase reflective practice, e.g., practitioners not only collect facts regarding their practice but reflect on their practice to uncover and understand tacit knowledge (i.e., knowledge that is not explicitly articulated (Lam 2000)).

Four literature reviews have examined what the authors refer to as "action research" carried out with and within health organizations (Munn-Giddings et al. 2008; Munten et al. 2010; Soh et al. 2011; Waterman et al. 2001) with the purpose of organizational change (e.g., improvement of care practices or policies). While the reviewed studies illustrate academics working with organizations through the action research cycle outlined by Kurt Lewin (1946), not all of them illustrate research co-governance. In our systematic review, we included 83 studies that represent research that was co-governed between academic and health organization stakeholders. That is, organization stakeholders and "outsider" university researcher stakeholders co-constructed the research, making decisions jointly regarding at least three phases: (a) identifying the research question(s); (b) setting the methodology, collecting and/or analyzing the data, or interpreting the findings/results; and (c) implementing or disseminating the research findings (Bush et al. 2017). This description of co-governance in research is in line with other typologies of PHR across community and organizational settings (Cornwall and Jewkes 1995; Hart and Bond 1995; Holter and Schwartz-Barcott 1993; Jagosh et al. 2012). Hereafter, we refer to this particular type of PHR as Organizational Participatory Research (OPR).

In our review of OPR, the comprehensive and systematic search of bibliographic and gray literature databases led to the retrieval of over 8000 records. Based on the above definition of OPR, two independent reviewers screened the records and read the subsequently selected full text publications to include 83 studies in the review (see Bush et al. 2017 for a detailed description). Sixteen of these were conducted in Canada or the United States. Drawing on these 16 studies, together with some examples from our own OPR, we will describe how this type of research has been conducted in North American contexts and with what effects. To this end, we provide examples of participatory processes in the key research phases and the outcomes associated with these processes. For the most part, we provide examples of OPR successes as these are the stories currently available in the empirical OPR literature. It is important to note that while the examples provided may help mitigate challenges, OPR requires effort, patience, perseverance, and resolve. We conclude the chapter with a discussion of some challenges North American OPR partnerships have faced and how they addressed them. Finally, to offer an integral perspective of the processes and outcomes of OPR, four vignettes are included, focusing on communication, research initiation, participatory data analysis, and challenges.

Organizational Participatory Research in North America

This chapter cites examples from 16 OPR studies conducted in Canada and the United States (Table 12.1). These studies are variously referred to by their authors as CBPR, PAR, participatory research, action research, and community-based action research, which emphasizes the need to better define the terminology in all forms of partnership research. Table 12.1 indicates the terms each study uses together with the literature authors cite as the basis for their participatory studies. For the most part, OPR in Canada and the United States has taken place in hospitals (e.g., emergency room, operating room, psychiatric ward, etc.). In five studies, the organization partners were all nurses (Smith 1995; Breda et al. 1997; Jones-Baucke 1997; Senesac 2004; Lausten 2005), whereas other studies illustrate multidisciplinary partnerships. Only three included patients or service users on the research team (Mirza et al. 2008; Williams 2009; Malus et al. 2011). This is striking and represents an area of development for future OPR. Patients and the public are affected by organization practices, and have experience receiving health and social services and navigating the system. They possess a wealth of insider knowledge that could be integrated into OPR to help improve the relevance of the practice changes sought. Perhaps in the coming years, more OPR studies will engage patients and the public in the research process given the current trend toward patient engagement in the United States with the Patient-Centered Research Outcomes Institute (PCORI)[9] and in Canada with the Strategy for Patient-Oriented Research (SPOR).[10] Working with patients may carry additional challenges. For instance, Ann Sawyer Williams (2009) discusses issues regarding adapting to the visual impairments of the patient partners. Examples of how to adapt to the needs of stakeholders are included in a practice guide for OPR (Bush et al. 2017) that is freely available from the Quebec-

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[9] https://www.pcori.org/.

[10] http://www.cihr-irsc.gc.ca/e/41204.html.

Table 12.1 Description of OPR studies included in the systematic review by Bush et al. (2017)

First author[a] (year)	City, province/state, country	Organization(s)	Organization stakeholders (as described in the publication)	Research objective(s) (as described in the publication)	Method(s)	Duration (months)[b]	OPR label (authors cited)
Barker & Barker (1994)	Richmond, Virginia, USA	Substance abuse inpatient unit in a large university teaching hospital	Key staff members including managers	To manage change in an interdisciplinary substance abuse inpatient unit	Qualitative	36[b]	AR (Lewin 1946; French 1969)
Smith (1995)	Alberta, Canada	Urban public health unit	Public health nurses	To explore to what extent and how is PAR a form of collective, self-reflective inquiry that supports the implementation of democratic, empowering healthcare practices	Qualitative	15	PAR (Freire 1970)
Breda et al. (1997)[a]	Waterloo, Ontario, Canada	A small, private psychiatric hospital in rural New England	Nurses	To increase nurses' autonomy by implementing changes	Qualitative	12	PAR (Freire 1996; Reason 1994)
Jones-Baucke (1997)	Washington, DC, USA	A large, urban, nonprofit, 477-bed hospital	Nurses	To increase nurses' use of standardized nursing languages	Mixed	Unknown	AR (Argyris & Shon (1991); Holter and Schwartz-Barcott 1993) and PAR (Elden and Levin 1991)
Mason (2003)	Toronto, Ontario, Canada	Sunnybrook and Women's College hospital community	Social workers, nurses, psychologists, and physicians	To influence the medical system to respond better to the needs of abused women	Qualitative	12[b]	AR (Carr and Kemmis 1986) and Community development (Labonte 1997)

Senesac (2004)	Northeast USA	295-bed community hospital	Nurses	To implement a pain resource nurse role in a community hospital	Qualitative	12	AR (Lewin 1946)
Lausten (2005)	Western USA	Hospital-based, operating room and post-anesthesia care unit in an urban, western, Veterans Administration hospital	Nurses	To address nursing behaviors with negative environmental consequences	Qualitative	8	CBAR (cites traditions from Freire to McTaggert; Reason to Minkler, Wallerstein, and Israel)
Williams et al. (2005)[a]	New Haven, Connecticut, USA	Leeway, Inc. (a 40-bed nonprofit, nursing facility dedicated to community-based AIDS care)	Staff	To test a randomized controlled trial of metta meditation and massage for adults with AIDS at the end of life	Quantitative	22	CBPR (Israel et al. 1998)
Eisenberg et al. (2006)	USA	An urban community hospital, emergency room	Emergency room managers	To gain a better understanding of the challenges facing emergency departments in a local context and to use these insights to help this particular department develop more effective responses	Qualitative	6	AR (Argyris 1995; Elden and Levin 1991; Greenwood and Levin 1998)

(continued)

Table 12.1 (continued)

First author[a] (year)	City, province/state, country	Organization(s)	Organization stakeholders (as described in the publication)	Research objective(s) (as described in the publication)	Method(s)	Duration (months)[b]	OPR label (authors cited)
Hamelin et al. (2007)[a]	Montreal, Quebec, Canada	Montreal area hospital	Head nurse, nurses and assistant nurses, head of service, project coordinator, attendants, support staff, and others with direct contact with patients, union representatives	To create an optimal psychosocial environment in the workplace	Qualitative	12	PAR (Green et al. 1995)
Mirza et al. (2008)[a]	Chicago, Illinois, USA	Centers for Independent Living (for people living with psychiatric disability)	Program directors	To gain a better understanding of the experiences of people with psychiatric disabilities within the program; to explore better ways of supporting them during the move into the community and during long-term community living and participation	Qualitative	15	PAR (Freire 1970; Selener 1997)

Williams (2009)	Cleveland, Ohio, USA	Diabetes Association of Greater Cleveland (DAGC)	Staff and patients	To identify changes needed to make the diabetes education materials and programs of the DAGC accessible for people who have visual impairment and diabetes	Qualitative	12	PAR (Coughlin and Brannick 2001; Stringer 1999; Greenwood and Levin 1998)
Dobransky-Fasiska et al. (2010)[a]	Pittsburgh, Pennsylvania, USA	Three community organizations committed to evidence-based care for minority elderly	Diverse blend of community partners from family health centers; social service and mental health consumer advocacy agencies; and a pharmacy services network	To create a depression care model for disadvantaged adults utilizing service agencies, through a community-academic partnership	Qualitative	60[b]	Cargo and Mercer (2008), Jones and Wells (2007), Minkler and Wallerstein (2003), and Israel et al. (1998)
Chen et al. (2011)[a]	Los Angeles, California, USA	The West Los Angeles Veterans Affairs Medical Center	Emergency department staff	To examine the implementation of nontargeted opt-in HIV rapid testing in an urban hospital emergency department	Mixed	4	CBPR (Israel et al. 1998)
Malus et al. (2011)	Montreal, Quebec, Canada	Primary care teaching clinic	Staff and patients	To adapt and implement a patient satisfaction questionnaire	Mixed	24	PR (Macaulay et al. 1999; Cargo and Mercer 2008)

(continued)

Table 12.1 (continued)

First author[a] (year)	City, province/ state, country	Organization(s)	Organization stakeholders (as described in the publication)	Research objective(s) (as described in the publication)	Method(s)	Duration (months)[b]	OPR label (authors cited)
Cashman et al. (2012)[a]	Worcester, Massachusetts, USA	Community health center and YWCA	Staff	To describe partnership approach taken by 2 CBOs, determine staffs' views of this partnership, highlight aspects of the partnership that contributed to its success, identify challenges and mechanisms for overcoming them, and note lessons learned	Qualitative	36	CBPR (Minkler and Wallerstein 2008; www.ccph.info)

AR action research, *CBO* community-based organization, *CBPR* community-based participatory research, *CBAR* community-based action research, *PAR* participatory action research, *PR* participatory research

[a] Organization members are co-authors

[b] Duration of partnership at the time of publication, i.e., ongoing partnership work

SPOR unit for the Support for People and Patient-Oriented Research and Trials (SUPPORT).[11] Additional lessons can be drawn from the patient engagement literature (see, e.g., https://ceppp.ca/en/).

Relationships

The relationships that develop among all stakeholders, including the university researchers, influence the OPR and the success and sustainability of their achievements and their partnership, making positive relationships the most important ingredient in OPR. It is common practice for university and organization stakeholders to form a working group and hold regular meetings. Working group members may not know one another at the outset or may even have strained relationships; regular meetings provide a structure to develop relationships while working collaboratively toward a common goal (Breda et al. 1997; Lausten 2005; Hamelin Brabant et al. 2007; Dobransky-Fasiska et al. 2009; Barker and Barker 1994; Smith 1995; Williams 2009; Senesac 2004). Moreover, meetings provide opportunities for communication among working group members, and between the working group and the rest of the organization, that may not exist without the research. Ideally, meetings are run by a member who can foster an environment where stakeholders can openly discuss and debate the research and related decisions, voice their thoughts and fears, and be heard and understood by others (Eisenberg et al. 2006). Speaking and listening are vital. For instance, clarifying goals and parameters, recognizing and respecting the complementary skills and knowledge of all partners, and commending achievements are all crucial to help build and nurture fruitful relationships (Dobransky-Fasiska et al. 2009; Williams 2009), work through challenges, remain motivated, and sustain the partnership (Bush and García Bengoechea 2016; Dobransky-Fasiska et al. 2009; Smith 1995). Barker and Barker (1994) wrote:

> In contrast to the initial assessment period, staff members were now openly supporting each other, asking for assistance from staff members in other disciplines and collaborating on problem solving. The sarcasm and blaming readily observed in meetings prior to the project were seen less often, with good-natured teasing and humor displayed more frequently. (p. 89)

The composition of the working group can impact the relationships and, ultimately, the research. Multidisciplinary working groups are common; the research and its outcomes are infused with the voices of a variety of stakeholders leading to research products and activities that are tailored to their context and needs (Barker and Barker 1994; Bush and García Bengoechea 2016; Malus et al. 2011).

Regarding the participation of management, in her dissertation, Smith (1995) mentions that the presence of managers at working group meetings led to health professionals holding back and adversely affected group dynamics. On the other

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[11] http://unitesoutiensrapqc.ca/.

hand, others underscore the importance of management being part of the working group because they can support the work by allocating resources and bypassing red tape, for instance (Barker and Barker 1994; Hamelin Brabant et al. 2007; Lausten 2005; Mason 2003; Malus et al. 2011). Ultimately, working group membership should be discussed and debated in relation to the actors and context involved. The working group may decide that while including managers may hold challenges, implementing communication and other group processes may help to overcome the challenges and enable the OPR to benefit from the input of multiple stakeholder groups. Vignette 1 provides an illustration of some benefits of extensive interaction via regular meetings.

Vignette 1: Communication

In Cleveland, Ohio, USA, a researcher sought to make the patient education materials and programs of the Diabetes Association of Greater Cleveland (DAGC) accessible to people with visual impairment. A working group of people with visual impairment and diabetes (PVID), DAGC staff members, and the researcher met regularly. To adapt to the needs of the PVID, meeting notes were provided in their preferred format (large print or audio) and were read aloud at the beginning and end of each meeting. Meetings provided a setting for extended direct contact and cooperation between the working group members, enhancing both the products of this project and the process of discovering ways to meet the needs of PVID.

PVID had felt anger and suspicion of the DAGC staff members at the beginning of the project, but those feelings changed as the DAGC staff members demonstrated their willingness to listen and change. In particular, the process gave the PVID an opportunity to communicate their own experiences of living with diabetes and visual impairment and to be heard by a group of professionals. Some PVID felt that participation in this project increased their skills for expressing themselves and confidence in doing so. One explained: “Medical professionals are a mixed bag. They don’t all know how to serve everyone. We often have to teach them how to serve us.” Another had a hospitalization following the project and later expressed that her recent experience with DAGC had prepared her to explain her needs clearly to healthcare professionals in the hospital. Furthermore, the PVID members’ communicating aspects of their experience that were unknown to the sighted participants gave the DAGC staff a deeper, more authentic understanding of accessibility needs. Notably, PVID mentioned the importance of opportunities for socializing, especially around meals.

Summary developed from excerpts from

Williams, A. S. (2002). A focus group study of accessibility and related psychosocial issues in diabetes education for people with visual impairment. *The Diabetes Educator, 28*(6), 999–1008. https://doi.org/10.1177/014572170202800614

Williams, A. S. (2005). Using participatory action research to make diabetes education accessible for people with visual impairment. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 66*(5-B), 2883.

Williams, A. S. (2009). Making Diabetes Education Accessible for People with Visual Impairment. *The Diabetes educator, 35*(4), 612–621. https://doi.org/10.1177/0145721709335005

Initiation and Focus of the Research

OPR begins in a variety of ways. In some studies, organizations may seek out academics with whom to partner to help them address an issue they have identified. Cashman et al. (2012) provide an explicit example in their health promotion study conducted with community health organizations. Other times, the idea for the focus of the research is proposed by the academics, and the organization stakeholders agree with the importance of the issue and choose to partner to address it. This is the model described in a study between university researchers and nurses in a public health unit in Alberta, Canada (Smith 1995). Finally, the research focus can be determined jointly among all partners. Lausten (2005) provides such an example in his study with nurses to improve ecological practices in a hospital. Agreeing on the focus of the research may not be simple. Sometimes, the various stakeholders each have their respective priorities and discussion and negotiations are needed to come to consensus on the issue to address through the OPR. Ultimately, addressing an issue which is important to the organization and that may be usefully addressed through research is paramount and contributes to the success of the OPR (Bush et al. 2017). A study that took place in Pittsburgh, USA, provides an example of researchers deferring to the organization's interest. Academics and leaders of 11 community organizations formed the Research Network Development Core to improve depression care. The authors write:

> Before the [Research Network Development Core] was created the academics had research goals of reducing depression among African-American and White older adults. However, the public organizations serve people of all ages and all racial and ethnic groups. Thus, the researchers shifted focus to include disadvantaged adults of any age in order to be aligned with the community partners. (Dobransky-Fasiska et al. 2010, p. 2)

Others illustrate some benefits of focusing on organization priorities. Lausten (2005) asked nurses participating in his dissertation work what they thought about being active participants in research, one said: "I think it's important because I think when you give people a choice to be involved in what their ideas are they're more apt to work harder on it" (p. 54). This is further underscored by Hamelin Brabant et al. (2007) who write: "the results revealed that the organizational changes are seen as less threatening when suggestions come from colleagues rather than from managers, who are often seen as less adept than the employees at solving the internal problems of a care unit or service unit" (p. 319).

It should be underscored that reaching consensus on a research focus that is beneficial to all working group members can be challenging. Developing a shared understanding of each other's needs and expectations, as well as feasible contributions of all working group members, may require multiple lengthy conversations and can be complex and even frustrating. The process will benefit from stakeholders' ability to express where they are and are not prepared to compromise as well as a willingness to understand and to learn from one another and to help achieve their respective needs. Other important qualities for working group members are patience and perseverance, together with group facilitation skills. These initial negotiations help set the foundation for the relationships among the working group members that are needed to conduct the OPR. Vignette 2 describes how one study was initiated, how ideas for action were generated by stakeholders, and the potentially sustainable effects of the OPR processes.

Vignette 2: Research Initiated by Organization Stakeholders
Seeking a better understanding of how to serve people with psychiatric disabilities in the community reintegration program, the program directors at two Centers for Independent Living (CIL) serving a large metropolitan region in the United States met with three researchers from the University of Illinois at Chicago, to discuss a research partnership. Together, they developed the project's aims: (1) to gain a better understanding of the experiences of people with psychiatric disabilities within the community reintegration program and (2) to explore better ways of supporting them in community reintegration. To begin the data collection process, they decided to hold a focus group, co-led by a researcher and a community partner, the content of which was determined with the community partners. Results revealed a need for increased communication between various organizations that provide services for people with psychiatric disabilities in the community.

To initiate a dialogue between the various entities involved in the provision and use of psychiatric disability services, a community resource meeting was planned. Meeting participants unanimously agreed that opening up lines of communication between the various stakeholders was the next step in the process of promoting community integration of people with psychiatric disabilities. It was decided that this process could be initiated through the creation of an email listserv, where individuals could post information on advocacy efforts and other local and statewide initiatives that they were undertaking to promote community services for people with psychiatric disabilities. Two of the participants, one of whom was a person with a psychiatric disability and CIL representative and the other a service provider, volunteered to take the lead in developing the listserv. This listserv is currently active and continues to be a forum where participants communicate and share ideas on an ongoing basis. Other steps recommended for developing a seamless service system included the creation of a clearinghouse of information and a toll-free number for service providers and consumers. While these latter steps have not come to fruition as yet, they are under consideration and being collaboratively worked upon. This project has laid the foundations for future bridge building between people with psychiatric disabilities and the broader disability community, particularly in the area of promoting community integration.

Summary developed from excerpts from

Mirza, M., Gossett, A., Chan, N. K., Burford, L., & Hammel, J. (2008). Community reintegration for people with psychiatric disabilities: challenging systemic barriers to service provision and public policy through participatory action research. *Disability & Society*, *23*(4), 323–336.

Participatory Data Analysis

Given the inclusion of the varied and complementary knowledge and expertise of all partners, a participatory data analysis process can enhance the work. For instance, organization stakeholders provide the necessary insider's lens to heighten the contextual relevance of the results, whereas the academic stakeholders contribute the research expertise needed to not compromise the scientific rigor. Again, lengthy discussions and negotiation are often involved and compromises required. Participatory analysis of data can take many forms. Although organization stakeholders may not have the expertise, time, or interest to complete the technical work of quantitative and/or qualitative analyses, their input in this research phase is possible and valuable. For instance, in Montreal, Quebec, Canada, Bush and García Bengoechea (2016) worked with a YMCA to evaluate their adolescent program. While the academic partners carried out the statistical analyses, decisions regarding how to analyze the quantitative program data were made together with YMCA partners. For example, partners had multiple discussions pertaining to questions and hypotheses and feasible analyses given the sample and the nature of the data. Similarly, the university partners coded the qualitative data, but the deductive coding framework was developed with the academic and YMCA partners and based on the peer-reviewed and gray literature as well as YMCA partners' knowledge. In other studies, the working group does the technical work of the analysis, working together to code qualitative data and develop themes as described in one article co-written by all stakeholders.

> All [working group]nurses met six times for 3 hours to analyze the research findings and to develop categories, or themes, of analysis. Breda [the first author] recorded each session on tape, listened repeatedly to the recordings, and pulled out salient topics for discussion at the following meeting. We spent the subsequent meeting reflecting on these topics and adding new input from events that had transpired in the interim. We continued this process until all components of the project were analyzed. All working group nurses were active in the dialogue and decided together on the meaning of experiences. In the end, we easily reached consensus on three themes that we believed reflected the major changes that were experienced in our collective inquiry. (Breda et al. 1997, p. 79)

Other studies follow this model, but only some members of the working group carry out the analysis. This is illustrated in a study led by one of our co-authors (Pluye). University and organization partners describe how they worked together, as co-researchers, iteratively coding qualitative data, discussing their codes, and inductively developing new codes to produce a reliable coding manual (El Sherif et al. 2015). Finally, others opt to have the researcher do some initial analysis and return preliminary results to the group for discussion as depicted in Vignette 3.

Vignette 3: Collective Data Analysis

In a primary care clinic in Montreal, Quebec, Canada, an interdisciplinary committee (patients, manager, psychologist, administrators, support staff, nurse, physicians, and researchers) evaluated a patient satisfaction questionnaire (PSQ) for its suitability in the clinic. The committee, chaired by the research coordinator, met monthly from 2007 to 2009.

The qualitative researcher completed semi-structured interviews with other clinic staff and patients regarding their perspectives of the relevance of each item in the original PSQ. She analyzed these interviews and presented the results to the committee. The content, wording, and appropriateness/relevance of each question were discussed until a consensus was reached, as follows. The chair ensured every member had a chance to express and explain his or her opinion, preventing any committee member from dominating the discussion and asking quieter members for their views. The chair continuously summarized the points of view, identifying similarities and differences. In one instance, voting was required to reach consensus. The committee divided into two groups and each group discussed and nominated a representative, who then presented their view to the full committee. Committee members then voted on the issue anonymously. This time-consuming, but enriching, process led to rewording, eliminating, or adding new items to the PSQ. This adapted PSQ was tested in three 1 h focus groups where patients were asked to complete the adapted PSQ and discuss their overall impressions of it as well as any issues with specific items. Again, the qualitative researcher completed the analysis of the focus group transcripts and presented the results to the committee for discussion. Finally, minor changes to the questionnaire were made.

Summary developed from excerpts from

Malus, M., Shulha, M., Granikov, V., Johnson-Lafleur, J., d'Souza, V., Knot, M., Holcroft, C., Hung, K., Pereira, I., Ricciuto, C., Salsberg, J., & Macaulay, A. C. (2011). A participatory approach to understanding and measuring patient satisfaction in a primary care teaching setting. *Progress in community health partnerships: research, education, and action, 5*(4), 417–424.

Returning Results

The research results, including preliminary ones, can have a profound effect on organization members, and the organization as a whole, and must be communicated to the working group and the broader organization throughout the study process. This allows for results to be put into practice, as noted by Eisenberg et al. (2006): "Our observations were used by a newly formed interdisciplinary organizational development team seeking to create baseline measures and begin a number of targeted interventions. Some of the changes that occurred were a direct result of this study" (p. 204). Beyond achieving their planned objectives, Canadian and American examples describe how research results can surprise organization stakeholders or confirm their perceptions, both of which motivate them to enact changes, even without the help of the academic partners (Smith 1995; Bush and García Bengoechea 2016; Mason 2003). Moreover, this process can help to keep partners engaged and even motivate stakeholders to continue the partnership work (Bush and García Bengoechea 2016). The following excerpt from Dobransky-Fasiska et al. (2010) illustrates this.

> Because of the time required for the participatory research process, success depends on both intangible and tangible benefits that the partners consider to be significant enough to sustain their effort. Both the process and the results of the needs assessment were early benefits. (p. 4)

Returning OPR results to the organization can be done in many ways. In Canadian and American examples of OPR, some have provided research results to staff and management both orally and in writing during their regular meetings (Eisenberg et al. 2006; Barker and Barker 1994; Bush and García Bengoechea 2016; Mason 2003) and with poster displays in key areas of the organization (Lausten 2005). Working with the organization partners at this stage is paramount to ensure the language, tables, and figures used to communicate the results are appropriate. In her dissertation, Bush (2014) cites an organization partner who alludes to some challenges and benefits of speaking different languages (i.e., research language vs. organization language).

> It kind of surprised me when I saw the [teenagers'] names [in your report of results]. So, it was little bit of a gasp reaction. It took me a while to get used to that. But, after a while it occurred to me that it's a very interesting way of looking at things. (p. 124)

Similarly, this organization partner found it challenging to translate the organization language to the university partners: "we don't always have those words because the things that are obvious to us we think are obvious to everyone" (p. 143). We suggest that additional insight for how to proceed may be gained from existing knowledge translation frameworks (Grimshaw et al. 2012; Lavis et al. 2003; Straus et al. 2009).

Changes in Knowledge, Attitudes, and Behaviors

The increased awareness and knowledge that all working group members gain through OPR should not be underestimated. Organization stakeholders, for instance, not only learn about research and the issue they are addressing through the study (Dobransky-Fasiska et al. 2010; Lausten 2005), but they also gain an understanding of each other and their needs and constraints regarding their respective roles in the organization. Some report how staff gained an understanding of and increased sensitivity to patients' needs (Dobransky-Fasiska et al. 2010; Williams 2009). Working group members also acquire or improve upon such skills as problem identification and solving, decision making, cooperation, leadership, and communication (Barker and Barker 1994; Williams 2009). In one study, a working group member said: "There were two benefits—first, we have a stronger working relationship with you folks [academics] and second, at least an understanding, if not a working relationship with the other partners that we probably would not have developed alone … It increased our awareness of the other agencies and what they do" (Dobransky-Fasiska et al. 2009, p. 959). In the few studies including patients in the working group, benefits for them are also apparent. For example, Ann Sawyer Williams (2009) writes about how the people with visual impairment and diabetes with whom she conducted the OPR described the benefit of learning more about diabetes, quoting two partners: "It made us a lot more conscious of what we're doing when we go into the store to buy food. Now, before I buy something new, I get someone to read the labels to me, so I know what is in the food" (p. 84). Regarding university partners, while we know from our own experiences that, as part of the working group, university researchers learn, for instance, about group processes, develop group facilitation skills, and gain awareness of organizational cultures and how to navigate them, such learnings are rarely documented in peer-reviewed journal articles. Indeed, only 6% of the studies in our systematic review of OPR documented such benefits for the university partners (Bush et al. 2017), one of which was North American (Williams 2005).

As a result of the OPR approach, authors report observing reduced resistance to change and greater acceptance for change (Mason 2003; Hamelin Brabant et al. 2007; Lausten 2005; Barker and Barker 1994). For instance, Mason (2003) noted that the approach "supported broad-based acceptance of the violence initiative at a time when other imposed changes were resisted" (p. 22). Many observed changes in culture, diffusion of change to other organization members or to the organization as a whole, and continued collaboration to improve practices (Mason 2003; Dobransky-Fasiska et al. 2009, 2010, 2012; Lausten 2005; Breda et al. 1997; Barker and Barker 1994). OPR authors have also found that the participatory research approach contributes to improved relationships and teamwork (Senesac 2004), increased professional satisfaction and excitement, and increased commitment to and responsibility for actions (Williams 2005).

Organizations and their stakeholders have used results for such things as informing modifications to work processes and practices (e.g., improve triage, implement staff meetings to clarify expectations, and improve support) (Barker and Barker 1994; Eisenberg et al. 2006; Dobransky-Fasiska et al. 2010; Lausten 2005; Mason 2003; Mirza et al. 2008; Jones-Baucke 1997), improving their programming (Mirza et al. 2008), informing their strategic planning and changing policies (Dobransky-Fasiska et al. 2009, 2010, 2012; Lausten 2005), improving the workplace psychosocial environment (Hamelin Brabant et al. 2007), and communicating with board members and funding agencies about their work (Bush and García Bengoechea 2016; Dobransky-Fasiska et al. 2010). Some authors write explicitly that the OPR approach produced research activities and products that were more acceptable and relevant to the stakeholders and were more sustainable than what the academic researchers could have produced alone (Malus et al. 2011; Williams et al. 2005; Dobransky-Fasiska et al. 2010; Chen et al. 2011; Williams 2009).

Challenges

Academic and health organization contexts and purposes are very different and this can translate into challenges for the working group members. For example, the organizational context influences all aspects of the research. Budget constraints, staff reduction and turnover, and broad organizational change and restructuring are all issues that have been faced in the North American context. As illustrated in Vignette 4, understanding each other's language can be time-consuming and challenging. The same is true for managing stakeholders' varying expectations (e.g., regarding the pace of the project (Bush and García Bengoechea 2016; Lausten 2005)). Moreover, the time investment required to build a common understanding and relationships, define mutual objectives, and work through the phases of the study together can be frustrating and, in some instances, may not be feasible for some of the partners. Ann Sawyer Williams (2009) provides an example:

> The major disadvantage of the [OPR] process for [Diabetes Association of Greater Cleveland] staff was the necessary amount of staff time spent in meetings. Generally, two or three staff members were present at the monthly meetings, for about three hours a month for 10 months. In addition, two staff members spent about three hours each making recordings, and the entire staff attended the in-service program. Therefore, the estimated total amount of staff time spent on this project was approximately 106–136 hours total. (p. 92)

Another example concerns randomized controlled trials where control group participants may feel denied the opportunity to benefit from an intervention. This was the case with a randomized controlled trial of metta meditation and massage for adults with AIDS at the end of life (Williams et al. 2005). The authors write about one of the most difficult challenges they faced in their OPR, explaining that "Once the initial cohort had a favorable study experience, they provided informal endorsement via the "grapevine" among the community, further fueling the sense of injustice among those who were ineligible or in the control group" (p. 99). While all the partners met to discuss possibilities to resolve the issue, the authors write: "it became clear that addressing the residents' perceived needs would involve a compromise of the randomized controlled methodology or a need for additional funding support. The former was not acceptable to the research partners, and the latter option was pursued unsuccessfully" (p. 99). In community contexts, some PHR researchers have dealt this issue by using a delayed intervention design, but this precludes long-term follow-up (Stein et al. 2003; Macaulay et al. 2013).

Although OPR can increase buy-in, implementing changes in a health organization with this approach is not always a seamless process. In a hospital in Montreal, Quebec, Canada, one working group sought to reorganize care to create an optimal psychosocial environment in the workplace. They obtained commitment from management and healthcare workers, collected their perceived work constraints, and implemented action plans to address them. Yet, the authors found that some employees were indifferent to or actively resisted changes. Reasons included failure of past projects, fear of losing privileges, and the need to acquire new technical skills. The authors write that establishing opportunities for discussion contributed to the involvement of staff in the change as they were able to share fears and feelings associated with the change (Hamelin Brabant et al. 2007). Another strategy to help mitigate potential challenges is for partners to agree on a set of guiding principles or terms of reference that make the needs and responsibilities of all partners explicit and details a process for dealing with disagreements. Such documents are rarely described in OPR publications. In Table 3.1 of her dissertation, Pamela Senesac (2004) provides one example where she outlines issues for which explicit clarification was required. These issues included the scope of the project, to whom the researcher and team were responsible, the process of reaching consensus, confidentiality, and the development of a 'parking lot' of future issues requiring attention.

Vignette 4: Working Through Challenges

In Allegheny County, Pennsylvania, USA, researchers from Western Psychiatric Institute and Clinic and leaders of community organizations formed the Research Network Development Core (RNDC) to create new research projects to pursue mutual concerns stemming from mental health disparities. The community/academic partnership was established slowly over a 3-year period and evolved through ongoing discussions and iterative review of ideas that eventually led to consensus at monthly meetings. Differences of opinion were discussed openly, and decisions were made through consensus. For the community partners, the challenges began with communications and developing an understanding of the mission of the partnership. One felt overwhelmed initially: "I'm going to be working with all these academics, who are all into research. I'm never going to be able to understand them, or to understand research." Another expressed, "I noticed that we speak different languages … It took time for both groups to develop an understanding of the languages." The problem with the languages was resolved over time through interacting, especially as the RNDC investigators spent considerable time at the community partners' sites. One partner commented, "The more you came here and got to know about what we did and how we worked helped us to trust you more. You were not just trying to get funding for yourself." The distinguishable gap between research and practice was another challenge for community partners. One said: "I think the major problem is with academics understanding the practical … It is frustrating. We function on two entirely different levels. We do not know academia, and academics do not know the day-to-day practice."

An essential part of developing and maintaining enduring relationships with the partners was to clarify goals and parameters that would facilitate the development of a constructive working framework. The principal investigator led discussions and facilitated input from all partners. The mechanisms of discussing issues were perceived by partners as follows: "Many ideas have been discussed around the table each month. Typically, we discuss ideas during a meeting … then present interpretation of ideas at later meetings, and discuss plans for moving forward." Another stated:

> It is an opportunity to keep on pursuing an issue until it is satisfactory to you and to us. It sometimes seems like it is too much, but you have to do it. You think there has got to be an easier way, but there is not. The variety of agencies involved is spectacular. It makes it harder to get a common understanding.

Although it has been challenging to find common ground, the diversity within the partnership provided an opportunity to develop a unique synergy to better serve economically disadvantaged adults. One partner stated, "The partnership allows us to have a voice and transform that research into practice. Often with researchers they come and do the research and then you never hear from them again. You come back and explain what you found." From this study's perspective, the participatory aspect is the essential element in this work, unifying the partnership and serving as a catalyst for designing and testing new models.

Summary developed from excerpts from

Dobransky-Fasiska, D., Brown, C., Pincus, H. A., Nowalk, M. P., Wieland, M., Parker, L. S., Cruz, M., McMurray, M. L., Mulsant, B., & Reynolds, C. F. (2009). Developing a community-academic partnership to improve recognition and treatment of depression in underserved african american and white elders. *American Journal of Geriatric Psychiatry, 17*(11), 953–964. https://doi.org/10.1097/JGP.0b013e31818f3a7e.

Dobransky-Fasiska, D., Nowalk, M. P., Pincus, H. A., Castillo, E., Lee, B. E., Walnoha, A. L., Reynolds, C. F., 3rd, & Brown, C. (2010). Public-academic partnerships: improving depression care for disadvantaged adults by partnering with non-mental health agencies. *Psychiatr Serv, 61*(2), 110–112. https://doi.org/10.1176/appi.ps.61.2.110.

Dobransky-Fasiska, D., Nowalk, M. P., Cruz, M., McMurray, M. L., Castillo, E., Begley, A. E., Pyle, P., Partners, R. N.-C., Pincus, H. A., Reynolds 3rd, C. F., & Brown, C. (2012). A community-academic partnership develops a more responsive model to providing depression care to disadvantaged adults in the US. *The International journal of social psychiatry, 58*(3), 295–305.

Summary

This chapter has provided an overview of organizational participatory health research in North America. Specific examples, taken from 16 studies identified through a rigorous systematic search, have been used to describe how this type of research has been carried out in North America, with what types of stakeholders, in what contexts, and with what types of effects. In summary, in OPR, academic researchers partner with organization stakeholders in a working group to co-construct research-related decisions throughout the study. This allows organization stakeholders to shape the OPR according to their perceived needs. Moreover, the challenges and barriers to change that all stakeholders experience can be brought to the fore and taken into account. The result is a practice change or improvement initiative likely to be acceptable, feasible, pertinent, and sustainable. In short, OPR is a research approach that facilitates the identification, evaluation, and implementation of health practitioner and health organization practice improvements.

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