


Missing Persons Alert: Finding the Lost “Person” in Patient-Oriented Research

Journal of Patient Experience
Volume 9: 1-6
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DOI: 10.1177/23743735221092628
journals.sagepub.com/home/jpx


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Abstract

After a decade of attempts at patient-oriented research, this article seeks to advance the approach, making individuals and communities active partners in health research. Patient-oriented research remains inconsistently implemented, tokenistic, and met with resistance—largely due to the system in which it was conceived and practiced. Patients remain bound by object-oriented medical cosmologies, thus reaffirming the hierarchical system underpinned by professional dominance. Until health research and researchers develop an awareness of the subtle injustices legitimized by the current approach, patient-oriented research will not actualize its mandate. This article does not challenge the healthcare system as that is beyond its scope; instead, it aims to develop further the “what” and “how” of public involvement in health research through the supplement of participatory research methodologies. In effect, setting the early foundations for transformation and encouraging a transition to a more just and equitable healthcare and research ecosystem.

Keywords

patient-oriented research, research methodology, participatory research, healthcare, social justice

Introduction

Insofar as the value of patient involvement in health research is well-documented, equally are the challenges (1, 2). Difficulties with adequate funding, increased timelines, lack of skillset, and research jargon act as barriers to involvement (2). To include patients in the research team presented a new way of working for health researchers (2). However, in 2011, this became the norm with the release of Canada’s Strategy for Patient-Oriented Research (SPOR) by the Canadian Institutes of Health Research (CIHR) (3). SPOR commenced requirements from funding organizations and research governance bodies to involve patients in health research whether researchers wanted to or not (2). Globally, many national granting agencies are requiring research partnerships with patients such as, INVOLVE in the UK, PCORI in the USA, and PHR, internationally (4). As such, similar considerations will apply.

Drawing from Nicholas Jewson’s seminal work (5–7), *The Disappearance of the Sick-Man from Medical Cosmology* (8, 9), this article will clearly detail the historical shift from a patient as a whole person, to set of organs, to a collection of cells. This provides a unique perspective into the institutional bedrock that often nullifies the impact of patient involvement in health research. POR will not fully realize its goals until there is an awareness of the persistent institutional, systemic and hierarchical injustices—as evidenced in the literature to date (1).

The following sections describe the origins of the current health system structure followed by an overview of POR. POR has been defined as promoting equity by helping patients change poles on a hierarchical structure (3, 10–12). Realistically, the system where POR is embedded may leave the hierarchy intact and may even strengthen the status quo (13). In its current form, POR may be an example of what Gillborn (14) refers to as a “public policy placebo.” (14). In essence, providing the community comfort something is being done, without the substance or effect. Instead, this article proposes a shifted approach drawn from participatory research. While appearing at face value similar to POR, its core differences move the dial toward empowerment and justice in the healthcare system.

Healthcare Autocracy: Medical Cosmologies

Bârsu (15) asserts that a correct analysis of the history of medical science allows us to understand the progressive

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phases of medicine and the periods of stagnation or regression to avoid future errors. Few papers have had as much significance or endurance in the academic discourse surrounding medicine (5–7, 16) than Jewson's (5–9, 16, 17) medical cosmologies. Jewson's cosmologies provide the framework to examine the evolution of social relations underpinning westernized medicine and its resulting consequences for knowledge and practice that endure today (6, 9).

Jewson's Sick[Person]

In the Galenic tradition, the imbalance of humors resulted in disease. Thus, health was restored through holistic mechanisms to balance the disrupted equilibrium (5). An individual's psychological and social circumstances, behaviors, and life history were central to diagnosis and treatment—the epitome of “bedside medicine” (6, 8, 9, 16). This system was also influenced by the economic power exercised by patients, or at that time, “patrons.” The fee-payer could choose the doctor who met their needs, and the clinical encounter shared medical knowledge between practitioner and patron (17). The well-informed layperson could converse on an almost equal footing with their physician. *Medical knowledge was exoteric.*

Around 1800, a new cosmology emerged, “hospital medicine.” This reflected a change in the space in which medical knowledge was elaborated and applied (8, 9). The setting for bedside medicine was domestic—at home, where the person exercised more autonomy. On the other hand, *the hospital was the physician's bailiwick.*

The visible shift from a person-oriented system in the early origins of bedside medicine to an object-orientated system in the era of hospital—or modern medicine prevails today. During the shift from bedside to hospital, patients slowly lost control of their bodies, forfeiting the validity of their concepts of health, illness, and physicality (8). An object-orientated cosmology, whatever its diagnostic power or its therapeutic potential, carries with it a tendency to be impersonal and disempowering.

In the mid-19th century, “laboratory medicine” appeared which sought disease at the cellular level and intensified the reductionist tendencies of the preceding stage. *Medical knowledge became esoteric.* The patient ceased to be a person with their own agenda and became a “case”—contributing to the broader pool of medical knowledge. The term “patient” is a medical construct rather than an entity in its own right.

Condrau (18) asserts that the “person” disappeared from the medical narrative, and “the patient” became the by-product of hospital medicine. To this present day, we continue to grapple with the consequences of a move from person-oriented to object-oriented health systems (16).

Patient-Oriented Research

Based on CIHR's (3) definition, POR refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes.

Despite this documented definition, Kaur and Pluye (19) attest, no single agreed-upon POR definition exists. To illustrate, Baumgardner (20, p5) defines POR as “research that focuses on an intact person or patient as the unit of observation”; Strom et al (11, p164) state POR is “research conducted with human subjects (or on material of human origin, such as tissues, specimens, and cognitive phenomena) that requires direct interactions with human subjects”—both, harkening back to object-oriented cosmology. Shimmin et al (21, p2) warns of POR approaches that,

centres on the primacy of researcher and system need over the needs of participants and communities; in turn replicating, reproducing and reconstituting already existing inequities by privileging certain voices—mainly white, middle-class people who: have relatively fair access to health care; can navigate the system with comparative ease; and feel comfortable with identifying as a patient—over others.

The Consequentialist Argument: Examining the Actual Contributions That Patients Can Make

The origins of patient engagement saw an attempt to shift the dynamics of the hegemonic medical gaze and disrupt the identity of “researcher” and, in doing so, upended assumptions and biases around expertise and knowledge (21). However, the continued utility of the medical construct of patient essentializes the identity of “patient” as a homogeneous group; therefore, engaging any one patient sufficiently engages all patients.

This current approach denies the reality that individuals' economic, political, cultural, subjective, and experiential lives intersect in intricate and dynamic ways—reminiscent of Jewson's person-oriented cosmology. It also inadvertently excludes the involvement of individuals who may not identify as patients, such as, individuals who cannot access the healthcare system because of systemic barriers (eg, racism, colonialism, sexism, classism, ableism, and heterosexism). Alternatively, individuals living with mental health or substance use issues may be hesitant to take up the patient identity due to the associated stigma attached to such a label, and people who refuse to engage or prematurely exit the healthcare system because of unresponsive or disrespectful care (21).

A POR inclusion process that does not explicitly address the simultaneous interactions between social categories functions as hidden exclusion criteria. Thereby rejecting the involvement of individuals who often carry the most significant burden of illness. The very voices are traditionally less heard in health research (21). These understandings of social position and situatedness (Figure 1) are critical to recognizing and addressing power inequities that permeate research, healthcare relationships, and should be a fundamental principle of SPOR.

Without attention to issues of power and privilege (Figure 1), tokenism and the co-optation of individuals and groups may result. In effect, reproducing systemic and

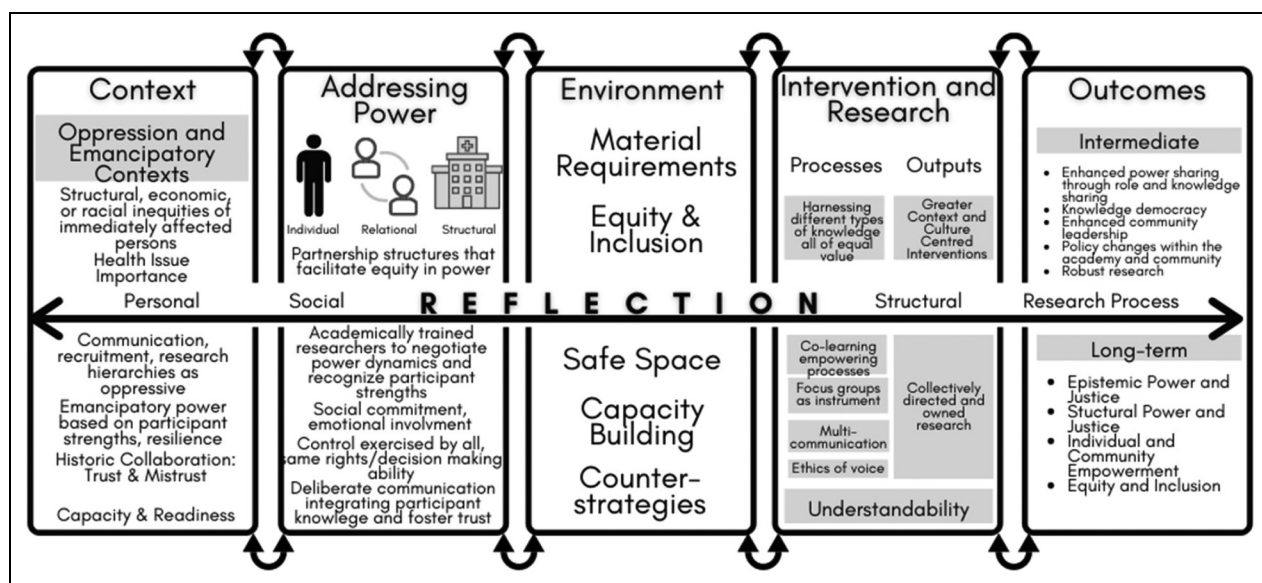


Figure 1. Participatory health research conceptual logic model adapted from Wallerstein et al (31).

structural inequities that are at the root of poor health (21, 22). For example, individuals may be chosen who present socially acceptable personas and do not threaten the existing power dynamics within the system and, in many cases, reinforce the status quo (10, 21, 22). Put simply, the people involved in POR do not reflect the diversity of the population such research aims to serve but are instead those more easily engaged with institutions, organizations, and society (23–25). Approachable patients tend to be “cherry picked,” with justifications listed in the study limitations as lack of time, resources, and inadequate support (2). Burgess et al remind, “the public is not a homogeneous entity. It is complex, composed of individuals, families, and other groups shaped by contexts, experiences, and desires in a constellation of communities with different patterns of health literacy, values, and expectations” (26, p3).

Minoritized (27) individuals, specifically Black and Indigenous peoples, necessarily have suspicion toward medical research and may be less inclined to participate (28–30). There is discordance in who gets studied, and who is doing the studying. However, several researchers with diverse participant pools note that studies are not making the efforts to build trust, create safety, remove barriers, and ultimately, to be inclusive (28, 30–32).

Experts who have successfully studied health in minoritized populations spend time with the individuals. This includes attending church services, engaging in local beauty shops, and easing childcare concerns by making childminding services available (30). This also includes scheduling “listening sessions” where affected individuals advise the researchers on their needs in their preferred language. Most importantly, this requires building long-term relationships with the individuals and community that goes *beyond* the research study (28, 30, 31, 33).

McLaughlin (34) describes the concept of “illusory involvement” through omission or commission. Omission occurs when material barriers are placed in the path of authentic involvement such that individuals cannot fully participate due to the risk of job loss or other essential life responsibilities. An act of commission occurs when the research team has determined the outcomes but requires endorsement from a patient and leads the patient in that direction. In both cases, while a patient is “engaged,” it certainly is not in a meaningful capacity (24, 34). In its current state, POR may remain peripheral and fails to make an impact leaving patients objectified and their contribution to research unrealized.

An inclusive and meaningful approach to patient engagement in health research that does not simply reiterate existing health inequities must reconceptualize patient engagement through a health equity and social justice lens (Figure 1). Drawing upon the expertise of Ocloo and Matthews (22) and Shimmin et al (21), by shifting the aims and equalizing power dynamics, we will begin to see the reappearance of person-oriented cosmologies.

Participatory Research

Participatory research (PR) began as a movement for social justice to help improve social and economic conditions, effect change, and reduce the distrust of the people involved in research (4). PR provides a framework to research health issues within a social and historical context (Figure 1). It also stresses the relationship between researcher and affected individual/community and the direct benefits to them as a potential outcome of the research (4, 35, 36). A goal of PR is that participants should “own” the research process and use its results to improve their quality of life—especially in disadvantaged communities. PR assists with self-

empowerment by removing barriers and promoting environments where individuals and communities can increase their capacity to identify and solve their problems (4).

PR is an umbrella term for a family of approaches that share a core philosophy. Vaughn and Jacquez (37) published a review of 27 different types of PR frameworks, orientations, and approaches. Among the approaches are community-based participatory research, participatory action research, dialectical inquiry, appreciative inquiry, decolonizing methodologies, social reconnaissance, and emancipatory research (4, 37). This article specifically draws from the “southern tradition” of PR based in emancipatory theory and practice that questioned the values of research in relation to political power and oppression (4).

A conceptual logic model (Figure 1), adapted from Wallerstein et al (31) illustrates a proposed approach to a participatory health research model. The focus is on the *transformational* elements of PR for use in health research. PR can shift the current structures toward a more democratic and socially just system. Thus, while POR may reinforce health-care autocracy, PR may slowly dismantle it (4, 13, 24).

PR is conducted directly with the immediately affected persons. The aim is to reconstruct their knowledge and ability through a process of understanding and empowerment (35). A fundamental principle of PR is to treat participants as co-researchers and knowing subjects with the same rights as academically trained researchers and not as objects of research (35). POR literature suggests that the research will become derailed (2) if nontrained researchers are considered at the same level as academically trained ones. This presumption derives from the object-oriented cosmology, or “expert view,” and a lack of understanding of different types of knowledge and knowing (4, 21, 35).

The proposed model of participatory health research (Figure 1) engages methods that seek to share power and control, creates environments of emotional involvement and social commitment. It builds capacity on existing embodied and subjugated knowledge (38), engenders trust on equal footings with those directly affected by the research (21, 31, 35) and through multivocality and multiperspectivity (35), builds individual and community capacity and social capital.

PR places critical reflection high on the agenda, requiring an engagement in self-analysis of the tensions encountered in conducting democratic collaborative research (39). The model (Figure 1) indicates 4 critical types of reflection: (1) reflection on personal and biographical attributes and dispositions; (2) reflection on social relationships among the research partners; (3) structural reflection on the social field of the research project; and (4) reflection on the research process (35). For example, researchers may use the model to engage in reflective practice to consider views on expertise, deficits, and, from what perspective?(34). Representatives of the dominant social group define deficits—in this case researchers, who specify the “necessary knowledge and ability” against the background of their familiar worldview and methodological requirements (4, 21, 22, 35).

Collaboration requires a different mindset from consultation. The professional researcher must be willing to share ownership of the research, acknowledge the contribution of others, act collegially, and ensure others can influence the research process and its results. This changed mindset is also reflected in how participant researchers or coresearchers are perceived and represents an alternative perspective to those commonly held. In this frame, co-researchers are viewed in terms of their abilities instead of their needs or deficits (34).

In PR projects, the role of active researcher—and knowing subject—is not held by the academic researchers alone but by *all* the participants. This includes all the subsequent consequences for data collection, analysis, interpretation, and the publication of the findings (35). The PR process “enables co-researchers to step back cognitively from familiar routines, forms of interaction, and power relationships in order to fundamentally question and rethink established interpretations of situations and strategies” (35, p2). PR offers the opportunity to disrupt the roles of patient and researcher and in doing so, individuals, and the research, may be transformed.

For academics, dilemmas arise in the use of PR because it necessarily requires additional time, and engagement with concepts like power and privilege. It may be unpredictable, or with community, concerns could lead to a perceived less rigorous design. For example, in a PR study, patients’ concerns conflicted with the research methods. This led to removal of the placebo arm of the study to ensure that participants knew if they were in the treatment arm or not (28, 30, 39).

This impacted the robustness of the study design for researchers; however, it provided a more ethical design for its participants (40). Researchers who lead research projects must balance constrained budgets, overtaxed schedules, standardized institutional performance evaluations, which are further challenged by PR. PR requires activities that traditional metrics do not recognize, nor deem valuable. Instead, PR adds an additional layer of resource management complexity to an already challenging process of securing and managing grant funding and carrying out research.

PR, as a legitimate research methodology, will require a change from health journals, funding bodies, and universities in the way that they judge and reward research performance (32, 41–43). The ability of a researcher to engage with communities and bring about real change to their quality of life and health status rarely counts (17, 44, 45). The global research community is already being urged to adapt its grant and assessment of research performance to ensure that the engaged processes typical of PR are valued, encouraged, and supported (43). Despite an imperfect process—partnering with individuals affected by the issues is of critical importance to inclusive knowledge production and is imperative for meaningful solutions.

Conclusion

Jewson’s work provides a historical account of the systemic issues that may undermine POR. This article argues that

despite these long-standing systemic issues, the inclusion PR philosophy, reflection, and approach will address both aims of patient-directed meaningful outcomes and health system change. If we shift our sights to a person-oriented cosmology, an equitable and justice-focused healthcare system, and the inclusion of the voices that often go unheard—health research could genuinely be a transformative practice. POR began this journey over 10 years ago in healthcare, and the literature suggests something is missing (10). PR may help us find our lost *person* in patient-oriented research.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Supplemental Material

Supplemental material for this article is available online.

References

1. Manafó E, Petermann L, Mason-Lai P, Vandall-Walker V. Patient engagement in Canada: a scoping review of the ‘how’ and ‘what’ of patient engagement in health research. *Health Res Policy Syst.* 2018;16.
2. Thompson J, Barber R, Ward PR, Boote JD, Cooper CL, Armitage CJ, et al. Health researchers’ attitudes towards public involvement in health research. *Health Expect.* 2009;12:209-20.19392833
3. Canadian Institutes of Health Research. Canada’s Strategy for Patient-Oriented Research—CIHR, <https://cihr-irsc.gc.ca/e/44000.html> (2011, accessed December 9, 2020).
4. Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, et al. Participatory research maximises community and lay involvement. *Br Med J.* 1999;319:774-8.10488012
5. Nettleton S. Commentary: The appearance of new medical cosmologies and the re-appearance of sick and healthy men and women: a comment on the merits of social theorizing. *Int J Epidemiol.* 2009;38:633-6.19433523
6. Nicolson M. Commentary: Nicholas Jewson and the disappearance of the sick man from medical cosmology, 1770–1870. *Int J Epidemiol.* 2009; 38: 639-42.
7. Pickstone JV. Commentary: from history of medicine to a general history of ‘working knowledges’. *Int J Epidemiol.* 2009;38:646-9.19433524
8. Jewson ND. The disappearance of the sick-man from medical cosmology, 1770–1870. *Sociology* 1976; 10: 225-44.
9. Jewson ND. The disappearance of the sick-man from medical cosmology, 1770–1870*†. *Int J Epidemiol.* 2009; 38: 622-33.
10. Pauly B, Urbanoski K, Hartney E, Shahram S, Marcellus L, Wallace B, et al. What is missing from “patient oriented research”? A view from public health systems and services. *Health Policy.* 2019;15:10-9.
11. Strom BL, Norman S, Margolis DJ. Patient-oriented research: Definitions and new paradigms. *Am J Med.* 2000;109:164-5.10967160
12. Canadian Institutes of Health Research. Strategy for Patient-Oriented Research—Patient Engagement Framework—CIHR, <https://cihr-irsc.gc.ca/e/48413.html> (2014, accessed October 31, 2020).
13. Giannakaki M, McMillan ID, Karamichas J. Problematising the use of education to address social inequity: Could participatory action research be a step forwards? *Br Educ Res J.* 2018;44:191-211.
14. Gillborn D. Citizenship education as placebo: ‘Standards’, institutional racism and education policy. *Educ Citizenship Soc.* 2006;1:83-104.
15. Bârsu C. History of medicine between tradition and modernity. *Med Pharm Reports* 2017; 90: 243-5.
16. Gillam S. The reappearance of the sick man: a landmark publication revisited. *Br J Gen Pract.* 2016;66:616-7.27884901
17. Foucault M. *The Birth of the Clinic.* Routledge; 2004.
18. Condrau F. The patient’s view meets the clinical gaze. *Soc Hist Med.* 2007;20:525-40.
19. Kaur N, Pluye P. Delineating and operationalizing the definition of patient-oriented research: a modified e-Delphi study. *J Patient Cent Res Rev.* 2019;6:7-16.31414019
20. Baumgardner DJ. Defining patient-oriented research for the average person (and potential research partner). *J Patient Cent Res Rev.* 2019;6:4-6.31414018
21. Shimmin C, Wittmeier KDM, Lavoie JG, Wicklund ED, Sibley KM. Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis. *BMC Health Serv Res.* 2017;17:539.28784138
22. Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf.* 2016;25:626-32.26993640
23. Hussain-Gambles M, Leese B, Atkin K, Brown J, Mason S, Tovey P. Involving south Asian patients in clinical trials. *Health Technol Assess;* 8. Epub ahead of print October 2004. doi:10.3310/hta8420
24. Smith YR, Johnson AM, Newman LA, Greene A, Johnson TRB, Rogers JL. Perceptions of clinical research participation among African American women. *J Women Health.* 2007;16:423-8.
25. Tremblay M-C, Bradette-Laplante M, Bérubé D, Brière É, Moisan N, Niquay D, et al. Engaging indigenous patient partners in patient-oriented research: lessons from a one-year initiative. *Res Involv Engagem.* 2020;6:44.32760594
26. Burgess RA, Osborne RH, Yongabi KA, Greenhalgh T, Gurdasani D, Kang G, et al. The COVID-19 vaccines rush: Participatory community engagement matters more than ever. *Lancet.* 2021;397:8-10.33308484
27. Sotto-Santiago S. Time to reconsider the word minority in academic medicine. *J Best Pract Health Prof Diversity.* 2019;12:72-8.

28. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D, et al. More than tuskegee: Understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010;21:879-97.20693733
29. Skinner CS, Schildkraut JM, Calingaert B, Hoyo C, Crankshaw SS, Fish L, et al. Factors associated with African Americans' enrollment in a national cancer genetics registry. *Community Genet*. 2008;11:224-33.18417970
30. Wendler D, Kington R, Madans J, Wye GV, Christ-Schmidt H, Pratt LA, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2005;3:e19.16318411
31. Wallerstein N, Muhammad M, Sanchez-Youngman S, Rodriguez Espinosa P, Avila M, Baker EA, et al. Power dynamics in community-based participatory research: a multiple-case study analysis of partnering contexts, histories, and practices. *Health Educ Behav*. 2019;46:19S-32S.31549557
32. MacKinnon KR, Guta A, Voronka J, Pilling M, Williams CC, Strike C, et al. The political economy of peer research: mapping the possibilities and precarities of paying people for lived experience. *Br J Soc Work*. 2021;51:888-906.
33. Washington HA. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*. Doubleday; 2006.
34. McLaughlin H. Involving young service users as co-researchers: possibilities, benefits and costs. *Br J Soc Work*. 2005;36:1395-410.
35. Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum Qual Sozialforsch/ Forum Qual Soc Res*; 2012;13. doi:10.17169/fqs-13.1.1801
36. Decker M, Hemmerling A, Lankoande F. Women front and center: the opportunities of involving women in participatory health research worldwide. *J Women Health*. 2010;19:2109-14.
37. Vaughn LM, Jacquez F. Participatory research methods—choice points in the research process. *J Particip Res Methods*. 2020;1:13244.
38. Minogue V, Girdlestone J. Building capacity for service user and carer involvement in research: the implications and impact of best research for best health. *Int J Health Care Qual Assur*. 2010;23:422-35.20535910
39. Dedding C, Goedhart NS, Broerse JEW, Abma TA. Exploring the boundaries of 'good' participatory action research in times of increasing popularity: dealing with constraints in local policy for digital inclusion. *Educ Action Res*. 2021;29:20-36.
40. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect*. 2014;17:637-50.22809132
41. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q*. 2012;90:311-46.22709390
42. McCartan C, Schubotz D, Murphy J. The self-conscious researcher—post-modern perspectives of participatory research with young people. *Forum Qual Soc Res*. 2012;13:1-18.
43. Macaulay AC. Participatory research: what is the history? Has the purpose changed? *Fam Pract*. 2017;34:256-8.27993909
44. Freire P. *Pedagogy of the Oppressed*. 30th anniversary ed. Continuum, 2000.
45. Freire P. Creating alternative research methods: learning to do it by doing it. In: Hall B, Gillette A, Tandon R (eds) *Creating Knowledge: A Monopoly*. Society for Participatory Research in Asia; 1982, pp. 29-37.