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ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/reac20

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To cite this article: Meghan Gilfoyle (05 Mar 2024): A square peg in a round hole: reflecting on using a participatory health research approach during my PhD, Educational Action Research, DOI: 10.1080/09650792.2024.2325058

To link to this article: https://doi.org/10.1080/09650792.2024.2325058

Published online: 05 Mar 2024.

EDUCATIONAL ACTION RESEARCH
https://doi.org/10.1080/09650792.2024.2325058

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A square peg in a round hole: reflecting on using a participatory health research approach during my PhD

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ABSTRACT

When reflecting on my years as a doctoral student, I recall several questions that often came to mind throughout my journey: what is participatory health research? Is such an approach to research truly feasible in the pursuit of a doctoral degree? Is it worth it, or have I inadvertently made things more challenging for myself? My response to these questions has evolved dramatically alongside my growth and development throughout my PhD. I was presented with an opportunity to explore an approach to participatory health research firsthand; a process which included many jumps, twists, turns, and slides, and at times, left me feeling like a square peg in a round hole. Throughout this process, navigating the breadth of challenges and opportunities presented along the way, I also learned the importance of one's narrative – in particular, the growth and development made possible when researchers and participatory partners share our stories and reflect together. This paper is part of my story, through my account of 'our story'. It embraces a narrative-style approach to critical reflection of the participatory process throughout my doctoral studies, emphasising the key challenges posed when working within the boundaries of traditional academic structures. I provide a reflexive account of how these challenges were navigated, which created a range of opportunities at both a theoretical and practical level. I conclude with a response to these initial questions and a hopeful call for change.

ARTICLE HISTORY
Received 29 April 2023
Accepted 16 February 2024

KEYWORDS
Participatory research; doctoral experience; reflection

Introduction

When reflecting on my years as a doctoral student, I recall a several questions that often came to mind throughout my journey: what is participatory health research (PHR)? Is such an approach to research truly feasible in the pursuit of a doctoral degree? Is it worth it, or have I inadvertently made things more challenging for myself? My response to these questions has evolved dramatically alongside my growth and development throughout my PhD. I was presented with an opportunity to explore PHR firsthand; a process which included many jumps, twists, turns, and slides, and at times, left me feeling like a square peg in a round hole. Throughout this process, navigating the breadth of challenges and opportunities presented along the way, I also learned the importance of one's narrative –

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in particular, the growth and development made possible when researchers and participatory partners share our stories and reflect together. This paper is part of my story, through my account of 'our story'. It embraces a narrative-style approach to critical reflection of the participatory process throughout my doctoral studies, emphasising the key challenges posed when working within the boundaries of traditional academic structures. I provide a reflexive account of how these challenges were navigated, which created a range of opportunities at both a theoretical and practical level. It is important to note that the views presented below are based on *my* experience of the participatory process. Considering this, I focus less on the study specifics and encourage readers to visit the following references (Gilfoyle et al. 2022, 2023; Gilfoyle, MacFarlane, and Salsberg 2022) to learn more about the work and for additional context. In these references you will find further details on the participatory approach used in the doctoral work (e.g. with the PhD Research Advisory Group) and on the PhD topic: exploring trust in PHR partnerships through a social network approach.

Setting the context

In 2019, I (a Canadian living in Ireland) was accepted to a doctoral programme situated at the University of Limerick School of Medicine, specifically within the Public and Patient Involvement (PPI) Research Unit. Within the PPI Research Unit, a project called PPI Ignite@UL was underway. PPI Ignite@UL was funded by the Irish Health Research Board (HRB) and Irish Research Council (IRC) as one of five institutions striving to build capacity for PPI and influence research culture within Irish higher education (HRB 2016a, 2016b). PPI Ignite@UL was working in partnership with nine academic, service, and community organisations. They were collaborating on three areas of work, involving training, networking, and policy change. They had been working together for over a year when I joined in 2019.

At that time, I was aware that my doctoral work would involve and contribute to at least two competency areas: *PHR* and *social network analysis* – but the how, what, and why of this effort remained undefined. Then, throughout the first year of my doctoral studies, all priorities shifted. There was a call from the HRB and the IRC to move from an inward-facing institutional focus of capacity development for PPI in Ireland (i.e. funded as 5 separate grants), to that of an outward-facing national focus where participating institutions (existing and new) would work together on one grant called the *PPI Ignite Network* (see: https://ppinetwork.ie/about-us/). The PPI Ignite Network would work together towards achieving the goals of capacity and readiness for PPI at a national level (commencing May 2021).

By 2020, a subset[1] of four partners working on PPI Ignite@UL (and later three of the four on the PPI Ignite Network) expressed interest in being involved in what eventually became my *PhD Research Advisory Group*.[2] From 2020[3] to 2023, we worked together to progress the doctoral work.

Challenges and opportunities

My first challenge came at the start of my PhD, specifically at a more theoretical level. This challenge pertained to the dominant philosophical views and traditions of health research

spaces that had shaped my experience in research up until that point. I had been continuously exposed to rhetoric like 'bias', 'control', and 'objectivity' as well as a seemingly engrained perception of what constituted 'valid' forms of knowledge. Formed in the moulds of this rhetoric, I had, until this time, very little exposure to 'other ways of knowing' inclusive of the PHR process. My paradigmatic assumptions (and eventual shift) were exemplified when I sought to navigate the conceptual enigma of PHR terminology.

Challenge #1 – limited exposure to other ways of knowing: moving beyond "objectivity" and "control"

With what I now see as a paradigmatic tunnel vision, I held a monistic (Spender 1998) epistemology congruent with a positivist ontology. This was evident when I asked an important question: 'What is PHR?'

Given my Canadian roots, I had been mildly exposed to terms like patient engagement (Manafo et al. 2018) and integrated knowledge translation (Straus, Tetroe, and Graham 2013) before my doctoral work, and then terms like Public and Patient Involvement (PPI) upon being situated at the *PPI* Research Unit in Ireland. However, even within the PPI Research Unit, there were discussions about how the work was guided by PHR principles and values. I immediately focused on understanding how they differed, fueled by a need to understand who was doing it 'right'? What ensued was a series of nose dives into a veritable warren of conceptual rabbit holes of collaborative approaches. Coming from a predominantly quantitative background, with assumptions aligning with that of a post-positivist worldview (*cf* Fox 2008), I was searching for the one true and/or the best way of 'doing' PHR. As such, I was getting stuck in the conceptual weeds of the various terms and 'how-to' guides that were available. I brought this concern to my supervisors which prompted extensive discussions like that of philosophical assumptions, such as introductions to what is epistemology and ontology (Lincoln, Lynham, and Guba 2011).

Opportunity #1: embrace multiple ways of knowing

These discussions with my supervisory team necessitated a critical reflexive process that created space for me to consider the lens through which I viewed the world and what I valued as knowledge. I started to appreciate the importance of multiple ways of knowing – a pluralistic epistemology underscored in a PHR paradigm (International Collaboration for Participatory Health Research (ICPHR 2013). Through this process, I noted a disconnect between my academic experiences and my beliefs/values. Thus, I needed to reconcile these predominantly post-positivist (Braun and Clarke 2013) assumptions I held at that time, including moving away from searching for a singular truth, and any pre-conceptions I had of what constituted 'valid' forms of knowledge (e.g. only using scientific methods that ensure 'context stripping', such as isolating and controlling for confounding variables and biases through randomisation) (Braun and Clarke 2013; DePoy and Gitlin 2015; Guba and Lincoln 1994). I began to understand at a deeper level that PHR extends beyond participation as a research method, wherein certain individuals are involved in health research such that research quality can be improved

(International Collaboration for Participatory Health Research (ICPHR 2013). Specifically, PHR as a paradigm means that participation is the defining principle through the research process"(International Collaboration for Participatory Health Research ICPHR 2013, 4), where those who will use/benefit from the knowledge are co-decision makers and research *partners* (Salsberg and Elmusharaf 2020). I also accepted what I thought was conceptual chaos, recognising that: 1) there is seemingly more variation within each of the terms used (e.g. participatory action research (PAR), community-based participatory research (CBPR), participatory rural appraisal (PRA)) than across the terms (Nguyen et al. 2020); and 2) there is often strong alignment across the many participatory approaches (e.g. PAR, CBPR and PRA), especially in their core values and principles (Nguyen et al. 2020). Ultimately, I – like others before me (Cargo and Mercer 2008), started to view PHR as an umbrella term encompassing a school of collaborative approaches (e.g. community-based participatory research, participatory rural appraisal, and participatory action research) (Cargo and Mercer 2008). This enabled me to focus on a fundamental commonality of such approaches: ensuring that those to whom the research topic/area of interest matters most are at the heart of the decision-making process (Salsberg and Elmusharaf 2020).

Challenge #2 – PhD temporalities vs PHR

'Walking the walk' – operating meaningfully within a PHR paradigm – was continually challenged by the traditional academic structures that persisted, especially in the world of health research. One of these challenges is what Dowling et al. (2012, 297), discussed as 'one of the hallmarks of doctoral education' inclusive of 'the planning, implementing and writing of a research project in a set time frame (Dowling et al. 2012).' They noted that this often involves 'supervisors, students, and departments have[ing] many "rules of thumb" about what should happen when.' For instance, I was funded for the relatively standard four-year period to generate novel, impactful evidence using a PHR approach. This is a feat in itself given the nature of PHR, where issues like partnership turnover (Armstrong et al. 2022) or decisions surrounding resource allocation (Wallerstein et al. 2017) can constrain the PHR process and in turn outputs (see Box 1 for an example from the doctoral work). For example, Wallerstein et al.,(2020) explored how such funding hierarchies perpetuating academic privilege can create barriers for power-sharing intentions. Indeed, this becomes further exacerbated by the omnipresent traditional academic structures and values that define the 'success' and 'importance' of research through quantifiable metrics, such as the number of outputs and journal impact factors. For example, at one point I applied internally for funding to cover open access fees and was rejected because the journal was not 'Quartile 1.' I often questioned whether PHR in doctoral studies was truly feasible, which was intensified when I compared my progress (through these metrics) to other doctoral students not applying a PHR approach. For example, despite the many benefits of PHR, the co-design and development process can add to the research timelines (Scher et al. 2023), which may delay outputs such as academic publications. Thus, this could lead to a fewer overall publications, which is detrimental when applying for funding or academic positions (*cf* Raynor 2019).

Box 1: An example of an experience that challenged our PHR process: partner turnover

After the time spent building relationships with individuals on the PPI Ignite@UL team, there was a change in two of the partners. At this point we had transitioned to solely a remote work environment (due to COVID-19) and the development of the PhD Research Advisory Group was underway. I struggled to harness a similar level of connection with the new partners, which was not surprising given, as noted by Armstrong et al. (2022), pre-existing relationships and shared experiences are key for influencing the evolution of trust. We did not have that time together previously, and I had to progress the academic work to finish within the funded timelines. I attempted to bridge this connection but was unsuccessful. I refer to the entry from my research diary entry from June 19th, 2020:

> 'I provided the partners with an update on the progress of the scoping review. There were two new members at this meeting (replacing previousmembers who left the position) so I thought I should send them additional information (what was provided at the last meeting prior to their involvement) and offered for them to meet with me 1:1 if they had questions about the material. So far, no responses from the new members.' (Meghan Gilfoyle)

As noted by Armstrong et al. (2022), continuing to share knowledge in an online environment, like emails or phone calls was helpful in maintaining 'trust at a distance (pg.1012)', but did not help when a foundational level of relationship development and trust.

Opportunity #2 – an expanded network of researchers with aligning values and interests

What was crucial in navigating these challenges was a supervisory team whose research values and interests strongly aligned with those of PHR. Their mentorship was instrumental, especially during the times when I did not see myself as having a seat at the table (as a student investigator) – at least not a comfortable one – and my supervisors often needed to advocate on my behalf (see Box 2 for an example).

They also helped me build a support network with others outside the institution who had a shared commitment to PHR. They introduced me to groups like the 'International Collaboration for Participatory Health Research (ICPHR)' and the PHR working group within the 'Committee for Advancing the Science of Family Medicine (CASFM-PHR).' Building relationships in these inclusive spaces with academics across all career stages

Box 2: Examples of creating space for student voice

1) When seeking to include the PPI Ignite Network as the case to explore our research objective of interest, the infrastructure was lacking for me to present the work to members of this new network. As my supervisor was a member of this Network, he leveraged his position to present the work on my behalf. Given the solely online environment at the time (COVID-19) and that the grant for PPI Ignite Network had recently commenced, it was imperative that members of the network had exposure to the work before recruitment, providing an opportunity to address any study questions and/or concerns before seeking their involvement via email.
2) When there was concern from members of the network about responding to questions of trust about other members in the network, my supervisor set-up meetings with each of the project members to clarify the work and answer any further questions/concerns. I was included in these conversations, creating a channel of communication and space for me to engage in dialogue with other members of the network.

was influential in strengthening my confidence and skills in the forum of PHR. Specifically, I took part in working groups, sometimes in leadership roles, as well as numerous online discussion platforms. This was especially important because although PHR is gaining momentum and recognition around the world (Cargo and Mercer 2008), it is it not (yet) the norm and still resides within traditional academic structures creating unique challenges for PHR researchers (e.g. funding and outputs as described above). Thus, having a PHR community of practice, support, and mentorship that includes various perspectives and levels of PHR experience, was vital for navigating these unique challenges.

Further, a supportive supervisory environment with aligning research values and perspectives was key, especially when I questioned the feasibility of a PHR approach in the allotted (*funded)* time for the doctorate. I often wanted to 'push ahead' to be 'on track' with those in my cohort (e.g. those who had clearly defined research questions). My supervisors strongly advised me (time and time again) not to rush. They would encourage me to embrace the uncertainty and take the time to invest in relationships. They helped to facilitate this process by: 1) ensuring I was working with what Lucero et al. (2017), described as a 'proxy level of trust' through their pre-established network of partners within the PPI Ignite@UL team; 2) introducing me to these partners at the outset of my doctoral work, involving me in the initiatives of the project, and encouraging me to get to know other members of the PPI Ignite@UL team; and 3) actively encouraging me to carve out protected time and space for developing relationships without academic agendas, which they respected and viewed as a valuable part of the doctoral work. I feel strongly that this was crucial for employing a PHR approach in my PhD – I was not starting from scratch. Indeed, I resonated strongly with Lachance et al. (2022, 521 and 524), who noted that 'time on the front end to build capacity and trust creates benefits to the partnership that act to reduce costs of participation over time.'

Challenge #3 – collective ownership

This 'time [spent] on the front end (Lachance et al. 2022, 521 and 524)' - approximately eight months – was influential when navigating other key challenges, like the tension between PHR – namely, collective ownership – and the need for independent intellectual contribution in doctoral work. Collective ownership is a central tenet of the participatory approach, where 'the research lies in the hands of the group conducting the study (International Collaboration for Participatory Health Research ICPHR 2013, 10).' The issue is that 'true' collective ownership is, in my view, not possible with such doctoral requirements. Inherent to the professional and academic development of a doctoral candidate is a display and proficiency in demonstrating independent scholarship, and thus, intellectual leadership over the content and execution of the study. I questioned if it would be possible to ascend the rungs of Arnstein's ladder (Arnstein 1969) toward of 'citizen power' with these barriers in place.

Opportunity #3: creating space for critical and open dialogue

Nevertheless, I felt it was important to work within these boundaries (e.g. independent scholarship and intellectual leadership) to facilitate change. I accepted an opportunity that was two-fold: 1) I could more fully appreciate the value of a PHR approach – that it is not in its essence one-size-fits-all (Israel et al. 2017) – and 2) we as members of the PhD

Advisory Group could acknowledge these barriers by carving out time and space for critical and open dialogue at the outset. For example, we had to navigate Challenge #4 together, which included difficult conversations around inability to compensate partners for their time, which was made easier by transparency as well as the level of foundational trust that had been built through the initial months of relationship development. We cultivated a strong rapport with each other that enabled productive discussion, even within the constraints of a pandemic and the use of Zoom and other virtual platforms. Thankfully, our work together continued.

Challenge #4 - inadequate PhD resources for PHR

Another challenge that posed a risk to the PHR process revolved around the funding barriers I faced which were two-fold: 1) as a researcher using a PHR approach and 2) as a doctoral student. In general, as highlighted by Scher et al. (2023), academic institutions need to consider flexibility in funding, procurement of additional funding, and a general appreciation of the additional complexities faced in PHR compared to traditional research approaches. This is exacerbated as a doctoral student, operating on a pre-determined budget (i.e. even less flexibility compared to more senior academics). In my doctoral studies, I did not have a budget that supported key aspects of PHR, such as a compensation fund[4] that recognised the PhD Research Advisory Group members for their time. As equitable compensation for project partners is a critical consideration for PHR (Scher et al. 2023), I worried about the potential for mistrust to develop if partners perceived the lack of funds as unfair or undesirable (Armstrong et al. 2022; Jagosh et al. 2015). Wallerstein et al. (2020) explored how such funding hierarchies (or lack of funding) can perpetuate academic privilege and create barriers for power-sharing intentions.

Opportunity #4 – focused areas of involvement and transparency surrounding capacity

This prompted another opportunity for transparent dialogue within the PhD Research Advisory Group to acknowledge the limitations such funding challenges could pose. The lack of funding did not limit our work together in this case, but it necessitated flexibility and transparency, acknowledging explicitly the potential for changing levels of capacity for the partners. As an example, I distributed emails to all partners to provide updates on our research but also to check in on their capacity at that time and gauge interest in their continued involvement. We had discussions about their specific interests to ensure their involvement reflected areas they deemed of relevance and/or importance for growth in their skillset/career stage. Some contributed more actively to certain areas of work (e.g. qualitative or quantitative components of the case study), while others were more involved in the overarching components of the doctoral work. For example, a central component included brainstorming/discussion sessions that were influential to the direction and design of the research (e.g. the generation and refinement of certain research questions). This aligned well with a key principle of PHR in that 'not everyone will be involved in the same way (Israel et al. 2017, 37–38).'

I also realised that this represented an opportunity to embrace what elements were within my power to affect change. For instance, I allotted an appropriate amount of time (based on partner capacity) for them to provide feedback (e.g. on manuscripts for publication). What was appropriate was ascertained by asking partners about their availability at that time and organising my schedule of work around this. I made sure to continuously thank each member of the team for their time and commitment to the work, at minimum acknowledging their contribution across outputs (e.g. manuscripts and presentations), and ensuring co-authorship was given when warranted.

In summary, embracing the theoretical flexibility afforded by PHR, surrounding myself with a supportive network of researchers and mentors that encouraged PHR, and appreciating the 'dialectical process characterised by messiness (International Collaboration for Participatory Health Research ICPHR 2013, 20)', were crucial when navigating the challenges reinforced at an institutional level – namely those that perpetuate traditional academic structures and ways of knowing.

Overview and considerations

I now look back on my initial questions: What is PHR? Is it an approach that is feasible in a PhD? And ultimately – is it worth it? I still consider definitions (e.g. (Green and Royal Society of Canada, and BC Consortium for Health Promotion Research 1995), and principles (e.g. (Israel et al. 2017; International Collaboration for Participatory Health Research; (ICPHR) 2013)), but also draw on my own experiences and reflections of PHR in my doctoral studies. At its very core, I would say PHR is about relationships and the process through which we develop and grow them. These relationships are with people who wear many hats, have a breadth of expertise and experiences, have varying levels of power in a given context, and are fundamental to the generation of impactful knowledge. From my experience, it is also these relationships (and their development) that continue to be impeded by traditional academic structures that impose barriers to a deeper and more meaningful collaborative process. However, I am hopeful. I feel if we continue to create spaces such as this for shared reflection and dialogue, we will continue to generate the necessary momentum for institutional change: change that incites accountability to 'talk the talk' and 'walk the walk'; change that ensures we as students do not need to depend on the institutional change-makers and mentors to help us navigate the challenges like those discussed above; change that ensures PHR is not only feasible but promoted. Reflected well by the influential words of Richard Shaull premised on that of Paulo Freire: 'There is no such thing as a neutral educational process. Education either functions as an instrument that is used to facilitate the integration of the younger generation into the logic of the present system and bring about conformity to it, or it becomes the practice of freedom… (Freire 2007, 34).' If we embrace the latter, then yes, it certainly is worth it.

Notes

1. I attempted to work with all of the PPI Ignite@UL partners for the doctoral work, but it proved too challenging due to the varied schedules. To address this, I tried to have such involvement tacked onto the already scheduled PPI Ignite@UL team meetings. However, the time and space provided in these meetings was inadequate, leaving a rushed and thus, surface-level

discussion. Furthermore, capacity had changed for some of the PPI Ignite@UL partners, namely those in the health sector, due to COVID-19.

2. The PhD Research Advisory Group Involvement Overview.

   (1) Agreed that the research aims and questions were of interest and a meaningful pursuit, while also suggesting revisions.
   (2) Ensured all content in the network surveys and interview guide were both accessible to participants and contextually relevant.
   (3) Reviewed and interpreted findings at a high-level from both the quantitative and qualitative phases of the PhD, confirming from their perspective, if they agree with the findings as a partner in the PPI Ignite Network.
   (4) Acted as a soundboard for brainstorming ways to address any research challenges.
   (5) Provided suggestions/feedback for ensuring dissemination materials and outputs (e.g. conference posters and manuscripts), were being communicated effectively for diverse audiences.
   (6) Some of the PhD Research Advisory Group members had co-authorship roles as they were further involved in the development of manuscripts from each phase of the case study (e.g. reviewing and revising manuscript content and language).

3. 2019–2020 was about relationship building, which took place before the genesis of the PhD Research Advisory Group.
4. There was compensation through their involvement with the PPI Ignite@UL grant and the PPI Ignite Network, but not the doctoral work specifically (Scher et al. 2023).

Acknowledgement

I would like to extend a big thank-you and acknowledge the collaborating partners from the PPI Ignite@UL team for their contributions through the PhD. I would also like to acknowledge my supervisory team, as well as members of the national PPI Ignite Network for their support for the doctoral work. I would also like to thank Professor Jon Salsberg for providing comments on drafts.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The work was support by the GEMS10-PhD-2017-001 scholarship from the University of Limerick (Ireland), and a scholarship from the Integrated Knowledge Translation Research Network (Canada: CIHR Foundation Grant; FDN #143237).

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