Using PAR to Promote Social Justice for Older People and People with Intellectual Disabilities

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Abstract
Qualitative research methods and participatory action research (PAR) share many intrinsic and complementary qualities. We present two cases, one adopted a broader PAR approach, a health promotion project with men with intellectual disabilities, and the other used participatory methods within a longitudinal qualitative study exploring the benefits of community choir participation. We discuss the nature of the methods adopted and how they helped and hindered both research projects. We conclude that despite some common challenges, qualitative studies can benefit from drawing on PAR principles.

Keywords
community arts, world café, health promotion, creative methods

Participatory action research (PAR) strives to work with communities rather than study them from afar and through this collaboration seek understanding and action (McIntyre, 2007). Qualitative research methods, through text, language, observation, and other various means, have the capacity to embrace the richness of human experience including social context, lived experience, understanding, personal and shared narratives (Willig, 2013). Qualitative methods therefore share many features and aims with PAR. The aim of this article is to illustrate the potential of PAR methods for enhancing the quality and impact of qualitative research.

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We present two case studies, the former is what we would describe as a *purer* example of PAR and the latter an example of how participatory methods can complement, and add richness and validity to traditional qualitative research. Each of these case studies is presented to illustrate both how and why PAR approaches were chosen and what exactly they were (and were not) able to achieve in combination with a qualitative approach.

A Health Promotion Project with Men with Intellectual Disabilities

This first case study aimed to explore the experiences of a group of men with intellectual disabilities in a health promotion project. The research uncovered the ways in which men with intellectual disabilities demonstrated understanding for health promotion using visual methods such as art, drama, sculpture, photography, and poetry. The research originated from a partnership between a museum and a local intellectual disabilities charity in the North West of England, UK, and the project ended with a 6-month community exhibition at the museum (Richards, 2014). Forty-five workshops were developed, one per week over a period of year, with each workshop lasting 3 hr and based at the museum. The group consisted of men over the age of 18 years who lived in the local area, with approximately 15 participants attending each week, with up to 40 men participating in the project at some point. The project was facilitated by MR (second author) in collaboration with the men, an artist and filmmaker (Richards et al., 2018).

Three examples at three stages of the project will be considered here referring to adapted extracts taken from reflective diaries that were developed during the project and presented in a PhD thesis by MR (Richards, 2014). The first example considers the initial enthusiasm and the outlining of roles and positions within the project, whereas the second example will explore one example of the tensions that emerged within the project, and the final example will consider what each stakeholder gained from the project.

Creating the Project

When the project was being created, the enthusiasm of creating a participatory action research project was infectious and fast paced. There was a clear commonality between all stakeholders that working together would provide an empowering project that promoted the voices of people with intellectual disabilities. For example, MR was happy that he was facilitating a project that would help him achieve a PhD, the charity was helping their service users to become actively involved in health promotional activities, the museum was meeting targets that aimed to reach out to marginalized groups in the local community, and the male participants were eager to participate in activities at a museum, where they could learn more and have fun. In addition, MR had previously facilitated similar participatory projects with marginalized groups such as with
young offenders (Kagan et al., 2011; Lawthom et al., 2012), using a range of creative activities through art and sport to challenge the stigmas young people faced who come from poor areas. MR was keen to take his experiences of facilitating creative workshops and to do this with one of the most marginalized groups in society, that being people with intellectual disabilities. Below is an extract of the initial enthusiasm of creating the project, and how the roles of the participants were decided:

I’m really excited about starting this new project at the museum. The more meetings that take place with the museum, the more I feel confident that the start of my PhD is going to be great, in a great setting with plenty of resources at my disposal. At the meeting the other day, the museum asked me and George (a participant within the project) to deliver some training, which I was happy to accept and do, but I emphasised to Janet (worker at the museum) that I want to do this in collaboration with some of the men I had been talking with at the charity like Gareth and Joseph. The training concerned providing information to the charity and museum workers about the best ways to work with people with intellectual disabilities. I am really looking forward to working with these men because they are humorous and creative and really want this new group to work. Additionally, the museum have asked us to complete some risk assessments, and again, I emphasised that the men should be a part of this process and not be the process. Both the museum and the charity seemed happy to accept this, which was a relief, otherwise it would be an awkward start to this new project, and indeed non-participatory. I’m determined to set a tone from the beginning that the men who are going to make this new project happen should be a part of the project in every way.

This extract suggests that there was a real determination to build a project that was empowering and participatory and in full consultation with the men who would participate in the project. The more MR, the men, the museum, and the charity met up and discussed how the project should work, the more MR felt relieved about laying down the foundations to completing a successful PhD, as well as a successful participatory project for a marginalized group. Thus, the process of PAR helped to bring organisations, charities, and marginalized people together, a collaborative effort albeit with the different stakeholders having different reasons for wanting to participate together. From this, it was decided by the organisations that MR would act as leader/facilitator of the project, and for practical reasons, the workshops would take place over the course of the year, every Thursday afternoon at the museum for 3 hr. In general, MR would ask for feedback from the group the previous week about what activities the men would like to do in the next workshop, and then MR would prepare any resources, invitations for special guests, and any administration duties in preparation for the next workshop at the museum. The workshops were mostly based around art activities and debates about key issues that affected their lives. These arts-based activities included using sculpture, writing poetry, taking photographs, and doing some drama work. However, the diary extract also highlights that MR was made the leader by the organizations, and this was never a decision made by the group, ensuring that the creation of
“positions” within participatory action research is difficult because it may mean that certain people/groups within projects have more power over decision-making than other people. This is significant because PAR recognizes that people are social beings, and are not subjects of research but are, and must be, active contributors at all stages of the research process (Kelly, 2005; Reason & Bradbury, 2001). In this project, the aim was to support the participants to engage in meaningful decision-making concerning the development of the project (see Sixsmith et al., 2017), to help achieve the full empowerment of the participants, although this is not always possible, in engaging in social change through building relationships with peers, organizations, and professionals to reflect a diverse, knowledgeable, and skillful group of experts, that being the men in this project (Kagan et al., 2011; Lawthom et al., 2012). Nevertheless, while this project aimed to do that, and everyone involved had the best intentions, it was clear from the outset that the participants were secondary when it came to major decisions, meaning that PAR is an almost impossible process to apply that is completely empowering. If PAR is to be liberating and consciousness-raising for people to reflect on their lives and develop further understanding of the world around them (Burton & Kagan, 2005), it must be through mutual collaboration with the community group and the researcher, to be able to eliminate or make changes happen (Brydon-Miller & Greenwood, 2006).

Developing the Project and Increasing Tensions

While the project involved creative and engaging workshops using visual methods such as photography, art, drama, filming, poetry, and sculpture, and the participants enjoyed and participated in all these activities (see Richards, 2017), there were obvious tensions between the different stakeholders. For example, in one situation it led to one of the men, Winston, being banned for life from the museum:

Winston had become agitated (having been to the dentist earlier in the day) and his carer thought it was best that he was taken away from the group, to another room with the aim to make him feel more relaxed. However, I have just been informed that Winston had assaulted a child who was visiting the museum, leaving a mark on his chest, whilst separated from the rest of the group. I’m not just surprised that this happened, but I’m wondering how the men feel and how Winston is. I can’t help but also feel worried about whether the project will continue now. But I am frustrated that the carer had taken the decision to bring Winston even though he clearly was not happy to be there in the first place. The museum is now suggesting that a barrier should be placed outside the room where we are usually based within the museum, and a note should be placed there to say that groups/the public could not access the men’s group space. I am not too happy with this because it feels like we are re-alienating the men, when the aim of this project was meant to be the opposite and it feels like we have little choice but to go along with this. Winston has now been banned from the museum for life, which is a real shame. Why can’t we work this all out together, and discuss the implications for this for all stakeholders within this
project? Some of the men in the group, however, have said that it was right that he was banned, maybe they feel uncomfortable with Winston, but I think it is harsh on Winston. Winston has not been consulted himself and there has been no acknowledgment from the carer that he made the wrong choices leading to this incident. From my view, the carer had made him participate after Winston had communicated his distress by grinding his teeth and making growling noises. What it means now for Winston is that he isn’t now going to benefit from the experiences of doing this project. I know carers are pressurised and poorly paid, but Winston’s agitated behaviour occurred before he came to the workshop and the obvious decision to me was to protect Winston and keep him away from that workshop that week. There was an assumption that he ‘would be ok’, but he clearly needed support. The other problem I have now is with the project still being fairly new, I’m concerned that the group might be asked to leave. I’m now guessing that there will be tensions between myself, the charity and the museum because there is now an uncertainty whether the project would continue.

The extract indicates that Winston found himself in a situation he should not have been in and was dealt with in an unsympathetic way. Yes, it is wrong for him to hit anyone, but it could also be said that it also was wrong to bring Winston that day, as he was uncomfortable and distressed in the first place. The museum reached the decision to ban Winston from the museum because they had to think about the safety of the public who visited the museum. The charity and MR were then informed, and the men in the group were the last to be informed. This suggests that PAR faces challenges in promoting empowerment within groups from powerful stakeholders, but it also indicates that if PAR is applied more effectively, then Winston and the group of men could have had a more democratic response to the situation, promoting fairness and respect within the project. After all, PAR concerns making time to learn more about the groups you work with and building knowledge about the communities you encounter, but importantly, PAR is about being sensitive to the participants’ agendas (see Greenwood & Levin, 2007), and in this instance, no sensitivity was shown to Winston, or appreciation for the views and opinions of the other participants and stakeholders. With hindsight, the issues with power imbalances and positions of the stakeholders needed to be firmly established at the beginning of the PAR process (Arcidiacono et al., 2017), which may have prevented conflict and misunderstanding of doing participatory research because discussions with the men only took place after the decision had been made. By doing so, the diverse perspectives and principles of the group would be more valued, and the group would be in better position to identify issues and reach solutions as quickly as possible (Rohleder et al., 2018).

Evaluating the Project—How Participatory Was the Project?

Despite the tensions over the course of the project, there were many positive outcomes for the stakeholders involved, including the development of a project that engaged with men who do not leave their homes much. Therefore, within the project,
friendships were developed and peer support was provided relating to the difficult issues they face in life such as abuse and lack of access to health services. In addition, MR went on to complete his PhD, the charity engaged more of their service users within the community, and the museum was able to engage with a local community and display the work of the group in the museum. But did Stephen (a participant) and the other men gain anything by completing the project and exhibition?

Stephen always says to me that he had a great time coming to the project and came to most of the workshops on offer. Stephen was listened to and he developed his confidence by getting involved with different activities, new and old. He was proud that he was able to help create an exhibition and for everyone to see it. He was able to see his work on display and to share his views with the public. Although he only saw it once.

Stephen recalled having a great time being involved with the project and contributing to the development of the community exhibition, which showcased the work of the men over the course of the 45 workshops. He felt proud to have engaged with new and old activities; for example, he had previously not only enjoyed writing poetry and did so in this group but also engaged in sculpture, which he had never done before. But despite his contribution to this exhibition, he only saw it once and other than personal pride being involved with the creation of the exhibition, we cannot be sure whether Stephen had gained much more than this. Overall, the charity, the museum, and MR all gained what they set out to do. We completed the exhibition successfully and gained much from promoting the project and exhibition. As an individual, MR gained the most, and it could be said that Stephen and the men, gained the least. However, the same men kept attending every week, and they clearly had fun and enjoyed participating in different activities. They enjoyed each other’s company and discussed important issues in their lives with each other, something they did not get to do very often because services are not available to do this, or for various reasons they have been unable to access other community projects. However, their time and efforts were restricted when making choices, sharing knowledge at crucial times and participation occurred at different levels, so full participation was rare, meaning that PAR can have its limitations even with the best of efforts, but can be a powerful experience for those involved (Richards, 2016; Richards et al., 2018).

Overall, while PAR can be messy, complex, and act as a disguise for further disempowerment for marginalized groups such as those with intellectual disabilities, PAR can help bring organizations and people together for a common cause to collaborate on making a difference in people’s lives. Additionally, PAR recognizes that all stakeholders in the research process must be active contributors relating to choices and decision-making, to help achieve the full empowerment of the participants engaging in social change. However, for PAR to fully achieve what it aims to do, more emphasis is needed on ensuring that there are no power imbalances, although there are always going to be power imbalances, it is how you deal with them that counts, and that all stakeholders know what their identity and role is within the process, to prevent conflict.
and misunderstanding. If this is achieved, then marginalized groups, such as those with intellectual disabilities, will be able to make more choices, share their expertise and knowledge, and participate fully throughout the PAR process.

**PAR Approaches in Mainstream Contexts**

Crucially, PAR approaches are not limited to research that adopts PAR from conception to dissemination. As discussed, it can be challenging to conduct a truly participatory approach in the purest sense and action researchers often struggle in striving for this. Increasingly, qualitative researchers are recognizing the value that participatory methods can bring to mainstream empirical research design. The world café method is one example of a participatory method that evokes many of the features of a PAR approach. We argue that the incorporation of engaging and empowering research methods into more traditionally designed research can and has strengthened the validity and impact of findings. This incorporation of participatory methods alone cannot transform mainstream research approaches into a PAR approach but participatory methods can provide much value and rigor to qualitative research.

Developed by Brown (2010), the world café is a participatory research method, which aims to bring together communities in conversation. Fundamentally, world café subscribes to the idea that we make meaning through conversations (Aldred, 2009). Brown (2010) described seven integrated world café design features for collective action which she argued work best when used in combination: set the context; create hospitable space; explore questions that matter; encourage everyone’s contribution; connect diverse perspectives; listen together for insights; and share collective discoveries. The subjective is crucial and the world café conversations can be a site of positive social change and are used in increasingly diverse contexts as part of the “participatory turn” in research and policy. World café has helped foster positive social change within a wide variety of community contexts and disciplines. Examples include social work (Fouché & Light, 2011), healthcare (Broom et al., 2013), consumer studies (Ritch & Brennan, 2010), and education (Dawson et al., 2010).

Procedurally, the world café involves a series of participant-led round table “café” like discussions among members of a community. Tables are usually made to look inviting and engaging through use of paper tablecloths which can be annotated, “menus” with the discussion questions on them and flowers, cakes, or decorations. Unlike a focus group, a researcher does not facilitate each world café table discussion though a note taker may be present. Brown (2010) states that the questions should matter. In other words, the community should be interested in the discussion of the research topic from the outset. Note that when adopting a PAR approach, researchers would strive for community involvement in setting the questions for discussion, though a minimum expectation is that the questions are of interest to the community and not simply the research team. There are various means of ensuring questions matter, from consulting with the community to developing questions from data already collected with that particular community.
A World Café to Explore the Benefits of Participation in a Community Choir

To date, world café has been discussed largely as a community development tool or method of appreciative inquiry (Aldred, 2009) used to break tensions in communities through conversation or identify community assets and strengths. We aim to demonstrate world café as a valuable qualitative research tool for use with community groups. In this second case study, world café was employed as part of a community project conducted within a PAR approach. The values and principles of world café were therefore entrenched in the research design and not simply a procedural stage in the research. This phase of the study was assisted by the first author and sought to examine the broad health and well-being benefits of involvement in a community choir in a city in the north of the UK (Lamont et al., 2018). The community choir consisted largely of amateur singers who were adults aged over 50 years, residing in Greater Manchester. The choir would meet for weekly rehearsals and perform to audiences several times per year in and around their host British city. The world café method was introduced in phase two as a means of gaining a sense of the collective benefits of the choir through dialog and shared experiences. PAR is most often conducted with communities as opposed to individuals or crowds of people with no shared sense of self or identity (Murray & Wright-Bevans, 2017). Conversations that matter require groups of people with a shared interest whether that be a geographical community, community of interest, or shared values.

In our case study, three questions were posed to the groups of participants “How do you feel after a choir rehearsal?” “Why do you feel the way you do after singing?” and “What are your hopes for the choir for the future?” Crucially, this final future facing question, enabled us to collectively examine how the choir might be sustained in a way envisioned by the choir members (as opposed to choir leader or council funders). The council funders had fortunately initiated the study, through front line work with some of the choir members. This crucially meant that they had witnessed the beneficial effects of choir and other social activities on these older adults. One goal of the study was therefore to identify what was working and what was not working in terms of the choir as a social project. In line with both good ethical practice and the first world café principle of “setting the context” (Brown, 2010), researchers visited a choir rehearsal to explain the nature of world café and give participants written information sheets. Researchers participated in the rehearsal singing and spoke to many of the choir members one-to-one and in groups. Although a longitudinal study, the research assistants at the rehearsal were new to the project, joining only at this phase. This informal introduction therefore served to build rapport, familiarity, and understanding of the context. Members of the choir offered encouragement to the research assistants about their singing during the rehearsal. This process of reversing the expert-participant dynamic in particular aided rapport building between researchers and the community choir.

The world café took place 2 weeks later, following a choir rehearsal, in the same building. Conducting the research in a familiar space aligned with principles of world
café, in particular, the principle of providing a hospitable space, and also no doubt fostered more open and honest communication. Three researchers and 33 choir members were present for the world café. For the choir members, this was an opportunity to unwind after rehearsal and reflect over lunch (provided through council support).

The preparation of the world café up until this point required extensive logistical effort. Eight tables were arranged, large enough to comfortably sit six to eight participants. Each table was covered with a paper tablecloth, large felt pens, a voice recorder, and potted plant (for decoration). Cakes, biscuits, tea, and coffee were arranged on a side table and researchers assisted with making refreshments as the group arrived from their rehearsal in the room below. Once people were seated with their refreshments, the world café plan was explained to the whole group. Researchers answered participants’ questions and consent forms were read and signed. This necessary and time-consuming process can be challenging as often, and certainly in this case, there is a tension between communicating the nature of the research in a detailed more formal manner in order to comply with university research ethics and also the need to connect ethically on a human level with the community. Having several fully informed researchers present was key to managing this tension. We were able to spend time with those who had questions, gaps in their understanding, wanted to discuss the nature of the research. or simply get to know the research team better before the world café began as not all choir members and research team members had met previously.

As participants are encouraged to move tables through each round of discussion, Brown (2010) recommended that one participant on each table act as a table host with the responsibility for welcoming new participants to the table, explaining any written notes and drawings and providing an overview on what has been discussed so far.

In our world café, each table nominated a host. Each topic of conversation was then introduced to the whole room, with supporting written information on menu cards (“Starter.” “Main Course.” and “Dessert”). The latter detail particularly helped to facilitate engagement of those participants with memory or hearing difficulties, a feature of the community that became known during our attendance at choir rehearsals but was otherwise not apparent. As stated, table discussions involved minimal guidance and facilitation: participants were simply asked to discuss the topic on their table’s “menu” and encouraged to make any notes or drawings they felt were relevant. Each round of discussion lasted approximately 20 min although the exact timing was judged to some extent by the team as the discussions took place. After each round of discussion was called to a close, the participants were invited to move to a different table. Brown (2010) described how participants are asked to move to a table that they have not yet sat at. We were however mindful of participants’ comfort and mobility and offered the opportunity for participants to move tables if they wished.

After all three questions had been discussed through three approximately 20-min rounds, a plenary Town Hall Meeting was held. In a divergence from the traditional world café procedure, the plenary meeting allowed the whole group to hear the collective thoughts and conclusions in relation to the final discussion question (the choir’s hopes for the future), from each table, either from the table host or other willing
volunteer. As many participants had moved around the room between discussions, these democratically produced thoughts and conclusions allowed us to address the principles of listening together and sharing collective discoveries. The first two discussion questions were not fed back through the plenary meeting due to time and energy. The world café lasted a total of 3 hr including lunch, refreshments, and a comfort break. Participants were thanked for their participation. The six audio recordings (one from each table) were later transcribed ready for analysis in tandem with the annotated tablecloths. A discussion of findings can be found in the article which reports the larger study (Lamont et al., 2018) of which this world café was a part. Ultimately, we were able to identify that the benefits of attending the community choir included but also extended beyond the act of singing. This was highly valuable to the community choir as the findings were fed back to the council funders, offering them the empirical (rather than anecdotal) evidence needed to secure future funds for the choir, the rental of their rehearsal space, and salary of their singing leader.

**Strengths and Limitations of World Café as a Qualitative Method**

Our world café took great time and resources to organize. This is in part due to the researchers striving to be embedded in the context, planning and attending rehearsals, and planning the world café in a time and place to suit choir members. Qualitative researchers experienced in mainstream methods such as interviews, focus groups, and participant observation might perceive challenges associated with PAR approaches and participatory methods such as world café to outweigh any possible methodological benefits. The benefits to world café, and indeed PAR methods more broadly, are not solely in the potential for positive action or change (though these are indeed integral). Action researchers undoubtedly strive for action, as is the nature of action research; however, the methodological strengths of participatory methods such as world café are abundant.

We will focus on three particular strengths associated with world café. These are its capacity to capture especially rich data because of greater participant engagement, its high ecological validity, and capacity to capture dialogical processes across larger communities much better than alternative methods such as focus groups. The richness of the resulting data from a world café results from a process of engaging with the community, devising questions that matter, and creating a hospitable environment. Although the importance of rapport is well established and discussed in most introductions to qualitative methods (Willig, 2013), the role of context, environment, and interest in engaging in discussion of the research topic are features that are less explored. Our world café data resulted in meaningful, honest, and emotive evidence in relation to the research question. Participant engagement was crucial to the elicitation of such data.

The second strength we wish to highlight is the high ecological validity that world café methods can elicit. Admittedly, conversations take place in timed rounds for
logistical purposes; however, the nature and style of those conversations are typically more true to the everyday than the typical focus group discussion, which tends to be steered and moderated to a much greater degree. This is not to say that focus groups do not sometimes take place in a more ecologically valid fashion: in a hospitable and familiar environment with refreshments and table decorations. It is however to say that a successful world café demands these features as participant engagement is central to the method. In our case study, the potted plants, food, refreshments, and relaxed table setup facilitated not only a more interesting experience for those involved but also better quality, more ecological data.

Finally, a further methodological strength of the world café is in its dialogical nature. For research where interaction is central to the question addressed, world café methods elicit discussion and debate, free from the restraints that the formality of focus groups can sometimes bring. Our case study was interested in more than the dialogical, however. The capacity to examine group conversation dynamics is undeniable given that the audio recordings capture just that. We are yet to identify any research that has used world café alongside conversation analysis, dialogical analysis, or social representations theory; however our experience of world café would indicate that the method is highly compatible with theoretical approaches that value and draw out interaction.

Some methodological limitations have been alluded to throughout our case study. We draw attention to three in particular. These are: a lack of control; messy data; and logistical challenges. High ecological validity and lack of control frequently go hand in hand and world café methods are no different. In our world café with a community choir, participants hosted round tables and researchers merely kept time and were close by tables to answer any questions if needed. This lack of control will always result in a risk of not answering the questions set out. Messy data are a result of a lack of control. Participants inevitably discuss with a passion, with an interest in a conversational style characterized by lengthy anecdotes and tangents that detract from the research question but serve another purpose, to engage and enjoy an opportunity to be open and unmoderated. Logistically, world cafés are somewhat more challenging to set up and require mutually accessible space and time as well as staff, food, and refreshments. While not all of these resources are available to small-scale research projects such as ours, with the collective efforts of the community this was made more achievable.

Reflecting on the Value of a PAR Approach for Mainstream Qualitative Research

Ultimately, qualitative researchers need to recognize and value participatory methods such as world café for both their capacity for change (in line with PAR) and their methodological validity. To talk openly and reflexively, it initially felt somewhat awkward and uncomfortable, the prospect of selling the value of participatory methods without a PAR approach, almost exploitative. In practice however, any
methods that aim to encourage greater participant involvement and empowerment can enhance both the research quality and impact of the research for the participants.

**Concluding Thoughts**

Our first case study demonstrated how challenging yet rewarding it can be to meaningfully engage participant groups from the outset of a project. Working in collaboration with artists, a filmmaker, and community groups provides scope for all stakeholders to input and gain from participation. Our second case study illustrated the benefits that world café, a participatory method, can bring. Both examples highlight a need for negotiation between researchers and the communities they work with. Both examples also highlight the challenges of working with messy, uncontrolled data; however, ultimately, both examples showcase the positive impact that working with meaningful methods can have on a community and on the quality of the research. We would encourage researchers to embrace PAR approaches and strive to work with communities in all stages of a research project from initial ideas and design through to dissemination. We further hope that we have encouraged traditional qualitative researchers to explore participatory methods even if that be (at least initially) as no more than part of a more traditional research design.

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