

# Exploring Participatory Methodology in the Construction of a Digital Archive on Recovery in Mental Health

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**Abstract:** This paper seeks to reflect upon the questions and tensions that arise from using Participatory Action Research (PAR) in the context of digital archiving. It draws on my experiences of using PAR to build a digital archive in collaboration with a small group of contributors with lived experience of mental health recovery.

It begins with an exploration of PAR in relation to archival discourses around participatory archives drawing out the synergies that exist around the notion of seeking to understand the world by trying to change it. It then seeks to explore the usefulness of the impetus within the methodology to continually question the nature of the collaboration that has been established. It explores how my own reflections on the relationships between myself and my contributors led me to significantly change the structure of our interactions; to enable the contributors to move into the role of strategic decision makers; and in doing so encourage a more balanced distribution of power and control. The paper seeks to reflect on how it is possible to be absorbed in the rhetoric around participation, and yet create approaches that actively curtail the participatory possibilities.

I conclude with a reflection on the value inherent in approaches such as PAR that encourage critical reflection on the developing action within a project. I suggest that it is in raising the tensions and making them explicit, acknowledging and confronting them that the research process is invigorated and the participatory potential can be most effectively realized.

**Keywords:** Participatory Action Research, Mental Health, Recovery, Digital Archives

## Context

This paper draws on a specific localized example of Participatory Action Research (PAR) in order to explore some of the questions and tensions that emerge from taking this particular approach to collection building in an archival context.

The localised example arises from the practical aspects of my PhD research where I am building a digital archive in collaboration with a small group of contributors with lived experience of mental health recovery. The digital archive is powered by Omeka and provides a space for each of the contributors to build a personal narrative of their recovery taking a multimedia approach drawing on text, audio, film, and images. Image 1 shows a work-in-progress section that is being put together by one of the contributors, Dolly Sen, exploring the relationship between humour and pain. Dolly is using examples of her humour at work in the form of images, powerpoint and film as well as pulling in material created by others that comments on the power of her own use of humour. She then draws all this together through her use of explanatory narrative text which contextualizes and frames the records she is using.



**Image 1: A work-in-progress by Dolly Sen exploring the relationship between humour and pain**

The digital archive is being created within the institutional context of the Wellcome Library in London. The Wellcome Library is one of the world's major resources for the study of medical history. It offers a growing collection of material relating to contemporary medicine and biomedical science in society. This includes 9000 manuscripts and over 800 archive collections. The themes of psychiatry, psychoanalysis and psychology are strongly represented within the Wellcome Library's archive collections as a whole.

The Wellcome is hosting the creation of the digital recovery archive and are also willing to take responsibility for its ongoing preservation. The deliberate intention has been to use Participatory Action Research as the framework in which these narratives are created in order to be able to confront and explore the implications of doing so.

### **What does participatory mean in an archival context?**

In this paper I intend to provide an introduction to PAR as a specific social research methodology before critically reflecting on my own use of it in the context of the mental health recovery archive. However, for context, I will briefly explore three different ways in which I see the term 'participatory' being framed within our field.

The first way in which we have defined what being 'participatory' is in an archival context is to examine it from a relational perspective, framing a 'participatory approach' in terms of a renegotiation of roles. In this context a 'participatory approach' is one which changes the traditional boundary between the 'professional archivist' and 'other stakeholders' with the hope of a 'democratization' that will dissolve the professional distinction. Here, 'shared authority' *between* 'professional' and 'other' becomes one of the driving aspirations.

A second way in which we have explored what a 'participatory archive' can be, focuses on the nature of the content and products that the participatory approach can generate. Here participation becomes a *process* used to reveal and explore multiple pathways, understandings and contextualities in keeping with our newly found post-modern and constructivist understandings of provenance, context and the active nature of archives.

A third way of framing the 'participatory' focuses in on the *transformatory* potential of the approach. It is different to the other two ways of framing the 'participatory' because it begins

with defining an injustice or social problem that ‘participation’ is specifically designed to address and change. This framing of the ‘participatory archive’ is illustrated in Shilton and Srinivasen’s exploration of ‘Participatory Appraisal and Arrangement for Multicultural Archival Collections’ (2007). Here, the uneven balance of power and control between mainstream and marginalized is the injustice in which the ‘participatory approach’ locates itself and which it seeks to transform. In a similar vein, there are now a growing number of archival endeavours framed around diverse social justice agendas, where a participatory or collaborative approach is used to bring about or advocate for transformation and change.

This third way, which roots the participatory approach into a specified injustice with the intention that the approach will change the status quo aligns most closely to the ideology and methods promoted within Participatory Action Research.

## What is Participatory Action Research (PAR)?

PAR ‘seeks to understand the world by trying to change it’ (Wikipedia, 2013). It is rooted in exploring a social problem, issue or injustice with the view to transforming the situation under scrutiny for the better. This strong ideological starting point forms the basis for an approach which is grounded in experience and is action orientated and that is underpinned by two key concepts; *reflection* and *collaboration*; and I will briefly look at these in turn.

Within PAR, the action which seeks to bring about the desired change is always balanced by reflection. Usually, this takes the form of iterative cycles of planning, action, and reflection which continually feed into each other (Muir, 2007). The methodology demands that those involved open themselves and the process up to continual questioning so that the actions are as far as possible informed actions. This encourages a transparent and open process where constraints and boundaries are explicitly acknowledged.

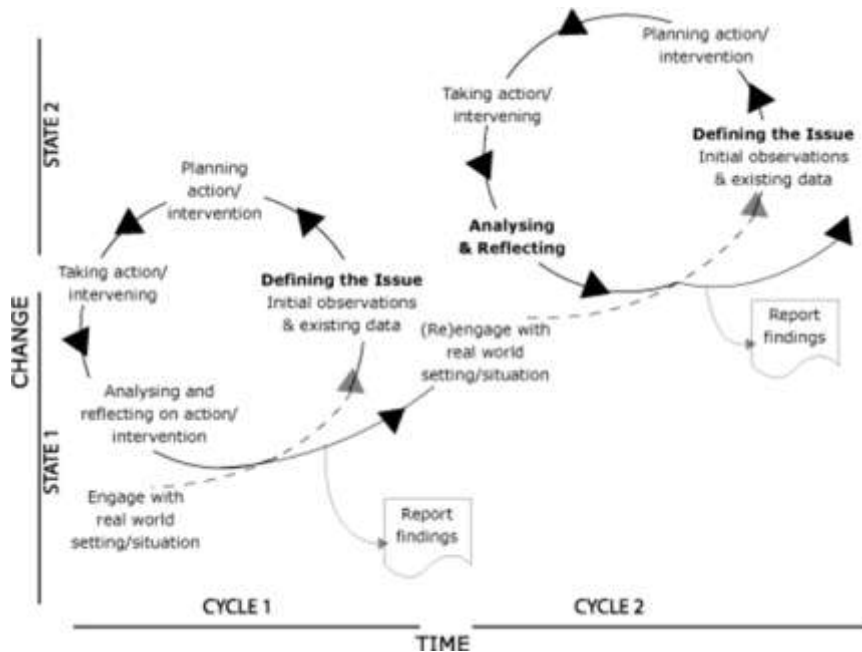


Figure 1: A model of Action Research (Muir, 2007)

Linked to this commitment to reflection is an understanding that the nature of the *collaboration* between the participants should be fully acknowledged and explored. Three considerations in relation to *collaboration* come under active and continued scrutiny within a PAR framework. The first is a consideration of who is included in the collaboration: who is in and who is out? And the implications this has on what can be achieved through the change process. Who can benefit from it? And who could even lose out because of it? The second is

a consideration of the relationship between participants and the balance of power and control within the participating group and their wider communities. The third is a consideration of the participants' involvement that assesses the degree of freedom for the participants to shape and push the boundaries of the project itself, to become active decision makers and controllers of the aims, objectives and outcomes. This also includes a consideration of the degree to which the project is or can become self-mobilized and self-sustaining.

## **Reflections on using PAR in the context of building the digital mental health recovery archive**

In using PAR as a methodology for building the mental health recovery archive the first, and most fundamental, question is whether my intentions and purposes align with PAR's strong ideological stance. Does my intention align with the notion of 'seeking to understand the world by trying to change it'? And is there an underlying social issue that I am seeking to address and transform?

The answers are more complicated than it might first appear. On the surface I can easily point to the ongoing research that I am conducting into representation of voice within the Wellcome Library's archives and manuscripts, which collectively tell the story of mental health. Through this research I am revealing a bias towards the voice of the professional expert within those collections as opposed to the voice of the individual with lived experience. I am exploring how recent socio-historical shifts in favour of better recognition on the autonomy of the mental health patient and the value of the knowledge contained within patient experience is not yet adequately reflected through the archive's more contemporary incoming collections. In this context, actively seeking to build a collection around the narrative of the individual with lived experience is a political act aimed at redressing the socio-historical balance of voice, as well as seeking to point to the equal value of the experiential knowledge of the individual alongside that of the mental health professional.

However, I must acknowledge the tension that is created by the fact that the participatory digital archive that I am creating is motivated by my desire to explore participatory approaches to archives for the purpose of my PhD. It is therefore, a contrived practice, instigated *first and foremost* out of an academic research agenda which engulfs any other motivations that there may or may not be behind the participation. This is something that I have had to spend time reflecting on, maintaining transparency with the participants about the academic frames that sit around what we are doing and honesty about my own motivations have been important ethical considerations for me.

The strong impetus within PAR to continually question the nature of the collaboration also raises questions for me. I am working with a group of four individual contributors. I established a relationship with Professor Jerome Carson, a former clinical psychologist who has co-edited books on service user stories of recovery, and he put me in touch with the four individuals I am now working with. Why choose them? And having chosen them how does that influence what is produced? This question can be approached from many angles, one of which is that the four contributors I am working with have found places from which to speak already, either through taking advantage of opportunities offered by others or through using their own initiative. They have websites, have written blogs, have produced films and published books in the past detailing aspects of their experiences. There are plenty of other individuals with lived experience who haven't been offered or been able to create the same platforms from which to speak. So in many ways I have to confront the question does the digital archive, simply re-enforce an existing power dynamic within society rather than challenging one?

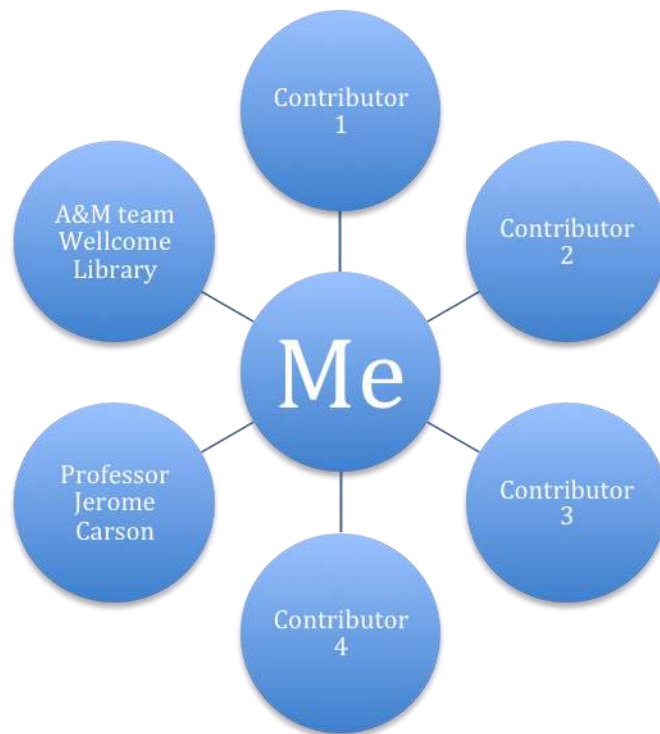
There is also a tension around the nature of the three-way relationship between me as the researcher, the four contributors, and the Wellcome Library as the host institution. There is the fact that the participatory practice is about bringing the archives of the individuals I am working with into the mainstream. How can this be achieved in such a way that avoids commodification of the stories? There isn't a self-mobilized element to the digital archive,

this isn't akin to a grass roots endeavour and there isn't any real scope for the digital archive to become self-sustaining. I find I am continually seeking to balance the sometimes competing intentions and approaches that exist between me, the contributors and the Wellcome Library as the institutional host – where does the balance of control in fact lie? PAR forces me to make these tensions explicit and continually reflect on these as an essential part of the process.

Here, I have brushed the surface of my ongoing reflections about using PAR. In sharing a few of the tensions with you it may sound like I feel negatively about the process; it is in fact the opposite. Raising the tensions and making them explicit invigorates the research.

I will finish by giving a concrete example of how the iterative process of planning, reflection and action running through PAR has helped me to positively shape the ongoing development of the digital archive.

Initially when establishing the digital archive, I met and worked with each of the four contributors on a one to one basis. In the early stages of the project this has many advantages. Over a period of six months, I was able to establish a relationship of trust with each individual and by the end of this time I was confident that I had their *informed* consent to being involved in the creation of the digital archive. Once they were up and running on Omeka, I started to reflect more deeply on the nature of the relational working structure that had been created and the balance of power entailed within it. Figure 3 represents this relational working structure diagrammatically in order to help make the issue under discussion clear.



**Figure 2: The initial relational working structure for the mental health recovery archive**

I realised that even though I could legitimately claim that the one to one relationship established between me and each contributor was a genuinely two way process through which we shaped and mediated each others understandings; the overall structure of the system meant that I was undeniably in the position of authority and control and that this had occurred because I had (somewhat unconsciously at the time) shut off the possibility of interaction *between* the contributors and the institutional host.

As part of my literature review I have drilled into a branch of action research known as action science, developed by Argyris and Schon (1974; 1985; 1996) which has resonance here. Argyris and Schon point to a gap that can appear in relational social practice where an individual espouses participation and openness, while simultaneously (and unconsciously) undermining possibilities for participation and openness in their actual dealings with others. The gap is therefore between the *espoused theory* towards participation and actual *theory in use*.

I find a specific connection with this in relation to my own research and practice. Clearly, there was an emergence of a gap in my own practice between what I was *espousing* to be my approach and the actual approach that had emerged *in use*.

Several factors influenced my conscious decision to shift the centrality away from myself. Firstly, I wanted to explore *participatory* processes and I had a growing unease that what I had in fact set up (with myself at the center) could not be evaluated as *participatory* but there was also other pragmatic reasons for seeking a shift in approach.

Through my one to one meetings with the contributors I had begun to appreciate that for several of the contributors, the primary purpose in telling their recovery story is to address societal stigma and negative attitudes towards mental health *through* the promotion of a positive representation of those who are personally dealing with mental health issues; so that they are valued and respected within society; and given equal opportunity to influence how mental health is perceived and addressed within our culture.

I became very aware that if the recovery archive was going to deliver on this purpose it would need to deliver a quality end product that would encourage its users to place a high value on its contents and all of the contributor's stories needed to be presented to a similarly high standard. Each contributor's one story is not a stand-alone autonomous entity it is *in relationship* to the other stories. Therefore there is an *inherent* collectivity to the recovery archive that should be reflected in how the relationships between stakeholders are established and developed; and how decision-making within those relationships is then undertaken. The current structure was not fit for purpose either in meeting my aims of exploring *participatory* approaches; or in meeting the individual aims being set by the contributors themselves. If the aims of the contributors were to be met; the opportunity to explore issues such as the quality of the end product, would need to be provided.

These realisations led me to contact each of the contributors to see if they would be happy in a shift in approach where I continued to work on a one to one basis with each of them; but where we also established a collective way of working where we would meet in order to make decisions on strategic ways forward. This was a pivotal moment in the research process. All four contributors agreed to be involved collectively and strategically. At this stage, I also sought participation from the A&M team at the Wellcome Library, and Professor Jerome Carson.

We have now established an ongoing series of collaborative workshops in which strategic decisions are taken collectively and as you can imagine this brings with it a whole new set of tensions and issues around authority and control that we can now confront and work through.

To draw this paper to a close I will re-iterate the statement I previously made in relation to Participatory Action Research. I am deeply appreciative of the fact that this methodology forces me to continually reflect on the action in an iterative cycle because in raising the tensions and making them explicit, acknowledging and confronting them the research process is invigorated.

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