Chapter title: More Voice, Less Ventriloquism: building a mental health recovery archive

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The mental health recovery archive[1] has been created in the context of Anna's PhD work to explore participatory approaches to building archives. The archive was built in response to the Wellcome Library's[2] existing archive and manuscript collections around mental health, which predominantly tell the story from the point of view of the asylum; the medical professional; the psychiatrist and the psychoanalyst. Within the existing archive collections, case notes of individuals enable us to gaze in at the patients within the system picking up details about pervading views on behaviour and treatment. However, what we can see, know, and construct about this past begins with us gazing through a heavily filtered lens controlled by those with power over the patient. Occasionally within case notes there are offerings penned in the hand of the patient, such as outgoing letters to family members or surviving examples of creative acts but these always and only have a place in the case notes because someone other than the patient has decided to keep them and place them in the surviving record. The mental health recovery archive was created in response to this. It aims to show that individuals with lived experience can tell their stories, valued as having permanent significance alongside the stories told by the system, the institution and the medical professional, open now for anyone and everyone to explore. The archive is based around the narratives of Anna Sexton, Dolly Sen, Stuart Baker-Brown, Andrew Voyce and Peter Bullimore. Anna came to the project as an archivist and PhD researcher interested in disrupting the power relations which can sit within and around archives. It was the relationships between Anna, Stuart, Dolly, Peter and Andrew that built the archive.

I couldn't leave survivor voices in the minority - Dolly

I hadn't worked on an archive before and I didn't really know what it entailed. But seeing it as a new, interesting experience, agreed to take part. When I heard how little survivor narrative and experience was kept in the mental health archives (only 7% found at the beginning of the project), I knew I couldn't leave those voices in the minority.

Archives show who has the power in a given section of society charting this through history - archives give a time and place its life. Apart from the lack of authentic voice, the representation of mental health, for instance in patient notes, do not give a person their life or voice, or their truth. It is a bit like lions representing bird song in roars. Why should the hunters give the hunted's history? Why should the people who've never visited a land be that country's prime historians? How can you arrive at truth when there is such imbalance of power, where there is censorship by

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[1] http://www.mentalhealthrevoery.omeka.net
[2] http://wellcomelibrary.org

omission or invalidation, where our words are seen as sickness? Who gets to speak in history, and who is listened to?

I realized I couldn't complain that the voices of survivors or people who have used mental health services aren't there if I am not willing to speak up myself.

What was valuable about the experience was the telling of my story. I haven't told my story yet in psychiatry. Mental health services read their script, I read my script, and nothing of any deep meaning is ever exchanged. Professionals may know the mountains, their climate, but they have ever climbed them? They might know what goes into the poisoned fruit of medication, but they have never eaten it. They might even know its language, but they will always speak with an accent, and lose so much in translation. They give observable data of an unobservable world. They objectify subjective experience and then wonder why there is a clash of mental and emotional cultures. Psychiatry has to rewrite and revise itself. Its story has hurt too many people, it needs to rewrite its script, and stop writing crappy sequels.

Psychiatry is not a mechanism that purports to relieve mental distress, it polices what is socially sanctioned behaviour, and one of the things it gives the people that goes through its system is a deep sense of shame that they were disgusting enough to be sensitive to trauma or the brutalisation of their situation in life. Anna had no such agenda. She wanted to hear my story without bringing shame or pathology into the equation.

Why does it need an archive initiated by somebody who has no mental health training for me to tell my truth? Truth is not sanity, truth is not in my medical notes. Truth is what I was able to tell Anna without it being undermined.

Anna was not an expert in the disempowering sense of the term, but professional in the sense that she knew about archives. She did what very few professionals do in mental health, she shared her life with me, in talking about her family for example. She also did something that allowed trust and authentic disclosure: she made me the mental health expert and the voice of my story, whilst offering support and guidance in the archival process. There was nothing to tell me that my guard should go up. From the start it was an open, fluid relationship.

What does it mean to work in partnership?

It was a true partnership because it was two people coming with different expertise to create something dynamic, new, and unique.

Anna and I shared a professional relationship but there were not the boundaries that are evident in working with mental health professionals, when you have to entertain risk assessments and guard against personal connection. Anna didn't have that baggage, she saw me as her equal. I didn't censor myself with Anna, she had the whole of me, and not some barely perceptible human being around the label some clinicians see you as.

Working with someone with little preconception as to how to work with survivors except to come to it from a position of empathy and intelligence was so palpable, I see that as a necessary precondition. Her approach was: what works for you? How shall we work when things get difficult?

25 years in the mental health system and this is still one of the first times that someone has asked me about my story. When you are in that relationship with a doctor or a psychiatric nurse they already have their own idea of what your distress is about, they don't ask you to know you. They look for the symptoms that is in their little book and that is how they make sense of your world and your distress. I think it would be more powerful if they asked what has made you distressed now? Is there something that has made you the way you are today? And that would give you a chance to say, actually yes, I know what has caused my distress, to me it is very obvious. Why couldn't I say that in psychiatry or the mental health system? Why does it have to be an archivist, with no clinical experience to ask that question? I saw the archive as a place for creative expression but I also saw it in a political context as well, to ask and challenge the system with: why aren't you doing this? Why haven't you done this for me?

My criticism of services wasn't seen as a personality disorder, my fear and mistrust of society's perception of mental distress wasn't part of paranoia, my sadness wasn't a sign of depression, my anger wasn't a sign of schizophrenia, my joy not a sign of mania. The emotions were seen as human and an appropriate response to experiences. It seems the only expectation this non-medical non-survivor has of you is to be a human. There are no symptoms, only difficulties, which can be discussed and negotiated and usually handled with compassion. My words and experience were meaningful to Anna.   What made it feel like a genuine partnership was that we shared in the proper sense of the word: ideas, thoughts, experiences, emotions, fun and work.

There was some imbalance of control. Anna got a bursary to work on her PhD; we got expenses. She framed the archive into being about recovery. So we didn't have complete choice in what the archive should be about; this was due to time constraints on all sides. But whatever the subject is, we can position ourselves to tell our truth.

The crux of why I did it is that in one hundred years time people won't get a whitewashed version of what it is like to be someone like me. They will get a truthful account, one that has both criticism and also hope. That was quite a hard balancing act. I want my story to be one of many as to why the current mental health system needs to change. And a voice and story without equality is an act of ventriloquism that can never be as beautiful as one with.

Blank canvas vs realisable venture

The mental health recovery archive aims to contest power relations running through the construction of records. It aims to challenge the status quo in relation to who

gets to create the types of records that are subsequently held up by society as significant and worthy of on-going preservation. I will try and unravel the complexity around the extent to which I feel we achieved these aims.

In short, I believe we pushed successfully on some boundaries, but we didn't fully disrupt ingrained power relations. Part of this felt beyond our control -constraints pushing in on us shaping what we could do, and unequal starting positions ingrained within broader societal systems. However, although at times I felt 'powerless' to do anything more than point the finger at the unequal balance between me and the participants, there were also times when I was perhaps 'powerful' and missed the opportunity to adequately share control. At times I was too quick to close down the doors of joint exploration, hurrying through the initial stages of the project to turn the blank canvas into a realisable venture. Reflecting back, I can see at least two points within the project which had what I will call 'participatory potential' where I could have invited the participants more fully into the process of shaping project outcomes but instead maintained (an unnecessary?) boundary between our roles. The first was in shaping ideas around what the 'archive' should be, and the second was in choosing 'recovery' as the theme for the personal narratives.

As an archivist, I have had a long relationship with this construct called an 'archive'. I was taught to perceive it with an organisational/administrative bias through my professional training. This view has been challenged from within my field through discourse that emphasizes archives can also be sites of 'evidence of me' (McKemmish, 1996) sites where personal and collective memory can be made and re-made. I was therefore keen to explore the 'archive' as personal narrative and I took this vision to the participants. This formed the basis of what we then went on to construct. What if instead of giving them my vision, I had initiated a two-way conversation? What might an archive reflecting Dolly, Andrew, Peter and Stuart have looked like if instigated from a blanker canvas? The decision that I made in shaping the project that troubles me the most is in suggesting to the participants that we use 'recovery' as the overarching theme for their personal narratives. My degree of influence here is difficult to disentangle. In making the suggestion, I was undoubtedly influenced by the recovery narratives that I had read where the term was framed positively as a concept that was being co-constructed by survivors and mental health professionals. I now have a more nuanced perspective on what 'recovery' represents as an ideology and as a system and in fact part of the backlash against recovery has evolved alongside the construction of the mental health recovery archive. Dolly, Andrew, Stuart and Peter recognized the potential within it to carry and give hope but they also recognized the potential for it to be used as a form of control. We agreed collectively that their narratives would be critically reflective about the concept of 'recovery' questioning it and challenging the way it is used (and abused) by the mental health system. That critical reflection is apparent when reading the narratives, but I am now aware that in using the frame 'recovery' we have potentially alienated those who have painful associations with the term (because of the ways in which it has been applied in mental health service provision). My regret is missing the opportunity to leave the frame of the archive open, as something that would emerge *through* Dolly, Peter, Andrew and Stuart's narratives. I wanted to get something solid in place for us to work around and in, but

if I could go back to the beginning, I wouldn't be so afraid of openness and a seeming lack of structure in the early phases of the project. I would go with the fluidity and trust that the doors would find their points of closure without being forced heavy-handedly. It has been a steep learning curve for me, lessons that I will take into future participatory work.

Part of the complexity in seeking to take a participatory approach to constructing an archive is the rhetoric around transformative participation. I have wanted to foster relational working that enables co-construction and a shared authority. The threads of power and control running through this type of work are a far more complex entanglement than simplistic mantras of 'give your control away' suggest. Co-construction can never erase all the differences between us but it does need to start by acknowledging those differences whether those are in expertise, experience, degrees of influence, or access to resources, recognizing that who holds the expertise and the degree of influence varies depending on context. It is about using these differences positively as constructive forces where possible, while also recognizing that at times the imbalances are negatives that should not be upheld but challenged and transformed through the co-working process. Discerning when an imbalance is negative rather than positive and then attempting to redress the power dynamic is a difficult process. In part I think success rests on the solidity of the underpinning relationships between the participants.

One area of imbalance that needs to be acknowledged relates to the gulf in access to resources. As the PhD researcher I came into the project with a bursary from the Arts and Humanities Research Board (AHRC) and the expectation was that Dolly, Andrew, Stuart, and Peter should give their expertise with no payment other than for expenses. This is in itself deeply unfair. However, the material divide on access to resource continues beyond the construction of the mental health recovery archive and into our dissemination activities. I have been able to access academic funds to travel internationally to deliver conference papers about the mental health recovery archive, but there is no provision to take any participants as co-presenters. This problem is bigger and more systemic than the mental health recovery archive. If academia wants to take participatory research seriously, then these divides need to be addressed and those of us who sit on the inside of academia need to be vocal about the need for change.

What does it mean to work in partnership?

In working on the mental health recovery archive I had the privilege to get to know four people who I feel I have shared (in different ways) a genuine connection with. I really like Dolly, Stuart, Andrew and Peter and I felt their warmth and acceptance from the very start. At times we worked collectively as a group, particularly when we were gearing up to launch the archive, but I also got to spend time with them individually and establishing one to one relationships was a vital part of the process.

From the start I have been aware that I am asking Dolly, Andrew, Stuart and Peter to publish their personal narratives in the online archive for all to see; I don't take that

lightly. If I am expecting them to share their lives and history with me and with others then it cannot possibly resemble an equal process unless I am willing to open myself up in a similar way both to them and others. I have deliberately pushed on the professional/personal boundary within this project. In my relationship with each of the participants, little by little I have been open about my past and present, everything that shapes who I am. Of course relationships take time to develop, and the degree of openness has been in response to the unfolding dynamic of trust between us, something which has been carefully weighed up and not naively assumed. I believe that my separation from the mental health system has enabled me to take this approach.

As well as opening up individually to the four participants, I took what I see as the more difficult decision to make myself, and aspects of my personal history, visible within the archive in a section where I talk about myself. I describe what has led me to want to be involved in the construction of the archive and aspects of my personal story that have an impact and a bearing in this context. This is because, firstly, I wanted to embed myself in the archive so that those who come to browse through Dolly, Andrew, Stuart and Peter's story can make an informed judgement on the degree to which it really is (as it set out to be) their story on their own terms, and the degree to which I am present as a co-constructer and shaper of the archive. Secondly, I have sought to make myself visible because I needed to experience something of what it is like to open yourself up to the public gaze, to make yourself vulnerable to the judgements of others on personal aspects of your story. If I expect Dolly, Andrew, Peter and Stuart to do this then I should be prepared to go through the same. I found it an uncomfortable and unsettling process and it taught me a great deal about the costs of making your personal history public from a contributor perspective. It has reinforced and underscored the deep respect I have for Dolly, Andrew, Peter and Stuart who continually put themselves and their experiences out there in differing forms. I hope that in a small way what we have created in the mental health recovery archive can add to the agenda for transformation across archives and mental health. In both contexts the stories of individuals with lived experience need to be heard in ways that as far as possible enable them to be the ones to shape the representation of themselves.

Possibilities in survivor/non survivor research

In many ways the 'survivor'/'non survivor' distinction between us was useful and constructive in enabling co-productive research. It meant that Dolly and the other participants were entirely and rightly the experts in relation to both their own experience and in relation to mental health contexts more broadly. The participants have shaped what Anna has learnt about mental health; she came with very little prior knowledge. The psychiatric labels that the participants carried were only vaguely familiar to her and she decided to only read survivor initiated (or co-produced) literature alongside listening to Peter, Dolly, Andrew and Stuart to shape her understandings.   Having not experienced anything similar, and being unconnected to the mental health system, meant that Dolly and the participants necessarily acted as Anna's guide.

The 'survivor'/'non survivor' distinction became more palpable, and for Anna more uncomfortable, during the dissemination phase of the project at the launch and at conferences and meetings particularly where survivors have been assessing the validity of the archive from their perspective. Anna's impression is that legitimacy for 'survivor/non survivor' collaborations is (understandably) not easily given. The starting point feels like it is 'what right have you as a non survivor to encroach on this ground?' Although it made Anna feel uncomfortable, that question is valid and important; trust has to be earned and it is particularly difficult for it to develop when there is the weight of past injustices and power imbalances. Imbalances which continue to inform the present.

Opening the archive up for comment from archivists, survivors, non survivors and others has been a useful process. In relation to reactions from survivors, most have been positive. Some comments and questions have prompted us to critically reflect back on the archive. Some have voiced concerns that removing an individual's story from the collective history of the survivor movement is a weakness of the project and is potentially disempowering for the survivor movement itself. This raises questions around whether it is legitimate to take a life history approach that is individualistic than collective in its starting point. Whilst it is vital to be aware and wary of the potential for the archive to disempower, our justification is that all starting points have strengths and weakness: in a collective there is a danger that the individual is lost; with an individual approach there is a danger that the collective (and its power) is dissolved. It seems that perhaps both are necessary and legitimate approaches that answer different needs.

Should survivors only undertake survivor history and survivor research? In circling around this issue it is reminiscent of the broader debates within the field of archives around independently formed grass roots community archives, which often grow in response to marginalizations and gaps in the records held by mainstream archival institutions (Gilliland & Flinn, 2013). Some community archivists opt to maintain and defend their boundaries: their power and legitimacy is gained from their distance from the mainstream. Others have opted to seek out collaborative relationships, sharing expertise and resources. This is most successful when a genuine 'shared authority' is sought on both sides with the community maintaining the right to contribute to steering the archive in relation to processes such as development, preservation and access. Rather than labelling one approach as 'right' and one approach as 'wrong', it is perhaps more helpful to evaluate each approach in terms of its opportunities and threats. Critically reflecting upon these is part and parcel of the process of history making.

References

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