Working Knowledge

Engaging Others

Engagement, experience and power: Working with an advisory group

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Engagement, experience, and power: Working with an advisory group

Working with an advisory group is common in large collective projects, especially those with a focus on interventions or implementation. It is less common in smaller, doctoral research projects, particularly within literary studies or the humanities more broadly. This Project Short reflects on my experience working with an advisory group throughout my PhD project, which researched fictional representations of self-harm. It explores some of the challenges I encountered, how I navigated making complex decisions, and how working with the group shaped my research.

Why work with an advisory group?

While the idea for a research project exploring self-harm in fiction originally emerged from my own experiences of self-harm, I was very aware that my personal experience could not and should not be taken as representative of the broader category of 'experiences of self-harm.' It therefore seemed important to work collaboratively with other individuals with experience of self-harm to form an advisory group for the project. Moreover, when I began my PhD, I was interested in the way that it often felt that self-harm was a topic and an experience that people drew back from, that they avoided, or weren't sure how to engage with. I wanted to think about why this was, but I also wanted to work in a way that didn't replicate this dynamic: **instead of treading gingerly around the edges of self-harm, I wanted to centre it**, to be close to it. And I wondered whether through doing this, through being close to self-harm, through making it integral to every part of the project, I might be able to find ways to care for and about self-harm, and for people who self-harm or who have self-harmed. One of the ways I did this was by working with an advisory group. This was a little unusual within literary studies and within academic research about fiction (for instance books, films, and TV shows), but I drew on expertise from other disciplines, where working in partnership and collaboration is more common and has a long history.

The Advisory Group

The Advisory Group were recruited through social media, via advertisements on X (formerly Twitter) and Facebook. Its members included:

- **Sarah-Jayne Hartley** – *a CBT Therapist working for the NHS and in private practice, with an interest in self harm and the cultural contexts it presents in*

- **Ashley** – *who has lived experience of self-harming as a teenager and adult, and works as a mental health nurse*

- **Eleanor Higgins** – *a therapist who has personal acquaintance with the area of self-harm and who would like to see the end of crude pathologisations and lazy formulations that seek to offer a short-hand instead of nuanced provisional understandings of what might be happening for people who make use of self-harm*

- **Naomi Salisbury** – *who leads a major self-harm charity*

All members of the Advisory Group contributed to this article, sometimes through our shared reflections, and sometimes through directly attributed writing. Some chose to use their own name, others chose or were assigned a pseudonym.

Approaches to collaboration in research

Patient and Public Involvement in health research emerged out of the Disability Rights movement, wherein patients and activists campaigned around the slogan **'nothing about us without us'** (Charlton). The movement emphases people's right to have influence and even control over decisions about healthcare and commissioning which so greatly impacted their lives. Similarly, participatory research emerged from International Development Studies and criticism of the way that scholars from the global north carried out research and interventions intended to 'transform' the societies and economies of the global south often in ways that simply replicated dynamics of colonialism and imperialism. Participatory research questions who is assumed to have knowledge and expertise and uses a range of methods to enable more equitable collaboration within research.

These varied approaches seem to me to be drawn together by a shared attempt to find better ways of being caring and careful within research. They include attention to the ways that research has harmed communities in the past, to the ways that people without whom research would not exist are often excluded from its benefits, to the ways that certain knowledges or ways of knowing are deemed superior, and others deemed illegitimate. Working in this way involves paying attention to who research really benefits, and to the way that hierarches of gender, race, class, and disability impact who has power within research, and whose knowledge and expertise is treated as credible. This doesn't mean that these approaches are perfect or have all the answers – they have been criticised for, for instance, failing to pay attention to hierarchies within communities, or for including people but only in limited ways, turning collaboration into a box-ticking exercise (Madden and Speed 2017,

> *Working in this way involves paying attention to who research really benefits, and to the way that hierarches of gender, race, class, and disability impact who has power within research, and whose knowledge and expertise is treated as credible.*

Martin, Carter, and Dent 2018). I drew on these traditions and histories when setting up the advisory group for my PhD project, trying to be mindful of both the good practice they documented and the limitations they might have.

Challenges and limitations

i) External constraints

Key aims of participatory or co-produced approaches to research often include **total power-sharing** in decision-making, **equal participation** in the research process, and **mutual benefit** from the research outcomes. I thought a lot about how these might be achieved, but often found that the nature and circumstances of my PhD made it difficult. For instance:

- The PhD was time-bounded – I only had funding for 3 years, and had to complete the project within that time
- I had secured funding through a detailed research proposal that I created before I set up my advisory group
- The PhD had to result in an academic thesis which met the requirements of an English Literature department
- The PhD had to be sole-authored – it needed to be entirely my own work

These circumstances impacted what level of involvement or shared control was practically possible, or indeed desirable. I was paid to work full-time on the PhD, and I enjoy academic work; members of the advisory group had full-time jobs and many other priorities. I tried to balance my desire for members of the advisory group to be able to contribute to decision-making and to the project as a whole in whatever way they felt comfortable, with an attempt to prevent the research from becoming an unsought burden to them. This was a complex balance to maintain. Although I am far from certain that I succeeded, I received positive feedback from group members. For example, Ashley commented: "From my experience I think you did this very well - I never felt pressured or that too much of my time was taken up."

ii) 1:1 meetings – uncertain implications

My own decisions also impacted how power and control functioned within the project. Most significantly, I chose to hold **one-to-one meetings** with each of the four members rather than meeting, as is more typical, collectively as a group. This

was primarily motivated by my concern that members might have very different experiences of and perspectives on self-harm; I worried that conversations might inadvertently become not just uncomfortable but potentially harmful, not because of any ill intent but because I was unable to effectively manage the group dynamics and the direction or boundaries of the conversation. It was my first time conducting such meetings and facilitating conversations about self-harm. I was aware that this lack of experience might put others at risk or might limit my ability to ensure that each individual felt heard and respected. In several ways this decision made participation in the group more convenient: meeting with each person individually meant that we could arrange a time that was easy for them, often at very different times or days of the week. It also meant that I could meet each member at the place that worked best for them, travelling to where each member lived. Meeting collectively would either have meant we were limited to meeting digitally or that several members would have to travel long distances each time.

However, this also limited the extent to which decisions made as a result of advisory group meetings can be described as collective or mutual. Rather than discussing opinions on a particular topic and then coming to a joint agreement, individual members discussed their perspectives with me and I then decided how to proceed. This granted me a greater role and influence in mediating between different perspectives and in making the final decision. In practice this usually meant that, rather than balancing different priorities, I found myself collating different, complementary suggestions and acting on all of them. I cannot recall an occasion in which the recommendations of different members were in direct conflict. Nevertheless, some avenues of either agreement or disagreement might have developed in ways that were vital and constructive had we met collectively. Meeting members individually also meant that I retained more control over each interaction than I might have done had we met as a group and I had been, as the sole researcher, in the minority. It is not easy to assess how well I balanced the responsibility I had to ensure the wellbeing and safety of members of the advisory group, with the responsibility I had to enable shared decision-making and collaboration.

Similarly, although I tried to make sure that there were time and space for broad dialogue and the articulation of concerns, I tended to come to each meeting prepared with particular areas of discussion or with questions about which I asked advice. These areas were often not completely open-ended – sometimes I presented different options or solutions to a problem and asked which direction to follow, at other times I brought work which I'd already done and asked for feedback. This certainly might have impacted the extent of the influence which advisory group members felt able to exert on the project; although in discussions with Ashley she mentioned that in fact she found this helpful, demonstrating that I wasn't simply relying on them to solve problems for me, but that I was willing to try to find ways forward myself while still valuing their advice and expertise.

What worked well

Other practical aspects of the arrangements around the advisory group hopefully also contributed to members' ability to feel comfortable participating in the project. These practices were all drawn from established good practice within participatory or co-produced research.

1. All participants were paid for their time at a rate equal to that of my own most recent hourly employment. This made explicit the equal value which was placed on all of our contributions.
2. I tried to check in with all participants both prior to and following our meetings to make sure they felt able to raise any concerns or difficulties.
3. At the beginning of each meeting, I tried to **make space for difficulty or emotion in our conversations** and also to explicitly invite questions to make clear that the conversation was not intended to be one-way but might rather be discursive.
4. I explicitly made it clear that participants would be able to both leave and re-join the advisory group at any moment, recognising that it's important not to take consent for granted, that people's circumstances might change, and that people might not have an unbounded desire to be endlessly involved in research – they might simply find it boring or too time-consuming.

I was also strongly aware that, as Diana Gustafson and Fern Brunger note, "being an insider does not eliminate the **potential power imbalance** between researcher and research participants" (2014, 1002). It was important to be aware that our shared experience of self-harm did not negate my responsibility to ensure that these meetings were

spaces in which care was possible. When Ashley read these reflections, she commented: "This has been one of the real strengths/positives of your approach for me because you always gave the impression that you genuinely cared about me as a person and not just as someone advising me. Having it as a more informal conversation and you asking about how things are going personally for me meant we built a good rapport I think!"

> I have been involved in mental health services, both as a service user and a clinician for many years, so when I saw an advertisement on Twitter to be part of a PhD advisory group I was keen to register my interest.
>
> When Veronica explained about the project and what being in the advisory group would involve I knew it was something I wanted to be part of. It felt very respectful and thorough to recruit a group of people with lived experience of self harm to help support and advise her work.
>
> I have advised Veronica every few months since 2019 on lots of different aspects of the project, from good practice in interviews to feeding back my opinion on specific sections of writing.
>
> I have thoroughly enjoyed being a part of the advisory group, Veronica made me feel valued, and supported throughout, her care and attention to the wellbeing of everyone involved in the project was outstanding. I believe this piece of work will be an invaluable contribution to the discourse on self-harm, both in the media and in wider society.
>
> - Sarah-Jayne

How the Advisory Group shaped the project

Working with the Advisory Group shaped my PhD project in a number of important ways (see i–iv below). This is particularly significant given the **widespread criticisms of engagement or involvement that is tokenistic** rather than having a genuine impact on how research is done (Evans and Jones 2004). Part of trying to care through and with collaborative and participatory practices is ensuring that they result in tangible, material actions.

i) Research questions and methods

Early discussions with the Advisory Board focused on my research questions and methods. All members agreed that the topic was interesting and that they were often frustrated by the way self-harm is represented in fiction. Eleanor was struck by how positive it was to see a research project in which those with experience of self-harm were invited to give an expert opinion on a topic, rather than simply to recount or explain their experiences, a comment which went on to impact how I approached the interviews. However, the project was initially framed around 'young people'. After one group member questioned this with respect to her own participation, I introduced it as a central topic of discussion with the others. Our conversations encouraged me to remove the focus on 'young people' from the project's research questions and to take a much more critical approach to the tendency for research on self-harm to focus on youth. The benefit of this criticality was very much borne out in the interviews and the analysis, and indeed it went on to become a key theme in my thesis.

We also talked about whether interviews or focus groups were the best approach. An academic colleague had suggested that interviews might not be sufficiently collective or collaborative; however, I was concerned about participants' wellbeing and my ability to manage group dynamics without any experience. These concerns were echoed by the Advisory Group. They suggested that while group interactions could open up new or interesting avenues of discussions, this might happen at the expense of individuals who felt less comfortable contributing in group contexts. These discussions were vital to my decision to specifically conduct interviews.

ii) Ethics and safeguarding

The Advisory Group also played a crucial role in ensuring that the interviews around self-harm were carried out in an ethical and appropriate way. Members gave feedback on information sheets and consent forms, particularly regarding their wording, clarity, and structure. We also spent a great deal of time thinking about **safeguarding**. Several members emphasised the need to discuss this with participants, and to be very explicit about what would necessitate a breach of confidentiality. This prompted me to outline this very clearly both in the information sheet and in the information that I provided verbally at the beginning of every interview. Rebecca also recommended using coloured flash cards so that participants could signal non-verbally that they'd like to stop or pause the interview, and Ashley suggested that it might be helpful to check in explicitly with participants about whether they had someone to contact if the interview became difficult or upsetting. I put both of these suggestions into practice and found them very valuable.

iii) Improving accessibility

All advisory group members emphasised the need to offer different forms of interview (in person, Skype, and telephone) to enable participants to select the method which suited them best. Rebecca suggested including the option of submitting written testimony, to make the study more **accessible** for those who might find spoken communication difficult. Both of these suggestions were hugely valuable and made it possible for individuals outside the UK to take part.

iv) Data collection, analysis and dissemination

I continued to meet regularly with the Advisory Board throughout the research process so that I could discuss recruitment, share the themes I identified in the interview data, and talk about what would become the structure of the PhD. I valued the opportunity to **sense-check** and receive positive feedback on not only the content and relevance of the themes but also on the way in which I was framing them. One particularly helpful suggestion was around dissemination. Sarah-Jayne prompted me to think about communicating the findings in a less academic style, not only once the PhD was finished (which had been my plan) but also more immediately. This countered the academic tendency to focus on the thesis as the most important outcome and pushed me to write more accessibly (particularly via blogs) throughout the PhD, and to explore other modes of dissemination such as zines and podcasts.

Reflections

My own sense is that working with the advisory group strengthened this project immeasurably. **This process was one of the most positive and rewarding aspects of the PhD**; to me, it demonstrated clearly the many benefits of working collaboratively both to the research in which it resulted, and to my own experience of the research process. I learnt many things from working with the members of the advisory group, some of which were concrete suggestions I imagine I'll implement in many future projects. More generally I refined my sense of how to work with care and ethicality when collaborating, and of the possibilities opened up by this form of collaboration. Much literature about participatory or collaborative processes emphasises moments of discord, difference, conflict or criticality (Oliver et al., 2019); yet what struck me in this case was how positive and constructive each interaction was, regardless of whether perspectives differed. I felt strongly that it was easy for different views, suggestions, and approaches to be incorporated within the project because it was evident that each person involved was motivated by a desire to act with care towards people with experience of self-harm, to ensure the research was conducted ethically, thoughtfully, and sensitively. It was clear that each of us brought our own experiences of self-harm, and our broader life experience and expertise, to bear in such a way that considered not only how we felt but how others might feel, others who might be very different from ourselves.

This desire to think with one another, and beyond ourselves as individuals, made it easy and pleasurable to work together. I was deeply moved that the experience was also constructive for members of the Advisory Group.

Being on the advisory panel has been an experience of true collaboration, recognition of my expertise in this area, a sense of respect for my input, and a clear willingness to be changed, to have the research potentially altered by our individual suggestions and our discussions. I have felt like my views are honoured and not just paid lip service. It feels like an ethical meeting place in which our mutual investment in research on this topic, which in this case I have found thoughtful and innovative, is taken seriously. To be paid for my involvement legitimises my contribution although I noticed a reluctance to take payment because I am used to giving away my experiences for free such as the current paradox of researching as someone with lived experience: we are said to have valuable contributions to make and yet are rarely remunerated except perhaps with the odd voucher. This process has also enhanced my own research practices in the sense of provoking in me a call to take myself and my experiences more seriously, to embody a sense of my own credibility and author of my own experiences, in my academic life.

- Eleanor

I don't want this generous feedback to allow me to regard the process as straightforwardly successful or unproblematic. I recognise the **significant limitation** posed by the fact that we met individually rather than collectively, and also by the timeframe of the advisory group. The advisory group was established several months after the start of my PhD program, and nearly a year after I submitted my initial application for funding. This meant that by the time I first met with advisory group members I had already formed a relatively clear idea of what shape the project might take, and indeed had been funded on that basis. While this shape did alter in response to our discussions, it is likely there are certain practical and conceptual avenues that this early work closed down; it is undeniable that on the whole the project was shaped by my own perspective, rather than by a more collective one. Moreover, the practical steps outlined above do not (and perhaps can not) easily resolve **complex interactions of power and hierarchy**. As a result, this project might be considered to have failed to be 'fully' participatory; rather, it might fall into what Margaret Cargo and Shawna Mercer describe as a 'lower bound' of participatory research (2008). They describe this as research in which "non-academic partners" are involved "at least at the project's front end, in defining or refining the research questions or otherwise contributing to the study direction, and at the back end, in interpreting and applying the research findings" (2008, 334).

> *The practical steps outlined... do not (and perhaps can not) easily resolve complex interactions of power and hierarchy.*

Yet this particular description is complicated by the fact that while I am a researcher, I am also somebody with experience of self-harm, and my decisions and actions occur in the context of that experience. In some, perhaps 'imperfect', way this research is in the control of someone with lived experience; it might even be described as 'user-led' research. In many ways, neither label feels particularly appropriate. Instead, the practices described above might simply be seen as one small way of attempting to hold onto (or stay with) care for members of the project's advisory group, for interview participants, for people who self-harm in general, and for the way we talk about and act around the topic of self-harm.
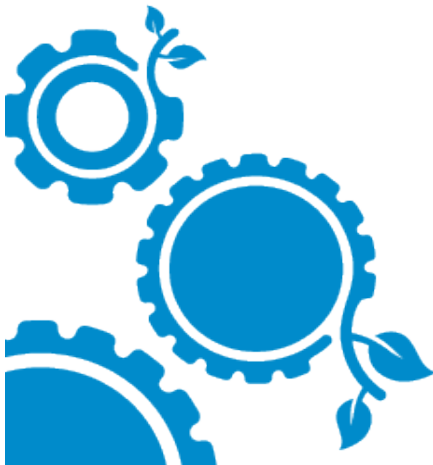
My experience of being part of the advisory group for Veronica's project was a complete antidote to many other experiences of research involvement, both professionally and personally. There was a real willingness from Veronica to engage with experience and expertise outside her own and to learn from, reflect on and synthesise that information into her work. She also started the process at the very beginning of her work, asking for input on how to shape the research as well as the protocols surrounding it, rather than just inviting comment on work that was already done. To me this speaks to a proper understanding of co-production and a genuine interest and commitment to collaboration and the richness this can bring, rather than seeing it as an added extra to be slotted on at the end to rubber stamp work already completed. I also appreciated the way she offered the opportunity to be involved both individually and in a group – there was no obligation to be able to contribute in a group setting – Veronica did the work of bringing together and acting on the diverse experiences she sought out and witnessed. It was also refreshing to be offered a clear route of direct payment for the time I invested, rather than a generic voucher which is for shops I don't use.

- Naomi

Donald Winnicott conceptualised 'good enough' parenting to avoid the dangers of over-idealisation and to recognise the care already present in families (1988). I was struck by Laura Salisbury's extension of this to speak more broadly of 'good enough' care (2021). In this spirit, we might consider the practices outlined above as an attempt at 'good enough' care within and through research. Through this I understand the work we engaged in together through the advisory group as not revelatory or radical, nor as entirely free from the complex power dynamics of research conducted within academia, but rather as simply a way of **doing the best I can**, with the more modest hope that it might be better than it would otherwise be.

I mentioned above that I drew many lessons from this project which I'll take with me, some of which might be useful for others. In particular, the features of the advisory group which worked well, around payment, making space for difficulty, and flexibility of participation, might be taken up and applied to other projects. Simultaneously, some of the external constraints with regards to the time-bounded nature of the PhD, and the structure of funding applications, might prove significant to those designing funding schemes in which collaboration is prioritised or required (for greater detail, see Heney & Poleykett 2022). However, I am loath to provide too many detailed recommendations, in part because one of the greatest lessons I have taken from this project was the value of specificity. This Project Short has recounted many decisions I made in quite some detail, in part to recognise the way they were impacted by the particular context and content of this individual research project. The success (and even the joy) that I found through working with this advisory group does not establish a failsafe set of rules or guidelines; rather, what it established to me was the benefits of a way of working. It clarified to me the **importance of care**, of the way that small, concrete decisions come together to create an environment of collaboration, and of the way that building relationships (an imprecise and intangible science), is often more important and valuable than any concrete outcome.

Bibliography

Cargo, M. & Mercer, S. L. (2008). **The value and challenges of participatory research: strengthening its practice**. *Annu. Rev. Public Health,* 29: 325-350.

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Univ of California Press.

Evans, C., & Jones, R. (2004). **Engagement and empowerment, research and relevance: Comments on user-controlled research**. *Research Policy and Planning*, 22 no. 2: 5-13.

Gustafson, D. L., & Brunger, F. (2014). **Ethics,"vulnerability," and feminist participatory action research with a disability community**. *Qualitative Health Research*, 24(7), 997-1005.

Heney, V., & Poleykett, B. (2022). **The impossibility of engaged research: complicity and accountability between researchers,'publics' and institutions**. *Sociology of Health & Illness*, 44, 179-194.

Madden, M., & Speed, E. (2017). **Beware zombies and unicorns: Toward critical patient and public involvement in health research in a neoliberal context**. *Frontiers in Sociology*, 2, 1–6.

Martin, G. P., Carter, P., & Dent, M. (2018). **Major health service transformation and the public voice: conflict, challenge or complicity?**. *Journal of health services research & policy*, 23(1), 28-35.

Oliver, K., Kothari, A., & Mays, N. (2019). **The dark side of coproduction: Do the costs outweigh the benefits for health research?** *Health Research Policy and Systems*, 17(1), 1–10

Salisbury, L. (2021.) Plenary Discussion, Contesting Care Conference, 30 June - 1 July.

Winnicott, D. W. (1988.) *Human Nature*. Schocken.

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