

Lived experience as service user led research:

***Much More Than a Label survey research design
2018***

Collective advocacy projects often consult on people's views and experiences, gathering them together in various ways – reports, presentations, workshops, exhibitions, booklets, films. This is valuable in promoting the voice of lived experience, raising awareness and working for change. It is part of contributing to ongoing dialogue in society and policy. I also think this can legitimately be seen as research. This document presents the design of a piece of collective advocacy by the Much More Than a Label project, about the lived experience of personality disorder diagnosis.

Following standard research practice, I will show how what we wanted to find out and do (the ontology) is consistent with the kind of information that is relevant to this (epistemology) and how we went about the piece of work (methodology). I will also consider ethical questions.

What did we want to find out and why?

The project steering group, and people they are connected with, felt that there was inadequate information available to people about borderline personality disorder around the time of diagnosis. What information there was available came from the perspective of professionals or 'experts' who did not have their own experience, which the group did not feel reflected their experience of the diagnosis. There is also a lot of negative information online. This same lack of information affects professionals, family members and the general public who want to inform themselves about borderline personality disorder.

The project wanted to produce a booklet that would present information about borderline personality disorder, from the perspective of people with their own lived experience. To do this, we wanted to hear how people experienced the diagnosis first hand, and what they wanted to be said in a booklet. We wanted to hear what the experience was like, from a wide range of people.

There was already an existing steering group of people with lived experience of personality disorder diagnosis. Some of this group would meet regularly for advocacy work, while others were connected by email and would contribute views from time to time. This group discussed and gave views about what they thought should be in the booklet, what the tone of the booklet should be and what they wanted to achieve with it. They wanted to represent as wide a range of views as possible, as well as be alert to the social and political contexts of the diagnosis. They wanted to represent those who have found the diagnosis helpful, as well as more critical perspectives and those views between. It was also important that the tone was somehow warm and encouraging, while not papering over the genuine distress and issues that they feel go with the diagnosis.

We were aware that while a range of experiences and views were represented in the group, we wanted to hear a much wider range of experiences. The project had conducted a consultation 10-11 years previously and the steering group felt that views may have changed since then. We wanted to get a better sense of the kind of views that were out there now.

There is a tension here, between the desire to neutrally hear what people are saying and thinking, and the fact that the booklet was formed by the views of the people currently in the group, as well as the things that were important to them. This is an important part of advocacy work coming from people themselves – we will not be neutrally representing views, but they come from a starting place of particular people and their lived experience, and a desire to widen those views. It is also for an end product, in this case a booklet, as we are not simply representing what people are saying but hoping to make a difference and change with those views. It is all relational and contextual, coming from the ground up.

What kind of information did we want?

We wanted to know more about what people were saying about the nature of the experience, and the things that were important to them. In this case, we were not looking for the full stories, but the key themes people were identifying. We wanted to hear what people really thought and honour the sensitivity of what they might say and how they presented that. We needed to be sensitive to the individuality of the experiences, but also present the range of collective voices and experiences.

How did we go about it?

How we gathered those views needed to be manageable and possible for the group to collate into a short booklet. We did also want to be able to use those views to inform our ongoing advocacy work, so we were representing what people were saying now in our training and campaigning.

We decided to conduct an online survey (with paper copies on request) as this would reach the most people. There is an active online community around BPD and many people find it difficult to come to meetings.

The steering group agreed on the key themes we wanted to ask about, that we hoped would be the sections of the booklet. These themes came out of what this group of people with lived experience agreed, through discussion, were the most important areas to communicate in the booklet.

In the interests of anonymity, we asked about limited personal and contextual information. However, this does mean we are missing relevant parts of context when we want to be alert to the social and political contexts of BPD diagnosis.

We wanted people to be free to share their experience as they understood it, and for us to be faithful to that in how we later represented it. For this reason it was important that the questions were as open as possible, while also giving sufficient

parameters that they did not feel too overwhelming for people. Hopefully, this would enable people to talk about a specific part of their experience, as they understood it, without being overwhelmed by all of it, as well as be presented in a way we could helpfully use for our booklet.

We were not trying to measure people or experience but gather qualitative themes and examples of this that we could represent through key quotes. Another advantage of this is that it can be evocative about the experience for people reading, by communicating the nature of the subjective experience.

We also recognise that there are limits to what can come across through words in an online survey. Ideally, we would hear from people in other ways that would communicate more textures of the experience, as well as how people talk about that in interaction with others. We hope to have an event to do this through discussion and creative means, but this may be beyond our time or resources.

The group took some time discussing the questions of the survey. They were aware of how questions could be read and interpreted by those reading. Some people would want starting places, while others would feel patronised or too guided by too many specific sub-questions. We chose to have open questions with optional prompts below it, in a paler font so they did not feel obligatory for those who didn't want those.

We wanted to be explicit about welcoming a range of different views. This openness, strangely, came with some 'leading' elements, as signals that we would welcome certain kinds of views. For example, some people might need to hear clearly that views critical of the diagnosis were welcome, so including some of this in the wording of the questions was important. On the other hand, those who found the diagnosis helpful, or who had found therapy helpful, also needed signals that they were welcome. This is particularly relevant to the nature of the experiences that may attract this diagnosis. People have often been invalidated and criticised, so are likely to feel unsafe in venturing their experience in contexts they perceive as unsafe.

Ethics

There are ethical issues in asking people to speak about their experience. We gave a lot of thought to how to word the questions sensitively. This has extra validity because the people designing the survey had their lived experience and knew lots of others with the diagnosis. This was an important barometer or how sensitively the questions were worded.

We were also very explicit about people keeping themselves safe and only answering what they were comfortable with. The questions were worded in such a way as to encourage themes rather than people going in depth into a traumatic experience, for example. The challenging nature of the material was explicitly recognised. Emergency support contacts were included.

We were also clear about what the information was going to be used for, as well as being very clear about it being anonymous. People had the option of separately

contacting the project worker to get involved with the project. This is a way they could have more involvement with how their views were being used, and some accountability for the project, without identifying which were their survey answers.

Collating, interpreting and presenting

These are suggestions for how we use the responses to the survey.

When it comes to collating the information into the booklet, we will be looking for key themes and select quotes to illustrate this. We will have a lot of information, but we are not looking to convey it all. We want to communicate the diversity of collective voices out there. This will involve the steering group making interpretative judgements about what broad themes are coming up in the survey results. I suggest we read through the answers first as each separate response, then grouped together as all the answers to each question, so we can get to know the responses to have a 'sense' of context, before moving away from the specific accounts towards topics and themes. I suggest we each write up on flip chart around the room the themes as we see them, with any helpful illustrative quotes to the side. We should also have sub-themes that can take account of the differences among views that are similar. We should also note things which come up individually but are not represented in other people's answers.

Since our objective is to communicate a collective voice, we do not need to include everything in our final booklet. We want to include different or disagreeing views, but ideally they would be what a range of people are saying rather than only one person.

There is the risk of this silencing peripheral voices, but the objective of this booklet is about collective voice rather than all the voices out there. There may be other places or ways to include these views, perhaps in our training.

We will also be losing some of the power of the specific examples as we group things into themes. There is a place for the in-depth example in advocacy – for example, in training, or a different kind of printed material – but this is not the aim of this booklet. We want to use quotes to communicate more texture, but not the whole individual context. We do, however, need to be sensitive to that.

Making an argument – what can these voices do?

The specific points we want to make will emerge from what people say in the survey, as well as the issues that are important to the people in the steering group.

This can provide a platform for people to hear what BPD is like from a lived experience perspective. It will be part of a wider dialogue about BPD that can include these voices rather than only the more privileged voices of professionals and diagnostic manuals. It can be part of making the case for the issues that are important to people with lived experience.

We want to be faithful to what people are saying. This booklet will also be influenced by the perspectives of the group. In terms of the group especially, this is appropriate (and inevitable) as this is research that emerges from people, at the grassroots, and makes contact with other people through the subjective ways in which humans communicate. This will not present an objective view, or a total view, but I would argue this is not possible or desirable – what we are presenting is a picture of how people feel about BPD diagnosis at this time and place.

Conclusion

The way this research has been carried out (a survey to gather people's views, with open ended questions) is consistent with the kind of information we want (the qualitative nature of people's experience, as they understand it, grouped into the key themes that are important to people, including differing perspectives) and what we want to find out and do (present what borderline personality disorder is like, from a lived experience perspective).

This consistency is important in all research and this kind of qualitative approach is relevant and important in this field. Collective advocacy can be an example of this being done in a grassroots way. While it is not usually considered formal research, I would argue that it can be seen this way, and presented this way where it is helpful. While it is, on one level, as simple as asking people what they think, I want to make an argument that the way this work is planned has enough rigour to be seen as research in itself, rather than a peripheral voice.

Here I have given an example of how this is being done in one piece of advocacy work, but similar processes can be applied to other work – making sure the way something is done is consistent with what kind of information we want and what we are wanting to find out or do. Other advocacy work may look different – an in-depth individual example may give more texture and context; a creative piece may make unexpected connections or communicate other parts of the experience.

While there may be a place for measuring things, this kind of qualitative work is most appropriate for communicating lived experience. It can be a strong and legitimate counter to mental health research that tries to provide objective evidence and misses how people understand their own experience.

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