EVALUATION

Involvement in Crisis Care Study

with-you

Prepared by With-You Consultancy

Evaluation of service user and carer involvement in the NIHR funded research study: The contribution of the voluntary sector to mental health crisis care in England: a mixed methods study

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Key messages about involvement in this project:
"The metaphor I would use is that it is like dancing. Sometimes they led, sometimes we followed; sometimes we led and sometimes they followed. ... I thought they were very good in facilitating that." [AG 5]*****

"I think that as a research community we need to be far more honest about the challenges of it and the messiness of it." [DG 7]*****

Themes:
- shared expectations of involvement
- importance of involvement
- size and boundaries of the project
- inclusive of diverse experiences
- valuing the work of the Principal Investigator
- co-production and creating a shared understanding
- support for involvement
- wanting the project to make an impact

Recommendations:
For this project:
- Compile and share the learning of involvement arising from this study where involvement was seen as a success
- Consider follow up interviews with people who have been involved in this evaluation to uncover the longer term impacts of involvement

For future projects:
- Use 4PI as a framework for planning, monitoring and evaluation of involvement
- Enable regular whole team meetings, including at the start, mid-point and end as a minimum
- Recognise the added requirements for administration support and resource accordingly
- Ensure there is evaluation of involvement, including longer term impacts, and including the impact on participants of the study (the people who were interviewed by co-researchers)

For funders:
- Recognise the resources required for thorough involvement and resource this appropriately throughout all funded studies
- Resource evaluation of involvement, as described above, to include longer term impacts and impact on participants

*Quotes are credited to Delivery Group (DG) and Advisory Group (AG). See full report, p.3.

1.   Background

At the outset of the national study, a clear statement was made that *'there will be service user involvement in all aspects of this study.'* The proposal included service users, carers and members of the public as active partners, able to *'shape, change and challenge the research process'*.

A range of groups were involved in the study:

Name of group	People within the group
Reference Group	People with lived experience of distress/service use
Steering Group	People with a variety of expertise including people with lived experience of distress/service use who brought a national perspective to their role
Co-researchers	People with lived experience of distress/service use who were employed on a self-employed basis as researchers with this specific lived experience
University team	Academics and administrators who were employed within the University on contracts related to this study. People within this group may have their own experience of distress/service use.

In January 2019, the team appointed us as an external organisation to undertake a service user led evaluation of the quality and impact of involvement.

All members of our team are also members of the Survivor Researcher Network, hosted by NSUN. The Network is a user-controlled independent network of services users and survivors with an interest in research and committed to a values base that is emancipatory, experiential, holistic, inclusive, diverse, respectful and anti-discriminatory. Details of the Network are available at https://www.nsun.org.uk/faqs/survivor-researcher-network-srn

Members of our team have a long history of involvement in projects related to improvement in mental health services, including research projects and also projects focussing on involvement such as Making a Real Difference, good practice guidance from the Mental Health Research Network, and the 4PI National Involvement Standards.

The 4PI National Involvement Standards were the result of an NSUN hosted project, the National Involvement Partnership (NIP), which was funded by the Department of Health (Innovation, Excellence, Strategic Development) voluntary sector funding. The aim of the three year project was to strengthen and 'hard-wire' involvement into the planning, delivery and evaluation of services. The framework encourages people to think in terms of Principles, Purpose, Presence, Process and Impact (4PI).

2.   Aims and objectives of the evaluation

The aim of this evaluation is to understand the quality of involvement drawing on the National Involvement Partnership's National Involvement Standards (National Survivor User Network for Mental Health (NSUN), 2013) and relevant good practice.

The evaluation will involve interviewing service users, carers, academics and partners that have been involved in the different activities, and preparing a brief report.

3. Method

The evaluation adopted an exclusively qualitative methodology. Interviews and a focus group were held using a semi-structured interview guide which was flexible to cover the key themes of 4PI while also enabling participants to discuss themes which they considered to be relevant. Everyone was invited to take part.

A focus group was held for members of the study reference group. All other participants, including co-researchers, the academic team, steering group and some members of the reference group, who were unavailable for the focus group, were interviewed using one to one interviews, held in venues as requested by participants. Many participants requested telephone interviews, primarily because of ease of arrangement and reduction in time for travel. In total 13 interviews were recorded and one focus group.

We heard views from:	
Academic team including admin	4
Co-researchers	3
Steering Group	5
Reference Group	5
(One person held roles on both steering group and reference group)	
The methods of interview were:	
Telephone interviews	9
Face to face interviews	3
Focus group	1
Emailed contribution	1
People employed primarily for their lived experience perspective	8
People employed for other skills	8

Interviews and the focus group were audio-recorded and transcribed. The anonymised transcripts were then subject to a thematic analysis by all members of the team. Interpretations and findings were discussed within the team.

This report summarises the findings. We present these in the initial themes and then discuss them in relation to the 4PI framework. Throughout, anonymised quotes are included as illustration.

4. Key themes

A note on language

Following lengthy discussions about how to attribute quotes, to ensure confidentiality and yet aid understanding, we concluded that the study could be

seen as teams consisting of a Delivery Group (DG) of academics, administration staff and co-researchers, and an Advisory Group (AG) of the Reference Group and Steering Group. These two groups were distinct with the Delivery Group being immersed in the day to day challenges of a complex project, and the Advisory Group meeting irregularly and feeling somewhat disconnected. We feel this division is sufficient to ensure confidentiality within a small number of participants, while aiding understanding about these different experiences of the study.

We emphasise that this division is not indicative of lived experience of distress/service use and professional/academic experiences. Co-researchers clearly contributed from both perspectives. Membership of the Steering Group included a variety of expertise. And people employed for academic skills also brought their own personal experiences to their work.

We would also note the many shared experiences, such that selection of a quote from one group does not indicate that it would be irrelevant for the other group. Where our discussion specifically refers to a general feeling from participants across our evaluation we use 'the team'.

We also distinguish our own 'evaluation' from the research 'study' on crisis care. Where we use 'participants' we mean the people who participated in our evaluation, the people we interviewed, unless we explicitly mention that the participants were the people interviewed for the research study itself. This reflects the language used in quotes.

Shared expectations of involvement

Many people, from both the AG and SG, talked about forgetting, reflecting the lengthy time period since the start of the project, it's complexity, the irregularity of meetings, the different terms used in simultaneous projects, and, for some people, a personal lack of concentration and memory. At times, they could not recall team members' names, or who was responsible for tasks. The names of the Steering Group or Study Steering Group (SSG) and Reference Group or Service User Reference Group (SURG) became confusing. There was a lack of clarity in response to many questions which went beyond any personal lack of memory or concentration: people were unclear about aspects of their own role and the role of others.

From the outset, some people were unsure how they were recruited to the study team, with a sense of people being asked personally to get involved whereas others noted a transparent recruitment process from start to finish.

People commented that they did not know what they had signed up to, and that the reality did not necessarily meet their expectations. This partly reflected the flexibility of the study team, and a desire to involve people as much or as little as they wanted, with changing needs over time. Additionally, the study itself changed in reaction to service user and carer involvement. But people wanted to know:

> "What can I expect of the university and what you know, the university can expect of me?" [AG 5]

This challenge of expectations was noted as being a common challenge for co-production:

> "Those are everyday challenges that everyday organisations need to tackle when they say they want to do co-production." [AG 5]

Importance of involvement

The study team and their participants (the people they interviewed) clearly understood the purpose of involvement and could witness the impact. Team members noted how the interviewees reacted differently to co-researchers; how the Reference Group were able to influence understanding of the meaning of crisis; and how this enabled the Principal Investigator to access increased funding for further interviews.

They recognised involvement as essential in hearing the views and experiences of people with direct experience of the topic. The topic was one that they had a personal interest and energy for, including that they wanted to make sure that diverse voices were included. They used words such as feeling *'strongly'*, *'interested'*, *'personal'*, *'emotive'*, *'a privilege'*, and *'drive'*.

They noticed the effort put into involvement across the study and also to reach participants for the study:

> *"the importance of ensuring that individuals who are involved in different pieces of work, are able to feel fully engaged and full participants in the process. I certainly saw efforts to make sure that was happening at the various different levels." [AG 4]*

> *"is definitely the one that's made the most effort to include services users and to, you know, have it more like co-production rather than just, you know, service users contributing to the project" [DG 2]*

Involvement was seen as providing the study with access to specialist knowledge of the topic. Throughout, people contributed their expertise and contacts, including their experiences of not being able to access appropriate services, and their networks within communities who might not access specific mental health services.

The flipside to this was a recognition that this could also challenge the boundaries of the project, extending it beyond its original remit, with consequences on resources.

Size and boundaries of the study

The scope of the study was initially large – the voluntary sector provision of crisis services. People who were involved from a perspective of lived experience of distress/service use then increased the scope of this in several ways:

- They illustrated that a crisis is not a one-off event, and insisted that the team conduct repeat interviews to gain a better understanding. This resulted in the team seeking and receiving further resources to complete this additional task
- They had a wider understanding of places where people might seek support in a crisis, taking the understanding of support services beyond the usual suspects to include groups such as knitting groups and faith communities.
- They held a variety of opinions within the group, reflecting a diversity of opinion, such that the group meetings were seen as places to discuss and challenge ideas, with solutions which then need to be acted on.
- The project was supported by a Steering Group and a Reference Group, the latter made up solely of people with lived experience of distress/service use, with some people suggesting this was a later

addition and to include some people who had not been appointed as co-researchers (although there were varying opinions on whether this was the case). While some valued this space to hold their own discussions, some questioned whether this was duplication, and suggested that it did incur delays as the project tried to incorporate ideas and seek permissions from both groups.

The study therefore had grown, beyond the initial estimate for support time including admin and academic support. This was particularly felt towards the end of the study at deadlines for completion.

Inclusive of diverse experiences

Everyone suggested that diversity had been a key feature of the project and recognised the importance of including a range of experiences of crisis. This was clear near the start of the study where the meaning of crisis had been a point of discussion, which impacted on changes within the study plan.

People said that diversity had been successful and they could name various categories of people who had been included while acknowledging that with a limited number of people, they could not tick every box. The reasons for the emphasis on involving people from Black and Minority Ethnic (BME) communities were based on an understanding of experiences as racialised people within the mental health system. People of similar cultures can pick up on subtler nuances of communication, as well as differences in language, which are important to researchers and also within the mental health system

> *"if you do not understand that, you can read into things that are not happening. Or you can read into things and it happens in crisis that some people misconstrue things badly and people get sectioned." [AG 5]*

People from BME communities also contributed specialist knowledge of community groups, including how they might experience and support crisis and the language they might use. They were able to challenge lazy assumptions and pre-conceived ideas, and speak from a personal experience which also helped with establishing rapport with interviewees. The Chair of the Steering Group brought with her a leadership focus informed by her experiences as a Black woman of African Caribbean descent.

However, while initial opinions were that the inclusion of diversity overall had been successful, more probing questions revealed some gaps, such as the involvement of specific ethnic groups and of carers.

The distinct views of carers were a gap in the study. Carers were seen as important as a source of support for family members in crisis, and it was recognised that carers don't know where to turn for support. Carers were noted as one area of the project where people would have liked to do have done more, but

> *"it is just limits around how much you can do within one project." [DG 7]*

However, carers were involved in the study, both as participants and on the Reference and Steering Groups. But their dual service user and carer role wasn't recognised, or their carer-specific views weren't voiced.

> *"We didn't know until we were in the project how kind of closely entwined these roles were and therefore how unique the carer or the blurred carer service user perspective could be" [DG 7]*

We were unsure how people's diverse experiences contributed to group discussions. This is not to say that it didn't happen, but we heard some experiences of not being able to speak in meetings, feeling overwhelmed by other group members, or not wanting to interrupt to contribute an opinion. This may lead to further marginalisation of specific voices.

Inclusion and diversity also goes beyond standard protected characteristics, for example to specific experiences of crisis such as self-injury which might be relevant to the study, so that it isn't just a tickbox to be checked off. It was suggested that it is important to include relevant people with a variety of experiences when decisions are being made in research: it's about who is in the room:

> "Someone was talking about her story…… seeing through, how crises, through that lens was an eye opener for me, it made me question" [AG 5]

However, people weren't sure about the recruitment process and told us

> "often people get recruited because they know other people" [AG 8]

but that this in turn could lead to projects not recruiting people who might be seen as

> 'a bit threatening'. [AG 8]

We questioned if the expertise of the Reference and Steering Groups had enabled the research team to reach out to wider communities. We heard of successes, that the researchers had been able to reach out to a faith group and hear about their experiences of crisis. But other people were unaware of such successes, and had not contributed their own networks to this process.

Valuing the work of the Principal Investigator

Everyone was extremely positive about the leadership and personal qualities of the Principal Investigator. They could see that the Principal Investigator genuinely wanted service user involvement, valued their input, made people feel relaxed, was respectful, supportive, encouraging and wasn't phased by change. The Principal Investigator was described as

> "a great investigator, extremely bright, extremely hard working and extremely nice ….. What more could you want really" [AG1]

> "I think how [Principal Investigator] led it in terms of a diverse and inclusive and very involved piece of research was exemplary" [DG 4]

Some people said they specifically became involved in the study because of respect for the Principal Investigator's reputation for projects with a strong level of involvement. They knew this would not be a tick box way of working.

There was some concern that the Principal Investigator was very busy, with delays caused by the initial changes, such that the study, and consequently the Principal Investigator, were always trying to catch up. This did not suit everyone's way of working, but was reflective of the size of the study. While for some this did not create a problem, for others it prevented them seeking her advice:

> "I was so snowed under …… I just had to trust [Principal Investigator]" [DG 4]
> "[Principal Investigator] was really busy so I didn't want to bother her" [AG 8]

Co-production and creating a shared understanding

The team have been very successful with the principle of building an equal team with people saying they had made
> *"friends for life" [DG 7]*

and
> *"there were strong attempts to make sure that people did feel included".*
> *[AG 4]*

The team created a shared language and understanding, with awareness that the technical language may need explaining, but also that it was not needed:
> *"didn't use a lot of jargon, and its so relatable, that helped people feel that actually I don't need to use jargon of research, I can use lived experience, but just creating a space where you just say it as it is and use everyday language". [AG 6]*

The team included people from a range of backgrounds, including professional and lived experience. One suggestion was for an early meeting where everyone involved could talk about their identities to develop a shared understanding of the perspectives available to the study, acknowledging that people have many experiences, including personal experience of distress, a caring role, and academic expertise. Sharing these at the start of the study would help to create an equal culture:
> *"it's important for those discussions to take place in an honest way, right at the start of the project and when people come on board" [AG 8]*

Responsibilities and contributions were shared amongst the team, and people valued the leadership provided by the academic team and Chairs of groups. The Steering Group was seen as a place for holding accountability, including of involvement.

However, there was recognition that 'co-production' needed defining and that, in a research project of this nature, true co-production might be impossible for various reasons:
> *"how do you move over from power over to power with?" [AG 5]*

> *"You need to be able to follow what comes up rather than follow a list of things you said you would do". [DG 7]*

All teams were brought together at the end, to help with the analysis and report writing. But some people said they would have welcomed more joint events at the start, to see how everything linked in.

Support for involvement

Participants talked of feeling disconnected, overloaded with paperwork, and rushed, particularly towards the end. Some felt overwhelmed by other members of the groups. Some members of the team and groups were clearly skilled around involvement, but felt jaded, while others admitted to a lack of confidence and experience. People questioned identities about co-researchers and academic researchers, including around perceived vulnerability and the support requirements for the two groups. This was described in general, rather than specifically for this study, as an issue for researchers with lived experience:
> *"Because you have lived experience your status is lowered. Sometimes you're treated as if you're a child." [DG 3]*

"It's like there's kind of the 'real' researchers and then the 'vulnerable' researchers… we need to protect them and look after them a bit more and obviously you want to make sure that people are doing okay but I think that works for everyone, that works both ways" [AG 8]

There were therefore various opportunities for support including:
- administrative support, including for contracts and payments and for the paperwork associated with meetings
- support for progression opportunities to include people with varying levels of existing expertise and knowledge
- emotional support related to the specific demands of this topic

The red tape and bureaucracy of working within a university system, including the language and processes, were seen as a potential barrier to involvement, but participants were grateful for the efforts made by the team to minimise these, and potentially were unaware of difficulties which other team members had faced. We did not hear anything about Occupational Health processes, including DBS checks, which might suggest that these were not a focus of concern for the people we spoke to. However, payment processes had been a challenge and created additional administration tasks, as well as the financial challenges for people waiting for payments:

"There were delays in payment pretty much constantly" [DG 2]

Paperwork for meetings was often provided at the last minute for meetings, causing some people some stress, although it was acknowledged that some people felt this more acutely than others. People were involved in the study on a part time basis. Most had other roles alongside this, as well as personal commitments. They commented that this could leave them unable to attend meetings or read paperwork, especially if arranged at short notice. One person noted that they had internalised this as their own responsibility, while others suggested that an increase in admin support may have been helpful. This was not a criticism of the admin staff: everyone praised their work, but suggested that the project had grown with insufficient consideration of the amount of admin support that was needed.

People enjoyed the opportunity to be involved in the study, saying they had learnt a lot, including about the process of research, and also about networks and other areas of interest. People also noted that others in their own network had shown an interest and asked how they could be involved. Some people wanted to progress and take up further academic opportunities, while others acknowledged their existing commitments and lack of availability to take anything further. One person noted they were pleased the project had come to an end as they had found it stressful. While others said the experience of involvement had helped them to secure their current post.

"I certainly wouldn't have got the job that I have now without being on that project" [DG 6]

"It looks pretty good on my CV… I've got another project … and I think having been involved in this was definitely a stepping stone to that" [DG 4]

"I was speaking to a lot of people, and they were saying how did you get involved? And they were saying if you hear of any other opportunities will you let me know?" [AG 5]

There were suggestions that additional training such as mental health or suicide awareness might have been helpful, and a recommendation that protocols for confidentiality and information sharing need to be given thorough consideration and agreed very early on.

The study itself was about an exceptionally sensitive topic, such that there could be an expectation that there may be difficult situations. There was recognition that the emotional labour involved in this work may be felt more by people delivering the work than by those advising, who were not in as close or constant contact. However, everyone seemed to know that they could ask colleagues for support, and made use of such support, for example with debriefing.

> *"we also debriefed after interviews as well, maybe 5-10 minutes in between on journeys from other places or where we came back together at the end of the period of the day, half day work a full day's work we debriefed. Any issues we raised them there, and then we also if we couldn't see each other we phoned each other"* [DG3]

> *"If somebody was having a bad day they would be supportive. "* [AG 1]

Emotional support seemed to be provided on this ad hoc basis as needed:

> *"I didn't feel there was a particular structure or strategy, I just felt that I was with people that I could talk to"* [DG 5]

Some people felt slightly out of their depth in providing support to others in this way as this was not their field. They highlighted that people becoming distressed or needing to take time out, impacted on their colleagues in an already stretched study, such that others then had to take on additional tasks:

> *"If I cannot do field work with somebody who is like you know really not okay you know I sort of needed more support with, what to do about that."* [DG7]

Consequently the professional expertise of the Principal Investigator and availability to offer this support was valued.
> *"The [Principal Investigator] was very much involved in taking a pastoral role. She's very involved in making sure they were ok."* [DG 6]

> *"I did find it helpful to talk to [DG colleague] about it immediately afterwards. Very helpful to talk to [Principal Investigator] the following day…… I was a lot happier for having spoken to [Principal Investigator]."* [DG 4]

But there was less certainty about any other institutional support that might be provided.
> *"access to counselling services …. I wasn't sure that was ever made clear"* [DG 6]

People were aware of their own boundaries and potential triggers and were able to take appropriate actions to maintain their own wellbeing through challenges, for example by declining to read transcripts. However, there were some situations where the impact could not be predicted, such as individual and specific interviews which were triggering for the researchers themselves. As might be expected, such situations had more impact on people with lived experience of distress/service use, who had a more in-depth understanding of the wider implications, such as a lack of available services for the person.

"But I also carried out of there this.. this just overwhelming feeling of tragedy that there was this extremely vulnerable person who was apparently getting no support" [DG 4]

Wanting the study to make an impact

Given people's personal interest and motivation to be involved in this topic, there was an interest in the outcomes and outputs of the study.

At the time of these evaluation interviews, the final draft of the report had recently been circulated but few people had felt able to read it thoroughly. The co-researchers had had opportunities to be involved in writing sections of the report, but not all had taken this opportunity. Members of the Reference Group and Steering Group had felt involved to some extent, and had valued the presentations given towards the end of the project, which they felt had given some insight to the anticipated report contents. But the report itself was large, and had arrived with an imminent deadline that did not fit with people's other commitments.

People trusted that the report would be thorough and useful. One person had already invited the Principal Investigator to give a presentation to a local group. They considered the report would be a
"reference document that you can dip into". [AG 6]

They hoped for events and other opportunities to share the information and findings. Some people wanted to be involved in dissemination opportunities including writing papers, but for others there was a realism that
"the project has ended and the contract has ended. We have all got to go on and make a living. To be involved in disseminating something that is like a year after they have taken part in it and they are now working in three other jobs or whatever is going to be really really challenging and I think that it would be really difficult for people to play an active role in that when they have actually moved on." [DG 7]

There were some concerns about the framing of the results into a specific agenda in order to make a difference. While relating to policy was understood as one way of ensuring impact, there were questions about whether the full findings would be heard. This final focus and narrowing down to reflect policy is in contrast to the rest of the process, where the study appeared to expand to bring in new ideas.

The team wanted the outcome to be more than a report that sits on a shelf:
"there's a kind of wish to let's get on with it, let's get something done, let's not keep talking, we've got a lot of research we want the action on it, is it going to go anywhere, where's it going to go," [AG 6]

5   Discussion

A challenge for us, in common with the participants, included that we had not read the final report. Consequently while some points have been emphasised above and included in our discussion here, these may already have been considered within the study's final report. For example, the experiences of specific groups such as South Asian women or carers may have been included from the literature or from interviews which had not been seen by the participants in our evaluation.

There was also a lack of knowledge specifically about 4PI. We had anticipated that this framework might have been a thread throughout the study to ensure it kept to its original aims, but several interviewees were not aware of it, and some, although they were aware of it through other work, had not noticed it being used within this study. People, who were aware of it, did suggest that 4PI would have been a useful framework for the Steering Group to use to monitor involvement and hold the study team to account.

Consequently, we have presented the findings as themes across the interviews, and relate these themes to the 4PI standards in our discussion here.

5.1   Principles
The whole study team assumed a fundamental understanding of 'nothing about us without us' that created a culture based on shared values, and including leadership from people whose work was inclusive and inquiring. Many people on the team were familiar with this approach, with a long history and expertise in involvement, and they were open to the discussions and debate that are an inherent part of co-production.

However, when we asked questions about principles, we were often met with responses about purpose. There seemed to have been little discussion about these core values to ensure a shared vision that was inclusive for people without a background in mental health activism and involvement. This might reflect a reluctance or lack of knowledge of values-based work, and would be worth further exploration in future studies. We suggest that explicit discussions about the principles of involvement might be a useful starting point in team-building.

5.2   Purpose
The team understood the purpose of involvement as ensuring that the research is grounded in and met the needs of people with lived experience of distress/service use. Involvement in research was suggested as improving the research by ensuring the right questions get asked, that the research doesn't make assumptions, and that a wider range of voices are included. The team were aware that people with lived experience can access knowledge that differs from that of traditional researchers without that experience: that they can offer a richer and deeper understanding of the topic.

The original consultations for 4PI suggested extending the purpose of involvement to include the promotion of recovery and challenging stigma and discrimination. These ideas were not explicitly mentioned in our interviews. This may suggest that involvement in the context of research may have a different focus to involvement in service improvement. The focus of involvement in research may therefore be a useful topic for further discussion on purpose at the start of any research study.

5.3   Presence
On first questioning, people felt that the project had been inclusive and diverse, with a genuine emphasis on involvement that was to be applauded. Involvement had taken place from the start, although not everyone was aware of people's involvement at the design stages or of specific recruitment processes. Of particular note, was the expertise brought to the steering group by a Chair with extensive experience and skills as a Black woman with her own experiences of mental health services including caring responsibilities, and also the visible differences of ethnicity and disability within the team. Diversity was a key value

of the leadership who placed an emphasis on including a range of people and used language which was inclusive and not academic.

However, within the boundaries of any limited project, it is not possible to include representation from every sector of the community, resulting in looking to the standard list of protected characteristics when thinking about who should be included. While this is essential, further thinking about the relevance to the topic might highlight a more nuanced selection process. For example a group considering the meaning and understanding of a crisis experience might have suggested involvement of people with specific experiences such as self-harm, substance use and peri-natal (while acknowledging that some experiences may have been exclusions within the study design). The 4PI report suggests such an analysis of the population under consideration should take place at an early stage of a project to ensure that the involvement activity reflects the population.

This is also reflected in participation within the study itself. While there may be good intentions to reach out to a diverse range of communities, it may be more realistic to set boundaries for an initial overarching sweep of a topic, and ensure that a range of follow-up studies are able to explore specific communities in closer detail. In relation to this crisis project, it would clearly be interesting to explore the variety of approaches to crisis within communities of various heritage and including refugees and asylum seekers, but inclusion of all such communities went beyond the resources of this study. The question then becomes about who is included and excluded, and where the efforts for involvement are targetted. And then about who makes that decision and how. This was not explicit within this study.

Within this study, carer involvement was seen to be weaker, but further discussions revealed that carers had been included, although, for some people, their primary identity was as a service user. People said they didn't know what experiences others brought to the group, that people didn't wear a badge of 'carer' or 'service user', and, for some people, that they felt daunted by others with more (or more professional) experience.

This leads us to question how the group can ensure that all experiences get heard. For example, it is a common experience that carers' views get lost with a focus on service user experiences, such that advice is often to hold separate discussions. This feeling of not being heard was mentioned across different groups and could perhaps be avoided with careful and conscious Chairing or meeting agenda. Additionally, there may need to be some consideration of disclosure, and how people are enabled to speak from their personal expertise. This may potentially be a training opportunity.

The study is to be congratulated for the breadth of involvement opportunities offered across the project. Co-researchers brought a range of academic, activist, and lived experience of distress/service use. The Reference Group was inclusive of people who were new to research. And the Steering Group brought in people with a range of expertise, at a national level and inclusive of experience of distress. Black African and Caribbean people, a group disproportionately impacted by use of the Mental Health Act at times of crisis, were represented in each group. An observation is that the academic team were wholly white. While this is balanced by the involvement in all other parts of the project, it may say something about power and University recruitment processes which privilege traditional academic experiences and exclude the knowledge of diverse communities.

5.4 Process

Process includes all the steps required to involve people throughout the project from start to finish, from design and recruitment through to report writing and dissemination. The 4PI report specifically emphasises the headings 'engagement, communication, support and training, and practical issues' (p.17), but it does not discuss who should take ownership of these elements of process within any project that might aim for co-production.

This research study was a large project with a culture of substantial involvement. However, participants shared a lack of clarity about the processes involved. Ownership of the study was seen to lie with the Principal Investigator, with the team looking up to them for explanations and a lead rather than co-producing solutions themselves. This expectation of leadership was perhaps related to personal qualities and expertise, with people recognising the reputation of significant previous work in this area. People valued the work of the Principal Investigator, could understand the range of responsibilities, and had an awareness of the potential complexity of 'behind the scenes' work needed to support the project. Furthermore, the model of involvement was seen as good practice as part of a nationally funded and large scale research study, focussed on specific outcomes detailed in an initial proposal to which the Principal Investigator is personally responsible.

However, the lack of clarity felt by participants, as they looked to the Principal Investigator for leadership, seemed in contrast to other projects where ownership of all the processes associated with involvement might be explicit, visible and shared, and all team members fully aware of the details. This may reflect the complex nature of this project which reacted to ongoing demands, and also the limits of resources, where participants described not having time to be more closely involved. Overall, this mirrors priorities for different funders where, for example, a full cost recovery approach might recognise the resources and risks of the process of involvement, thereby ensuring that participants have sufficient time for development, in comparison to funders who are more outcomes-focussed.

With projects that are more closely aligned to co-production, we might expect to see an alternative model of leadership such as an inverted pyramid with the Principal Investigator actively and explicitly supporting others to success in their own roles, thus optimising communication between members so that they are more agile, responsive and creative. Clearly, this happened in this project to some extent. However, for this to work successfully as co-production, funding needs to recognise the extra time and complexities of this model, and support the team to work in this way.

Across the teams, people said they would value more clarity, particularly at the start of the study, to include job descriptions and procedures, and also the opportunity for whole team meetings to gain a broader understanding of the scope of the study. Many participants voiced their confusion and lack of clarity about expectations, although many suggested that, given the time period since the start, they may have forgotten details. Additionally, in a large study, especially one with boundaries around personal confidentiality, people only see the parts of the study that are specific to them. They may therefore realistically be unaware of decisions or activities that are outside of their remit. However, we became familiar with the range of documentation supporting the study, including role descriptions, recruitment processes, terms of reference and protocols, and acknowledge that we may have been asking for reflections about information that had become less immediately relevant to individuals as the study developed. There is a challenge of being provided with the right amount of

information at the right time in the right way. The group might need information provided in a variety of ways, to include presentations and team meetings as well as written documents so that the information becomes meaningful to everyone.

This demand for clarity and certainty needs to be balanced against the flexibility to adapt to changes required or recommended by the involvement. This study had reacted to learning, with changes to processes and procedures which may provide valuable learning for similar projects. But this emphasis on clarity and certainty, creates a tension for any project with significant involvement, which would still need the capacity to adapt to ongoing learning and emerging findings. The need for flexibility should be made explicit to everyone at the start of involvement.

As the study grew bigger, it became clear that it required more admin support. Every decision to increase the number of people involved has a consequent impact on admin time beyond straightforward details of creating and distributing minutes of meetings or making travel arrangements. People involved in involvement work may be on benefits, or have requirements around disability needs which require an increased amount of admin support. There may also be people with issues around passports and right to work, as well as the challenges of the university bureaucracy when employing people who are self-employed or on short term contracts. With increased numbers of people, there is also a growing demand of ensuring communications across the team. People praised the admin support, but suggested that more resources were needed for this element of the study.

A framework of considerations for process is given, as mentioned above, in the 4PI report and we emphasise the relevance of these factors to involvement in research. In addition, we would emphasise the need for training for all parties, including academic partners, to develop a shared understanding specific to the study and including involvement. For example, academic partners may have additional responsibilities because they are working alongside less experienced researchers, and require consideration for specific processes or procedures. Additionally, researchers from less traditional backgrounds bring specific expertise which could be valuable in developing procedures and learning.

5.5 Impact

Participants were very clear about the positive impact of involvement within this study, pointing to specific areas where service user and carer involvement had influenced development of the study after funding had been secured.

Impact could be witnessed on many levels:

Impact of involvement on the study itself:
- The team discussed and amended the definition of crisis to meet service user understandings of crisis over a period of time rather than a unique event
- The team redesigned the study to include re-interviews so that people had a second interview where they could offer more reflections, again related to the definition of crisis
- The funders increased the funding for the study to allow the repeat interviews
- Team members brought specialist knowledge and contacts/networks into the study to enable access to contact with specific communities

- People who were involved suggested they 'chewed things over' and challenged ideas to give a richer understanding for the study
- Some people felt they had influenced the final report

Impact on the individual people involved:
- People made long-lasting friendships and relationships
- People with experience of distress gained in confidence, and were pursuing academic opportunities
- Academics had an increased awareness of service user and carer experiences and views
- Academics had an increased practical understanding of involvement and co-production beyond anything provided in a text book
- People witnessed that interviewees felt more comfortable speaking to someone with personal experience of crisis services
- People also witnessed that interviewees with a professional role were challenged rather than giving stock answers

Impact on the impact of the study:
- While the study would have an impact without involvement, it was felt that involvement had improved the final report which in turn would increase the impact of the study
- People involved in the study felt very strongly about the need for this project and therefore are more invested in ensuring that the results are disseminated to influence future service provision

However, these positive impacts of involvement also created some negative impacts as the study grew, increasing pressure as it reached its deadline. Involvement situated within different groups across the study caused delays because of the timing of seeking agreements and permissions from the different groups. The new knowledge contributed by people with experience of crisis expanded the remit of the project, requiring an additional ethics approval process. The increased levels of involvement created additional pressure on the finite resources available for admin support. Involvement in dissemination which occurs after the end of the study may need to be funded separately.

The work of people with lived experience of distress/service use can be 'emotional labour', with additional stresses where they take a liminal position between service user and academic. Additionally, for this study, the academic team also contributed emotional labour in their support of colleagues. There were some comments, such as that academic researchers were uncertain about how to provide such support for co-researchers or felt that they had to provide more support than anticipated. In other settings, where people with lived experience of distress are well-supported in their employment, their time off due to sickness is no more than other staff, and they often take less time out because of their self-awareness and organisational support. We question the potential pressure on colleagues to support each other through absences, and whether there is anything different about academic settings in general, whether there was something specific about this study, including the nature of the topic of the study, or whether this was related to the specific group of people.

5.6   Beyond 4PI

We felt that three factors should be emphasised. These are already within the 4PI framework, but we felt could easily be overlooked. We recommend to NSUN that these three factors might be useful additions to the framework.

Planning

Planning lies within P of 'process' of 4PI. However, we felt that the emphasis on the requirement for clarity suggested that planning is an essential component that would benefit from singling out for emphasis.

Specific details that were considered helpful about planning included:
- clarity of roles, including specific responsibilities such as for Chairs of groups
- clear recruitment processes including role descriptions and expectations
- ensuring that involvement is included at all stages of the study from initial concept
- understanding of the population for the study to enable planning of diverse representation
- resourcing for admin arrangements
- clear procedures and processes for support and for risk assessments
- timings for meetings that support people's travel arrangements
- environment for meetings
- prompt sharing of minutes and paperwork for meetings

Progression

Progression can include training opportunities which are also included within the P of 'process'. However, it also includes opportunities for progression once a project is complete: the 'what's next?'. People who are introduced to research through involvement in studies, can find this whets their appetite and they want further opportunities. The academics involved in a study face similar issues with short term contracts, but they have an established CV and qualifications to take them through a career path that might not be available to people who participate through an involvement route.

We did not ask about pay scales for involvement, but we recognised that people brought a range of expertise and were employed in different roles. We were unclear about the progression from the potentially liminal position as co-researcher to the more established role of academic researcher. Acknowledging that they each brought equally valuable expertise to the study, we would recommend further consideration of whether these two positions should be equally valued in terms of payment and contracts.

Power

Power is fundamental to 4PI. In this study, it was notable that some people, at some points, felt unable to share their views, opinions, knowledge and contacts. Despite the underpinning aims for co-production and equality, in practice it can be challenging to ensure that people feel empowered to join in discussions because of the assymetrical relationships due to power differentials. This is an ongoing challenge beyond the boundaries of this study.

The work of the team was highly dependent on the values of the Principal Investigator. However, where we initially took the model of leadership to be a central and traditional model of top down leadership, but using shared values conducive to co-production, we came to an understanding of a leadership model based on an inverted triangle, with a role to provide sufficient resources, communications and boundaries to enable others to complete the work. However, we acknowledge above (in the discussion of Process) that working in this way requires additional and flexible resources.

Explicit consideration of empowerment might further extend this model to bring the work nearer to true co-production, with a longer term aim to consider service user and carer led work.

Additionally, it would also be worth considering the format for meetings and for involvement to encourage new or more creative ways of working that might move away from a traditional meeting agenda to hear a wider range of voices.

6   Limitations

While the invitation to interview for this evaluation went out to everyone, only a limited number of people responded. There is the potential that people who were less, or more, satisfied with their involvement did not speak to us.

7   Recommendations

For this project:
- Compile and share the learning of involvement arising from this study where involvement was seen as a success
- Consider follow up interviews with people who have been involved in this evaluation to uncover the longer term impacts of involvement

For future projects:
- Use 4PI as a framework for planning, monitoring and evaluation of involvement
- Enable regular whole team meetings, including at the start, mid-point and end as a minimum
- Recognise the added requirements for administration support and resource accordingly
- Ensure there is evaluation of involvement, including longer term impacts, and including the impact on participants of the study (the people who were interviewed by co-researchers)

For funders:
- Recognise the resources required for thorough involvement and resource this appropriately throughout all funded studies
- Resource evaluation of involvement, as described above to include longer term impacts and impact on participants (the people who were interviewed by co-researchers)

8   Concluding remarks

During this evaluation, participants spoke positively about the consistency of service user and carer involvement throughout the research project, the equal opportunities for involvement, the meaningful nature of involvement in all aspects of the research process and the avoidance of tokenism, the recognition of the value of experiential knowledge of distress/mental health service use, as well as the flexibility of involvement. Evaluation participants also highlighted the inclusivity and diversity of the crisis care research project acknowledging the constraints with regard to the 'representativeness' of involvement. Even though evaluation participants indicated that they would value more clarity with regard to job descriptions and procedures, this need for further clarity appeared to be counterbalanced by the genuine nature of involvement and the increased oppor-

tunities for learning the research project afforded. Finally, evaluation participants were very clear about the positive impact of service user/carer involvement within the crisis care research project – impact on the research project itself as well as on the individual people involved.

As survivor researchers who have been involved in similar projects for many years, we would suggest that people from traditionally disempowered groups can feel very grateful for any involvement work that enables their voice to be heard. Consequently immediately after a piece of work, they hold very positive views, with limited reflections to offer a constructive critique. Just as this study heard that people have changing views of crisis and that repeat interviews would be useful to gain a more nuanced understanding of crisis over time, we would suggest that the same is true for people's experiences of involvement. We recommend follow-up interviews with the participants of this evaluation to understand the full impact over time.

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