

Meaningful Engagement with Real People

A case study on how lived
experience can be included in
research reports

Overview

The purpose of this case study is to describe the approach taken by the National Child Mortality Database (NCMD) to engage with charities and those with lived experience of an issue. NCMD considers it essential that the voices of those with experience of issues relating to child death are heard within our programme of work.

The case study will be of interest primarily to three groups of people, and it is organised by the perspectives of each of these groups in the partnership. They are:

- those wishing to undertake work in the patient and public involvement (PPI) space,
- charities who may be approached to collaborate in PPI workstreams; and
- individuals themselves who may want to share their experience of an issue or may be approached directly and asked to do so.

The Approach

The NCMD Approach to patient and public

Collaboration

- **Identify experts in the field you are interested in.**
- **Remember that people can become experts either by personal experience, professional background or both.**
- **Have a clear idea of the purpose of including lived experience in your project and communicate this to all collaborators early on.**

engagement is based on the following principles:

1. Collaboration
2. Flexibility
3. Respect
4. Closing the loop

The case study below focuses on how this approach worked in practice for a specific PPI project. The project was to include lived experience in a thematic report on suicide in children and young people, however it is important to note that the approach described below can be applied or adapted for other outputs from PPI workstreams.

Our aim

When the NCMD team set out to write our thematic report on suicide in children and young people, we knew immediately that we had to help people to really understand the impact of suicide on families and the impact of suicidal thoughts for children and young people. One of the main reasons for this was to play a part in reducing the taboo around discussing these issues in the public domain. They are certainly not easy things to acknowledge and discuss, but nothing and no-one is helped by brushing these issues under the carpet and hoping they will go away. That being said, we were also aware of our strong duty to conduct these conversations sensitively and responsibly and to ensure that we do not inadvertently cause more harm in doing so.

NCMD perspective: Vicky Sleep, Programme Manager

So, having decided that this was our goal, how do we go about achieving it? The first and most important step is **collaboration**.

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We recognised that we could not achieve this alone and that those who were experts in this area, either by personal experience or by professional background, must be involved in developing and directing our process from the outset and in a meaningful way. Our first step was to contact PAPYRUS Prevention of Young Suicide and to invite them to join the working group for this report. One of the key principles of the work of PAPYRUS is to influence change at a national level and to contribute to suicide prevention strategies, ensuring lessons can be learned and implemented to help save young lives. This meant they would be well placed to advise who else we may need to join our collaboration.

Once we had identified that there were people who were willing to share their stories for our report, the next most important thing was to be **flexible** in our approach. I think the sensitivity of the topic helped to highlight the importance of flexibility and perhaps my own anxiety about ensuring that our collaborators were properly supported to contribute kept this in the forefront of my mind. Flexibility became a thread that ran throughout our work together and from my perspective, it was this feature that helped to create and

maintain a positive experience for everyone.

The first way in which we wanted to achieve flexibility was to not be too prescriptive about what we wanted in terms of content, word counts and detail. It was very important that our collaborators felt that they could express their stories in the way that felt most authentic to them. So, our initial communication to PAPYRUS gave brief details about the kind of thing we were looking for. This was helpful for one of the contributors, but for the other, we needed to provide more detail about what we were looking for to ensure they had everything they needed to be able to contribute fully. It was not a “one size fits all” approach and responding to the individual requirements of each contributor





was essential in achieving meaningful engagement.

Respect might sound like an obvious necessity, but experience has shown us that sometimes it is so obvious it is forgotten. Often when writing reports or other communications, I think people become very focused on what they want from the report and what is useful to them and can sometimes forget that those sharing their stories are giving something enormous of themselves. Sharing your experience in the public domain is brave. For us as authors of this report, I wanted to acknowledge that

Flexibility

- **Recognise that lived experience remains the experience of that individual**
- **Ask what way they would like to provide their story e.g. written or verbal**
- **Ask whether they would like support to tell their story, and consider which of the collaborators is best placed to provide this**
- **Consider drafting some questions to help guide people to tell their story**

and to achieve a balance between having something we could use and respecting the description of life experiences provided by our contributors. In addition, we knew that our report would carry a high public profile because of media interest in mental health issues and suicide, particularly during the pandemic. It was essential that our collaborators knew that we were expecting a lot of public interest in the report so they could make an informed decision about what level of anonymity they wanted. This meant we could support them to remove identifiable details or change details to ensure they were comfortable with what was included.

In practice, this meant that NCMD did not edit what was written by our collaborators at all. When you are asking someone to write about their lived experience, everything they include is important to them. If you want something shorter or more specific, it is better to ask for answers to a list of questions and then construct a piece of prose yourself using the answers. In our piece of work, we used both of these approaches.

The first collaborator, Ray, was supported by POPYRUS to write his story.

For the second collaborator, who wished to remain anonymous, we drafted a short list of open questions to give a bit more guidance on the kind of information we were looking for. It was important that the list was short, so it did not feel like a burden on the person answering the questions. Careful drafting of the questions means a

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lot can be revealed in a few answers.

1. What was your life like before you started to experience challenges with your mental health? (for example, think about what you enjoyed doing? how you spent your free time? what were your dreams/ambitions?)
2. How did you first become aware of your mental health challenges? (for example, was there a specific event or events that happened? Was it something that happened over a period of time?)
3. Were you able to talk about how you were feeling with anyone? If you did, what was that experience like for you?
4. When you started to have suicidal thoughts, what did you do and how did you get help?
5. What is your life like now? (what are you doing? what are your dreams/ambitions now?)
6. Lastly, if you have any advice for a young person who might be going through something similar, what would it be?

Finally, when it comes to **closing the loop**, the most important thing is recognising that the involvement of your collaborators does not end when you have received what you want to include in your report. They can and should have an opportunity to review the whole report if they wish to. Not only does this provide them with the chance to see their story in the context of the whole report, but it gives them an opportunity to read the rest of the report and give their feedback and reflections on the other parts of it. This validates their experience and

acknowledges the value of their personal stories.

We wanted to give our collaborators the opportunity to review the report and provide their feedback in whatever way was best for them. The report itself contained confidential and sensitive data so we needed to ask them to sign confidentiality agreements before we could send it over. This was done by email and the report was then sent by email to POPYRUS.

The report was shared with each volunteer, and 1:1 sessions with POPYRUS provided an opportunity for clarification, processing and feedback. Once this had occurred, we worked to establish a date with the NCMD where we could have a shared conversation regarding the content and experience of the process.

We agreed that the best way of receiving feedback would be to arrange a video call so the collaborators could ask questions and give any comments. This was a wonderful experience from an NCMD perspective. Having the opportunity to hear their thoughts and understand what stood out to them in the report was helpful, but the most important thing was to be able to personally thank them for agreeing to share their stories in the report and to explain to them what would happen in the next few months leading up to publication of the report.

PAPYRUS perspective: Imogen Capper, Volunteer Coordinator and Sarah Skelton, Head of Programme Development

PAPYRUS was founded on the personal experiences of loss due to suicide. Those experiences drove a prevention agenda, informed and driven by the desire for it not to happen to another family.

As organisations and professionals, we must recognise that whilst we hold knowledge and experience, we also have a position in relation to systems of power and privilege. Whether we mean to or not, in knowing this, we must proactively work on how to respond to this. In the instance of this report, we wished to ensure that a space was created to share the story behind the data, and to provide an authentic and honest narrative told by those lives that had been impacted by suicide.

We chose to work with our Volunteers who had been bereaved by suicide and experienced thoughts of suicide to show a breadth of experience in regards to the impact that suicide can have. The Volunteer Coordinator role was a key partner to the process. Through established relationships

between volunteers and the coordinator, we were able to identify volunteers who had a motivation, and willingness to share their story. Mechanisms available through the volunteer framework ensured that we were able to offer robust wellbeing support. This was an important consideration when inviting engagement on a subject that may cause emotional vulnerability.

What was important for all involved from the start was to ensure that the volunteers' stories remained their stories. As the outline intentionally wasn't prescriptive, we agreed it would be best to start at the beginning and write everything down that they were comfortable sharing and just went from there. With that, it was found that a lot of what was shared reflected what was in the report.

Having flexibility in the way in which we captured the story enabled us to meet the needs of the individuals who kindly agreed to share their story. Not knowing which method worked best required additional time, support, solution focused thinking and strong relationships to navigate the process. This was balanced against the fact that each party understood their right to

Respect

- **Remember you are asking a lot from someone to talk about difficult life experiences in the public domain**
- **Give them time to think about what they want to share**
- **Acknowledge and respect their experience and the way they choose to describe it**
- **Consider what level of anonymity they might want and how you can achieve it**
- **If they choose not to be anonymous, respect this right and ensure everyone is acknowledged accurately**
- **Offer them the opportunity to withdraw from the process at any time**

withdraw from the process at any time. Managing expectations was an important consideration throughout. Negotiating an editing process of a piece where every detail is so important to the story, against a backdrop of formal reporting was not straight forward. Relationships and partnership working were key to ensuring content remained authentic to the authors and matched to the needs of the report audience.

With Ray's story in particular, it is very much the volunteer's story but there is the story of Ben within it which is why we had to be conscious of what was shared as part of this story. This is because Ben's story is part of other people's stories and experiences and therefore, we had to be mindful of what is shared to preserve anonymity and other people's experiences.

We provided the second contributor with questions to help better understand their experience, but questions can also help break down the experience to make it easier to share, as often reflecting on these experiences can be challenging.

Lived experience perspectives: Ray, a bereaved father of Ben, 14 years old

I was honoured to be asked to contribute to this report. It took a while for me to fully understand exactly what I was contributing to. But I have a lot of trust in POPYRUS and will do anything I possibly can to help reduce young person's suicides. My only concern was whether I was the right person to be able to contribute.

When I was asked by POPYRUS to



contribute to the report, we discussed how I was going to compile my story.

I didn't want to be restricted to a word count, or only what happened to Ben, so we agreed for me to write it all and then go through an editing process and review with myself and Imogen.

I felt it was important to write about my experience and inner feelings of my suicide attempt, alongside Ben's death, and how, with these experiences I was able to help and support others.

When I presented my first draft to POPYRUS, it was proofread and edited. It then came back to me for approval via Imogen. I wasn't entirely happy with the edit due to some things, which were very important to me, being edited out. After a long conversation with Imogen, we compromised on some things, restored some parts back into the story, and she explained to me the reasons some parts had had to be edited out or changed. This I did find very hard, but Imogen was very

understanding and empathetic, and worked with me to come to an acceptable edit.

It was very important to me that Ben's name was used, so he wasn't just anonymised and thought of as just a statistic. I needed it to be known that he was a fun, outgoing, 14-year-old boy with feelings and emotions, and with a large circle of friends and caring family, and not just written off as another troubled teen, as society often misconceives.

I don't feel that the NCMD could improve the experience. It is a tough subject that hurts and leaves people sad.

At all times I was reminded by Imo that help was available through PAPYRUS on an emotional level should I at any time require it.

I explained to my partner about the report I was asked to contribute to. She offered her full support and gave me the space on my own, over a period of a couple of weeks, to write my story. We went through it together a number of times getting things into the right order and context. At times, committing my story to paper was a very

difficult and emotional undertaking.

Since then, I have read it on a number of occasions, and it generally fills me with sadness thinking about the different impacts suicide has had on my life. At first, I wasn't going to inform Ben's mum, brother or sister about my participation in the report, as we are all at different levels of grief and emotions. I'm divorced from Ben's mum and at times the relationship is strained. But after chatting to Imogen and understanding the possible implications of the report going into the public domain, I informed my children and we all agreed they would tell Ben's mum. I had a message back from her to give me her full support.

The feedback sessions we're very helpful. The session I had with Imogen, Sarah, and Vicky gave me a chance to completely understand where my story fitted into the report.

It also gave me the opportunity to ask Vicky how the information and statistics were gathered and collated. Having read the completed draft report, I was shocked at the statistics on young people's suicides. There were no negative points in any of the feedback sessions. Overall it has been a very emotional task, but one that only good can come out of.

Closing the loop

- **Give your collaborators an opportunity to review the report when it is in its final draft**
- **Be flexible in how you engage them in the feedback process**
- **Answer their questions and incorporate their feedback where possible. If you can't, clearly explain why.**
- **Show your appreciation with thanks and, if possible, a token such as a gift voucher**
- **Explain what will happen between the meeting and the publication date**

Lived experience perspectives: An anonymous young person

Although I found it difficult to think back to a time in my life that feels very distant to how I feel now, it is something that is very important to me. I was keen to do something that may potentially help people understand suicide and give someone

“People hear statistics – but they feel stories”

Brent Dykes, author

struggling with suicidal thoughts some comfort knowing others have felt what they feel, and perhaps hope that these thoughts can stop and life can be enjoyable again. I initially struggled when trying to put into words how I felt, but after some guidance from PAPYRUS, I found it came together naturally.

I struggled at first with the openness of the question. It felt daunting and immense, and I found myself putting off writing anything down. But after some guidance questions, it felt more manageable, and I drafted out my response. I had some worries around the content of what I was writing. I was very aware that many people reading the report may be vulnerable, and I wanted to be sensitive.

I started the process of writing by taking time to think back to when I first started experiencing problems with my mental health. Reflecting on the circumstances around this was difficult at first, and my memory of this time was fragmented and patchy. I struggled most with remembering a time before my mental health deteriorated, as it took up such a huge part of my adolescence. I began going through each question and writing bullet points, then fleshing it out once things started flowing. The questions were really helpful in getting me to think about certain points in time and made writing it far less daunting.

The feedback session was a really lovely way of putting a face to the report and

getting a sense of the report as a whole and the huge collaborative aspect of it. It felt like I had contributed to something really important, and I am really grateful of the opportunity to share my story.

Conclusions

Reports can tell us the numbers and what that says about the problem we are trying to address, and that is very important, but including personal stories of people with lived experience enhances the data and this is often what people remember most.

Including personal stories in our reports is one of the things that really drives people to change things, but to do this in a meaningful way means following a few simple principles: collaboration, flexibility, respect and closing the loop. Understanding your request from the point of view of the person receiving it and thinking about their experience of collaborating with you ensures a positive and rewarding experience for everyone.

