Suicide Prevention Co-Production

A 2-year volunteer led co-production project

Contents

Background to Project

This project was funded to address challenges in suicide prevention work across West Yorkshire. Leeds Mind were directly funded by the West Yorkshire Health and Care Partnership with the support of Mind in Bradford to ensure coproduction was at the heart of suicide prevention across West Yorkshire.

All of our work around suicide prevention & postvention champions peer support and seeks to shine a light on the importance of lived experience.

Often in our front-line services, we see how service users are not fully understood and the impact that this can have on their support, their engagement, and the detrimental impact on every aspect of their life.

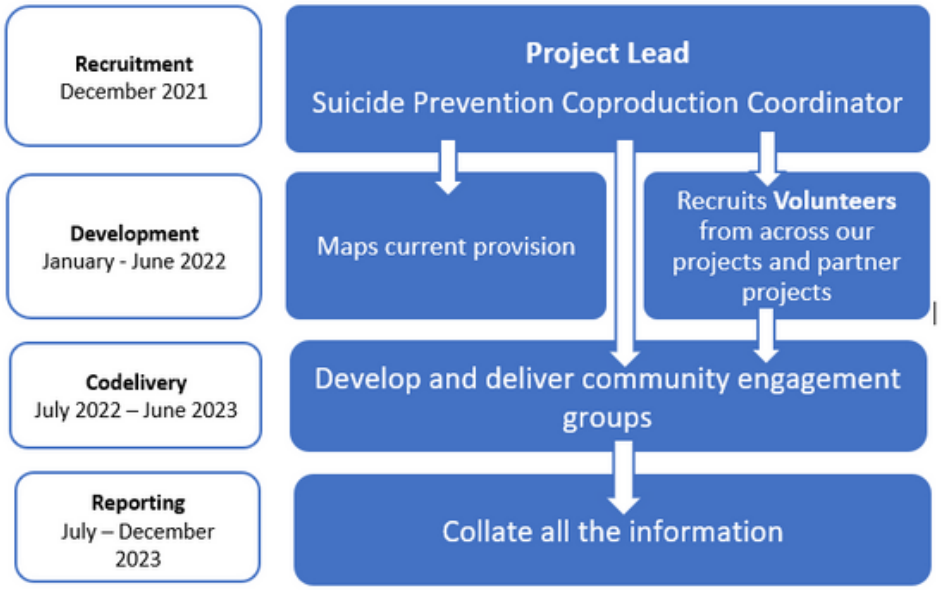
This project aimed to involve and empower individuals with lived experience of suicide in the shaping of system-wide changes in the West Yorkshire area.

It sought to champion co-production as a method for sustainable and impactful approaches to suicide prevention.

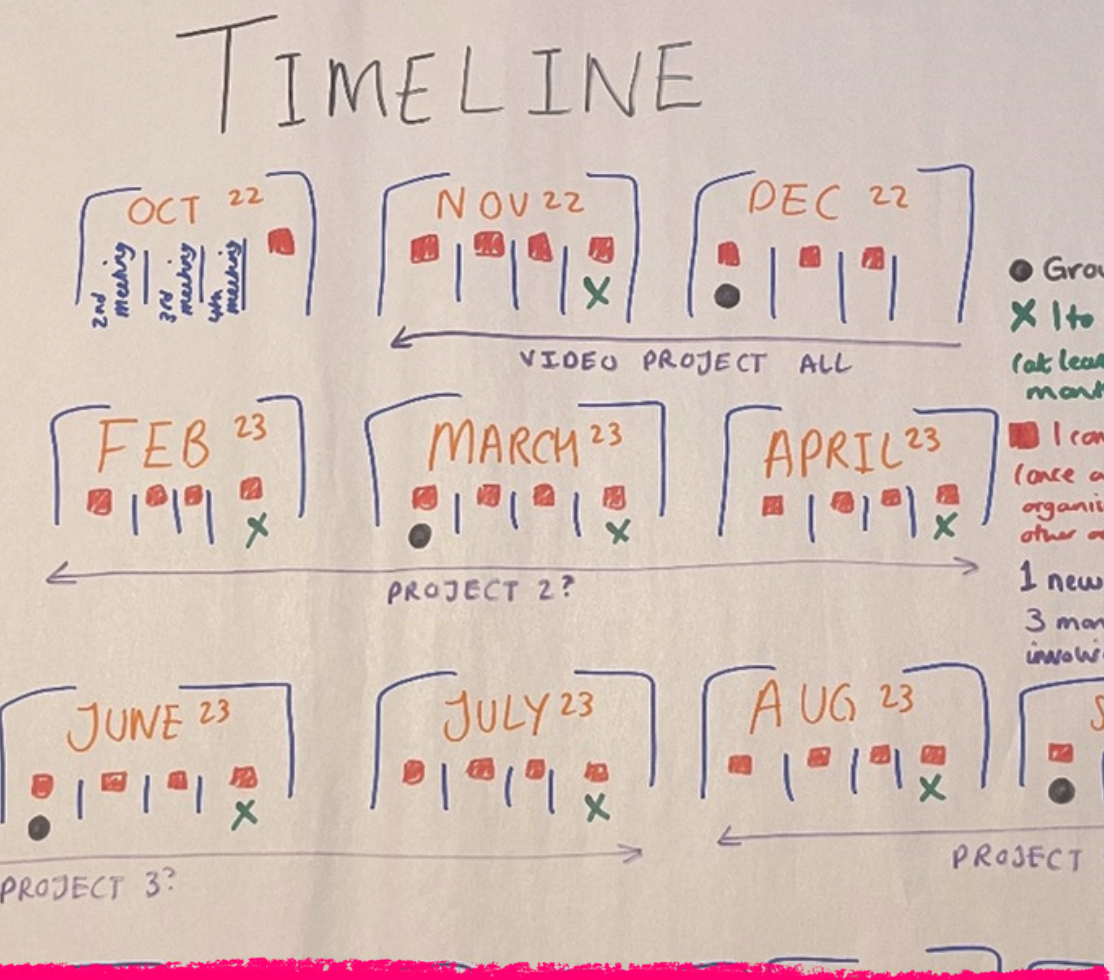
We aimed to make this happen through creating a series of smaller projects, resources, and partnerships. All our outputs will act as legacy pieces, that will continue to have an impact, long after the project's funding runs out.

Due to recruitment and appointment, the project started March 2022 which delayed the overall delivery of the project.

Planned delivery



The structure of the project was designed so that it would be a 'blank slate' for volunteers to design and deliver, in line with the overall project aims as detailed on the next page.



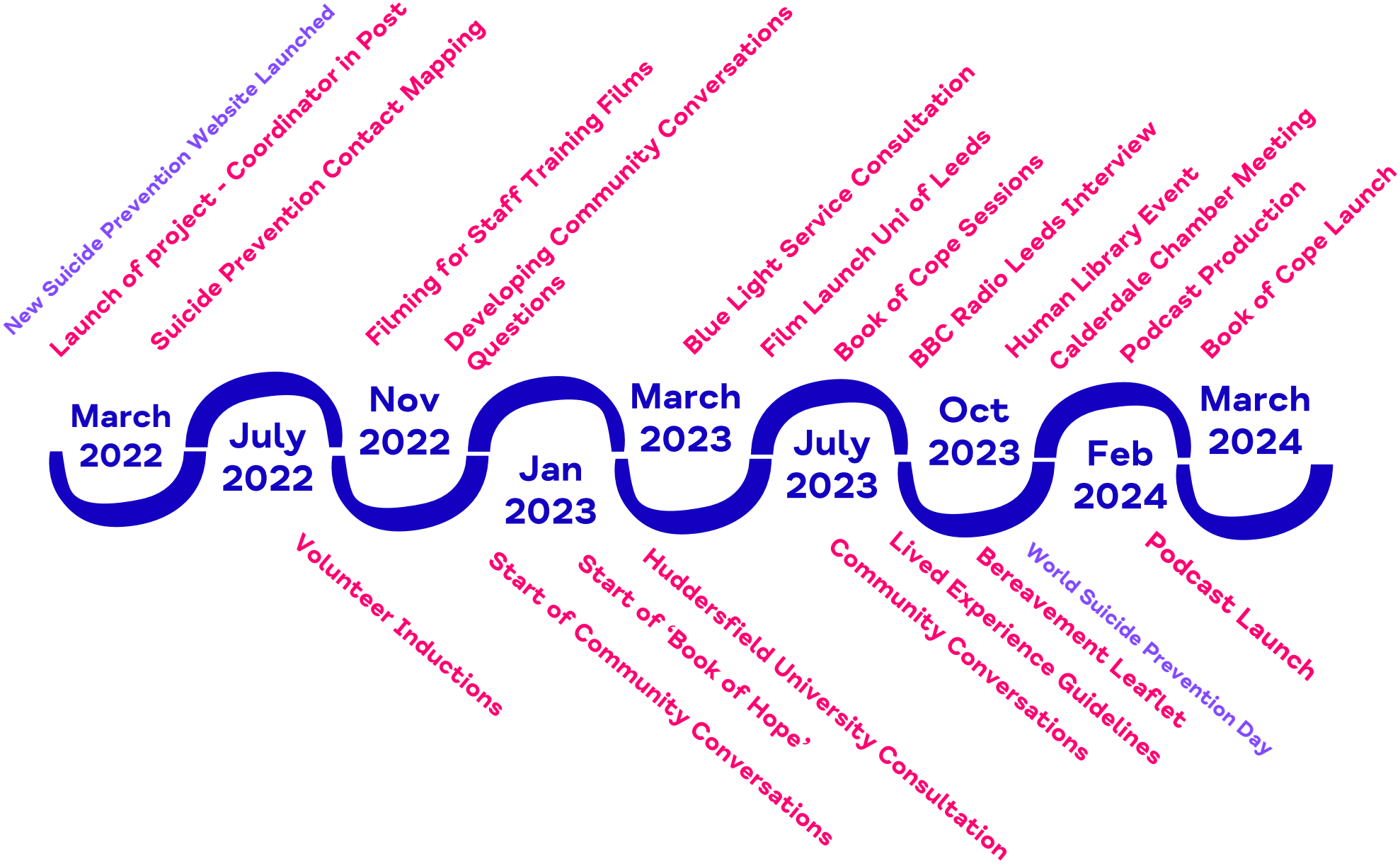
"I hope to achieve positive change for others; ideally, a more refined, one point of entry mental health system that doesn't adversely affect people's mental well-being, that is fit for purpose. But also, to raise awareness of suicide and get more people talking about it openly in conversation. The people who have had the courage to ask me about suicide are the ones who have facilitated me getting some more support. If everyone knows how to correctly ask about suicide and talk about suicide we could save more lives, which is the ultimate goal."

Our Goals

1. Reduce stigma around mental health and suicide.
2. Raise awareness.
3. Champion the voices of people with lived experience.
4. Challenge and influence decision makers to improve mental health support for clients and families.

Project Delivery

Contents



Recruitment, Induction & Support for Volunteers

The recruitment process happened throughout the project but initial recruitment took place between March 2022 and October 2022.

Volunteers shared that they felt well supported throughout the recruitment and induction process as well as the wider project work over the two years.

Volunteers received mandatory training, an induction and had options for further training and several development opportunities such as speaking at Public Health & Integrated Care Board (ICB) events.

We were flexible and open with volunteers with regards to their involvement, ensuring to make reasonable adjustments to the recruitment, induction and supervision processes.

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Recruitment

Volunteer roles were advertised via a range of organisations and platforms to reach a wide pool of individuals.

The recruitment process consisted of a simple application form and an interview with our Project Coordinator.

Volunteers had to complete a DBS check and we had individual conversations with applicants with criminal convictions.

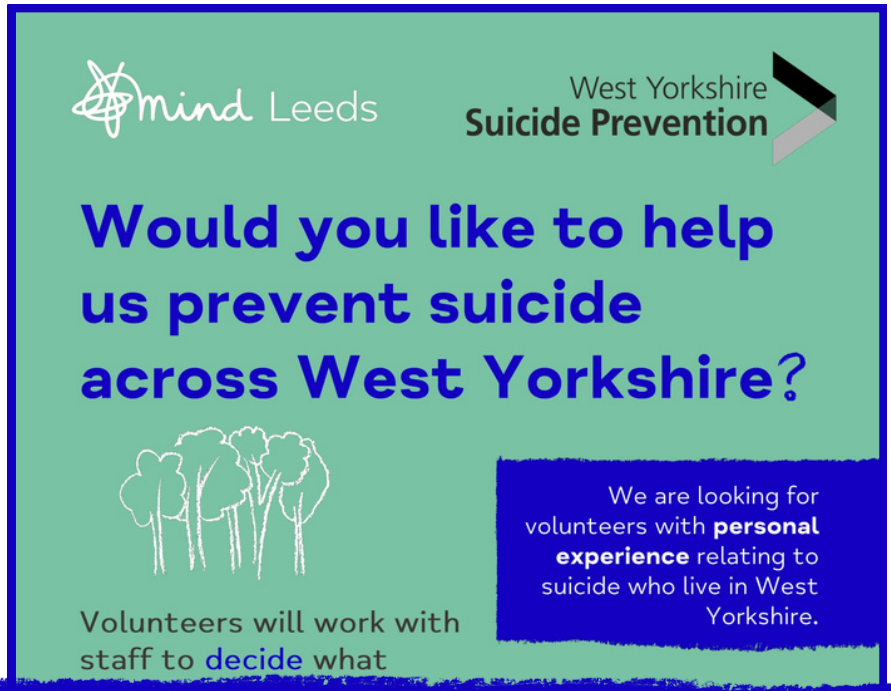
“The recruitment process was fluid, open, transparent, inclusive, empowering, and meaningful.”

“I quite liked that there was a short interview over the phone as this made it feel more professional and that I was really becoming part of something desirable to be involved in.”

One volunteer with a criminal conviction fed back that the discussion was made comfortable and supportive by our coordinator.

There were an additional 32 people who expressed an interest in the project but we did not have capacity to take them on as volunteers.

Read original volunteer advert here



“It was smooth, easy and comforting. It's my first volunteer role and i had been out of work due to disability for roughly 3 years prior to joining the project. I was made to feel welcomed and valued . Easily the most pleasant recruitment process I've ever been through.”

Induction & Support

Volunteers on this project completed the standard Leeds Mind Volunteer induction.

This includes training on Mental Health Awareness, an Introduction to Leeds Mind, reading through our policies and completing mandatory online training.

We offered adjustments to these initial processes through online options for training and induction.

Our coordinator offered reasonable adjustments and created an adapted version of the Wellness Action Plan for the project. They completed these with volunteers to ensure we were aware of any support and wellbeing needs throughout.

Volunteers were offered one-to-one supervisions every three months to review their progress and discuss any support or wellbeing needs.

“‘I’m really impressed with the organisation and how inclusive it is’ and ‘we are made to feel important and valuable. Volunteers aren’t just on the periphery’.”

Involvement

At the time of finishing the project, we have 14 active volunteers who have been engaging in ways that have been meaningful and accessible to them.

We met as a project team on a fortnightly basis to discuss ideas and offered hybrid-style meetings to make the project more accessible, especially as volunteers were living across different parts of West Yorkshire.

Volunteers were reassured throughout the project of our flexible approach and that they could contribute in whichever format and frequency that was most accessible to them.

As many volunteers worked full time and struggled to attend meetings during the day, we often did engagement activities outside of normal office hours.

Several individuals applied and/or were also involved during the early stages of the project but at some point felt that they needed to take a step or leave the project.

Our project coordinator has also offered extra IT support to volunteers who need it, to make sure the use of Teams is a comfortable experience for them.

Leeds Mind has been flexible with expenses and have lifted the travel renumeration limit, to account for the project covering West Yorkshire.

“[Our coordinator] was very personable, explained the project well and very mindful of individual circumstances/ toll”

What prompted you to get involved?

> “As soon as I heard about the project, I knew I wanted to be involved.”

> “ I have been a victim of the incredibly underfunded, understaffed, and ill-equipped mental health system that currently exists. I want to be able to use my experiences to create positive change in the hopes that fewer people have to go through some of what I have done in the last few years.”

> “I also felt that I offered a unique perspective, as a family member of someone who has struggled, rather than having directly struggled myself.”

1. Using our lived experience connection to suicide to help others
2. To create positive systemic change, particularly at a local level
3. To avoid & prevent anyone else experiencing similar challenges
4. An opportunity to talk to and work alongside others with similar lived experience
5. To use free time and give back
6. To work on a project that champions and prioritises lived experience voices
7. To contribute to reducing suicide rates

Many of us knew that we 'immediately' wanted to be involved as the subject 'resonated with us' and was 'close to our hearts'

"It felt important to me to get involved in a project that prioritized the lived experience of those who have struggled with suicide to raise awareness and hopefully contribute to lasting, positive changes to the mental health system across West Yorkshire."

"Having being bereaved by suicide, I experienced a trauma like no other and the 'average person 'could not comprehend... I also wanted to see changes at local level."

"I have lived experience of an attempted suicide and have found it difficult to talk to anyone about the subject as most people do not want to discuss it, so the idea of meeting people who had also lived experience and were happy to talk about it, felt like a great opportunity for me personally."

Diversity of Volunteers

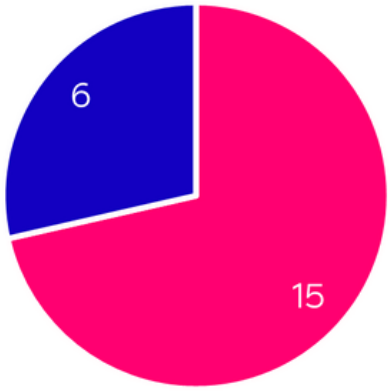
At the time of finishing the project, we had 14 active volunteers and across the course of the project, there were 22 volunteers involved in total.

There was one volunteer we did not receive diversity information from so they are not included in the following graphics.

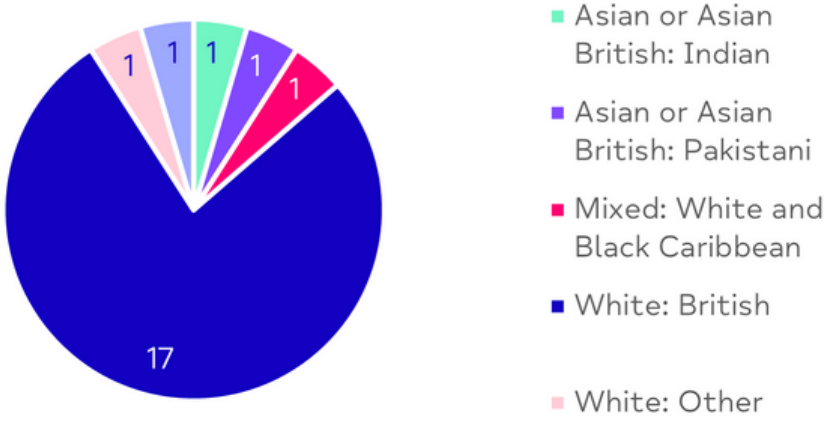
We have only included the categories which people selected within the diversity monitoring form, but we do offer wider demographic options on the forms.

Therefore, any options not represented here were due to not having anyone volunteering on the project from that background.

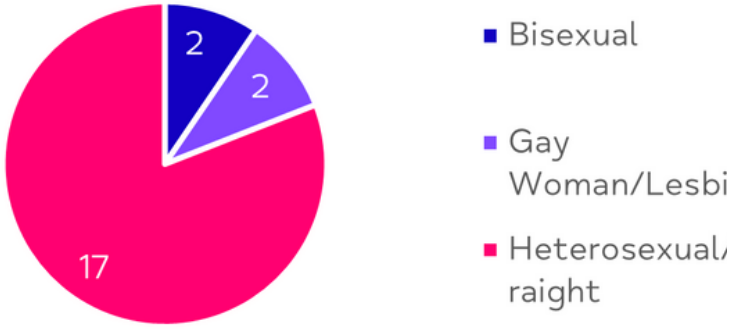
Gender of Volunteers



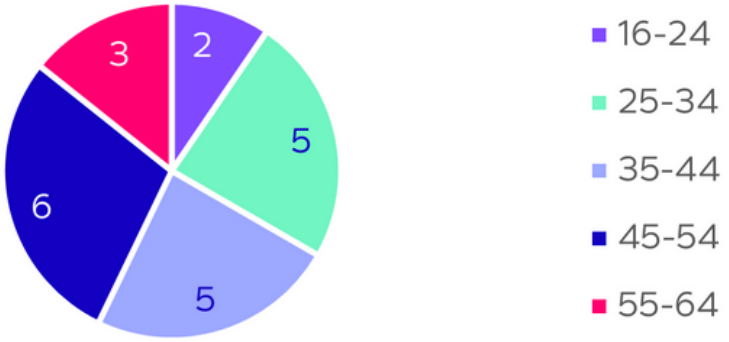
Ethnicity



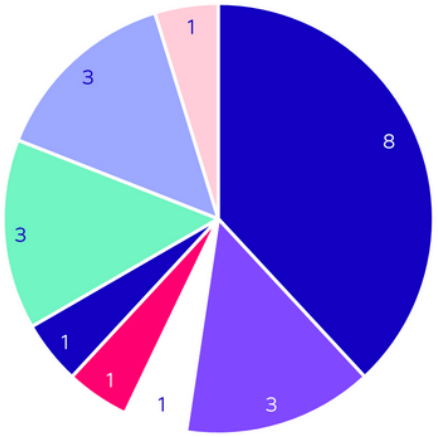
Sexual Orientation



Age Bracket



Employment Status



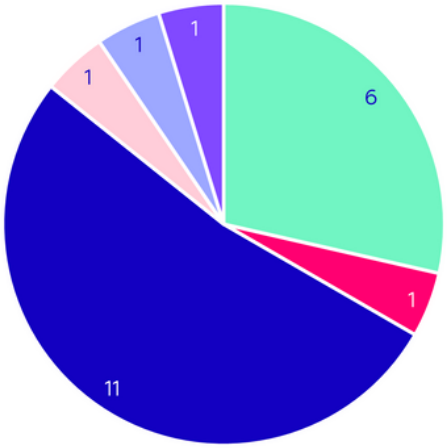
- Employed full time (35hrs+ per week)
- Employed part time (Up to 35hrs per week)
- Prefer not to say
- Retired
- Self-employed
- Student
- Unable to work
- Unemployed and looking for work

If we were to undertake this project again, we would like to increase the diversity of our volunteer group.

We would hope to do this through reaching out to various community and support groups that work with diverse communities to talk to them about the project and the opportunities

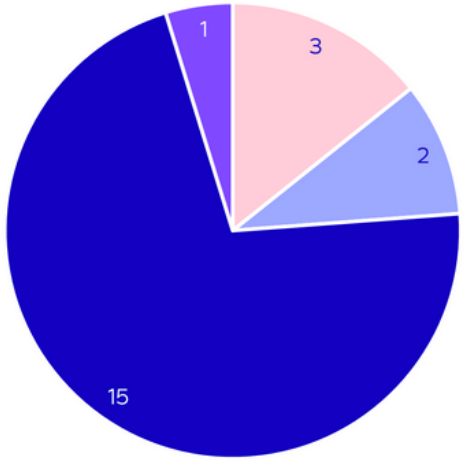
"I wish we'd managed to recruit a more diverse representative group, in particular more black and asian voices. I think this would have helped diversify the community conversations in particular. So it would be good to reflect on this and how it could be better in future."

Religion



- Christian
- Muslim
- No Religion
- Other/Prefer to self describe
- Prefer not to say
- Sikh

Other Health Challenges



- Health problems or physical disability (including sensory impairment)
- Learning disability (including developmental disorders)
- No
- Prefer not to say

Lived Experience

The majority of our volunteers were living in Leeds but with at least one representative from each of the focus areas of the project.

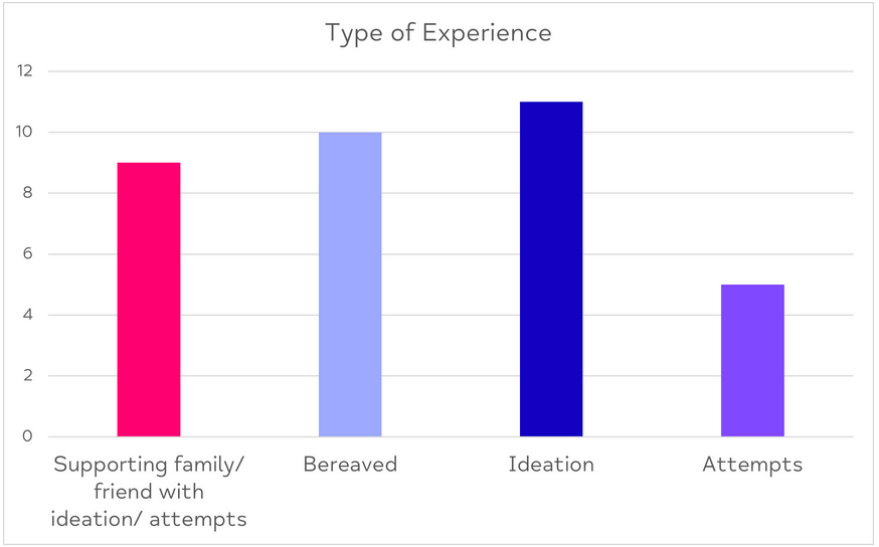
All of our volunteers had a personal connection to suicide which was one or a combination of:

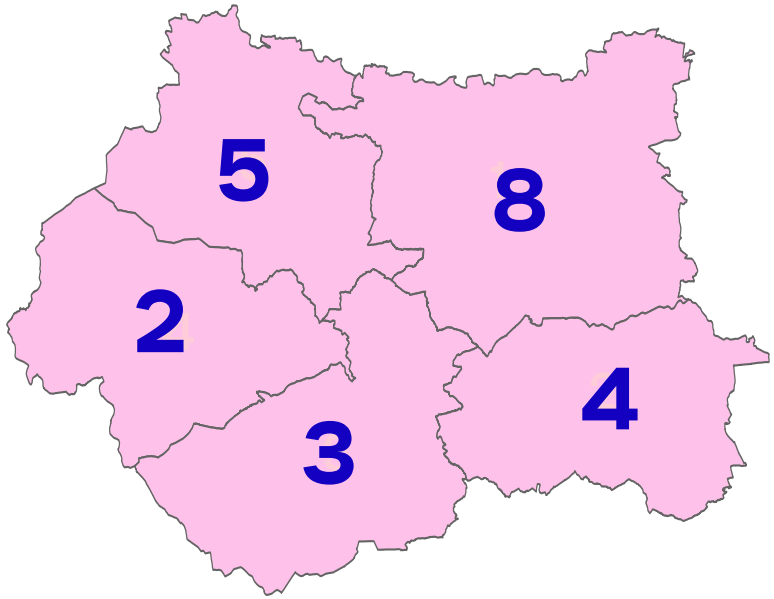
- Personal experience of ideation or attempts
- Bereaved by suicide
- Supporting a family member

Many of our volunteers have more than one type of lived experience.

We also recorded extra lived experience data due to specific risk factors around suicide. From across the project, this is the additional lived experience that volunteers brought:

- Having a mental health condition.
- Adverse experiences in childhood.
- Involvement with the criminal justice system
- Recovery from alcohol addiction.
- Surviving domestic/sexual abuse.
- Eating disorder.
- Neurodivergence.





Reflections

Diversity of Volunteers

Despite a diverse range of lived experience, our overall demographic of volunteers was predominantly from a white, heterosexual, and middle aged background.

While attempts were made to do some specific outreach into culturally diverse communities, LGBTQIA+ people and younger people, there was not huge success in this area.

Our wider work with communities through a couple of the projects aimed to address this but our overall reach was very similar.

With hindsight, our coordinator reflected that they would have invested more time into diverse recruitment, and fostering partnerships with organisations who work with these groups.

Attracting an even spread of volunteers from across the five areas in West Yorkshire has been a challenge throughout the project.

There was greatest representation from Leeds and Bradford, potentially owing to the lead partners being based in these areas.

Our coordinator paused applications from these areas and focussed on attracting individuals from Calderdale, Wakefield and Kirklees.

"I wish we'd managed to recruit a more diverse representative group, in particular more black and Asian voices... I think this would have helped diversify the community conversations in particular."

Mixing Lived Experience

There has been real value in having a variety of perspectives represented in the project.

We have people bereaved by suicide, carers of others and people who live with suicidal ideation and/or may have made previous attempts on their own life.

Whilst all united by the impacts of suicide, the actual experience of each volunteer can be very different. People who have made attempts for example, often came at things from a different perspective to someone bereaved by suicide.

Our coordinator reflected that some of our bereaved volunteers sometimes felt that they couldn't contribute in the same way.

This was echoed by volunteers who were supporting from the perspective of bereavement and is something that would require greater thought for any similar project work in future.

A conscious effort was made to always reassure them that their experiences and perspectives were valued, and what they had to say was just as valid.

"Working alongside volunteers who have lived experience of ideation, did help to put into context some of the things my husband might have been thinking"

Projects

Community Conversations

The ‘Community Conversations’ project aimed to capture people's views on what has worked well, what didn’t work and if anything was missing from mental health services and support.

We went out and spoke to local people across West Yorkshire about their experiences of accessing mental health support in terms of:

- What worked well
- What didn’t work
- What was missing

This was later supplemented by an online survey with the questions we formulated.

This has culminated in a written report which maps out the findings and makes recommendations for future care.

Contents

Inspiration and Aims

This was the first project that the group pursued once initial volunteers had been recruited and inducted.

This was one of the pieces of work that fitted really well with the aims of the project in terms of finding out:

- What works well?
- What doesn't work well?
- What is missing?

In terms of people's care across West Yorkshire.

"We wanted to capture people's authentic voices on the subject of suicide and suicide ideation."

The aim of the project was to hear a range of perspectives on how individuals across West Yorkshire experienced seeking support for their mental health.

We wanted these lived experiences to feed directly into a report which would showcase best practice and make recommendations for mental health support and care.

It was hoped that the lived experience responses would give authenticity to such recommendations, in order to encourage practitioners to make changes geared towards preventing suicide.

The goal was to reach 100 responses by the time of writing the report.

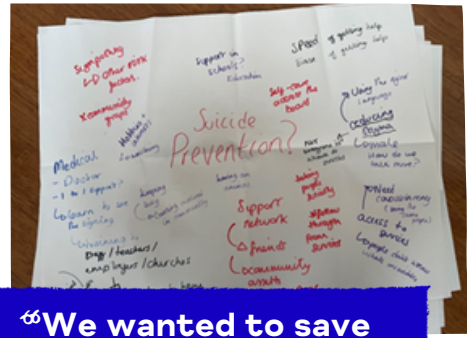
Initial ideas

Initial meetings focussed on forumalting the language of the questions being asked.

While initially discussions centred on people's experiences of specific 'mental health systems', this evolved into considering a more holistic view of someone's experiences of 'asking for help' due to a recognition that answers to preventing suicide do not solely lie within mainstream mental health services.

The group then had discussions around 'what is suicide prevention?' Initial thoughts surrounded service provision such as access to services, consistent staffing, staff knowing how to spot key signs, being curious and appropriate training for staff within mental health.

When encouraged to broaden beyond formal service provision, we discussed personal support networks, community assets (e.g. barber shops, nail salons) and self-care, education in schools, general wellbeing. These discussions were wide ranging and so the group agreed that 'suicide prevention can be all encompassing' and this was an important consideration for when having community conversations.



"We wanted to save lives!"

Formulating questions

The intention behind the survey was to produce qualitative data as opposed to tick box answers to be able to identify patterns and understand good practice and challenges at a local level.

Initial meetings were used to identify what language would be used within the three questions. The groups delved deeper into each of these themes to explore what they might ask someone. This helped us to refine our questions that we used, shown on the right-hand side of the page.

1. What worked well for you?

'What would make it comfortable for you to speak to someone?'

'What would support look like for you?'

'Where did you go to access support?'

'When you are struggling, what helps you?'

2. What was missing?

'When you needed help the most, what do you wish someone would have done?'

'Did you face any barriers to accessing help? What were some of those barriers?'

'Was there anything stopping you from asking for help?'

3. What could have been improved?

'Did you feel you knew where to go for support?'

'What would you change/implement to make accessing help easier?'

'Did you feel supported by people who were supposed to support you?'

'When you are struggling, what doesn't help?'

Questions

1 **When thinking about asking for help, what have you tried (if anything) and what do you feel worked well for you?**

Prompts: Did you have a positive experience with something in your local area? Did a specific person or organisation make a difference? Have you accessed any non-traditional support (for example, not through the NHS?)

2 **When thinking about past experiences of asking for help, what didn't help? Did you have any issues accessing help?**

Prompts: Did you feel any barriers when reaching out? What were they? Did you come up against any challenges with the support you received?

3 **Looking back, was there any help that wasn't there, which might have helped? Anything missing? Something you wished had been there**

Prompts: Did you think something was missing in the support you received? How could it be better? Was something that could have helped not available to you? Are there any changes you would make?

4 **Anything else you would like to add?**

Conducting the conversations

The approach to reaching different communities was co-produced over a series of meetings with some great suggestions around how to reach those who are more likely to have needed to reach out for mental health support.

The volunteers had ideas around approaching gyms and speaking with people at the food festival events used for fundraising.

> **"We discussed a questionnaire and believed that the best way of gaining trust and more in-depth answers was to have conversations with people with lived experience."**

When completing community conversation surveys in person and over the phone, individuals were given a brief introduction of the purpose and context of the project by volunteers so they could understand the context in relation to suicide prevention. They were also asked to complete equality monitoring data such as postcode, gender, age and ethnicity so that a greater understanding of risk factors in relation to responses could be understood.

The project later evolved to create an online version of the survey which individuals could fill out independently.

This online version increased the number of responses. It was also agreed that we would accept respondents from outside of West Yorkshire as this may highlight best practice to learn from outside of the region.

Read the call out for perspectives here

Analysing the data

Analysing the data involved a smaller working group who formulated the approach.

There were 78 responses to analyse which were a combination of in person and online data collection.

Initially we attempted to establish some key themes by working through the raw data as a group. The handover between coordinators delayed this process.

When revisiting the themes, we felt that too many assumptions had been made and some of the groupings didn't feel reflective of the raw data.

Our coordinator went back and coded the data to identify the number of times particular words had been said. We then analysed responses to each of the questions in the subgroup.

This revealed similar but slightly clearer themes which attempted to use the language of those with lived experience to characterise them.

This led one of our volunteers to map out a fantastic process flowchart of a client experience which became the base structure of the report.

"We hoped to get 100 people to respond through direct conversations, mainly on a 1-2-1 basis but also in small groups if that felt more conducive to a more in depth conversation. Whilst we didn't hit that target, we were still happy to have found so many people willing to share this most personal and often privately contained experience."

Output and Reflections

The project resulted in the production of a report which summarises the findings and aims to inform decision makers.

Some challenges we faced along the way included:

1

Generating enough responses:

While we did increase our responses from having an online version of the survey, we did not quite reach our target of 100 responses.

2

Online vs in person

The online survey reduced the opportunity to ask follow up questions to understand more of the details and nuance behind responses. Some people wrote very short answers such as "GP" which limited the analysis we could do.

The in person conversations did at times start to feel more like a therapeutic conversation which we were not best placed to deliver.

3

Language of the Questions

The open nature questions allowed a fantastic variety of responses which produced excellent qualitative data. However, this also meant that in some cases the responses did not necessarily answer the questions how we might have anticipated. There was lots of overlap between 'what didn't work' and 'what was missing' and some people gave limited detail in their responses.

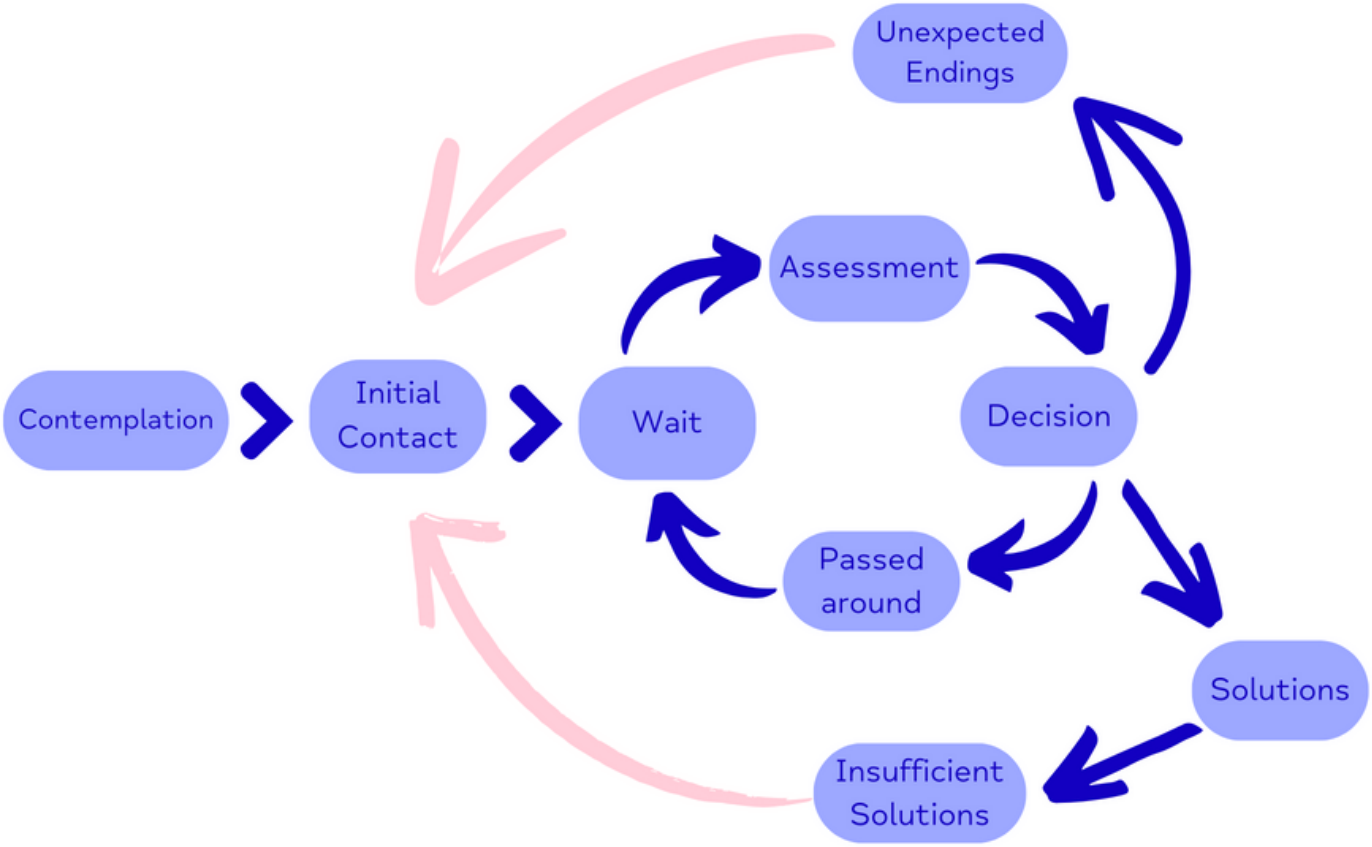
Key Findings

After discussions of the key themes across the three main questions, one our volunteers came up with a fantastic infographic.

This demonstrates the how he and survey respondents have experienced the mental health system across different sectors.

This led to us structuring the report by analysing these various stages of reaching out and accessing support.

- Contemplation
- Initial Contact
- Wait
- Assessment and Decision
- Passed Around
- Unexpected Endings
- Solutions, including insufficient solutions.



Impact

We hope that this report will inform future practice for Leeds Mind and beyond about the value of and considerations for conducting this kind of survey to understand mental health needs.

We aim to share this report with key decision makers within mental health care and suicide prevention.

The impact we feel this project has had so far is:

- Giving a voice to people in West Yorkshire to share their experiences and have them represented in this report.
- Holding space for people to talk to someone else with lived experience (in person conversations).
- Interesting conversations for the volunteers which validated some of how they have felt.

“I think we've had some great conversations that in themselves will have helped people feel heard and given them some autonomy in influencing change”

“While we couldn’t offer support to people for the challenges they shared, we feel that holding space for people to share their challenges was valuable in itself.”

“I thoroughly believe that the conversations themselves allowed people to be heard and helped with the healing process.”

“I enjoyed bringing my skills and knowledge to the development process. It helped me regain confidence, reminding myself that I did have some value to the world and could influence a project for the better.”

Staff Training Films

We created a series of short films to reinforce good practice amongst staff working in health and care.

'Preventing suicide: communication, support and follow-up' is relevant to anyone working in health and care to hear perspectives from those with lived experience connected to suicidal crisis.

They serve as a staff training resource to encourage good practice from staff. After watching the films, staff are given prompts for discussion, asking them how the films made them feel and what they might now do differently having watched them.

- Communication
- Support
- Follow-up

Read about this on the Suicide Prevention Website here

Watch the film here

Contents

Inspiration and Aims

This area of work was inspired by the core aims of the overarching project of providing people with a viewpoint on how people with lived experience around suicide experienced accessing services, their treatment with those services and the follow up.

We then wanted to expand on that by providing guidance on best practice for staff based on the experience of the group.

The Deputy Heads of Nursing asked the group to create something to encourage 'good practice' amongst front line staff in statutory services. This came from data around death by suicide in people known to services within one month of their death.

The aim of the project was to bridge the disconnect between service providers and service users.

We felt that there is no real way for people to feedback directly to staff on ways they could improve their handling of difficult situations for people in crisis. Therefore, it felt like a fantastic opportunity to provide insights the staff may not otherwise have had.

Initial ideas

The project began with discussing the brief that had been presented by the heads of nursing around showcasing best practice.

The group unpicked what 'good practice looks like' and 'feels like' from a personal lived experience perspective, discussing the positive practice and the negative practice.

We equally reflected on some of the key challenges among NHS staff and systems which can stand in the way of good practice such as desensitised staff, compassion fatigue, staff burn out, capacity of GPs and lack of time among staff.

We discussed the content of the films as well as the way in which the messages would be delivered e.g. role play/ examples of bad practice etc.

Initial ideas to increase engagement was to have very short films of around 40 seconds to increase impact, but as discussions progressed it was felt it would be difficult to convey key messages in such a short time frame.

Designing & shooting the films

It was agreed that volunteers would focus on communicating their own points as it is more powerful having individuals speaking their own words.

Individuals had the option of being on camera or just having their voice recorded. Those who did not want to feature directly were able to submit their perspectives to be captured throughout the films.

From an accessibility perspective, it was agreed that there would be captions.

Stuart; CLEAR: Community Engagement Lead

We partnered up with Men's Talk Digital, a men's Mental Health group in Kirklees, who helped us to film and edit the videos.

This felt like a special and important partnership, as it meant that everyone at all stages of the project had lived experience of mental health challenges.

"Despite having initial reservations about appearing on Camera I thought all five participants rose to the occasion and worked alongside myself and the guys from Men's Talk Digital in a very professional way and delivered the script they had written without very much guidance on my part. They were all complete stars"

"Following discussions, Leeds Mind co-produced an initial script. After further discussions this was re-worked with the group and the story board agreed. In advance of the filming, we had good communications – and a clear brief. The filming day was well organised, running to time. All of the participants were clear about their involvement and understood how the filming day would run."

Output of the project

We created 3 films, which became one long film, called: 'Preventing Suicide: Communication, Support and Follow Up'.

It speaks directly to health and care staff about their experience of good practice within mental health services in West Yorkshire.

1 Communication

Explores what good communication feels like from a client perspective. Watch here

2 Support

Looks at 'support through the system'; how staff can support clients navigating secondary mental health services. Watch here

3 Follow up

Shares the best way that staff can conclude their time with clients, for example the end of a 1 to 1 appointment, or if a client is discharged. Watch here

There is also a slide deck that can be downloaded to supplement discussions for this as a training tool.

"Good practice would feel like 'holding space'. Being present with us and inviting us to speak openly. Staff will work with us to reflect and clarify during appointments and will phrase things thoughtfully, to build trust and make us feel supported."

"It's important that we feel fully supported throughout our journey. This includes person centred support built around us and keeping me informed as to what is happening with our case. This is what will help to keep us safe".

"Good support at the end of appointments is just as important as the content. Be prepared to follow up and take action. Remember that signposting needs to be person centred in order to work. All of this is key to building trust in the system."

Promotion

The films were launched at an event at University of Leeds.

They have also been promoted among the following Yorkshire & National organisations/ groups & meetings:

- West Yorkshire Health & Care Partnership
- Suicide Prevention Networks
- Papyrus training recipients
- Harnessing Power of Communities Newsletter
- Yorkshire Ambulance Service
- Violence Reduction Unit West Yorkshire

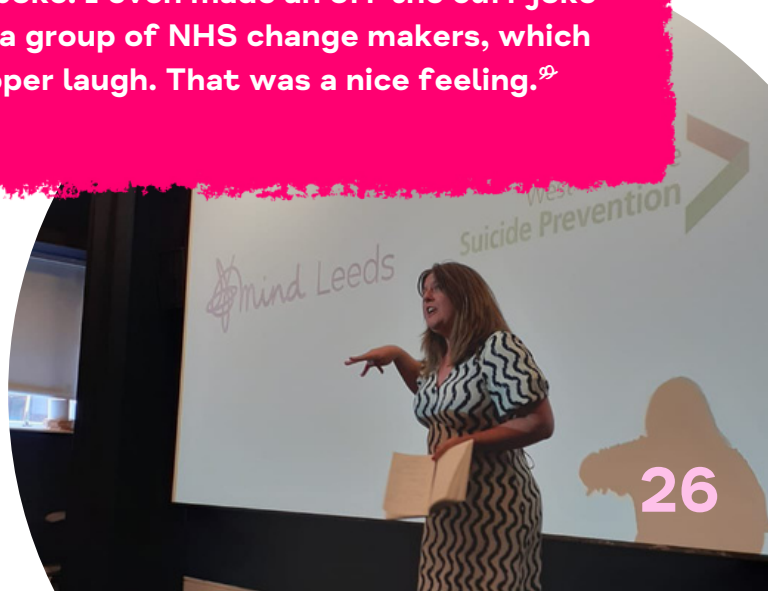
"These films are about providing care and support based not on what we think people want and need, but based on what they're telling us they want and need.

This is an approach we take with all our mental health support at Leeds Mind. But what's great about what the lived experience volunteers have designed here is, it seeks to raise awareness and change practice.

Our volunteers have been brave and generous enough to share their lived experience - we hope the local health and care community in West Yorkshire listens and takes positive action."

Arlie Haslam, Co-ordinator

"I went to visit the people who made these videos for us at the launch event of their own new play. The play was great and was performed in front of many key influencers and change makers in the NHS, public and third sectors. It was a great play and really good to see how these projects can change the lives of its members and share challenges around mens mental health. For me, it was the first time I'd sat in a room of 40 or more people in a conference style set up for a long time and I did eventually manage to relax into it. In fact, I challenged myself to ask a question a question at the end of the performance, which to my surprise got selected first. I was further surprised by how calm and assured I spoke. I even made an off the cuff joke after with a group of NHS change makers, which got a proper laugh. That was a nice feeling."



Impact

Challenges faced:

Early discussions featured concerns from a volunteer who has a nursing background and reflected on the busy nature of the role and challenges around time to dedicate to resources such as this. Volunteers proposed great ideas about promoting the films via tools that healthcare staff already had at their disposal such as desktop screensavers and mandatory training courses.

During the initial stages of the project, it was also challenging to decide on questions as there were so many ideas. However the group worked well together and volunteers commented that it never felt that we had to compromise on any one persons opinions.

At a Bradford Suicide Prevention Strategy Meeting, someone raised an idea about the films being available in other languages which is not something we have been currently able to facilitate but could be an important future consideration if the project was recommissioned.

Our hopes for impact:

- An effective training tool for frontline healthcare professionals who come into contact with people in crisis.
- Offers an alternative and lived-experience led perspective on how to provide effective crisis care.
- Demonstrates the need for greater investment within mental health and crisis care to enable staff to have more time with service users and provide quality care.

“There is no real way for people to feedback directly to staff on ways they could improve their handling of difficult situations for people in crisis so it felt like a fantastic opportunity to provide insights the staff may not otherwise have had.”

“What a brilliant video - really powerful and informative”

“Thank you, an excellent film, shows understanding, compassion and clarifies so much. As a Samaritan, I can connect with it. Just to let you know Mind is on our signposting list. “

Read the blog post here

Lived Experience Involvement: Guidelines for Best Practice

Following a difficult external lived-experience event, we created a new resource called ‘Lived Experience Involvement – Guidelines for Best Practice’, which you can read and download on our Website.

This resource is aimed at all staff working within health and care who involve people with lived experience in their work. Involving people with lived experience might take the form of service design, inviting people with lived experience to sit on an interview panel, or on an advisory group. There are many forms it can take!

Our volunteers have drawn upon their own lived experience of involvement, and on the Mind ‘Influence and Participation’ toolkit to create this resource.

We encourage everyone to read it, use and share it. It’s suitable for anyone working in health and care, whether you’re experienced in lived experience involvement, or are just starting out.

Blog Post

Contents

Inspiration and Aims

In April 2023, the group was hosted by a Blue Light Service in West Yorkshire.

Feedback from staff around challenges they were facing meant they were seeking lived experience involvement. They felt that it would be beneficial to hear from individuals with lived experience in order to co-produce a tips and tricks sheet to help staff.

Our project coordinator, alongside 7 volunteers attended. The event presented some challenges, there were last minute staff sickness on the day meaning the event was facilitated by someone unfamiliar with suicide prevention.

This meant that the event and conversations were not facilitated in the most effective way and therefore led to a triggering experience for volunteers.

As a result, we wanted to do something positive to follow the event.

The aim was to create a set of guidelines for organisations who are thinking about lived experience involvement in order to encourage positive and safe practice.

Output of the project

We created a set of guidelines on involving lived experience experts in a safe and effective way.

The guidelines come from the lived experience perspective of our volunteers, but we feel the guide is applicable to lived experience work more generally. We have created this alongside the Mind 'Influence and Participation Toolkit'; condensing the toolkit into the areas we feel are most applicable. The guide focusses on four areas

1 **Planning**

2 **In the moment**

3 **After**

4 **Making people feel comfortable**

Read & download it online here.

Impact

Our hopes for impact:

- Support other organisations who are interested in involving lived experience within their work to do this in a way that ensures the safety and comfortability of volunteers.

- Since sharing the lived experience guidelines, we have had another researcher get in touch to ask for further guidance and support.

“[coproduction is] very important but the brief and shared understanding needs to be correct from the outset”

Our Lived Experience Guidelines have been promoted and commended by:

- West Yorkshire Health & Care Partnership
- Forum Central
- Nova Wakefield
- Mindwell
- National Suicide Prevention Alliance
- Director of Research, Bipolar UK
- Lincolnshire City Council
- National Mind

“We worked with Arlie and the volunteer co-production group to co-develop a set of guidance materials...[the coordinator] and her team were very accommodating and helpful on how the process would work, and the people who attended on the day were all professional and helpful. We developed a very useful crib sheet for staff and an intranet page with further resources suggested as part of the workshop. This was the first time we had co-developed with a partner and it was very productive.”

Book of Cope

The ‘Book of Cope’ celebrates and shares the different strategies people from West Yorkshire use to boost their mental wellbeing, to help others when facing their own challenges.

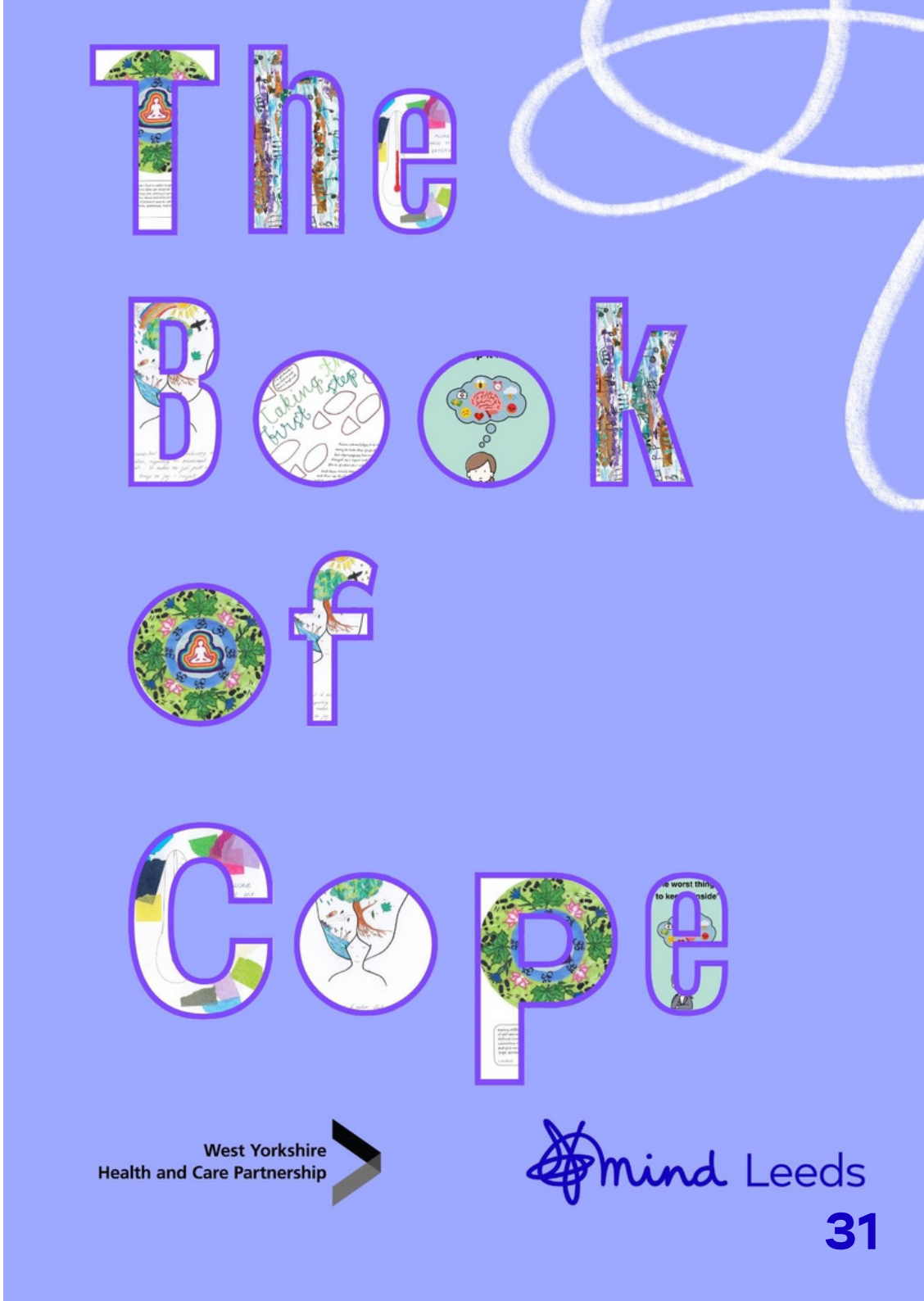
We came up with the idea for ‘Book of Cope’ when we were talking about coping strategies and how important peer support can be on your mental health journey.

We went out and about holding drop-in sessions across West Yorkshire, for people to design their own creative pages for the book. We also accepted online submissions.

This culminated in a 44 page book of coping strategies which are categorised by the ‘Five Ways to Wellbeing’.

Read the Book here

Contents



Inspiration and Aims

Following the release of the films and the Lived Experience Guidelines, the group decided they would like to work on a project as a larger group.

Discussions around ideas took several directions and talked about reaching high risk groups/ wider communities that hadn't been targeted in the work so far.

Inspiration and ideas were sought from existing workshops, events and exhibitions such as the Suicide Bereavement Service's virtual art exhibition,Yorkshire 'Speak their Name' quilt and Wakefield's postcard project.

So far, most of the projects had been geared towards systems work, and there was an appetite amongst volunteers to do something a bit more creative and community based. This would help us to meet our aim of reducing stigma.

The group aimed to create an in-person activity or workshop that could be 'toured' in different locations and amongst different community groups. The hope that it would be an activity or workshop that fostered individual and group discussions among different groups which would result in a co-produced 'end product' that could be displayed or used.

"This project came about as a way to co-produce a resource for a more public audience than specifically health care staff, that people can use to understand what sort of coping strategies people with lived experience use"

Initial ideas

Initial ideas for the format of the event were creating beer coasters or signage to go in train stations.

However, it was felt that something artistic might not resonate or feel comfortable to everyone.

This led to the concept of gratitude journaling as a workshop activity, due to the known benefits of writing things down and cultivating gratitude. One volunteer shared that during difficult periods they didn't have the motivation to look for help but seeing something like this journal idea would have made them hopeful and feel that they weren't alone.

This sentiment was echoed across the group about how hearing other's perspectives and knowing about shared experiences can be very powerful tools of recovery.

This concept developed further through discussions around potential challenges of identifying something you are 'grateful' or something you value about yourself. This evolved into the final concept where the group agreed that they would instead ask workshop participants 'what helps you?' to collate a diverse series of coping strategies, positive stories and real voices.

"I got involved in this project because if I can help just one person, not only will it help that person but it will make a difference to their family and friends, so they don't have to go through the trauma that nobody should have to experience."

Community Sessions

The title of the book is of great significance as it relates to the way in which people have experienced unhelpful mental health conversations.

It started as the 'Book of Hope' but individuals shared their reservations about the use of the term 'hope' as this can feel like a difficult word when it comes to having suicidal thoughts. Group members had experienced this in a negative way from various professionals

Out of this came the concept of 'The Book of Cope' out of reflections that 'The best you can possibly do in this situation is cope'.

"When being asked 'Have you lost hope?'; it can feel very difficult to have something brought to your attention that you used to have but don't have now."

"When we chose the book's name, there was a collective 'oh yep, that's the one'".

Participants at the various workshops were asked 'When you're struggling with your mental health, what is something that helps you, that you think could help someone else?'

Participants were encouraged to offer something in the form of writing, a quote, art or any other way they felt they wanted to represent their coping strategy.

Sessions took place in:

- Wakefield Central Library
- Bradford City Library
- Halifax Central Library
- Huddersfield Library
- Slaithwaite Library

We then opened up for online submissions.

Read the blog post here

"This is a fantastic project from our volunteers and we hope the end result will be a book packed full of useful strategies and advice, offering something for everyone."

Associate Director for WY HCP's Improving Population Health Programme

Designing the Book

The way we would structure the book began to take shape as we identified common themes among the submissions.

We had originally thought about focussing on each of the senses but the submissions began to align with the 'Five Ways to Wellbeing'.

For those who didn't feel comfortable creating something visually and had submitted their thoughts in writing, our volunteers created drawings and other visual representations of people's voices.

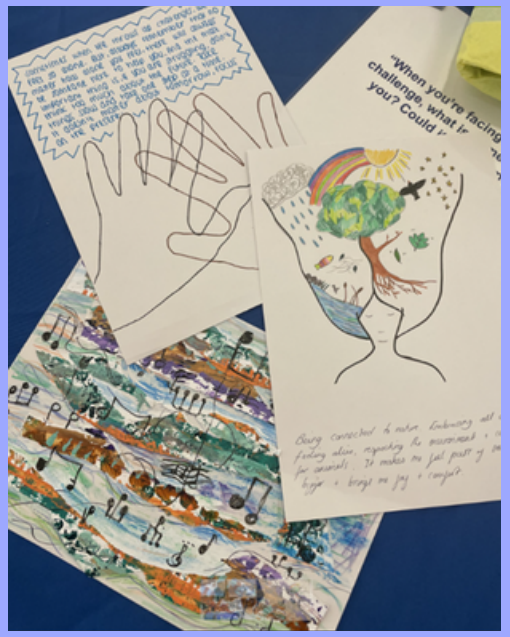
Yahoo News Yorkshire Post Keighley News

"We saw ourselves as a group of people with lived experience who could make a difference... many people such as friends and family don't talk about suicide. When seeing professionals, it could often feel like a 'tick-box' exercise...you would be left with a series of print-outs of coping strategies or to work out your own self-led coping strategies."

Output

Our final output was a 44 page Book which has a digital and print version.

We printed 500 copies and have distributed them across West Yorkshire.



We have given out 'master copies' for community groups, libraries, GPs, local mental health services and places where people might 'usually' go.

People can also create their own on the blank page at the back. This can both be useful for people who need it for themselves, but hopefully it also helps staff for use with clients.

Impact

Impact on volunteers

“Engagement with individuals was the most meaningful for me”

We enjoyed the Book of Cope community engagement sessions as it brought about lots of interesting conversations.

It was nice to have so many people come and chat to us as it showed the importance of the work we have been doing.

“We have got people with lived experience to share important stuff. It’s a reminder that we’ve got human potential”

Read the book here

‘it’s highlighted how far I’ve come in that I can talk about it now. We all still have crap days, weeks, months sometimes but it doesn’t feel like my life now so that’s really positive for me’

What we hope will be the impact

“Your concentration often isn’t great when you are in the midst of mental health challenges; it can be hard to read a text book or self-help book.”

We hope that the colour and the hand-written nature of The Book of Cope is much more user friendly and accessible and that it brings the various coping strategies to life and shows people that they are not alone.

We know that everyone has different experiences and not all strategies will work for each individual. However, learning about them feels more meaningful, interesting and engaging when it comes from the heart and from others who understand.

We wanted to collect a ‘rich knowledge’ that people with lived experience have and have it in something that is ‘usable’.

‘It’s great to have a resource for service users by service users with recommendations for coping strategies. I find myself making the same suggestions when making safety plans with service users but I am not someone who has ever found themselves in crisis. This way, I can send service users the book of cope and not only do they have a variety of strategies to try but they can feel less alone as they know theirs is an experience shared by those featured in the book!’

- Psychological Wellbeing Practitioner

Bereavement Support Leaflet

Created in collaboration with Leeds Mind Suicide Bereavement Service, this leaflet was created to offer simplified and concise support to those bereaved by suicide.

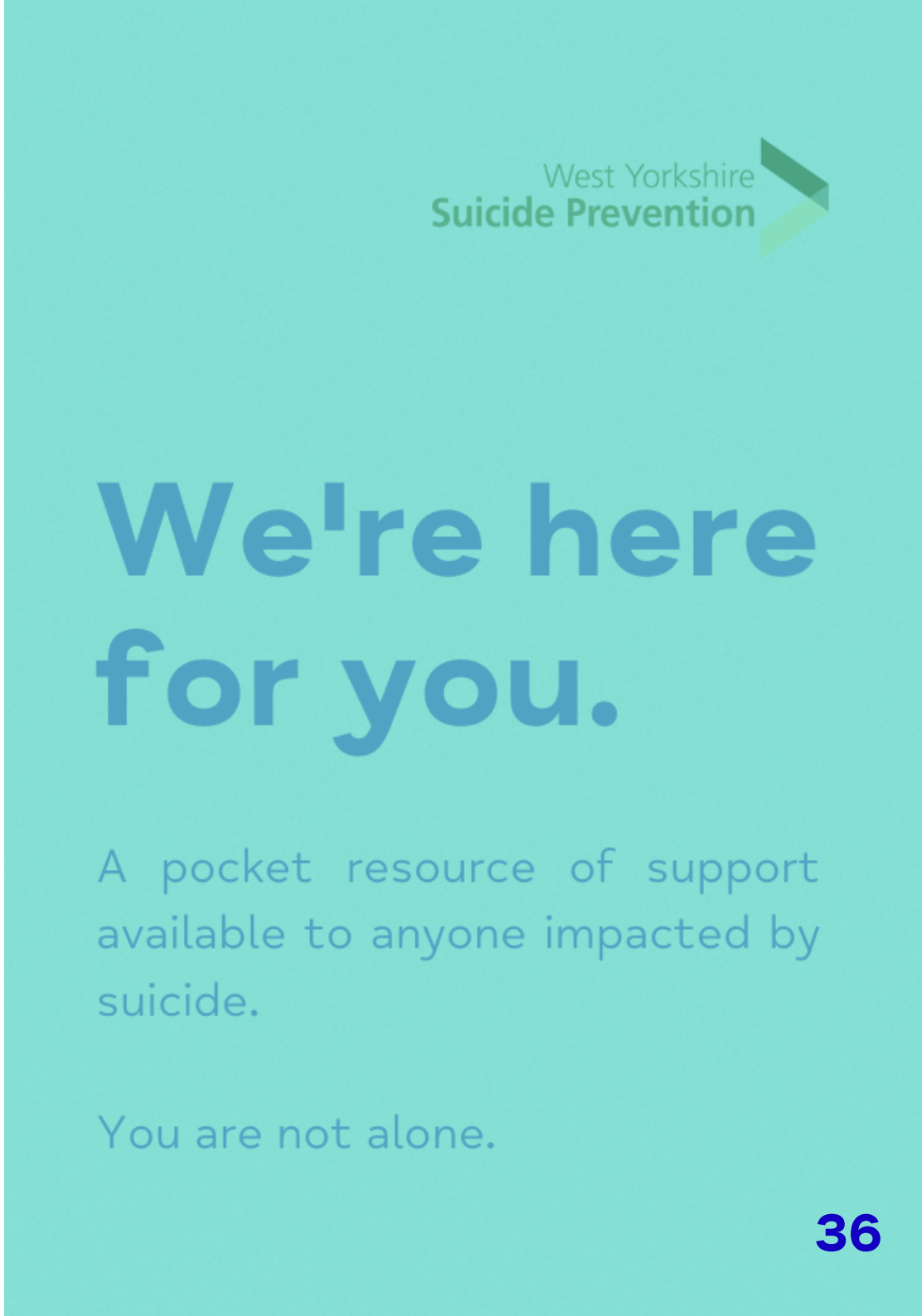
This project utilised lived experience of bereavement by suicide to understand the support and signposting needs when going through a “trauma like no other”

A tri-fold suicide bereavement support leaflet was produced by the volunteers and the Suicide Bereavement Service.

In conjunction with this, volunteers wrote a blog post about how they kept themselves well throughout their bereavement. This is linked to in the leaflet.

Download the leaflet here

Contents



Inspiration and Aims

We wanted to represent all the lived experience we had in the team. So far, nothing had specifically addressed bereavement by suicide.

The project started with discussions around whether to pursue something for staff supporting people bereaved by suicide or to create something directly for people who are bereaved. The group looked at existing resources such as the Help at Hand Booklet, The Creating Language through Hope Crib and The Guide to Coroner Services.

“Having being bereaved by suicide, I experienced a trauma like no other and the ‘average person ‘could not comprehend.”

We spent a few weeks exploring what our new contribution to this conversation could be – there was a lot that already existed. Eventually we felt like that was the answer in itself – there was just too much out there in terms of resources for bereaved people.

Too much meant that the information was overwhelming, and often meant that people wouldn’t engage with it.

Our idea was to create something, informed by lived experience, that would provide concise, specific signposting that volunteers knew worked and could support people in the early days; ‘a single point of access’ for wrap around support.

The local Suicide Bereavement Service, as they told us they had a similar issue; the initial pack they gave out to clients was so dense that it was overwhelming.

Initial ideas

The group explored what guidance for staff might look like based on the common encounters with staff after a suicide bereavement.

Usually following a loss, someone would interact with the GP, Police and Coroner and it was felt that from lived experience, there was limited signposting support that happens at each of these stages and interactions. This was in terms of mental health signposting for those affected, specific bereavement support and support around practical issues such as resolving someone’s finances.

“We are a post-vention service and research shows people bereaved by suicide are at a higher risk of dying by suicide themselves. We wanted to involve more volunteers and service users with the ideas some of our own service users and staff had around drink coasters as promotional materials and information we include in our initial pack when people first refer to our service”

Lisa Bourne, Senior Practitioner, Leeds Mind Suicide Bereavement Service

Output

A tri-fold suicide bereavement support leaflet was produced by the volunteers and the Suicide Bereavement Service.

In conjunction with this, volunteers wrote a blog post about how they kept themselves well throughout their bereavement. This is linked to in the leaflet.

Reflections

Challenges and Key Learning:

One of the volunteers felt that the services that were selected for the leaflet were not the ones that resonated most with them. They felt that the end product did perhaps focus too heavily on those who are bereaved by suicide also being in crisis which isn't always the case.

Therefore, this project presents some important reflections on how we ensure that all voices are heard and that those with the relevant lived experience can direct decision making.

This project also re-emphasises the importance of a 'family focussed' approach within suicide bereavement and postvention support.

What we hope for impact:

- Individuals bereaved by suicide will have a simple, digestible guide to local services.
- Leaflets in local places across West Yorkshire will raise awareness of post-vention support

"I wanted to help other families in my situation"

Surviving Crisis: Learning from Lived Experience Podcast

We created a podcast series with the aim of supporting staff who work with people in mental health crisis.

The series – 'Surviving Crisis: Learning from lived experience' – consists of five episodes, each 20-30 minutes long and covering different themes.

The episodes have been developed using insight from frontline health and care staff, who were asked in advance to share their thoughts and opinions on what they would like to hear discussed.

The five episodes can be found on our Leeds Mind Spotify and on the West Yorkshire Suicide Prevention Website, with episode one taking a look at what staff might want to ask a person with experience of suicidal ideation that they feel they can't ask in every day work.

Listen here

Contents

mind Leeds

West Yorkshire Health and Care Partnership

Surviving Crisis: Learning from Lived Experience

A Leeds Mind Suicide Prevention podcast

Inspiration and Aims

The inspiration for the project was twofold. Firstly, it was to understand what questions staff had for those with some sort of direct relationship with suicide and suicidal thoughts. Secondly, to provide an informed response to those questions from the perspectives of people with lived experience relating to suicide

Originally, there were talks about hosting a live event (human library/Q&A style) where staff could ask volunteers questions about crisis. However, there were some concerns that this could be triggering and may not be the most effective format.

We then decided to create a podcast, for which where staff could submit questions and thoughts, and these could be discussed during the podcast episodes.

We aimed to create a resource that lived beyond the lifespan of this project and could help practitioners, support staff, change makers and influencers understand the service user experience and what change we believed needs to happen to save more lives.

We wanted to take advantage of a rare opportunity for people with lived experience to directly address staff and to better understand the questions and issues staff had when dealing with a person in crisis.

Initial ideas

We began by co-producing the wording of the questions to send to frontline staff. Our coordinator then distributed these to various frontline staff.

In the wake of receiving the responses we then broke down what we though the most important themes and common characteristics of the responses were.

1. **Is there anything that you would want to ask a person with experience of suicidal ideation, that you feel you can't ask in your everyday work?**
2. **What ideas/tips/advice that you are advised to give out do you feel works for people in crisis most effectively?**
3. **Does anything worry you about having a conversation with someone who is suicidal?**
4. **Accessing services – 'what do you see as a barrier to accessing crisis services? What do you think would encourage people to access crisis services?**
5. **From a professional perspective, do you feel that you face any barriers/frustrations to offering support to someone in crisis?**
6. **Based on your lived (and/or) professional experience, what changes would you like to see in crisis services?**
7. **Think about crisis situations you've been part of previously. Was there anything you found difficult about it? Is there something you would like to ask someone with lived experience about that could help you in the future?**

Creating the podcasts

The podcasts were recorded both over video call and in person to ensure accessible involvement for volunteers.

Our coordinator then edited the audio content into one file and these were uploaded onto Spotify.

“One challenge faced was that while we wanted it to overall be a positive message, there was one particular response the group found troubling and i firmly stood by the fact we should address the negative as well as the positive...

... felt like I was heard when I raised this and the group agreed overall and we incorporated both the good and bad into the final podcast.”

“I was really nervous about the podcast I contributed to and it was really hard to do. However, the coordinator was brilliant at putting me at ease and I was able to say what I've been wanting to say for years. After I'd added my bits I got a really big complement about being articulate, able to speak with real feeling and meaning and that I was a 'one take wonder'. None of these things I could have imagined about myself up until this point.”

Output

Based on the questions submitted by the frontline professionals, the volunteers produced a 5 episode podcast series with the following titles:

Ep.1 **Is there anything that you would want to ask a person with experience of suicidal ideation, that you feel you can’t ask in your everyday work?**

Ep.2 **What ideas/tips/advice that you are advised to give out do you feel works for people in crisis most effectively?**

Ep.3 **Does anything worry you about having a conversation with someone who is suicidal?**

Ep.4 **Barriers to accessing crisis services.**

Ep.5 **Recommendations for change and our visions for the future**

Each episode runs for about 20-30 minutes and features a diverse range of the volunteers discussing their perspectives on the questions submitted.

Spotify **Sound Cloud**

Promotion

The West Yorkshire Health & Care Partnership suggested using their Soundcloud account as the hosting platform. The volunteers asked for us to host on Spotify as well to maximise the reach.

Some national organisations that promoted our podcasts included:

- Voiceability
- National Suicide Prevention Alliance
- NSUN

Total Listens

69 - Spotify

241 - Soundcloud

(**At time of report**)

Some Yorkshire organisations who promoted our podcasts included:

- Yorkshire Autism AIM Equity Project
- Gamcare Yorkshire & Humber
- Restorative Justice West Yorkshire
- Community Matters Yorkshire
- West Yorkshire Health & Care Partnership

Some organisations beyond Yorkshire that promoted our podcasts included:

- Proud to Care North Linconlshire

Whilst the promotion and response to the podcast has been largely positive, the engagement with the podcast has tailed off towards the end of the series.

Impact

Impact on volunteers:

Volunteers enjoyed the process of creating the podcasts on the whole and many felt they found their voice during this process.

> **“After I'd added my bits I got a really big complement about being articulate, able to speak with real feeling and meaning and that I was a 'one take wonder'. None of these things I could have imagined about myself up until this point.”**

> **“It was exceptionally interesting to hear directly from staff...as they could be completely honest without fear of any repercussions. This gave me very valuable insight into the people that work for these services and their behaviours and attitudes towards those in crisis.”**

Key Messages:

1. **Focus on the individual patient and be person centred.**
   Don’t make assumptions about people and make people feel listened to and validated. This will foster a sense of hope in people.

2. **Normalise ‘bad days’ and realise that people have different baselines on what their ‘normal’ is.**
   It’s okay to not be okay all the time, and staff normalising this can make it that little bit easier to get through difficult times.

3. **Please always believe people – when they are brave and strong enough to approach services,**
   it’s important to believe, listen and validate their experiences in that moment.

4. **Consider reframing language when talking about mental health to a strength-based approach, rather than from a deficit perspective.**
   For example, reframing a pain-scale to a comfort scale. Positive language can encourage and empower people on their mental health journey.

5. **Exercise professional curiosity when working with people in crisis.**
   Explore the nuance in people’s personal situation, and create an appropriate response/follow up based off that, rather than a set of predetermined criteria.

6. **As a staff member, it isn’t all on you.**
   Spend time with someone in crisis to explore what options are available to them, and what they feel would support them the best. This will look different to everyone.

7 **Call for staff to consider if they feel they may have been desensitised to mental health crisis.**
Staff have a significant role to play in supporting vulnerable people and this should be done with care and compassion.

8 **Recommendation to staff to be mindful that it could be hard for people in crisis to trust them right away.**
Try to make people feel as at ease as possible to build a rapport and trust.

9 **First impressions count.**
A negative first encounter with a service can make people in the community feel like services aren't for them, and prevent them from accessing support in the future.

10 **Community members understand that a lot of the issues around accessing crisis services is a consequence of cuts to public services and austerity, not the fault of individual staff.**
However, staff do play a significant role in crisis services, and there are things staff can do within their personal practice that can make mental health support more meaningful and accessible to people in the community.

11 **Genuine empathy and support from staff doesn't go unnoticed, and is appreciated by those accessing crisis services.**
We are on the same side.

12 **More support and training should be available to staff, so they have the emotional capacity to support people in crisis.**
Community members can sense when someone is 'fed up', and this can make people feel like a burden.

13 **People are complex – a crisis service alone won't make someone well.**
People need wrap around, holistic, person-centred report. A better joined up approach of services within West Yorkshire could be lifesaving.

What we hope will be the impact...

The podcasts have had a significant reach and a positive response.

We hope that the podcasts can be utilised as an ongoing training tool that new and existing frontline staff in the health and social care field can learn from. We hope they offer staff a different perspective on supporting those in crisis. We also wish to offer solidarity to those struggling to navigate support and services when in crisis.

"There is nothing better than learning from someone with lived experience to help inform practice and the way forward."

"The more we can do to close the gap and make a more positive experience for everyone, the better the mental health of people accessing services will be in the long term."

Other involvements & consultations

Throughout the course of the project, we have been involved in several events, involvements and consultations.

While these have not been fully co-produced as the group did not initiate and design these involvements, we have been able to share our lived experience to inform various practice, strategy and research.

Involvements have included:

- Research Project on the role of pharmacies in suicide prevention
- Consultation on the use of memorials
- Chamber Meeting

Contents


Special Report

Preventing suicide

Suicide is a devastating event, that has wide implications for the families, friends, and all associated with the victim.

Whether it be male or female, young or old, for those left behind there is a very complicated grieving process and for those lost a sense of a life cut short.

The West Yorkshire Health and Care Partnership, which includes Leeds City Council and the NHS, has a Suicide Prevention Programme which has been carrying out intensive work and aims to reduce the suicide rate by 10% before 2027.

Recent measures include rolling out a targeted training programme to workforces across health, care and beyond, including frontline rkers such as in job centres GP practices, which will thousands with the skills a life.

rtnership's ongoing With Your Mate' ention campaign, ay 2021, aims to conversations and mental ly among

eaturing their ludes and

posters to help spread the word, with messages including: 'Is your sporty mate suddenly off his game?', 'Does your mate always want to have one too many?' and 'Has the mate who's always got something to say gone quiet?

You can download free resources and join the campaign at staffcheck-in.co.uk/campaign-toolkit/males

Other initiatives include the Leeds Suicide Bereavement Service, which offers support to individuals, families or work places. The service provides 1:1, peer support and groups, family and counselling.

Whether you were affected by a suicide that was a few days, weeks or decades ago. They can support you whoever you have lost – this may be a parent, child, partner, sibling, other relative, friend or work colleague.

You can use the service if you believe someone you care about has ended their own life, even if this has not been officially recognised or you haven't had an inquest. They also support people who feel affected by a suicide but do not identify as bereaved, for example if you witnessed a death. Leeds City Council commissions Leeds MIND to provide the service. Go to www.leedsmind.org.uk or call (0113) 305 5800

Suicide Prevention Training is being targeted at workforces where those with higher risk factors are employed. In addition, Mindwell is the mental health website for people in Leeds where you can find out about support and services in Leeds, understand common mental health

sector support engagement with loc build capacity an emerging groups an support innovative wa connecting with those who be socially isolated; address stigma, discriminati and loneliness. Apply to Leed Community Foundation leedcf.org.uk

training

Grants are ava organisa empower

The Suicide Bereavement team at Leeds MIND. "We get it because we've been there."

vs for positivity

mphrey

Research Project

We were approached by Dr Hayley Gorton who is a Pharmacist and Senior Lecturer around supporting to design a research proposal around the role of pharmacy in suicide prevention.

Pharmacists have shared that they have had service users with limited prescription quantities but were not given information about the reasons for this. This feels like a missed opportunity to include pharmacists in the circle of care which can include suicide prevention.

The research aims to understand whether limiting medicines within a prescription works to prevent suicide.

There is already an understanding that limiting medications may have a negative impact on individuals such as the inconvenience or inaccessibility of collecting them leading to not taking the medication for another health condition.

Dr Gorton was keen to hear from:

- People with experience of having limited medication quantities prescribed in order to keep them safe.
- People who have been offered medicines in a limited quantity by the Doctor (or other prescriber) and did not go ahead with these medicines.
- People bereaved by suicide.

Some of our volunteers and our Project Coordinator attended the research consultation.

“We have invaluable information which needs to be fed in to research. Hayley was interested in our responses”

How did involvement impact the research?

1 Hidden Harms

The group endorsed the need to balance poisoning risk and appropriate treatment considering potential ‘hidden harms’.

These included distress about obtaining supply in time, with people sometimes going without treatment; feeling disempowered and ‘counterproductive’ as people may substitute methods of self-harm.

2 Work package sequence

Discussions showed that themes from interviews with people with experience will inform the interviews conducting with healthcare professionals

As a result, the order of these studies have been swapped.

3 Big data study

Members felt this study was an appropriate use of anonymised, linked healthcare data.

Restricting the cohort to people who self-harmed would be unrepresentative, as their experience was that their prescriber did not know about their self-harm.

4 Interview studies

- Opinions differed about whether 1:1 interview or focus groups would be preferred but, on balance, interviews will be offered.
- Ensuring people from all communities can participate is essential, particularly those from ethnic minorities.
- Flexibility of interview times and modality was deemed crucial.
- Members agreed that secondary care doctors (e.g. pain specialists) were important but questioned the value of including GP receptionists, citing some poor experiences. As this in itself could be informative, this group will be included.

Next steps:

These suggestions have supported Dr Gorton to develop her research proposal further and will continue to inform the work going forwards.

Reflections

One challenge was that for co-production to feel meaningful, it is important to have regular updates and feedback on how input has impacted on outcomes and changes.

Due to the long-term nature of research and some changes in circumstances for the researcher, it was not possible to share many updates with those who gave their lived experience perspective.

However, the researcher was careful to be transparent and open about this and has more recently followed up with our Coordinator to maintain contact and showcase the changes that the consultation has led to as shown above.

Impact for researcher:

"I have been humbled by people's generosity of sharing their experience, in a sensitive and constructive way. Arlie led the group with compassion and supported me to ensure my approach was optimal and sensitive to people's needs. I hope members of the group can continue to be involved in the project, as working with them so far has been an absolute privilege."

Memorials Consultation

We attended a consultation session with Calderdale Council around managing memorials in public spaces.

The Public Health Team at Calderdale Council were looking into memorials and public tributes at locations of suicide, to try better understanding the risks, benefits, and best approaches for supporting those who are bereaved and at risk.

They had examined the research and professional guidance but were hoping to gain more personal and meaningful insight from people with lived experience. It was hoped that the findings and suggestions will be shared across West Yorkshire for a more shared approach.

Our Project Coordinator alongside 5 people with lived experience attended this consultation.

A Public Health Practitioner from Calderdale Council facilitated the discussion along a range of discussion areas and heard lived experience perspectives throughout.

“I did not have lived experience of a memorial in a public place but obviously I have seen some and have clients whom this has impacted. I believe the project came about as a result of staff having to move memorials from a public place (due to multiple concerns- safety, messages to others etc. It is an area which opens up a ‘can of worms’ but nevertheless needs addressing.”

Discussion areas

1 Policies of memorials and roadside tributes

There are no policies or guidelines in place currently and a need for this has been raised in the past.

There is little support in place for staff who remove memorials and each site is handled on a case-by-case basis currently. Staff managing or removing memorials can also face criticism.

Questions were raised around whether a policy would cover all public deaths or whether it would be different for deaths by suicide - there was a sense that this could help to normalise the grief people feel.

Recommendations/ suggestions:

- Policy to remove memorials 4 weeks after death (subject to concerns about 'contagion effect' - if at a high risk location, may be removed earlier)
- Policy to explain risks and why we need memorials policy, in a way that is sensitive to variety of experiences, and opinions.
- Memorials to be taken down at night to reduce any upset and people should be pre-warned about it being taken down. Also important to avoid removal on any anniversaries.
- Items removed to be held in storage so loved ones can access if they wanted.

2 Risk of memorials

Some research suggests that memorials at sites of suicide may increase risk in others by highlighting possible locations.

Could equally be triggering for vulnerable groups, witnesses or front-line staff. However, this contagion effect is hard to prove and research is limited.

There were also discussions about particular locations and how risk will vary based on location e.g. different in a quieter area like a wood to a more public place like a bridge. From a CCTV perspective, memorials can also obstruct cameras.

Recommendations/ suggestions:

- Understand that we cannot eliminate all harm or upset, with a matter like memorials.
- Understand that for some, the site of death is important for a memorial and for others this will be triggering.

"For someone who is vulnerable or predisposed to suicidal thoughts, it could create negative and intrusive thoughts, it links present with past"

3 Role of memorials

There were discussions about the role of memorials in providing a way in which people can grieve with a 'physical outlet' and a 'meeting point'.

This, coupled with concerns about risks of existing memorials led to discussions about other forms of memorialisation or utilising other locations and not the site where somebody died.

One challenge was that it can be difficult to have communication with those who create memorials due to GDPR and not having a Police Family Liaison Officer like with other deaths in public places.

Recommendations/ suggestions:

- Recognise and respect different ways of grieving and importance for some in having this physical space to grieve.
- Annual memorial events with safeguarding measures in place, a permanent memorial like a bench, plaque or garden and memorials held at places that were special to the person who died e.g. clubs or sports venues.
- There were some suggestions around the use of the term 'action grief' being positive as it recognises that not everyone wants to talk.
- Explore mechanisms to open up communications with those who are bereaved.

Impact

The consultation discussion notes have been passed on to the public health team who manages this area of work and will be followed up.

This approach is then hoped to be rolled out at a wider level across West Yorkshire and our coordinator has had conversations with the Public Health Lead in Bradford who is keen to explore a similar consultation.

"It was an incredibly powerful discussion with lots of difference of opinion, but it was obvious the network had been coordinated in a way where everyone's voice and opinions were valued. And we felt very reassured everyone was safeguarded. The discussion really enlightened the work we are planning around memorials. We feel more confident that we can find a way forward that is sensitive to the needs of bereaved people."

Public Health Practitioner at Calderdale Council

Chamber Meeting

Our project coordinator alongside two volunteers attended the West Yorkshire Health and Care Partnership Board meeting in Calderdale.

We were invited to talk about the project and lived experience. Our coordinator and two project volunteers attended. Two of our volunteers who wanted to be there but couldn't make it on the day shared their stories to be read out.

In many ways, it was a pretty intimidating space, but a hugely empowering experience and a great opportunity to be in a room with decision makers.

The West Yorkshire Mayor invited us to apply for their funding pot during this Chamber meeting in order to extend this project but unfortunately this funding pot was closed.

We also had a follow up meeting with West Yorkshire Healthwatch after the meeting to discuss how to make such meetings more accessible for lived experience participation in future.

Impact

Project Officer, ICB

“Just to say you were amazing! Just incredible to hear what you both said – so powerful. Hopefully something will come out of it too...”

Volunteer:

“You were amazing. Thank you so much for being my voice. I really hope you were able to soak up the whole experience and recognise what phenomenal work you have done for the project”

Associate Director, West Yorkshire Healthwatch

“Iit was inspiring to hear the lived experience of the volunteers and for the Board to see first hand why it is so important to involve people with lived experience in this and other projects, and the positive impact this can have on people and services.

The Volunteers and coproduction coordinator from Leeds Mind played such an important role in bringing people’s voices into the meeting and gave the partnership’s aim to reduce suicide by 10% across West Yorkshire real meaning. The project has been hugely successful in empowering people with lived experience of suicide, and providing peer support to those who are impacted by suicide. It is an essential service that puts people at the centre.”

Watch the Board Meeting Here

(skip to 1hr 7mins to see our bit)

“Being able to speak at the WYHP board meeting in Halifax was something else... what an honour to speak on behalf of so many in the mental health arena /system and to so many in powerful positions to hopefully make an impact or indeed start much needed conversations toward systematic change.”

Overall Conclusions and Reflections

Overall Reflections & Conclusions

Our project group has felt positive about this Suicide Prevention Co-Production Project.

We have reflected on each of the projects and pieces of work we completed in terms of the impact for policy makers, frontline services, the public and those who provided their lived experience perspectives.

The next section will reflect on:

- Overall impact on volunteers
- The role and value of co-production
- External impact & perspectives

Contents

Meetings, engagements and promotion over the project

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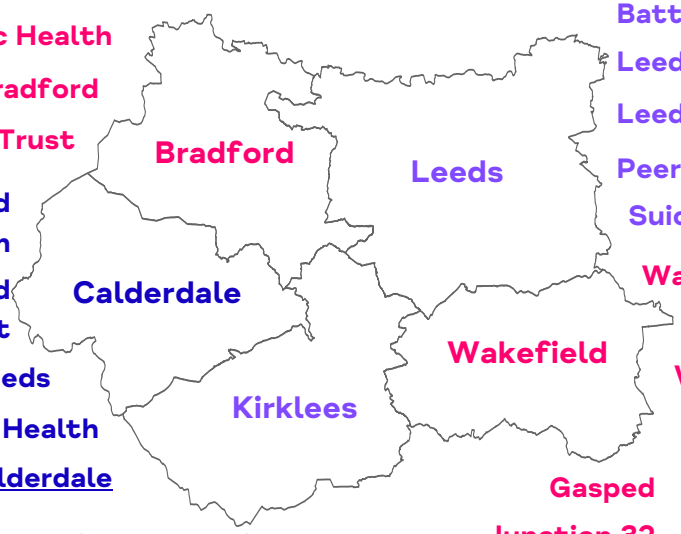


Men's Health Unlocked
Leeds GATE
Resisterhood
Health Watch Leeds
Forum Central
Workplace Leeds
Mindwell
Women's Health Matters
Leeds Autism AIM
Day One Trauma
Multi Agency Support Team
Tea and Talk Group
Leeds Women's Aid
Barca Leeds
Aspire
Leeds Beckett
Equality Partnership
Leeds & York Partnership Foundation Trust
Advonet
Bernados
Leeds Dads
Cook and Eat Group
Suicide Prevention Action Network
Patient Safety Conference LYPFT
Yorkshire Mesmac
BBC Radio Leeds
Touchstone
University of Bradford
Leeds Mental Wellbeing Service
Voluntary Action Leeds
Bradford Library
Bradford District Care Trust
Man about Town
SSAFE LUU society
Mentally Healthy Leeds
Healthy Minds Summit
Safe Spaces Bradford
Barca
5 Ways
Community Links
Leeds Health & Care Academy
Healthy Minds Bradford
Forum Central
Battle Scars
Ahead Partnership
Forward Leeds
Bradford Council
Bradford Public Health
Leeds Public Health
Women's Health Matters
Calderdale Armed Veterans
Mind in Bradford
Leeds Rhinos
Leeds Survivor Led Crisis Service
Suicide Prevention Action Group
The Cellar Trust
Peer Talk
Public Health Resource Centre
Calderdale's PCNs Personalised Care Team
Suicide Bereavement Service
Suicide Prevention Network
Piece Hall
LGBT Youth
Calderdale and Huddersfield Foundation Trust
Wakefield Council
Well Women Centre
Nova Wakefield
Take 10 Mental Health
The Basement Project
Men in Sheds
Wakefield Public Health
Liaison and Diversion
Healthy Minds Forum
Calderdale Public Health
Healthwatch Wakefield
Carers Wakefield
Staying Well Team
Healthy Minds Calderdale
Gasped
STAR Bereavement
Suicide Bereavement Service
LGBT Youth
Peer Talk
Kirklees Public Health
Junction 32
South West Yorkshire NHS FT
Suicide Prevention Advisory Network
Support 2 Recovery
Healthy Places
Well Women Centre
Spectrum People
Suicide Bereavement Service
Healthy Minds Calderdale
Prosper
Local councillors
Wakefield Co-production Conference
Kirklees Volunteer Fair
Huddersfield University
Timestep Community Dance
5 Towns Veterans
Wakefield Library
Platform 1
Kirklees Crisis Cafe
Kirklees Council
The Big Conversation
Suicide Prevention Action Group
Healthwatch Kirklees
Al Hikmah Centre
Slaithwaite Library
Older Adults Exercise Group (Kirklees)

Engagements over the project - UK/ WY wide wide

Role of Coproduction

Many of us had never been involved in co-production and so we reflected on our feelings on the role of and importance of co-production.

“[coproduction is] massively important – lived experience is massively key.”

“I think co-production is invaluable because even if you don’t have an idea and you’re sat in a meeting, you might come away 3 days later and have a spark/ ingenious idea. Next thing you know, we are all bouncing off each other”

“I’ve never had anything to do with co-production until this – I like how it works, having many minds together on a constant basis. You get different outcomes from their different experiences.”

“[it is] absolutely paramount! The number of ideas, perspectives, experiences that have shaped the design, delivery, and implementation that have come from lived life experiences is so invaluable”

Volunteers were extremely positive about the role of coproduction and have been very sad to see the project come to an end.

“I feel it’s really important – got to have people who know what it feels like – its not something that’s done to service users, that should be part of the picture… done with, rather than to.”

Overall Impact on Volunteers

1 Solidarity & Peer Support

"Being able to talk freely about something that you know only a few people understand is a really freeing experience, it unleashes something in you"

"[it] has helped me feel less alone and part of a community."

2 Voice being heard

"Personally, I feel seen, heard, I have found my voice again through this project."

3 Growth in confidence and self-esteem

"I feel I have grown in confidence, self-worth, &, self-esteem. I have found that spark again, something that I believe in & want to be part of every step of the way wherever possible."

"I didn't really know i had a quotable way of speaking until this project."

4 Reaching those with influence

"I feel I have been given an amazing opportunity to be a part of something that is so integral & pivotal in system change within mental health (NHS) and beyond."

5 Meeting new and different people

"It has been great meeting different people from so many walks of life, who usually I would never cross paths with, and coming together for such a good cause."

6 Hearing a range of perspectives

"Working with other people with lived experience is very humbling. There are people from all walks of life and backgrounds which allows different opinions and views, this is invaluable. No two people have been through the same experience, so we have been able to reflect on an idea in a different way."

Reflections and Learnings

Focus on bereavement

10 of our volunteers who were involved in the overall project at some stage have been bereaved by suicide.

Considering this, it feels that perhaps there could have been a greater focus on and conversations around bereavement by suicide.

Indeed, one of our volunteers felt that there was only a small part of this project that they could support with due to the unexpected nature of their family member's passing, not being known to any mental health services.

Accessibility of involvement

A few volunteers commented that they found evening meetings challenging to attend due to long working hours, work-life balance and other commitments. It would be important in any future project to consider how to maximise a range of engagement when people have different availability.

Some volunteers also would have preferred to attend in person but due to distance and personal circumstances were unable to do so. There were discussions about rotating the location of the meetings to the various areas which could be a future consideration.

"I feel very content with the way I have been heard throughout the entire process, and all the various aspects of the project. I do believe, in my experience there was a fairness and balance throughout that was inclusive of all voices being heard regardless of what that looked like."

"The project has been coordinated fantastically well throughout. I've always felt listened to and valued."

"I feel like my voice was heard a little too much. I was always shown the upmost respect and if something I said was implemented it was done with respect and with regard to me as a person."

Factors to consider for meaningful coproduction

It takes time

One reflection and learning many had was that co-production takes time as you have to consider and utilise a wide variety of ideas and perspectives. This was a source of frustration at times but we all understood and appreciated the time given.

Therefore, it is important to manage expectations around the time that co-produced projects might take.

Keep feeding back on progress

We have fed into lots of amazing projects, events and consultations run by other providers which have largely been positive experiences. One key learning from this is the importance of updating those who have shared valuable lived experience on any progress made and how you intend to use input.

“I’ve felt incredibly supported, heard, and validated, which is something I have little experience of when it comes to my mental health. Everyone is so friendly, and I really look forward to the group meetings as it provides everyone with an opportunity to catch up.”

“My experience of mental health services over several decades had been a very negative one. I was rarely asked my opinion, rarely listened to and rarely felt supported. The project was a sharp contrast to this – it gave me, and others like me, a voice.”

“It’s been a privilege to work in a group of people with shared lived experience. Everyone’s story is unique, but they share so many common characteristics. You’re not as alone as you may have thought. To work collectively and to advocate for others in this way is incredibly empowering.”

What we hope is the impact of this project

1. More funding for Coproduction Approaches and Projects
2. Embedding lived experience voices and coproduction into local and regional suicide prevention strategic and frontline work
3. Resources to be used to improve staff approaches to care and support for people prior to, during and after crisis and/ or bereavement
4. See meaningful changes in local and regional approaches, policies and strategies
5. Inspire and inform other lived experience and coproduction work in Third Sector and Statutory Services
6. Greater investment in suicide prevention and mental health work

"Where do I begin.... systematic change, to give a voice to those that have been silenced for so long. That the government will take notice and invest in the mental health system utilising people with lived life experience to coproduce a much-needed systematic change."

"I hope it carries through to making change and encouraging more funding that's desperately needed in mental health support. Having been involved in this project for two years and following numerous conversations with people with lived experience and with practitioners, I firmly believe that more money, well spent is essential to saving more lives and that every life lost destroys countless others. This is a contagion that we simply have to address."

What we hope is the impact of this project

"Wish we'd not had to do it at all. The NHS is broken. Resources tend to concentrate on downstream interventions. Upstream intervention is required."

"I'm very hopeful that our labours come to something and that we get to hear about some meaningful change going forward. This would mean the world."

"I want to use this platform as a means to create positive change... I would like to reduce the number of people who feel suicidal but also to try to create a world where people receive more kindness and compassion."

"That someone understands that without hearing from people with lived experience, their attempts to improve our lives will almost always fall short of what's required. That those with the power to change things are cogent and compassionate enough to understand that without us, there is no way forward that will realistically see suicide rates drop substantially."

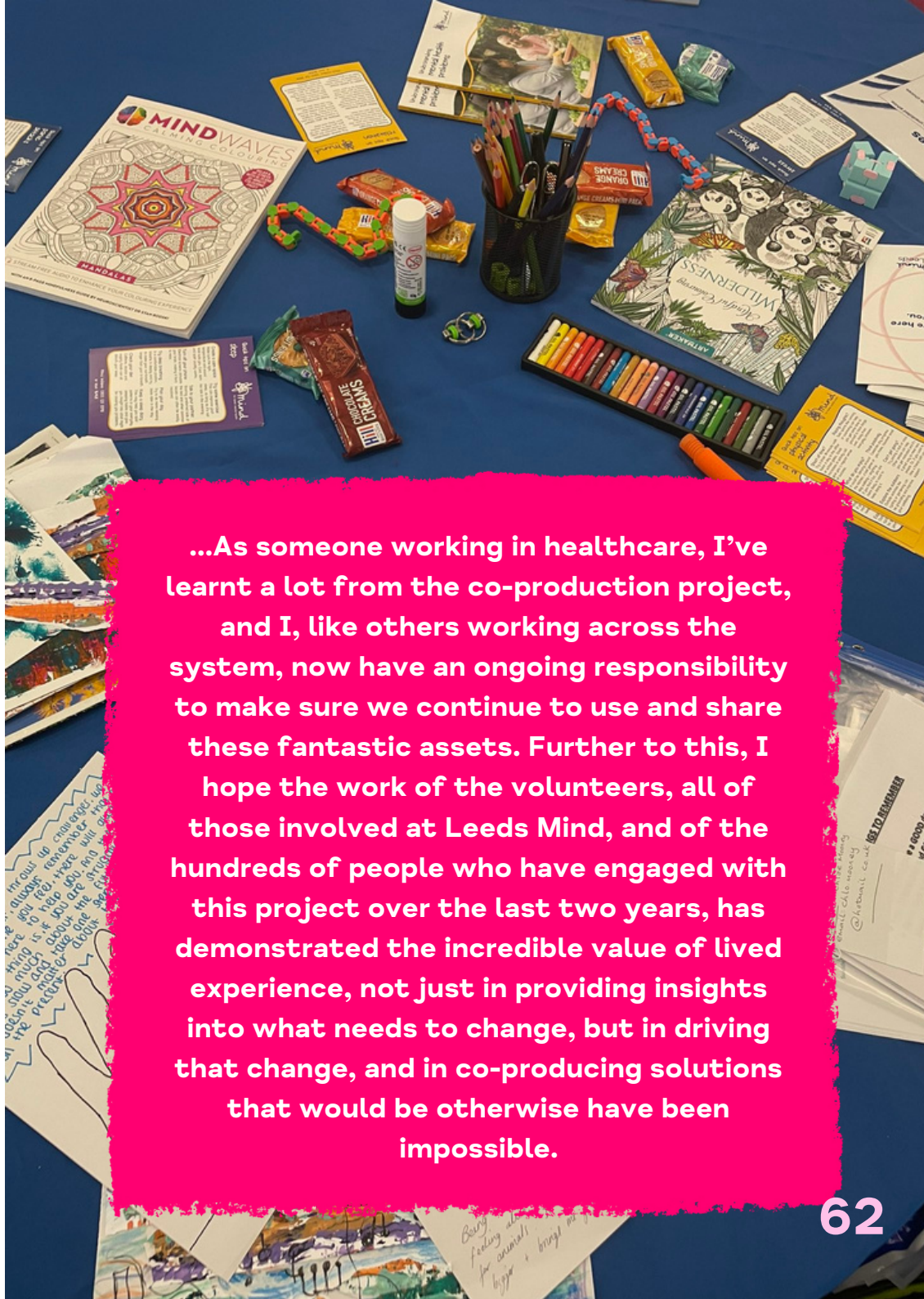
".It would be amazing if we could evoke changes in the law (specifically around the Personal Injury issues & whether those affected by the death have/have not actually witnessed the incident). The bereaved are likely to suffer lifelong from deaths by suicide and there are many effects/situations that the judicial system would not even be aware of let alone recognise."

External Impact & Perspectives

Our partners and those we have engaged with throughout the project have been incredibly complientary about the work produced and have emphasised the need for this coproduction to continue.

Lead on ICB's Suicide Prevention Programme:

The phenomenal work done by the volunteers has already been incredibly valuable, and will continue to inform the way we think about suicide prevention, the way we provide services, and the way we involve lived experience, for many years to come. Not only has the work done helped inform and inspire people across the system around the need for change, but the resources produced support people working in health, care, and beyond, in realising this change, and ultimately, in achieving our ambition as a health and care partnership, to reduce the number of suicides in West Yorkshire...



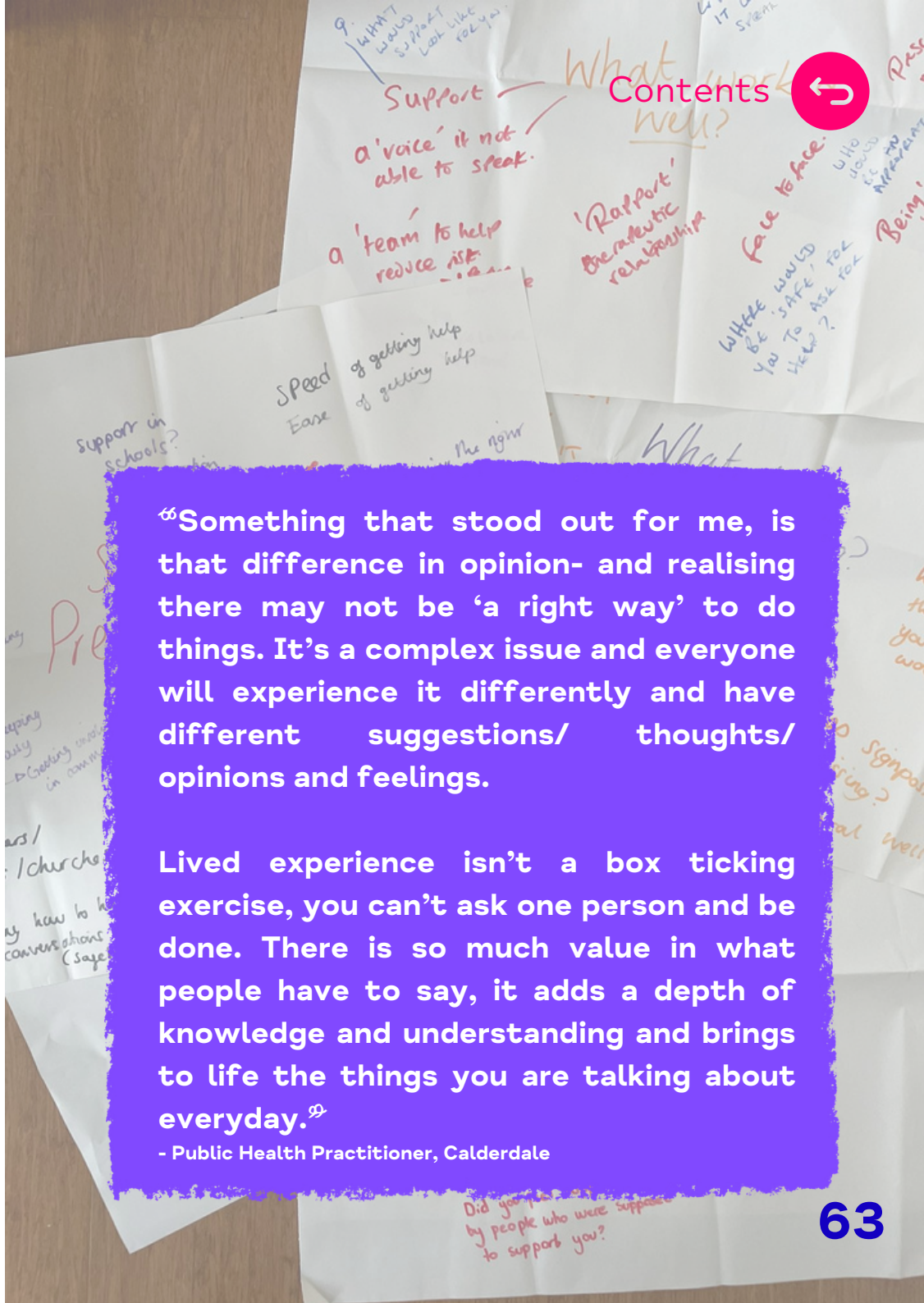
...As someone working in healthcare, I've learnt a lot from the co-production project, and I, like others working across the system, now have an ongoing responsibility to make sure we continue to use and share these fantastic assets. Further to this, I hope the work of the volunteers, all of those involved at Leeds Mind, and of the hundreds of people who have engaged with this project over the last two years, has demonstrated the incredible value of lived experience, not just in providing insights into what needs to change, but in driving that change, and in co-producing solutions that would be otherwise have been impossible.

External Impact & Perspectives

Our partners and those we have engaged with throughout the project have been incredibly complientary about the work produced and have emphasised the need for this coproduction to continue.

Senior Public Health Specialist, Bradford:

“I really value lived experience input, but it can be difficult to coordinate and recruit people to projects that have strict timelines to work to. This project has served as a really important reminder to prioritise this. These resources are completely unique, hold a real and personal perspective and help fill a bit of a void around peer support by sharing the voices of people with lived experience to others who may also be struggling and those who work with them. They transcend the timeline of the project. I hope to try and do more work involving people with lived experience.”



“Something that stood out for me, is that difference in opinion- and realising there may not be ‘a right way’ to do things. It’s a complex issue and everyone will experience it differently and have different suggestions/ thoughts/ opinions and feelings.

Lived experience isn’t a box ticking exercise, you can’t ask one person and be done. There is so much value in what people have to say, it adds a depth of knowledge and understanding and brings to life the things you are talking about everyday.”

- Public Health Practitioner, Calderdale

Conclusion

“This project has given a voice to so many that have been silenced”

We would like to say a huge thank you to all of our wonderful volunteers who have driven the fantastic outcomes of this project.

Thank you to all of those who attended our community conversations sessions; those who contributed to the Book of Cope.

Thank you to local Public Health Teams and the West Yorkshire Health and Care Partnership for championing the work we have done and anyone who we have liaised with and collaborated with over the course of the project.

This project has been integral to giving a voice to so many who have not been given a platform before.

We have demonstrated the importance of and need for lived experience involvement and coproduction in any work towards suicide prevention. Without this, solutions and approaches can never be effectively tailored towards local and individual needs.

This involvement should not be reserved solely for projects specifically funded for coproduction but should be embedded within all approaches towards suicide prevention and post-vention. Imperative to this is the need for coproduction to have resource and specialist support to ensure people sharing their expertise through lived experience are fully supported.

Therefore, lived experience voices should feature at all meetings with key decision makers and at every local and West Yorkshire wide strategy group.

The power of this project has been involving lived experience voices throughout the entire project and at all levels of influence.

It is important to keep lived experience experts consistently involved and avoid ‘one-off’ consultations. Therefore, it is important to continuously feed back on the impact of projects to demonstrate the impact of someone sharing their valuable lived experience.

We hope that this project is recommissioned in future and can continue to produce fantastic guidance and outputs for frontline practitioners and the wider public.

The importance of this work has been recognised by multiple external partners and key decision makers. This report aims to demonstrate the level of its impact and make a strong case for coproduction approaches across all suicide prevention work.

“I think it’s just a brilliant project and I wish someone would pick up the funding and it could carry on”

Find out more at: https://www.leedsmind.org.uk/services/suicide-prevention-co-production/

mind Leeds

West Yorkshire
Health and Care Partnership

Leeds Mind
Clarence House
11 Clarence Road
Horsforth
Leeds
LS18 4LB

T: 0113 305 5800
www.leedsmind.org.uk
Registered charity number 1007625