# 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







## 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.

of 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



#### 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.

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.<sup>99</sup>



# **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

<sup>66</sup>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 <u>Here</u> (skip to 1hr 7mins to see our bit)

<sup>66</sup>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.<sup>96</sup>





Meetings, Engagements and	54
Promotion	
Role of Coproduction	56
Overall impact on volunteers	57
Reflections and Learnings	58
Factors to Consider for	59
Meaningful Coproduction	
What we hope is the impact	60
External Impact and	62
Perspectives	
Conclusion	64