Suicide Prevention Scotland.

Working to deliver Creating Hope Together

Case Study

Wave After Wave: Involving Lived Experience in the Co-production of Training Materials

Glasgow City HSCP
Health and Social Care Partnership

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Who was involved?

Glasgow City HSCP, NHS Greater Glasgow and Clyde, Glasgow City Suicide Prevention Partnership, Glasgow Association For Mental Health, Pure Potential Scotland & Third Sector Lab.

What did we do?

Following identification of a need for multi-agency training on suicide bereavement in a scoping of local provision, Glasgow HSCP, on behalf of the Glasgow City Suicide Prevention Partnership, commissioned the development of training using a co-production approach. The process for the development of the training included:

Commissioning: A competitive commissioning process was used with weighting and scoring criteria chosen to reflect the needs of the specific project. A lived experience volunteer sat on the commissioning group.

Staff consultation: A questionnaire was disseminated to HSCP staff, third sector organisations, NHS employees, front line emergency services and religious institutions asking what they felt they needed to know to better support those who had been bereaved by suicide. 71 members of staff, peer supporters and volunteers responded. 27 members of staff, peer supporters and volunteers were interviewed to gain further insight into wellbeing needs and existing concerns about working with people bereaved by suicide.

Lived experience consultation: Individuals with lived experience of suicide bereavement were recruited through the dissemination of an information and sign-up form. Consultation was carried out by a skilled and sensitive facilitator either online or face to face using semi structured interviews. Contributors were provided with an information and consent form to sign prior to engaging. 16 people were interviewed. Follow up support was offered.

Development of Training Materials and content: The contributions from the sessions with staff and people with lived experience were collated and key themes for training content were explored. The lived experience group were given the opportunity to comment on learning outcomes identified by staff. It was decided that quotes from the co-designers would feature heavily throughout the materials. The training benefits from this richness and authenticity and is impactful, moving and grounded in real life experience.

Remembering lost loved ones: It was agreed collectively that the loved ones of those who took part should be recognised and remembered in some way through the materials. The lived experience group came up with the idea for an illustrated remembrance quilt which sits within the presentation and it was agreed that a letter from the lived experience group would be included in the training handouts. With consent, the names of their loved ones were included in the acknowledgements in the training for trainers pack. The training hugely benefits from this emotive and powerful addition.

Development of Digital Media: One to one consultation meetings and a group workshop were used to develop key themes for content and ideas for the style of delivery. Those who had agreed to participate in the co-design process of the digital materials were interviewed and audio from these conversations were used in the videos, bringing the messages of the training to life. A review session was carried out with the lived experience group following the development of the media and they were extremely well received.

Pilot and Testing: Wave After Wave was piloted via face to face and online sessions. Some of the staff and Lived Experience group members took part and the feedback was extremely positive.

The materials were reviewed and amended following the pilots to reflect feedback from the participants and the project steering group.

As a result of attending the pilot, of those who attended:

84%

84% agreed or strongly agreed that they had a greater understanding of the statistics and context around suicide bereavement in Glasgow*

100%

100% agreed or strongly agreed that they had a greater understanding of grief and suicide bereavement.

100%

100% agreed or strongly agreed that they had a greater understanding of how to provide a compassionate response to suicide bereavement.

100%

100% agreed or strongly agreed that they had a greater understanding of the impact that suicide bereavement can have on staff.

100%

100% agreed or strongly agreed that they felt more confident signposting people to relevant supports.

100%

100% agreed or strongly agreed that the training materials were helpful and relevant.

100%

100% agreed or strongly agreed that they would recommend the training to their colleagues.

94%

94% would consider delivering the training to their team.

*(reflecting the fact that many who attended were already experienced in the delivery of suicide prevention training).

Training for Trainers: Two 'training for trainers' session were organised to support existing trainers in Glasgow to familiarise themselves with the resource and create a network of people who could support each other through the delivery of it.

Feedback from those who attended said that Wave After Wave was **'incredibly powerful', 'something that is sorely needed' and that 'you have something special here'.**

Feedback Loop: The HSCP agreed to keep in touch with the lived experience group via GAMH. A first written update was shared in November 2022 and an in person update and thank you event was held with the group early in 2024.

"This training will create more compassion, empathy and awareness in a world where organisations and staff are firefighting and forget to stop, think and process."

"It has been an honour to be part of such an important piece of work. When there is still so much stigma around suicide, the grief can feel very lonely. Working on this training with other people with lived experience has been healing for me, even this far along in my journey. Feeling like our experiences can make a difference, can encourage people to open up conversation and can ultimately get the right support at the right time to those who need it, feels like a gift. One that allows me to heal, to honour the life of my husband and what he meant to me and to encourage others to reach out to others who find themselves dealing with the tragedy of bereavement through suicide."

"I will be able to have more open conversations about suicide with my peers, family and friends. It has given me the tools to assist someone who is currently grieving."

"It has 'wakened me up', made me alert to the massive impact that suicide bereavement can have on individuals and reminded me to respect each person's feelings and not get de-sensitised".

"The involvement of lived experience was very powerful and made a huge difference to the course. It felt very real and valuable."

Sharing what we learned

Centring Lived Experience: It is vital to put lived experience at the forefront of everything you do. Listen and use their experience to guide the development of the work and keep them involved throughout. It was clear how much this meant to people and how important they felt it was to share their stories to help others. While existing literature was extremely useful, the personal experience of suicide bereavement shared by participants was integral to developing the training in a way that felt authentic, powerful and meets the needs of the people on the receiving end of support. The voices of lived experience feature through quotes in the presentation and spoken word in the videos in a powerful and emotive way. The training provides practical suggestions directly from the voice of experience.

Consent & Information: Clear and robust consent processes are vital and were supported by the development of a comprehensive project information sheet which allowed potential participants to make an informed decision about their involvement. This included information about the people who are involved in the research and their background in suicide prevention work. Flexibility in the ways that people could contribute supported safety, inclusivity and comfort.

Safety First: The safety of the lived experience group, staff, future trainers and participants was at the forefront during development. Being sensitive to the needs of those you are engaging with is vital, even if it does not fit with your expectations and plans. In this instance the commissioners, on the advice of GAMH allowed a delay in the timeline for the project to avoid consulting during the festive period and January, recognising that this can be a particularly sensitive time for the bereaved. A decision was also taken that the loss of the loved one should be no less than one year ago. While for many the loss was still extremely raw, this meant that they weren't still in the process of legal arrangements or any other formal procedures associated with their loss.

Support: It was important for participants to be aware that there was further support available for them as they participated, and that people would not be left to sit with any distress caused from sharing their experiences. It was also important for the interviewer to be comfortable checking out any risk of suicide and to be able to support the person should they disclose this. Given the nature of the interview the interviewer had regular scheduled supervision either internally or externally in order to ensure that they had the space to talk about the experience and have their own emotional support needs met throughout. The impact of this focus on safety can be seen in the final materials which have a laser focus on the safety and wellbeing of participants undertaking the training.

Time, Space, Compassion: These were vital components of the engagement process and should be a key part of any lived experience engagement. Compassion, active listening and validation were key to the interview process. For many people involved this was the first time they had ever had the opportunity to speak openly about their loss and be listened to. Having a planned structure and set questions are important for containment and safety, allowing people space around those questions to feel heard and the time to tell their story without feeling rushed was important. Conducting the interviews in a safe and physically comfortable environment was also key.

Skilled Interviewers: Ensuring that those conducting the consultation have appropriate skills and confidence is important. Key qualities include the ability to demonstrate compassion, use of active listening skills, warmth, empathy, the ability to sit with difficult emotions and distressing information, and safety planning skills. The ability to reflect on how the process is impacting on their own mental health and use supervision effectively is vital.

Diversity: Ensuring a diverse lived experience voice is important but can be a challenge. In this instance it was difficult to find representation from BME groups. Through discussions with community members and faith leaders, it appeared likely that the cultural taboo associated with suicide bereavement may have prevented people from coming forward to talk about their experiences. Further projects should explore this further and attempt to address this gap in engagement.

Flexibility & Openness: Part of the beauty of lived experience work is what comes with being open and responsive to new ideas coming from participants. The memorial quilt is a good example of this, and adds such richness to the final product and was a true gift from those who gave their time and experience to the project.

Benefits to Participants: The extensive involvement of the lived experience group was not only been of benefit to the training development, but also to those involved. For some the consultation sessions were the first time anyone had allowed them space to talk about their loss or due to their relationship with the person who has died, had their loss acknowledged and their grief validated. Contributors fed back that they found the consultation to be a helpful process in their grief journey.

Involving the Key Target Audience: This was a vital part of the co-design process. Consultation with staff provided rich and new information about the gaps in knowledge and confidence around supporting people bereaved by suicide, and was vital to the development of materials which would meet existing needs, and provided a good indication of key target audiences for the training once developed.

Maximising Impact and Reach: One of the challenges was making decisions about what could and could not be included in the materials – a result of the breadth and the richness of the stories and thoughts of participants in the process. Where there was further learning that was not included in the training materials produced this was, where appropriate, fed into the relevant agencies and organisations. A summary report of the process which also highlighted key themes and suggestions for further action was provided.

Do Not Rush: It is important to allow enough time for the consultation and development process. This process should not be rushed. Allowing those involved further opportunities to hear how the project is developing, access to the resources (and any updates), and feedback about the difference it is making should all be factored in to any project plans.

Wider Interest: It was clear from the outset, and as the project progressed that there was a national gap around cost free suicide bereavement training. As a result there as been wide interest in how the materials can be used in other areas across Scotland. The materials were written in an accessible way, with clear trainers notes to facilitate usage, and an ability to localise if needed. They are protected under a Creative Commons license which stipulates attribution to the original authors and zero charge to training participants. Links have been made with relevant individuals working in suicide prevention nationally to consider how this can be supported.

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