

# The co-production of an intervention facilitating informal caregivers to support adults at risk of suicide and serious self-harm: A brief report

Debbie Frances

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Résumé de l'article

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In response to the theme of poor family involvement consistently identified in reports into deaths by suicide in Devon (UK), Devon Partnership NHS Trust has developed Stronger Together, a training programme for carers of suicidal adults. The programme, co-produced with carers and service users, also includes a collaborative learning component with healthcare staff.

This report explores the programme's co-production and my personal involvement. Co-production shaped Stronger Together, aligning it with national policy and research findings. Its co-delivery and co-learning approach uniquely addresses carers' needs and fosters staff-carer collaboration. Learning from this initiative could help other mental health trusts foster a culture of carer collaboration, potentially improving patient safety, reducing caregiver burden and enhancing support for patients and families to reduce deaths by suicide. It also strengthens the case for co-production of training that effectively meets the needs of participants and delivers on its outcomes.

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## The co-production of an intervention facilitating informal caregivers to support adults at risk of suicide and serious self-harm: a brief report

Debbie Frances MSc



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**Keywords:** suicide prevention, carers, caregivers, patient safety, co-production, psychoeducation

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### Abstract

The recovery model in mental healthcare increasingly recognizes suicidal behaviour as an interpersonal issue, with caregivers seen as essential in prevention. In the UK, as in other parts of the world, there is growing consensus in policies, guidelines, and academic research towards carer involvement in a person's mental healthcare, yet inconsistency in practice remains commonplace.

In response to the theme of poor family involvement consistently identified in reports into deaths by suicide in Devon (UK), Devon Partnership NHS Trust has developed *Stronger Together*, a training program for carers of suicidal adults. The program, co-produced with carers and service users, also includes a collaborative learning component with healthcare staff.

This report explores the program's co-production and my personal involvement. Co-production shaped *Stronger Together*, aligning it with national policy and research findings. Its co-delivery and co-learning approach uniquely addresses carers' needs and fosters staff-carer collaboration. Learning from this initiative could help other mental health trusts foster a culture of carer collaboration, potentially improving patient safety, reducing caregiver burden, and enhancing support for patients and families to reduce deaths by suicide. It also strengthens the case for co-production of training that effectively meets the needs of participants and delivers on its outcomes.

### Introduction

Globally, suicide and attempted suicide are serious public health issues. Over 700,000 people die by suicide every year,<sup>1</sup> and in the UK alone, 115 people die by suicide every week (2). Figures for attempted suicide are estimated to be at least 20 times higher.<sup>3,4</sup> Yet suicide is seen as a preventable phenomenon, and as such the World Health Organization has prioritized its reduction as a global target.<sup>1</sup>

Within the recovery model of mental healthcare, suicidal behaviour is increasingly understood as an interpersonal phenomenon,<sup>5</sup> and as such family, friends or carers (hereinafter referred to as 'carers') are seen as a protective factor in suicide prevention. Carers can play a key role in an individual's recovery from suicidal behaviours through

providing emotional support, sharing activities and remaining connected to the suicidal individual in everyday life.<sup>6</sup>

Due to the potential benefits of carer involvement in suicide prevention, working together with carers is increasingly emphasised in policy, practice guidelines, and quality indicators for suicide prevention and patient safety.<sup>7-11</sup> The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) has identified carer involvement as one of ten key elements in this respect<sup>12</sup> (Figure 1). Notwithstanding, audits continue to highlight poor levels of carer collaboration and integration within mental healthcare.<sup>13,14</sup>

In response to the theme of poor family involvement consistently identified in inquest reports into deaths by suicide in Devon, UK,<sup>15</sup> Devon Partnership Trust's (<https://www.dpt.nhs.uk/>) (DPT) Safe From Suicide team was tasked with developing a quality improvement intervention that addressed this problem. This brief report discusses the co-production of *Stronger Together (ST)*, a training initiative which aims to improve patient safety and reduce deaths by suicide through carer involvement and collaboration which was piloted from January-July 2023 and externally evaluated by University of Exeter. It explores how co-production was fundamental to shaping the content, structure, and delivery model of *ST*, and how this has impacted on the quality, success, and relevance of the final training program.

Co-production is a way of working that acknowledges that those who use services and their carers are often well placed to advise on what support or help will make a positive difference.<sup>16</sup> In validating and utilizing the strengths of experts-by-experience, co-production fits within a recovery-oriented framework of mental healthcare.<sup>17</sup>



Figure 1 NCISH - 10 ways to improve patient safety (© www.manchester.ac.uk/NCISH)

## Research Design and Methods

This report utilizes a mixed-methods approach,<sup>18</sup> combining autoethnographic and questionnaire methods to examine the co-production of *ST* and its implications for wider practice. I have extensive personal experience of caring for an adult with a long history of

suicidal behaviours, as well as being a key member of the co-production and co-delivery team for *ST*. Whilst I have attempted to retain a neutral perspective in this report, it is important to acknowledge my involvement and potential subjectivity.

The Safe from Suicide (SFS) team entered a process of co-production with carers and service user experts-by-experience to identify the problems and challenges experienced by caregivers of suicidal adults and how these could be addressed through a co-designed solution. The co-production group comprised of seven DPT clinicians, three experts-by-experience, and four carers met over a 15-month period. The group had a core membership of six, including myself and the SFS clinical lead, with others joining as commitments allowed.

All individuals involved in the co-production were invited to complete a self-administered online questionnaire to gather their views on the process. Ethics approval was obtained from the Health, Science, Engineering, and Technology Ethics Committee at the University of Hertfordshire in November 2022 (protocol number HSK/PGT/UH/05174) as part of my Master's dissertation.<sup>19</sup> As the co-production group was small, all those involved at any point were invited to respond, and no sampling was necessary. The questionnaire comprised open and closed questions, including nominal variable, Likert scale, and free-text questions. Respondent demographics are shown in Table 1.

Characteristic	n=	%
<b>Gender</b>		
Female	4	57
Male	2	29
Prefer not to say	1	14
<b>Age</b>		
25-34	1	14
35-44	3	43
45-54	1	14
55-64	2	29
<b>Ethnic background</b>		
White/Caucasian	7	100
<b>Role in co-production process</b>		
Service user expert by experience	3	43
Staff member/clinician	4	57

*Table 1 Demographic characteristics of respondents*

## Results

*ST* is a two-day training programme aimed at carers of suicidal adults. Workshop One provides suicide psychoeducation for carers, whilst also teaching skills and techniques to

help carers manage their wellbeing and build resilience in themselves and the cared-for person. Workshop Two utilizes a co-learning model for carers and staff to explore together the challenges of consent and information-sharing while also providing a space to share about attitudes (of both professionals and carers) that may hinder collaborative working, and how these might be overcome. During a 6-month pilot, 14 workshops were delivered to a total of 87 staff and 12 carers.

From the outset, the SFS team committed to allowing experts-by-experience to define the problems for carers of suicidal adults, what was needed, and to co-design a solution, rather than this being pre-defined by mental health professionals. This is in accordance with NHS England's co-production guidance,<sup>16</sup> but in my experience it is rare that experts-by-experience are given such a degree of autonomy and leadership in co-produced projects. I was therefore interested in how this influenced the development and end-product of *ST*.

From reviewing the questionnaire responses, I identified three themes. For this report, I will mainly focus on the first two themes but make brief reference to key learning points that might be more widely relevant.

1. **Value of the co-production process:** Conversations between experts-by-experience, carers, and professionals allowed understanding to grow between the different perspectives. The genuinely collaborative nature of this project allowed trust to build, with people feeling heard and respected, and able to share openly to mutual benefit. Some respondents described feeling personally impacted by the honesty in the group, and how that shaped their thinking.

*"The openness of all those involved really was humbling ... It made me be more open about my experience/vulnerabilities as a clinician."* (clinician)

2. **Impact on content development:** All respondents felt their involvement had helped shape *ST*, and there was particular recognition from clinicians of the integral role experts-by-experience played in content development. The co-production process allowed the content to emerge and be revised collaboratively over time, bringing the training to life, and making it more meaningful and accessible.

*"Discussion with other experts-by-experience as well as assorted professionals allowed for interesting revisions - both to my own perspective and the content."* (expert-by-experience)

There was recognition that input from experts-by-experience significantly affected the end-product: the need and content for Workshop Two emerged entirely from the co-production process and was not originally part of the plan. Experts-by-experience recognized that providing psychoeducation to upskill carers was insufficient without a corresponding change in working practices and clinician's attitudes towards carers, and a willingness to recognize and work collaboratively with them as equal partners to achieve better outcomes for patients.

*"The honesty and experience of those with lived experience meant it went in a direction I would not have perceived myself as a professional."* (clinician)

3. **Challenges and learning:** The main challenge identified through the questionnaire related to the time taken to do 'true' co-production, especially when balanced against the pressures from senior management to deliver an end-product within a specific timeframe. This required the project lead to fully embrace the co-production process

and the time needed, and to defend their commitment to the senior executive.

Other challenges related to accommodating differing needs and viewpoints, working online, and maintaining project focus. There was also recognition of the emotive nature of the content, and how that impacted everyone but especially those working from a lived experience perspective. Although email check-ins took place after every meeting, with hindsight, experts-by-experience would have welcomed supervision or reflective practice space.

For my Master's dissertation,<sup>19</sup> I carried out a comprehensive literature review to establish what is known regarding the role of carers in suicide prevention. Whilst it is beyond the scope of this brief report to explore the findings in depth, it is important to reference them here to demonstrate how the co-production process has allowed *ST* to address these key issues. This is summarized as follows:

1. **Family as a protective factor:** There is growing recognition of the role of carers in supporting suicidal adults, with healthy family connections associated with *“a sense of belonging, protection, and a sense of worth.”*<sup>20</sup> With the shift towards community and home-based treatments,<sup>21</sup> carers frequently provide high levels of practical and emotional support following a suicide attempt,<sup>22,23</sup> without the benefit of psychoeducation, training, or support.<sup>24</sup>

**ST:** Allowing experts-by-experience to define the challenges faced by carers of suicidal adults, and to co-create a solution, to invest in an external evaluation of the pilot and its continued roll-out within the Trust, show DPT's acknowledgement of the importance of carers and their important role in suicide prevention.

2. **Caregiver burden – impact on family:** Caring for a suicidal individual is deeply traumatic and can have a profound impact on caregiver wellbeing, family functioning, and relationships. The psychological distress can lead to burnout and high levels of psychiatric issues in carers,<sup>22</sup> exacerbated by inadequate professional support, information, and involvement.

**ST:** By providing knowledge on the neurobiology of suicidal behaviours, psychoeducational resources, and strategies to enhance resilience in both caregivers and the person they care for, *ST* aims to equip caregivers with a 'toolkit' to identify warning signs and respond appropriately to suicidal behaviours. It also aims to reduce caregiver burden by improving their ability to manage their own emotions, fears, and behaviours.

3. **Caregiver needs:** Despite carers and service users making it clear they want to be involved, caregiver support needs remain largely unmet.<sup>25</sup> These needs can be broadly categorized as psychoeducation, empowerment, and inclusion and acknowledgement in their caring role. Meeting these needs can lead to caregivers feeling less isolated and more confident and competent in their caring role, and ultimately to better patient outcomes.<sup>24-28</sup>

**ST:** Most suicide prevention psychoeducation programs target the general public and help identify and manage risks but do not address caregivers'

unique challenges and needs due to their emotional connection to the individual.<sup>30, 32</sup> The co-production process was invaluable in integrating the perspectives of both carers and professionals, ensuring the final content was both clinically accurate and aligned with the lived experiences and needs of carers. My literature review<sup>19</sup> (1 and the co-production group identified that co-delivery is vital in carer psychoeducation programs, providing carers with a peer they can identify with, learn from, and be inspired by. The peer support from other participants has also helped carers feel less alone.

4. **Barriers to caregiver involvement:** Carers describe feeling marginalized, invalidated, and even blamed or stigmatized by mental health professionals. Although attitudes toward carers are crucial, the primary reason for their exclusion relates to patient confidentiality, consent, and information-sharing procedures, which hinder involvement and transparent communication.<sup>20, 25, 29-31</sup>

**ST:** This co-learning model of Workshop Two fosters collaboration and has positively influenced both healthcare professionals who have found personal testimonies persuasive and carers who have felt empowered by lived experience input. A greater understanding between carers and professionals has emerged from this workshop.

From the pilot, key findings have been:

#### **Clinicians:**

- now having techniques to overcome barriers to collaborative working (100%)
- an improvement in knowledge and understanding of consent, confidentiality and information sharing (86%)
- an increase in self-reported confidence in working with and supporting caregivers

#### **Carers:**

- greater understanding and skills to support those at risk of suicide
- greater awareness of burnout and new techniques to prevent burnout
- increased knowledge and understanding of consent, confidentiality, and information-sharing
- the importance of peer support through connecting with other carers with similar experiences during the workshops

#### **Conclusions**

It is clear from both international and domestic policy and best practice guidance that collaboration and information-sharing between healthcare professionals and carers are fundamental to suicide prevention. Research also recommends carer involvement in the production and delivery of suicide prevention psychoeducation for caregivers. The co-production of *Stronger Together* has resulted in the development of a quality improvement initiative that aligns with national policy and guidance and with the findings and recommendations of international academic research, not only in terms of content but also in its use of lived experience throughout. *Stronger Together's* co-delivery and co-learning model is unique in addressing both the needs and challenges of carers supporting suicidal adults, and in helping staff and carers to develop skills and knowledge to overcome the barriers to carer inclusion and collaboration in suicide prevention.

Learning from the co-development and implementation of this program will be of value to mental health Trusts looking to find ways to embed a culture of carer collaboration to improve patient safety. It also strengthens the case for the use of co-production in developing relevant, effective, and accessible training within mental healthcare.

### Acknowledgements

I am paid as a freelance trainer to co-facilitate the *Stronger Together*. However, the research I carried out on which this report is based was done independently of that process as part of my Master's dissertation.

For conciseness, I have used the term 'carer' throughout this report to mean anyone – family member, partner or friend – who provides unpaid support to an individual experiencing mental distress, whilst acknowledging that not everyone will identify or be comfortable with this term.

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