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# Co-designing a peer support programme for carers of people treated under the Mental Health Act: views from stakeholders

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## Abstract

**Background** Relatives/friends (carers) of people who are involuntarily admitted to a psychiatric hospital report high levels of stress, feelings of isolation and exclusion from their patient's care. One-to-one peer support is widely implemented for patients, facilitating mental health recovery. Preliminary evidence reports that peer support may benefit carers too, but a one-to-one peer support programme to help carers when their relatives/friends are in hospital has not been developed.

**Objective** To explore carers', patients', and professionals' views on what an accessible, feasible and helpful one-to-one peer support intervention should consider for carers of patients treated under the Mental Health Act (MHA) in England.

**Method** Nineteen one-to-one interviews were conducted online with five carers, four patients, four clinicians, four independent mental health advocates and two behaviour change experts. Participants had experience of either being treated or supporting someone treated under the MHA within the last 10 years. Audio recordings of the interviews were transcribed, and data were analysed using thematic analysis.

**Results** Five themes were identified: (a) carer availability and awareness; (b) peer support flexibility; (c) early promotion of peer support; (d) appropriate training and support for peers, and; (e) anticipated impact of peer support. Carers' lack of time and awareness of support were reported as key barriers to accessing peer support. To address this, participants emphasised the need for early introduction of support following patients' hospitalisation and flexible delivery through various communication channels. They also highlighted the need for robust, interactive training for peer supporters. Expected benefits included improved carer and peer supporter wellbeing and increased carer knowledge and empowerment.

**Conclusions** These findings highlight the need for structured training for peer supporters and a flexible, accessible peer support programme for carers. The findings can inform evidence-based co-production of a carer peer support programme for use in England, which could improve carer wellbeing, knowledge and empowerment.

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**Keywords** Peer support, Family members, Relatives, Carers, Mental Health Act, Mental health, Qualitative

## Background

Involuntary admission to a psychiatric hospital has a significant impact not only on the lives of the patients who are detained, but also their relatives and friends who support them, also known as carers [1]. The experience of involuntary hospital admission was described by carers as traumatic [2]. Carers reported feeling isolated during the detention of their relative/friend and often felt excluded from their relative's/ friend's assessment and care, causing frustration with mental health services [1–3]. If carers are left without support, it can have a detrimental impact on their mental and physical health [4], increasing their risk of developing diagnosable physical and mental health disorders [5]. These negative experiences could, in turn, limit carers' capacity to provide the necessary support to their relatives or friends, potentially leading to poorer patient outcomes [6].

Currently, carer support groups are available, delivered by carers with lived experience, also known as 'peer supporters', which have been associated with lower rates of depression and caregiver burden [7]. However, these support groups face challenges, including carers having to repeatedly discuss their situation, difficulties finding a convenient time to meet and personal, intimate feelings not being adequately addressed [7]. Two recent trials of online carer support programmes, which included a peer-to-peer web chat group forum moderated by both professionals and trained peers, were not effective at reducing carer distress or increasing wellbeing [8, 9]. However, online support has been found to be helpful and as effective as face-to-face support in other mental health contexts [10–12]. The National Health Service (NHS) recommends using various communication channels to engage carers [13], suggesting that both online and in-person peer support should be made available. However, it may be that one-to-one peer support models are required.

One-to-one peer support could effectively address the challenges associated with previous peer support programmes. One-to-one peer support for mental health patients has been found to be feasible and effective in facilitating recovery following an acute episode of mental illness [14]. However, there is currently little evidence available regarding the benefit of one-to-one peer support for carers of mental health patients.

To our knowledge, there is only one, one-to-one carer peer support programme that has been developed, the Experienced Involvement (EX-IN) programme, created in Germany. Carers who participated in this programme

reported a significant reduction in caregiving burden and an increase in mental health-related quality of life [15]. Part of this programme's success may be attributed to its flexibility in both delivery and content, which was identified by previous research as key to successful peer support programmes [16–18]. However, this programme needs to be adapted in view of the differences surrounding mental health legislations between England and Germany, and the current context of carer-focused work within the mental health system in England. To effectively adapt the programme, it is important to understand how carer peer support should be developed in England to support carers and contribute to long-term improvements in the mental health care system.

We previously explored what type of support carers of patients treated under the Mental Health Act (MHA) would like to receive [19]. We found that they required more information surrounding mental health service processes and legalities, including their rights, the rights of their relatives/friends and practical aspects such as a carer's assessment. Carers also wanted a single, named contact, ideally with lived experience, to provide ongoing information and emotional support. This previous study, while focusing on general support, highlights the value of peer support and provides a strong understanding of carers' needs. However, it is important that specific needs relating to peer support, including for example organisational barriers and requirements, are explored to fully inform a peer support model for carers.

Incorporating users' perspectives in the design of a carer peer support programme, known as co-design, is important in ensuring that such a programme is suitable, acceptable and beneficial [20]. Without these perspectives, peer support programmes risk missing important information required for both peer supporters and carers, and may fail to address key support needs [21]. It is also important to consider the views of not only carers but those directly in contact with carers, such as professionals and patients. These groups bring varied experiences and knowledge of the mental health care system, and their input can help to ensure the programme benefits all parties. A programme shaped by this range of perspectives is more likely to be successfully implemented and sustained within the mental health care system, positively impacting these services long-term. Therefore, the current study aimed to explore carers', patients', and professionals' views on what an accessible, effective and impactful peer support intervention for carers should look like.

## Methods

### Design

This was a qualitative, semi-structured interview study. Data were analysed using thematic analysis [22] with codes and themes identified using a hybrid inductive-deductive approach [22, 23]. This approach combines analysis using a pre-existing framework, based on previous research on carer peer support [15], with direct analysis of this study's interview data to identify new themes. This approach provides a more comprehensive understanding of the research topic than either an inductive or deductive approach alone [23]. Specifically, this analysis helped identify key elements from a successful carer peer support model in Germany [15] that were relevant to the English context, while also highlighting aspects unique to professionals, carers, and patients in England.

Ethical approval was granted by the West of Scotland REC 3 (REC reference: 21/WS/0098). The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [24] were used to report on the methods and results of this study. As part of this criteria, researchers' background, including their relevant experience, are reported in appendix 1.

### Participant recruitment

Participants were eligible to take part if they were either: (1) a relative or friend with experience of supporting someone treated under the MHA in the last 10 years; (2) someone who had been treated under the MHA in the last 10 years or; (3) a professional (clinician, Independent Mental Health Advocate (IMHA) or Behaviour Change Expert (BCE)) with experience of treating someone under the MHA within the last 10 years. All participants had to be from England, 18 years or older and have the capacity to consent.

We aimed to recruit five carers, three patients and nine professionals including three clinicians, three IMHAs and three BCEs. We aimed to recruit a range of participant groups to capture diverse experiences to ensure the programme benefits all those likely to be involved in carer peer support. In these cases, alternative strategies for ensuring research credibility and rigor are required, such as investigator triangulation [25, 26]. Therefore, we employed three multidisciplinary researchers (IW, AGM, KW) to code the data, with decisions regarding final themes made by four multidisciplinary researchers (IW, AGM, KW, DG).

We aimed to interview nine professionals to understand how to develop a peer support programme that is effective for beneficiaries and feasible within mental health care services. We focused primarily on professional groups whose roles emphasise person-centered care, empowerment, and autonomy.

Participants were recruited using a purposive sampling technique [27], considering participants' role (carer, patient, professional), geographical location (Coventry, Warwickshire, East London and Devon) and ethnic group. This was done to capture insight from those with varying experience with carers and mental health services. Carers and patients were identified through NHS records accessed by the clinical team at each participating site (Coventry and Warwickshire Partnership NHS Trust (CWPT), East London NHS Foundation Trust (ELFT) and Devon Partnership NHS Trust (DPT)). Carers were also identified through carer groups and flyers provided in NHS facilities at each participating site. Professionals were identified through principal investigators' (PIs) personal networks and invited to contribute. Demographic details of recruited participants were regularly monitored and discussed with both lived experience and professional groups involved in this study, who offered suggestions on ways to obtain a more diverse sample. From these suggestions, clinical staff discussed the study with communities frequented by those from typically underrepresented groups (e.g. minority ethnic groups). Lived experience and professional members who were themselves part of an underrepresented group also discussed the study with their personal contacts.

Participants received a brief overview of the study. Those who agreed to take part were contacted by the research team by either telephone or email to arrange a suitable time for interview. Carer and patient participants were compensated £25 for their participation. Written or verbal informed consent was obtained from all participants. No participants dropped out once they had consented.

### Procedure

All participants were interviewed one-on-one by the study co-ordinator (IW), which they were informed of prior to their interview. IW contacted participants to arrange a suitable time for interview, but did not have any contact with participants prior to this. The interviews were conducted online via Microsoft Teams. No repeat interviews were carried out. Field notes were made by IW after each interview to aid analysis. Transcripts were not returned to participants for comment and/or correction.

Semi-structured topic guides were used to guide the interviews, one for each participant group (see appendix 2). The topic guides focused on questions that encouraged participants to generate ideas about how to develop an accessible and effective peer support programme for carers as well as the potential impact of such a programme.

All interviews were audio-recorded and transcribed verbatim using an external transcription company (Dictate2Us), omitting any personal data. This company

respected the same standards of confidentiality used in the University of Warwick and NHS.

### Analysis

The interview data were analysed systematically using an inductive-deductive thematic analysis [23]. A deductive coding framework was generated by a member of the research team (AGM) using findings obtained from previous literature [15], with input from IW and DG. The deductive coding framework developed was used for our previous interview study on 21 carers [19] as well as the current study. The transcripts were then systematically coded line-by-line according to this framework. From this deductive analysis, our transcripts identified eight out of the 11 possible codes from the original framework. Each transcript was then coded openly to explore any additional codes, themes or subthemes found as well as to rearrange themes or subthemes based on additional codes. Interviews were coded independently by three researchers (IW, AGM, KW). This analysis was facilitated by NVivo version 12.0 for Windows [28]. The codebook was refined through several discussions among authors (IW, AGM, KW, DG). Participants did not provide feedback on the codebook. The final codebook included two subthemes based on codes from the deductive framework while the remainder were generated through our inductive coding process. We then generated a logic model from the findings to showcase how an effective carer peer support programme should be carried out and its expected benefits. This model could be used to inform implementation of carer peer support by healthcare organisations or in future studies.

### Co-design process

This study incorporated co-design through two facets: a lived experience advisory panel (LEAP), who shaped the design, data collection and analysis of the study, and the participants, who used their experiences to inform considerations for the development of a carer peer support programme in England.

The LEAP involved nine carers of people who had been treated under the MHA. Discussions were held with the LEAP to inform topic guides, ensuring questions captured relevant information for informing an effective peer support programme. They also reviewed participant-facing materials for clarity and accessibility for carer and patient audiences.

In the analysis phase, the LEAP provided feedback on the draft deductive codebook, reviewing the codebook and engaging in discussions with the research team to ensure that the themes identified were relevant to carers. This feedback was incorporated, and six LEAP members later reviewed a draft of the inductive-deductive

codebook, helping to identify important themes and refine subthemes. Their input was crucial in shaping the final codebook. Two members further contributed to this manuscript, reviewing and sharing their perspectives and recommendations.

Professional, carer and patient participants in this study have provided insightful suggestions for designing an effective carer peer support programme in England. These suggestions can inform co-production of a support programme for carers, ensuring that stakeholders' experiences are considered and utilised throughout the entire process.

### Results

Nineteen participants across three sites (nine from DPT, six from ELFT and four from CWPT) took part in an online one-to-one interview between December 2021 and August 2022. Participants included 10 professionals, five carers and four patients. Interviews lasted between 20 and 50 min.

The majority of professionals were clinicians, primarily mental health nurses, and IMHAs, specifically mental health care and complaints advocates. One of the BCEs also reported having experience as a carer for someone treated under the MHA. Details on the characteristics of each participant group can be found in Table 1.

#### Thematic data analysis

Five overarching themes were identified from the thematic analysis: (1) carer availability and awareness; (2) peer support flexibility; (3) early promotion of peer support; (4) appropriate training and support for peers, and (5) anticipated impact of peer support. Within the themes are various associated subthemes. An overview of the themes and subthemes identified are outlined in Table 2. Supporting quotes have been provided to illustrate the themes and can be found in-text.

### Carer availability and awareness

#### Time restraints

Both carers and professionals identified time restraints as a potential barrier to carers accessing peer support. Each group highlighted their respective busy schedules. Carers and professionals felt that the demands of supporting a relative or friend during treatment could make it difficult for carers to seek or receive peer support. They highlighted that carers' time is often taken up by caregiving responsibilities, including frequent communication with ward staff and professionals, and managing day-to-day tasks. Professionals' limited time could make it difficult for them to discuss support options with carers, including promoting peer support, or for carers to approach them to discuss support options.

**Table 1** Participant characteristics

| Carers (n = 5)                                 | Mean years (SD) | N (%)  |
|--|-----------------|--------|
| <b>Age</b>                                     | 52 (17.0)       |        |
| <b>Gender</b>                                  |                 |        |
| Female   |                 | 2 (40) |
| Male   |                 | 3 (60) |
| <b>Relationship to patient being supported</b> |                 |        |
| Parent   |                 | 2 (40) |
| Sibling  |                 | 1 (20) |
| Spouse   |                 | 1 (20) |
| Uncle  |                 | 1 (20) |
| <b>Ethnic group</b>                            |                 |        |
| White  |                 | 4 (80) |
| Black  |                 | 1 (20) |
| Patients (n = 4)                               | Mean years (SD) | N (%)  |
| <b>Age</b>                                     | 39.5 (10.7)     |        |
| <b>Gender</b>                                  |                 |        |
| Female   |                 | 1 (25) |
| Male   |                 | 3 (75) |
| <b>Diagnosis</b>                               |                 |        |
| PTSD*  |                 | 1 (25) |
| Psychosis                                      |                 | 1 (25) |
| Paranoid schizophrenia                         |                 | 2 (50) |
| <b>Ethnic group</b>                            |                 |        |
| White  |                 | 2 (50) |
| South Asian                                    |                 | 1 (25) |
| Black  |                 | 1 (25) |
| Professionals (n = 10)                         | Mean years (SD) | N (%)  |
| <b>Age</b>                                     | 46.5 (12.9)     |        |
| <b>Gender</b>                                  |                 |        |
| Female   |                 | 7 (70) |
| Male   |                 | 3 (30) |
| <b>Professional role</b>                       |                 |        |
| Clinician                                      |                 | 4 (40) |
| IMHA*  |                 | 4 (40) |
| Behaviour change expert                        |                 | 2 (20) |
| <b>Ethnic group</b>                            |                 |        |
| White  |                 | 7 (70) |
| South Asian                                    |                 | 2 (20) |
| Black  |                 | 1 (10) |

Note: \*PTSD=post-traumatic stress disorder, IMHA=independent mental health advocate.

*“I guess, one [challenge] is going to be time because people are going to have to commit their time to this while struggling in lots of other, I guess, things” (BCE 1).*

*“I think sometimes just...because the wards tend to be so busy, information doesn't always get passed on to the right people.” (IMHA 1).*

*“it's knowing that actually resources are limited and getting somebody's time is quite hard” (Carer 1).*

*“I've got three kids, and with running a business, and it's a bit like, oh my God, trying to do it all is really hard” (Carer 1).*

**Table 2** Overview of themes and subthemes

| Themes   | Subthemes   |
|--|---|
| <b>1. Carer availability and awareness</b>           | Time restraints<br>Awareness of available support   |
| <b>2. Peer support flexibility</b>                   | Offer various channels of communication<br>Tailor support to the individual   |
| <b>3. Early promotion of peer support</b>            | N/A   |
| <b>4. Appropriate training and support for peers</b> | Deliver robust, interactive training<br>Define expectations and boundaries<br>Provide continued psychological support |
| <b>5. Anticipated impact of peer support</b>         | Increase in psychological and social wellbeing<br>Empowerment through knowledge                                       |

### Awareness of available support

All three participant groups felt that carers are often unaware of services that could benefit them, which could become a major barrier to carers accessing peer support. Carers and patients suggested that this may be because carers are not always provided with this information. They felt that professionals should clearly and concisely communicate this information to carers and ensure it is offered alongside other essential information.

*“I think it's just understanding, because there's a lot of legalities obviously, there's a lot of stuff that they [professionals] may not have offered.” (Carer 1).*

*“Professionals have to realise that a lot people don't know about what's available to them, especially in this situation [having a relative/ friend detained].” (Patient 1).*

*“I mean, [carers] are going through a hell of a lot when, you know, when this is happening to their family, the last thing they want to do is basically have to go looking for support themselves when the NHS can quite easily do this.” (Patient 1).*

One carer reported receiving almost no information from professionals when their relative/friend was receiving MHA treatment.

*“[Hospital staff] tell you the bare minimum. When you go and visit, you're allowed to visit and that's about it// you don't get any information, none at all” (Carer 2).*

Professionals in this study also identified the role mental health professionals have in the providing this information to carers so that they are aware of the support available. However, they also emphasise that it can be difficult to ensure that this occurs due to the busy ward environment.

*“the communication isn't always great, from the professionals to carers. // I think sometimes just...because the wards tend to be so busy, information doesn't always get passed on to the right people.” (IMHA 1).*

## Peer support flexibility

### Offer various channels of communication

The findings highlighted the importance of offering carers multiple communication channels for peer support. Some carers and professionals preferred written communication, considering it to be the most desirable option. This method was seen as particularly useful in cases where communication barriers exist, such as language differences or limited time with professionals, as it remains easily accessible.

*"it's knowing that actually resources are limited and getting somebody's time is quite hard, so maybe just some kind of information sheet, as simple as that really would be good"* (Carer 1).

*"So I'd prefer having it sort of written down and sort of something that I can access straightaway."* (Carer 3).

*"A printed version that's available with links for other easy read versions or foreign language versions, for example."* (Clinician 1).

Written communication was also seen as an opportunity to signpost carers to relevant services through an information sheet. Carers wanted these sheets to also include details about the treatment process, helping them understand what will happen to their relative/friend.

*"Just saying, if your friend, family member, whatever it is, is being sectioned under a section 2, then, this is what will happen next, or this is the process that they're likely to follow. Just because it was all so new, we've never been through it before."* (Carer 1).

Other participants thought that the provision of support through online platforms could be a way to increase accessibility. They suggested that these platforms would allow carers who are restricted due to geographical or other accessibility issues to access relevant services.

*"I think it's about accessibility. So, I think if it was easier for a carer to join the meeting remotely especially if their loved one is out of area, then that would be adequate."* (IMHA 2).

*"I think like [online support is] more...it's easier...I guess if you're a bit like I don't know if I want to go to the carers [support] tonight, if you know that you could just log in and log out on your laptop rather than have to drive somewhere and park especially now with petrol prices and stuff."* (Clinician 2).

Some carer, professional and patient participants felt that information or support communicated through telephone or face-to-face interactions would be preferable as this would generate a direct line of contact between the carer and peer supporter. This would also give the carers an opportunity to have a more in-depth discussion about their concerns and receive information that is more personal to their situation.

*"I personally would much rather a phone call and talk to somebody"* (Carer 4).

*"the information online...it doesn't apply to everyone because [patients'] health conditions are actually different...it should be said in person because all mental health conditions are not the same thing"* (Carer 5).

*"I think sometimes people just need someone to talk to, and let off steam and, someone else to listen to what they're experiencing. So, if that is on the phone, then, it's better than nothing, yeah"* (IMHA 1).

*"someone to be able to just go for coffee with and be able to talk about how things are and share their experiences"* (Patient 2).

If multiple communication channels are offered to carers, both carer and professional participants suggested that the optimal approach would be for a peer to first provide information and support through a phone call or face-to-face interaction. This could then be followed up with a written summary of the conversation, including key information and signposting to relevant services. This approach ensures that carers receive direct support while also having a tangible resource to refer to in their own time.

*"So, I think initially you want to speak to somebody and make sure everything's all right. And then I think, follow that up with something written in the post or an email, anything, really. Something written that you can read and just remind yourself of the conversation you had."* (Carer 4).

*"I just think it's a very emotional time because I feel like being given information alongside of having it explained, then they can go home and refresh their memory of the conversation they have just had."* (IMHA 2).

### Tailor support to the individual

Both carer and professional participants mentioned the need to make peer support person specific. The previous subtheme highlights the heterogeneity of views regarding optimal communication, emphasising the need to adapt the support offered case-by-case. One way to tailor the peer support would be to allow for flexibility in the content of support offered, adapting the support to fit the individual needs of the carer.

*"Again, it's blue sky thinking but tailor [peer support] to the family member or the person at the time that you're dealing with [them]."* (Carer 1).

*"And I'm sure that everyone's going to be different because there's no one diagnosis fits all. Everyone has to be treated in according to what their particular problem is"* (Carer 2).

*"I think it [peer support] should be individualised to whoever it is really."* (Clinician 2).

In terms of when support should be delivered to carers, both carer and professional participants emphasised the need for flexibility, with regular check-ins, to accommodate carers' other commitments. Carer participants



highlighted that some carers, particularly those who work, may struggle to access support during standard working hours. Carer participants also expressed concerns about carers' limited emotional capacity to take on additional commitments, including peer support, while caring for their relative/ friend. Professionals echoed these concerns, reinforcing the need for an adaptable peer support programme.

*"I think it would have to be something that would be done on an individual basis, because there are people that work a lot, and then there's people that don't work, and obviously, it's almost kind of having a conversation again, or some kind of an email conversation again whether it's a case of like, is there a good time to get hold of you" (Carer 1).*

*"You'd be setting up carers and service users to fail if you do it [peer support] between 9:00 to 5:00 because everyone works as well and we need to take account of that." (Clinician 3).*

*"I don't know how quickly [peer supporters] can give a lot of information because, you're trying to deal with the here and now and like, where is [the patient] going right now, and what's going to happen to them right now." (Carer 1).*

*"You actually don't think about anything else except how poorly that person is and how you can get them the help they need. So, [support has] got to be flexible to the differing times and needs of the carers." (IMHA 3).*

### Early promotion of peer support

While participants emphasised the need to adapt the delivery of peer support to fit carers' circumstances, some patient and professional participants stressed the importance of introducing this support to carers as early as possible. This early introduction would ensure that carers are aware of the support available and can access it when it best suits their needs. These participants suggested that support should be offered as soon as possible following the involuntary hospital admission of a carer's relative/friend, ideally within 24–48 h. They felt that this would remove the need for carers to look for support themselves or go through potentially time-consuming processes such as referrals.

*"As soon as someone is, you know, sectioned under the Mental Health Act, you know, one of the first things that I would recommend is that the family are... like, you know, through some type of leaflet of literature of information, they are told about this [peer support] straight away." (Patient 1).*

*"So, I think it [peer support] needs to come sort of, you know, within 24 hours, 48 hours, from the peer support worker directly explaining what they do." (Patient 2).*

*"So, I think, yeah, the salient issue would be how can people get access to that peer support worker as soon as*

*they want it basically? So, it's not like a referral that then takes a week." (IMHA 2).*

### Appropriate training and support for peers

Professionals identified the need for peers to receive appropriate training and support to effectively support carers during their relative's / friend's MHA treatment. Using their expertise in delivering support, they provided training recommendations and emphasised the importance of establishing boundaries. Carers, drawing on their own experiences, identified key information and support techniques that peers should provide to carers during this challenging time. This can be used to inform the content of training for peers, equipping them for effective discussions with carers.

### Deliver robust, interactive training

Professionals felt that peer supporters should be given robust, interactive training. They believed that the training should focus on information relevant to supporting carers of involuntarily hospitalised patients. It was also suggested that using multiple methods to communicate this information, such as combining informative teaching with interactive activities and vignettes, would enhance engagement and promote learning.

*"So, they [peer supporters] need to have a robust kind of induction, teaching and supervision process with giving that information in multiple forms with some teaching embedded" (Clinician 1).*

*"perhaps, have the bit of the challenging scenarios where perhaps the carer is really struggling and perhaps not really listening or engaging in what you're saying, and you're trying to offer support, how would they deal with that situation" (BCE 1).*

*"I think, to make that training very interactive will be important. So, in terms of giving them ways of actually experiencing what that role may involve." (BCE 1).*

Carers, drawing on their own experiences of the information and support they received during their relative's/ friend's MHA treatment, highlighted the need for peer supporters to provide information about the MHA, including general hospital procedures and details on specific treatments.

*"So, personally for me, I'd like to know that are there regular staff there? That's something else I'd like to know. But other than that, it's just the practicalities of will [the patient] be looked after?" (Carer 4).*

*"I don't think we really knew what was happening because we've never experienced any kind of mental health service. So, it was all new. So, I think some kind of guidance or support, saying this is what will happen" (Carer 1).*

*"I think you've got to understand the system, got to know how that system works because none of us really on the outside understand how the system works."* (Carer 2).

Carers also emphasised the need for peer supporters to understand how to effectively communicate with carers and share their experiences in a pragmatic yet compassionate way that will practically and emotionally benefit carers.

*"I think [peer supporters], what I think is important is to share the story and they also shouldn't just show the negative side, both positive and negative, it's so important to know what's expected of them and know how to prepare."* (Carer 5).

*"I think from my point of view, I suppose having a compassionate person to talk to."* (Carer 1).

### **Define expectations and boundaries**

Boundaries are important to protect the safety and well-being of both the peer supporter and carer receiving support. One carer highlighted the potential risks of a peer support programme lacking clear boundaries, noting that peer supporters might unintentionally reinforce distressing or harmful attitudes instead of offering balanced and supportive guidance.

*"It could be really helpful// but then it could go the other way, where you will feel that you...you need to complain and rebel about what is going on//so maybe if you're all a little bit fiery, it could go the wrong way// you could fire up other people as well"* (Carer 2).

Professionals also emphasised the importance of establishing and maintaining boundaries within the peer supporter role. They suggested that peer supporters should be made aware of the expectations of their role and associated boundaries, and for these to be clarified during any training that may take place.

*"I don't think the training has to be sort of like a month worth of training, but it's really, you know, this is what the role involves, these are the expectations, these are the aims"* (BCE 1).

*"Perhaps just being really clear on what the expectations of the role are and who the point of contact is"* (BCE 1).

*"It's about providing how to set those professional boundaries as a carer providing support to other carers."* (BCE 1).

*"You have to be very, very boundaried about how you take that and how you deal with it because you've got... actually, a carer is very vulnerable in that situation. I think it would be very easy between two carers to be in quite an unboundaried relationship"* (IMHA 2).

One professional suggested playing out scenarios where boundaries between the peer supporter and carer are blurred so that peer supporters gain a further understanding of the consequences of this and how they could deal with this situation.

*"You can have scenarios where you, perhaps, have some case studies where you test where the boundaries are being blurred, and get the carers to explore what that means, how would they deal with these tricky situations"* (BCE 1).

### **Provide continued psychological support**

Professionals mentioned that offering peer supporters psychological support and supervision throughout the programme was important. Professionals reported that the provision of peer support could expose peer supporters to potentially triggering situations, which could be emotionally taxing. Professionals recommended regular support from a psychologist as well as group meet-ups with other peer supporters to share experiences of support. Professionals felt this would help peer supporters feel they were looked after, that they could decompress and were not alone.

*"And then I think also just like, yeah, how triggering it can be to be speaking with someone who's been through something very similar to you and making sure that those people [peer supporters] have the right tools to decompress."* (IMHA 2).

*"I think the first point is adequate supervision, like absolutely like regular supervision, really important, probably from psychology, I think. Yeah. So, like supervision, regular supervision"* (IMHA 2).

*"Regular get-togethers of other carers, peer support carers for that kind of like team feeling because I think a lot of this work would probably be quite isolative."* (IMHA 2).

One professional highlighted that providing this support could also ensure that a peer support programme for carers is sustainable as it could improve peer supporter retention.

*"I think, definitely, we have found retaining staff, or you know, laypeople involved as having contact with them, making sure everything's okay, giving them a safe space to kind of debrief as well."* (BCE 1).

### **Anticipated impact of peer support**

#### **Increase in psychological and social wellbeing**

All participants felt that a key benefit of a peer support programme would be an increase in carer wellbeing. They felt that receiving appropriate support could help reduce carers' worry, anxiety or stress.

*"I think it will, perhaps, for the actual carers, it hopefully will help with their own emotional challenges in terms of, like I said, anxiety, worry, guilt, all those sort of things."* (BCE 1).

Carers and professionals also felt that receiving peer support could improve carers' wellbeing by giving them reassurance and hope for the future that their relative/friend can improve, and that there is support available for them.



*“it’s a case of somebody just making you feel a bit more assured that things will be looked after”* (Carer 1).

*“Just reassurance that you’re not alone. And if you are worried about anything, get support”* (Carer 4).

*“just giving them some kind of hope that there are, you know, there is light at the end of the tunnel, that things can improve and, there is help out there as well”* (IMHA 1).

One patient felt that carer peer support could also increase peer supporters’ wellbeing. They thought that engaging in actions which they know will be beneficial to someone else could make them feel good as they are making a difference.

*“I think it could be beneficial for both sides on, obviously the family are getting the help that they need and the support worker is basically, you know, like in a position to feel good about themselves, like they’re making a difference in a small way, trying to help them”* (Patient 1).

Carers and professionals also highlighted how peer support could help alleviate feelings of isolation. A peer support programme could offer carers a safe space where they can openly share their experiences with someone who understands their struggles.

*“Well, I don’t know because if I met someone with a similar attitude to myself, you know, I probably would (pause) maybe get some comfort, out of having someone else to talk to, who understood what I was talking about”* (Carer 2).

*“I think to have an outside community support system where you could fall back on people that weren’t in the professional side of it to give their opinions on things then I think that would definitely be helpful.”* (Carer 3).

*“I think a lot of the time it’s just reassurance or understanding because I think if you kind of feel// like you’re going through this for the first time and you’re probably the only one who’s ever gone through it, it’s that typical feeling of, like no one could probably feel how I feel at the moment. And obviously, a lot of people would feel it because they have been through it.”* (Carer 1).

*“And I think, the reason why peer support is important is because, like I say, sharing those experiences, you have that connection, that common goal. You have the common struggles or challenges that people may have experienced.”* (BCE 1).

### Empowerment through knowledge

Carer and professional participants felt that a peer support programme would facilitate information sharing, helping carers, especially first-time carers, better understand MHA processes. They believed that gaining this knowledge would further empower carers to engage with professionals, which may support them in advocating more effectively for their relative/friend.

*“Well, I think it’s like any situation. If you understand it, you can find a way through it, you can find little openings that may help”* (Carer 2).

*“I think they’ll be more informed; they’ll know their rights. I think it will give them more confidence to be able to kind of speak up in ward rounds and things like that”* (Clinician 2).

*“Knowledge is power and if you know and understand what’s going on, you’re less worried about it as well and you’re more informed and more confident to be able to speak up and advocate for your family member.”* (Clinician 2)

All three participant groups also pointed out that a peer support programme could equip carers with further knowledge on how to best support their relative/friend. They felt this could help carers become more involved with their relative’s/friend’s care, which could improve their relative’s/friend’s recovery as well as their relationship with them.

*“it can be so stressful and sometimes if you become unwell yourself, then you’re not able to support them. Simple, it’s just as simple as that. And if you fall away from them, then unfortunately, who have they got that knows them best at that time?”* (Carer 4).

*“I think you’re important in these people’s lives and you need to look after yourself so that you can fight for them. And so that in itself is big.”* (Carer 4).

*“So, that would then have an impact on the carer hopefully, feeling a little bit more equipped to deal with the situation, and knowledgeable. Which would hopefully, improve the carer-patient relationship consequently.”* (IMHA 1).

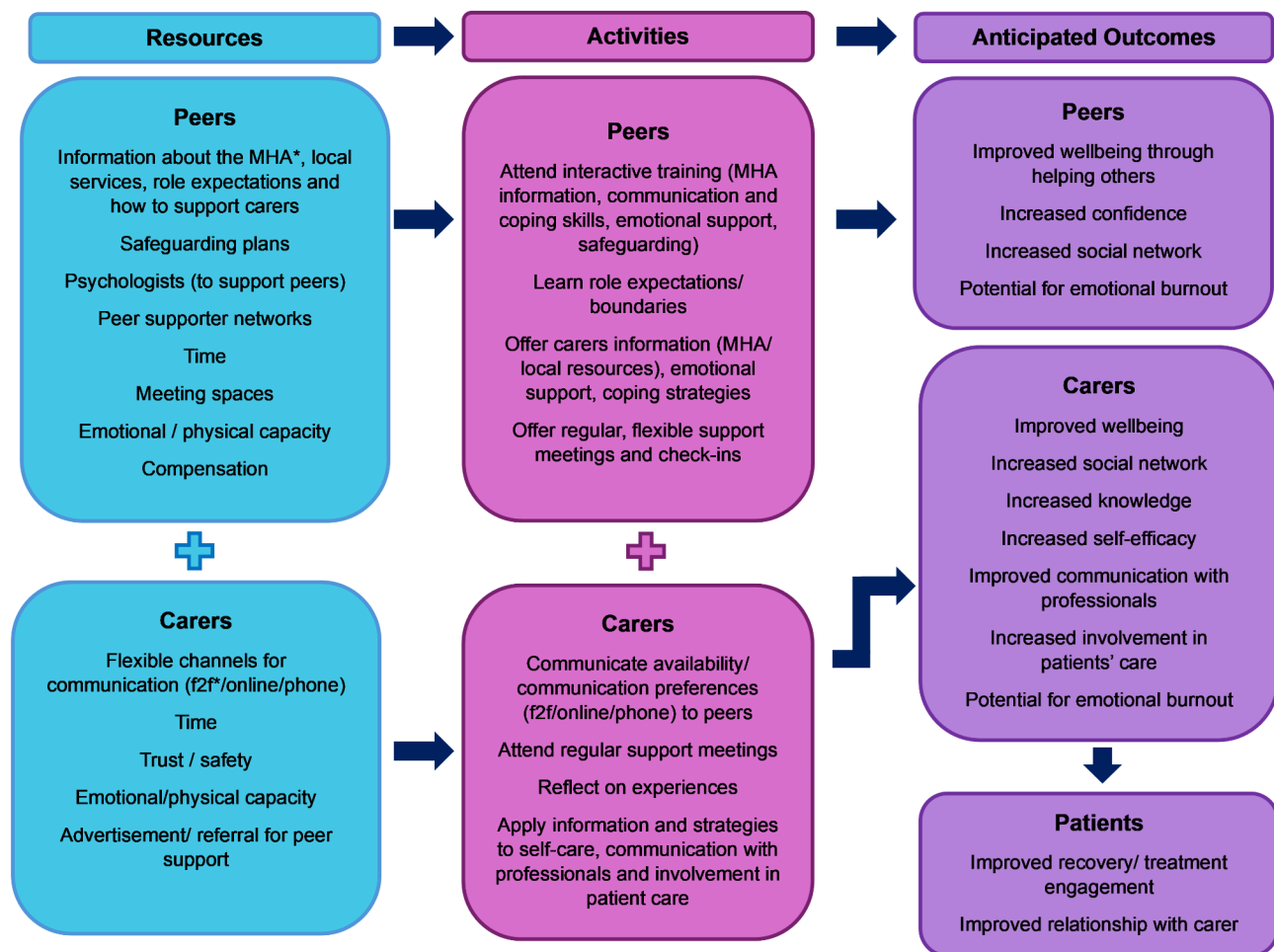
*“The kind of [carer] being able to do something for me whilst I was in hospital such as, you know, look into recovery groups or things like that would have been really—will help keep that connection there definitely.”* (Patient 2).

This benefit was reported by carers and patients with varying relationships, including spouses and parents. One patient did specify the influence of gender roles on why her spouse being more well equipped would have improved their relationship while she was under MHA treatment.

*“this is specific to me being a woman, him being a man; men quite like a job and actually, you know, if [carer] had known when I came out of hospital, it’s his job to help me access the Recovery Learning College or go and join this group, that would’ve been really helpful because it would’ve given him something to do.”* (Patient 2).

### Carer peer support logic model

Our logic model, developed based on the findings of this study and literature on a previously successful carer peer support model [15], is shown in Fig. 1 below. The model is organised into three categories: (1) resources required



**Fig. 1** Logic model for a one-to-one carer peer support programme. *Note.* MHA\* = Mental Health Act. f2f\* = face-to-face

to run a peer support programme for carers, (2) activities necessary to ensure that peer support achieves the desired outcomes, and (3) the anticipated outcomes of such a programme. These categories are further divided by population group, including peers, carers, and patients, to illustrate how each category applies to the respective groups.

## Discussion

Multiple stakeholders highlighted the importance of a peer support programme directed at carers of people who have been involuntarily hospitalised. The key benefits expected were improved carer and peer supporter wellbeing as well as increased understanding of MHA processes among carers. This increased understanding could enhance carers' communication with professionals and positively impact their relative's/friend's treatment. To achieve these benefits, three key factors should be considered. The first is for peers to receive an interactive training programme that clearly defines their role and boundaries. The second is to offer peer support to carers

as early as possible, ideally within the first 24 to 48 h after their relative's/friend's admission, to ensure they are aware of the available support. Finally, to overcome time constraints, flexible delivery of the programme using both remote and in-person communication channels should be offered to carers.

The findings of the current study closely align with the views expressed by carers in our previous study [19], particularly regarding carers' requests for further information and guidance on mental health services [19]. However, this study goes further by providing insights into how peer support can be designed to be accessible, effective, and impactful. Additionally, it incorporates perspectives from a wider range of stakeholders with diverse experiences of the MHA, identifying key factors such as organisational barriers and requirements for a successful peer support programme.

The need for peer supporters to receive training and support has also been highlighted in previous research on mental health patients [21]. However, patients reported their training to be over-professionalised,

lacking role-specific knowledge and failing to address their wellbeing as peer supporters [21]. This can have a detrimental impact on peers' mental health due to the highly emotional nature of peer support [21]. Co-producing a peer support training programme with stakeholders can help empower peers and ensure their mental health needs are met, further enhancing the benefits for both themselves and the carers they support.

Carers in previous studies reported feeling distressed and isolated during their relative's/friend's treatment process [3, 19], highlighting the need to offer carers peer support early on during this process. An early introduction can ensure that carers are aware that peer support is available and that they can access it from the outset, helping to reduce distress. Lower distress and greater satisfaction among carers during their relative's/friend's treatment can, in turn, positively influence patient outcomes [6].

Offering flexibility in the delivery and content of peer support for carers, as suggested by stakeholders in this study, can help maximise accessibility and engagement [13, 16–18]. Offering remote delivery of support can save carers time and transport costs while maintaining the effectiveness of face-to-face support [10–12]. However, factors like connectivity and digital literacy would need to be considered [10]. Face-to-face support may be most appropriate for those with limited digital skills or those who would feel safer discussing their experiences in-person [29].

Beyond delivery methods, tailoring peer support content to carers' specific needs and commitments is key to programme success, as highlighted in both the current and previous studies [15–18]. This need for flexibility extends not only to carers but also peer supporters, who may have their own commitments. For peer support to be successfully integrated into healthcare systems, organisations should provide flexible working arrangements. This would allow them to both excel and to remain well in their role [18].

### Implications

This study builds on existing literature and guidelines around peer support to identify three key factors to be considered when designing an accessible and effective peer support programme for carers of people who are involuntarily hospitalised.

First, peer supporters should receive comprehensive training on MHA processes, effective communication with carers, and safeguarding. This training should use interactive methods such as roleplay to promote engagement. While peer supporters can provide some guidance around MHA processes, professionals must remain responsible for providing legal and procedural information to carers. To support peer supporters' wellbeing,

regular psychological support should be provided by professionals and fellow peers.

Second, carers should be offered peer support as early as possible following their relative's/friend's hospital admission. This could help reduce carer distress.

Finally, peer support should be flexible in both delivery and content. Offering a mix of remote and in-person support, along with adapting the length and objectives to fit carers' individual needs, can improve accessibility. However, factors such as digital literacy and internet access must be considered to prevent exclusion.

These factors can be used to inform co-production of an accessible, engaging carer peer support programme. This co-produced programme could improve carer and patient wellbeing, reduce psychological distress and promote patient recovery, leading to lower long-term healthcare costs. Future research should explore the feasibility and cost-effectiveness of embedding peer support into existing healthcare structures to ensure sustainability.

### Strengths and limitations

To our knowledge, this is the first study to explore the perspectives of carers, patients, and professionals on developing a peer support programme for carers of individuals who have been involuntarily hospitalised. All interviews were coded by three multidisciplinary researchers, with final themes discussed among four multidisciplinary researchers. Additionally, carers with experience supporting someone who had been involuntarily hospitalised were actively involved in the study's development and analysis.

Although efforts were made to recruit a more diverse sample, including reaching out to underrepresented communities and approaching personal contacts of lived experience and professional members involved in the study, we received interest mainly from those who were of white British ethnicity. As a result, their voice and preferences are represented more strongly than other groups. We faced challenges in recruiting participants for this study, particularly carers and patients. While it is difficult to determine the exact reasons for this, one possible explanation is the difficulty in accessing these groups, which are often noted as challenging to reach for recruitment purposes [2, 3, 30, 31]. Another possible explanation is the limited research on carers in this area, which may mean they are less familiar with research processes, potentially influencing their decision to participate. These recruitment challenges may have affected the generalisability of our sample.

It is also important to note that over half of our study sample were mental health professionals, which may have shaped the scope and focus of the themes. Recruiting professional participants through our PIs' personal networks could also have implications for the

representativeness of our professional sample, as participants may have shared similar views. Additionally, some professionals may have felt a perceived obligation to participate. To mitigate these concerns, we emphasised confidentiality and voluntary participation during recruitment and interviews. However, further research is needed to capture the perspectives of more diverse communities and improve recruitment strategies.

While our analysis did not find differences based on the relationship between carers and patients (e.g. parents, siblings), it is still possible that these relationships influence carers' experiences and the type of support they need. Our study may not have included questions that would capture these potential differences. Future research should explore this aspect to determine whether a carer peer support programme should be tailored based on the carer-patient relationship.

Finally, whilst we examined three sites that are markedly different in their diversity and deprivation levels [32, 33], there are still several other regions across England and the UK that differ from the sites included. To enhance representation of the findings, further studies could examine wider geographical regions.

## Conclusion

A peer support programme for carers of people who have been involuntarily hospitalised is seen as beneficial by stakeholders. An accessible and effective programme should include comprehensive training for peer supporters, early introduction of the programme for carers, and flexibility in its delivery to meet diverse needs. The key components identified in this study can be used to inform policy recommendations to integrate carer peer support into UK mental health services, helping to improve carer wellbeing, support patient recovery, and ultimately reduce long-term healthcare costs.

## Abbreviations

|      |   |
|------|---|
| MHA  | Mental Health Act                               |
| IMHA | Independent Mental Health Advocate              |
| BCE  | Behaviour Change Expert                         |
| NHS  | National Health Service                         |
| CWPT | Coventry and Warwickshire Partnership NHS Trust |
| ELFT | East London NHS Foundation Trust                |
| DPT  | Devon Partnership NHS Trust                     |
| PI   | Principal Investigator                          |
| LEAP | Lived Experience Advisory Panel                 |
| PTSD | Post-Traumatic Stress Disorder                  |
| F2F  | Face-to-face                                    |

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12888-025-06851-y>.

Supplementary Material 1

Supplementary Material 2

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## Author contributions

I.W. contributed to the formulation of research questions, conducting interviews, analysis of data and writing the manuscript. K.W. contributed to the formulation of research questions, analysis of data and writing the manuscript. A.G.M. contributed to the formulation of research questions, analysis of data and reviewing the manuscript. D.G. contributed to the formulation of research questions and topic guides, analysis of data and reviewing the manuscript. K.N. and Z.M. contributed to the development of the study, analysis of data and reviewing the manuscript. B.L.E., S.G., R.M., M.Y.M., C.M., S.S. and S.P. reviewed the manuscript.

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## Data availability

The data that support the findings of this study are available from the corresponding author, D.G., upon reasonable request.

## Declarations

### Ethics approval and consent to participate

This study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Ethical approval was granted by the West of Scotland REC 3 (REC reference: 21/WS/0098). Written or verbal informed consent was obtained from all participants, including their consent to publish their data.

### Consent for publication

Written or verbal informed consent was obtained from all participants, including their consent to publish their data.

### Competing interests

The authors declare no competing interests.

### Clinical trial number

Not applicable.

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