



Evaluation Report: Southampton Eating Difficulties Peer Support Network

2 January 2024

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EXECUTIVE SUMMARY

Background and Aims

The Southampton Eating Difficulties Peer Support Network (EDPSN) launched in 2023 to provide peer support to adults who either have eating difficulties/disorders themselves or are supporting someone else with these difficulties. The network provides group, one-to-one and online peer support. This evaluation is undertaken early following the network launch and is exploratory in nature. It aims to understand how the network is currently operating and the impact is having in order to inform changes and improvements as it is further developed and scaled. It also aims to begin to explore the range of outcomes and impacts that the service may have for both the service users and the volunteers, the mechanisms by which positive outcomes and impact are achieved, and any relevant contextual factors.

Evaluation methods

The evaluation was conducted by an independent evaluator. A mixed method approach was chosen, comprising interviews with those delivering the peer support network and an online survey of service users (people with eating difficulties and their supporters). A document analysis (the EDPSN project plan, materials relating to Mind's Side by Side Peer support approach) informed the development of interview and survey questions. The interviews were analysed using inductive thematic analysis and the survey was analysed using descriptive statistics.

Findings

The newly founded peer support network service shows encouraging results. Limited but positive service user survey results indicate that the network aligns well with its intended purpose and the six peer support 'core values' of experiencing a safe environment, meeting people with similar experiences, connecting with others, having choice and control, being able to both give and receive support, and being able to be oneself. It seems to help users to find useful coping strategies and manage difficult feelings and experiences. No negative impacts were reported. The Volunteer Peer Supporters feel well-trained and supported and expressed personal and career development gains from their roles. Staff and advisors affirm that the network operates as planned, ensuring a safe and appropriate space for valuable peer support. Those delivering group sessions have observed encouraging signs of benefit for people with eating difficulties and their supporters, including individuals settling comfortably into the group environment, engaging in group activities, sharing experiences, providing emotional support to others and reporting changing perspectives. Overall, the network exhibits promise in delivering effective peer support, with both users and volunteers reporting positive experiences.

Recommendations

This evaluation has three main recommendations.

Recommendation 1: Continue to offer and promote the service

Based on the available evidence, the evaluation concludes that the peer support network, encompassing group, one-to-one, and online elements should continue. Continued or additional financial support should be obtained to coordinate, sustain, and expand the service's reach. A strategic plan should be created to raise the network's profile and inclusivity, emphasizing partnerships with local organizations.

Recommendation 2: Develop and optimise the service to address emerging issues

The evaluation evidence also suggests that the operational model of the network, guided by values and a trauma-informed approach, should continue. The continued incorporation of creative activities in group sessions is encouraged, with attention to group dynamics and participant comfort. Volunteer training and supervision should address handling self-doubt and performance anxiety, small group dynamics, and potential psychosocial impacts on volunteers. The unique benefits and risks associated with peer volunteer involvement necessitate ongoing attention, with a focus on maximizing positive outcomes while mitigating risks.

Recommendation 3: Embed evaluation and monitoring into network routines.

Lastly, the embedding of data collection into the network's routines is recommended. Many items from the survey used in this evaluation can be reused for this purpose.

These recommendations collectively aim to enhance the effectiveness, sustainability, and inclusivity of the peer support network for individuals with eating difficulties and their supporters.

BACKGROUND TO THE EATING DIFFICULTIES PEER SUPPORT NETWORK

Comprehensive details of the background and plans for the pilot Eating Difficulties Peer Support Network service are available elsewhere (e.g. the Southampton Peer Support Network for People with Eating Difficulties and their Supporters; 'Project Plan' document produced by Options/Social Care in Action - SCIA¹). However, a brief summary is provided here.

The Southampton Eating Difficulties Peer Support Network (EDPSN), hereafter referred to as 'the network') was launched in March 2023.

The network is for adults (18+) who have either an eating disorder or disordered eating and their supporters (e.g. a family member, friend). The term 'eating difficulties' is used to capture the range of experiences the service users may have and recognises that people in need of the network may not have a diagnosed condition.

The network aims to offer peer support through volunteers and staff with lived experience of recovering from an Eating Disorder or caring for someone who has, defined in the network 'Project Plan'¹ as *'what happens when people who have similar experiences of something difficult come together to support each other'*.

Need for the network

The need for the network was established based around a high prevalence of eating disorders and difficulties locally and nationally. The Project Plan¹ outlined how local NHS Eating Disorders service has reported a 48% increase in referrals since the Covid-19 pandemic. There are long waiting times for treatment and high thresholds for access to treatment for adults with eating difficulties in the local area. Long waiting times can have consequences including people making themselves more ill in order to try to get help sooner, and developing harmful doubts around whether they are indeed deserving of treatment. People with eating difficulties may also have suboptimal recovery and high relapse rates.

The network aims to help people cope and self-manage with support when feeling isolated or marginalised and having difficulties accessing necessary services.

The plans for the network also mapped onto five priorities recognised from a recent Southampton Mental Health Network consultation on making Southampton a Mental Health Friendly City

- Generally maintaining a good level of mental health through life's challenges & to prevent deterioration in their mental health
- Early intervention
- Dealing with challenges – financial, housing, & navigating the system
- Support and education for friends / relatives / colleagues of people with low mental health (flagged by both sufferers and carers)
- Being better able to use and engaging with other opportunities to boost their wellbeing / demand will increase if they first get support

Overview of the volunteer peer support network

The network offers three key modes of peer support

Online

- Dedicated, monitored closed social media/messaging pages via a Facebook group- 24/7 access
- Online, password protected (secure) client portal on Options Wellbeing Trust website for use as a document and resource hub

Group

- Monthly facilitated face-to-face groups with trained Volunteer Peer Supporters

One-to-one ‘Buddying’

- Face-to-face peer support in the community or via online communication platforms (e.g. Zoom) with trained Lived Experience Volunteer Peer Supporters

The network expects to help people to engage in, maintain or sustain recovery by:

1. Providing a safe environment and relationships with Volunteer Peer Supporters to share and find practical ways to cope and manage day to day. The peer supporters have lived experience of eating disorders and/or other issues such as self-esteem, confidence, emotional resilience/distress or anxieties around body image or life transitions that act as a catalyst for eating difficulties.
2. Providing information and education through tools and resources
3. Signposting to other local organisations and agencies to support people with broader life difficulties that might exacerbate and intensify eating difficulties
4. Encouraging attendance (when ready) on the ‘Tastelife’ courses, delivered by Options and other Course Leaders in Southampton
5. Encouraging participants of the ‘Tastelife’ course to continue to be involved in the peer support network and help and support others by becoming Volunteer Peer Supporters

Training and supervision

Volunteer Peer Supporters have comprehensive preparation training courses and monthly group clinical supervision and 1:1 support where any complexities or transference/counter transference issues arise.

Peer support theoretical framework

The framework for the peer support models Mind’s ‘Side by Side’ programme for mental health which has been extensively evaluated²⁻³. Key features of this approach include peer support being shaped by those involved and adapting to the needs of the community. Therefore, it is an evolving service and will be expected to adapt and change over time in response to informal feedback and requests as well as insights and recommendations from formal evaluation.

Following the ‘Side by Side’ approach, there are six core values underpinning the support network which are considered essential to all modes of peer support (see Figure 1).



Figure 1: core values underpinning effective peer support

1. **Experience in common:** Peers share similar backgrounds (Eating Disorders / Disordered Eating), goals, experiences or interests.
2. **Safety:** structures are in place to create physical and emotional safety;
3. **Choice and control:** about how they are involved in their peer support;
4. **Two-way interactions:** people have opportunities to both give and receive support;
5. **Human connection:** Peers develop meaningful connections with each other;
6. **Freedom to be oneself:** Peers feel able to express themselves, and to be themselves in peer support.

The core values are interconnected and are all considered necessary for peer support to be effective. Experience in common, safety and choice and control are considered foundation values which allow people to have a human connection and two-way interactions. When these are in place, this facilitates comfort required to express oneself honestly and authentically; freedom to be oneself.

Within the early months of the network, members co-developed a name for the network 'Kick ED together', developed the purpose and some ground rules for the group (known as their 'Let's be ...' agreement) as well as a network logo.

EVALUATION AIMS AND APPROACH

This evaluation is purposefully undertaken early following the network launch and is fundamentally exploratory in nature. It aims to understand how the network is currently operating and the impact it is having in order to inform improvements as it is further developed and scaled up. It also aims to begin to determine the range of outcomes and impacts that the service may have for both the service users and the Volunteer Peer Supporters, the mechanisms by which positive outcomes are achieved, and any contextual factors that impact on outcomes and mechanisms.

An independent consultant conducted the evaluation in order to bring an expert outsider perspective and to deliver a rigorous mixed-methods evaluation. The consultant is a Health Psychologist with 17 years of experience researching health topics. She has conducted and published mixed-methods evaluations of a range of health interventions and uses approaches that prioritise the experiences and perspectives of service users.

The ethos of the evaluation was that it must be sensitive to the emerging peer support network and its intention to create a safe and welcoming space for people to talk about their eating difficulties and broader life circumstances. It was therefore carefully designed to not interrupt the normal activities of network. That meant that data methods that were intrusive or highly visible were avoided, as were methods that were too intertwined with or undifferentiated from the service itself.

Key evaluation questions

The evaluation was exploratory, with a wide scope including:

For service users

How and why are people using the network? Is the way the network is being delivered aligned with the six core peer support values (described above)? In what ways does the network help people? Are there unintended outcomes? What are the barriers and facilitators to engagement? What are the characteristics of people being reached and helped by the network?

For those involved in delivering the service

How do they understand and experience their role? Do they feel they are helping service users? How? What helps and hinders them being effective in their role? What impact does involvement in the network have on them?

Ethical research conduct

As a Health Psychologist, the Consultant conducted the evaluation in line with the British Psychological Society's Code of Human Research Ethics⁴. As the evaluation was independent of an academic establishment or the NHS, no external ethics committee review was conducted. However, prior to commencement, the Consultant carefully reviewed ethical aspects of the evaluation, conducted risk-assessments and put procedures in place to ensure ethical conduct.

This included:

- ensuring that those involved were offered the chance to participate but not coerced or pressured to be involved

- ensuring that consent to participate was given and that this was fully informed
- ensuring participants could withdraw at any time (without concern for an impact on their volunteer role or relationships within the service)
- considering and mitigating possible harms from participating (especially with regard to covering sensitive and personal topics)
- having a plan for dealing with disclosures raising concerns about risk of harm to self or others
- ensuring confidentiality and safe storage and processing of data
- ensuring debriefing procedures were in place to deal with possible emotional upset or concerns about how data would be used.

Data storage and processing was compliant the Data Protection Act 2018 (DPA 2018), and the UK General Data Protection Regulation (UK GDPR). As the topic was health, the data was considered personal, 'special category data' and as such required particularly careful and sensitive planning with regards to how it was processed and held.

METHODS

A mixed methods evaluation approach was planned

- qualitative research (in depth interviews) with service providers
- quantitative research (an anonymous online survey) with service users.

This data collection was supplemented with the analysis and presentation of data routinely collected by SCIA/Options about service use.

The original intended timescales were to collect data during summer 2023 but timelines were extended to winter 2023 (see below).

Qualitative data collection: interviews with service providers

Participants and recruitment

Interviews were used to gain rich, in-depth descriptions of experiences and perspectives. This also allowed for data to be collected on unanticipated issues. This approach was also suitable given the small sample size. The initial plan was to interview the five original Volunteer Peer Supporters. Because some volunteer peer supporters left the network prior to, or at the beginning of the evaluation period, only two of the five were actually available for interview. Therefore, the evaluation plans were adapted to also include interviews with other people involved in setting up and delivering the network; a staff member leading the development and delivery of the service and an individual with an advisory/expert role.

Interviewees were approached by SCIA/Options staff and given a written summary of the aims and scope of the interviews (written by the consultant as an invitation/information sheet). They could then contact the consultant to ask for further information and/or to express interest in taking part. In some cases, they agreed for staff from SCIA/Options to pass on their details to the consultant. Written consent was provided by everyone who took part.

Both of the volunteer peer supporters who participated in interviews were female university students in their 20s. Both described personal experience with eating difficulties and body image.

The volunteer peer supporters and advisor/expert were interviewed in summer 2023 (therefore capturing the first few months of the network), the staff member in winter 2023 (capturing reflections on a longer period).

Data collection

Interviews were arranged for a convenient time and were conducted using Microsoft Teams videoconferencing software. The interview schedule for Peer Supporters covered how they had got involved with the service, how they had experienced the training and the role, positive and negative experiences so far, if and how they felt they were helping service users. They were also asked about difficulties and problems and any perceived effects of the role on themselves (Appendix 1a). The interview schedule for the expert advisor/trainer and staff member covered how they had got involved with the service, their role, their views on its strengths and weaknesses of the network (Appendix 1b). Questions were open-ended and neutral and invited story-telling and extensive discussion. Neutral prompts and probes were used to keep the conversation going and to delve deeper into topics that arose.

Interviews lasted 68 to 90 minutes and were audio-recorded and transcripts produced. At the end of the interview, participants were thanked and debriefed.

Data analysis

Transcripts were subjected to an inductive thematic analysis (broadly corresponding to the approach described by Braun and Clarke, 2006⁵). This began with familiarisation with the data which was achieved through listening to audio-recordings and reading transcripts. Next, descriptive labels (codes) were attached to words or phrases that captured ideas relating to the evaluation aims and scope. The analysis proceeded to cluster the codes and develop them into themes which captured patterns and features of the data. Themes were iteratively reviewed, refined, organised and relabelled. They are presented in the findings section alongside anonymised quotations.

Quantitative data collection: survey

A survey was used to explore the experiences and perspectives of the services users. This approach was chosen in order to gain more structured data on service use and a range of indicators of impact and barriers and facilitators to using the network. Interviews or focus groups may have been better able to explore unanticipated issues and understand the service user perspectives in more depth, but this type of data collection was considered too intrusive and a threat to the safe environment for sharing and supporting each other that was fundamental to the network. In order to try to capture some of the benefits of qualitative approaches to data collection, some of the survey items were open-ended, allowing for longer, free-form responses.

Due to slow recruitment of people with ED into the network in the first few months following its launch, the survey element of the evaluation was delayed by three months.

Participants and recruitment

All service users who had been in contact with the Network were sent a link to the survey along with an invitation to participate. The number of service users that were sent the survey link was 13 via email and the opportunity to participate was also promoted on the members closed Facebook page. The invitation came from SCIA/Options but it was highlighted that the evaluation was being undertaken by an external consultant. One email follow-up reminder was sent to each service user. The survey was also promoted in online communications and within group meetings.

Data collection

An anonymous online survey was developed by the consultant.

The survey began with a short information section and a tick box to indicate consent. It then presented survey items presented as either likert style items, categorical responses or open-ended question/response formats (Appendix 2).

- **Demographic and clinical characteristics-** i.e. about their eating difficulties/the person they are supporting's eating difficulties and service use/help seeking
- **Use of the network:** including hopes and expectations about the network and self-reported use of the online, group and face-to-face elements
- **Outcomes and impact.** This section was developed based on questions that captured the six values underpinning the peer support network. This included; a safe environment, a way of meeting people with similar experiences, feeling connected to others, having choice and control about how to engage, two-way giving and receiving of support, being able to feel oneself. Impact on coping and ability to manage difficult experiences was also asked about. Open-ended questions allowed respondents to describe ways the network had helped or been unhelpful and enabled identification of the barriers and facilitators to accessing and engaging with it.

Pilot testing of the survey items indicated that it would take 10-15 minutes to complete, depending on the detail given to open-ended questions. A longer or more complex survey than this would have exceeded recommendations with reference to reducing burden and minimising drop-out or thoughtless responding patterns.

The survey ended with a thank you section, a reminder of how the data would be used, and options for contacting the consultant with any concerns or questions about the survey. Contact details for the network were also provided and suitable mental health crisis services were signposted to for anyone experiencing acute distress at the point of completing the survey.

SCIA/Options staff set up the survey within SurveyMonkey software and shared it with service users. The survey link was shared with service users between 6 October and 30 November 2023.

Surveys often suffer low response rates. A number of different strategies were used in order to maximise the chance of a high response rate. This included an invitation which highlighted the benefits of the survey, issuing reminders, promoting the survey online and via group sessions. Survey completion was further incentivised via the chance for completers to enter a prize draw for a £50 gift voucher.

Data analysis

The data were analysed using primarily descriptive statistics. Due to the small sample size and lack of hypotheses to be tested, inferential statistics were inappropriate. It was planned that open-ended responses would be reviewed, coded and summarised or categorised according to patterns of responses. However, there were so few responses and they were very short so they were all included in the report verbatim.

EVALUATION FINDINGS

Volunteer peer supporters: recruitment, training and supervision

Five people were initially trained in early 2023 and 3/5 began their roles as volunteer peer supporters in March 2023. They undertook the Taste Life course and Health Education England Peer support course, bespoke training from SCIA/Options and had the opportunity to undertake a Peer

Supervisor course. In addition to the initial training, the volunteer peer supporters have also received monthly group supervision, with some also receiving one-to-one supervision.

Two volunteers did not continue to practice as Volunteer Peer Supporters due to personal circumstances and one left in summer 2023 (moving to a different city for University).

In December 2023 another 5 participants began volunteer preparation training (delivered by SCIA/Options). A brief pre and post-training survey showed:

- That they were more knowledgeable about the range or presentations of eating difficulties
- That everyone’s journey with ED and experience of support or is unique
- How to communicate sensitively and motivate at the right pace
- They clearly understood Options safeguarding procedures and escalation processes
- Who/how to ask for support and access clinical supervision 1:1/group
- They were more confident working with members with complex needs and sharing what they felt comfortable sharing from their own experiences to help others move forward
- Improvement in Group and buddying skills
- Recognising what part of the network they would like to work in to make the most impact of their skillset. i.e. online-closed Facebook page and developing the online portal, within groups or 1:1 buddying in the community

To date, all 8 volunteer peer supporters self-identified as female aged in their 20s. 6 have been students (6 psychology students). Most volunteers are White British, one is Indian.

Use of the network

From its launch, to the end of the evaluation period (March 2023- 30 November 2023) a total of 56 individuals used one or more of the peer support network services. 53 of these were people with eating difficulties, 3 were support people (family or friends).

Data about demographic characteristics or types of eating difficulties have not been routinely collected. Staff report that all people with eating difficulties attending so far have been female with the exception of one non-binary individual.

Group sessions

A total of 17 people with eating difficulties/support people attended the group sessions, some attending multiple sessions. The attendance at each monthly group is shown below.

Table 1: Group Attendance

	Service users		Service deliverers	
	Number of people with eating difficulties	Number of supporters	Number of staff	Number of Volunteer Peer Supporter
March 2023	3	1	1	3
April 2023	5	1	1	3
May 2023	6	1	1	3
June 2023	6	1	1	3
July 2023	3	1	1	2
October 2023	5	2	2	1
November 2023	6	1	1	1

One-to-one support

11 people have had one-to-one support with a Volunteer Peer Supporter. They have had an average of 3 sessions each, with the majority of sessions happening online or by telephone (85%) with some face-to-face meetings (15%).

Online support

28 people are members of the Facebook group .Table 2 shows that the posting activity so far is a mixture of introductions, information (psycho-education), motivation, requests for help and advice, information about upcoming groups and post-group activity posts and encouragement. Posts tend to be seen by around half of the group members and receive a small number of likes/loves and comments. No content has been posted that staff or Volunteer Peer Supporters deem inappropriate or harmful.

Table 2: Summary of Facebook Group Activity 1 March 23 to 30 Nov 2023*

Types of posts	Number of posts	Average number of members looked at the posts	Average number, of likes/loves	Average number of comments
Introductions/Welcomes	7	14	3	2
Informational/Motivational posts	13	14	2	1
Member posts asking for information, help and advice	11	16	3	3
Group invite posts	9	16	2	2
Post-group activity posts	9	14	4	3
Encouragement of Action/Interactive posts	10	16	2	4

*This data was provided by a staff member who moderates the Facebook group and is deliberately kept to a high-level summary. It was deemed intrusive and unethical for the evaluator to access and analyse the group postings.

21 people have accessed the online self-help portal where resources are available. It is not currently possible to track what has been viewed and downloaded.

Qualitative findings: interviews

The thematic analysis identified ten themes in the interview data, as shown in Figure 2. The following sections discuss each theme, alongside supporting quotations. Quotations are identified by whether they came from one of the Volunteer Peer Supporters, the Advisor/Expert or the Staff Member. Occasional and very minor changes to quotations have been made to improve readability, without changing meaning.

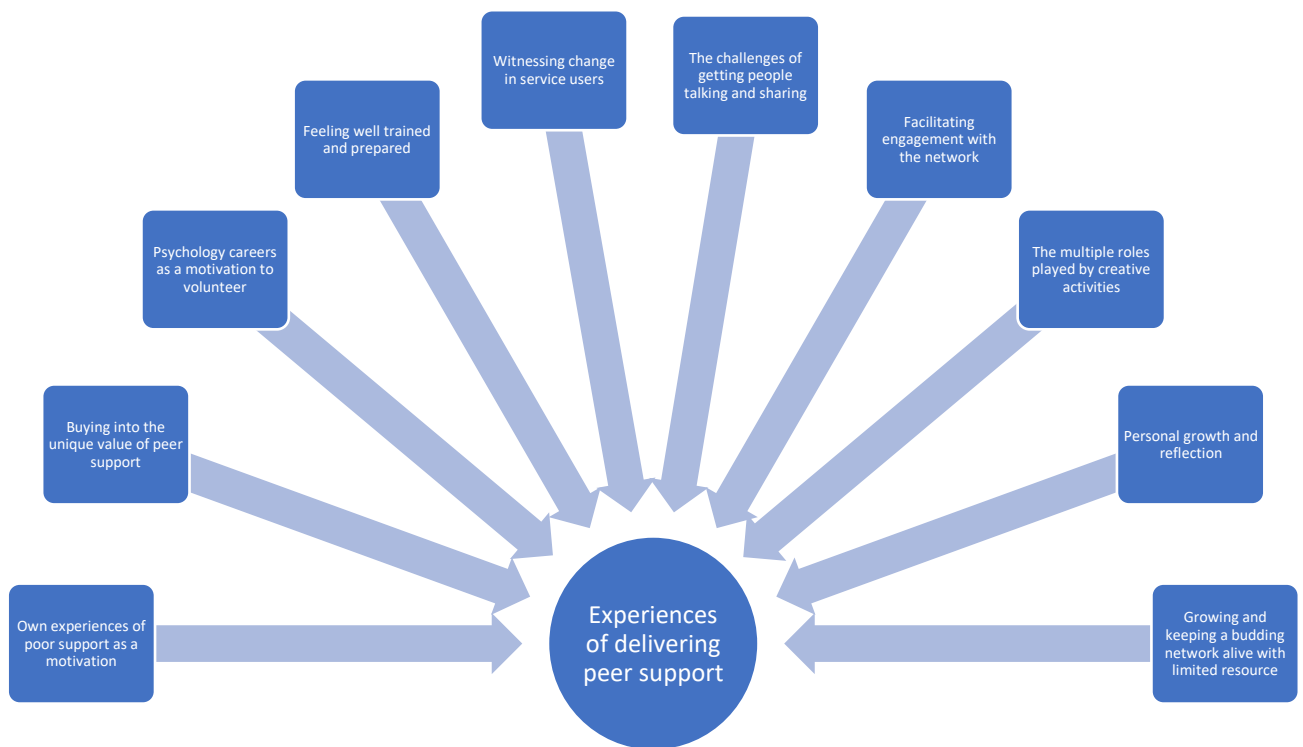


Figure 2: Themes identified from interview data

Own experiences of poor support as a motivation

Both of the volunteers highlighted how their own family support had drawn them to involvement in a peer support network. Both identified ways in which family dynamics, communication and support had been inadequate or damaging.

There just wasn't any support there. There was a lot of hate coming from like the family (Volunteer Peer Supporter)

Neither had accessed formal/organised peer support programmes but they both recognised that the only or main valuable support came from those with similar experiences. For example, one volunteer described how one family member showed little interest because he *“doesn't particularly believe in mental health”*, while another *“would try to make me eat...constantly kind of scolded me for thinking the way I do, still does”*. The family were *“more angry than you would want them to be rather than that understanding and acceptance that you want”*. The exception was one relative whose lived experience of poor mental health was perceived to facilitate appropriate communication and support. They were *“more accepting and understanding because they had their own issues. ... so they were more understanding of the situation”*.

Both the staff member and Advisor/Expert also reflected on difficult interactions and lack of support that people with eating difficulties tend to encounter.

A person with an eating disorder can feel very judged. [Other people] tell you what to do, and that's the last thing you want really (Advisor/Expert)

Buying into the unique value of peer support

Both volunteers perceived peer support to be valuable to people with mental health problems in general and eating difficulties specifically. The idea was familiar to them before they became involved in the network; they had a 'mental model' for what it would be like

I guess it reminded me of support groups that you often read about in books and movies.... I find those to be really interesting (Volunteer Peer Supporter)

Despite having not previously received peer support themselves, the volunteers had clear ideas about what peer support could achieve and why. They frequently returned to the idea of a unique sense of connection being possible when interacting with people with past or current shared experience. This perspective was also expressed by the Advisor/Expert.

the greater sense of connection that it gives you to like-minded individuals and people who have had similar experiences to what you're currently going through. And also a connection to people who are going through the same thing as you are right now because they're not just connecting with us, but they're also connecting with each other. (Volunteer Peer Supporter)

You may not have opportunities to do that anywhere else. That's the thing. (Advisor/Expert)

An important part of this was the flipside; a discourse (present within the volunteers) that strangers or professionals would be unable to relate, understand or respond well and that others without lived experience might be judgemental or not maintain confidentiality.

rather than strangers or someone who can't relate. (Volunteer Peer Supporter)

the psychologist might not relate to what I'm saying. (Volunteer Peer Supporter)

like a little small community where they can be themselves and they can be open about whatever they're facing without any judgments. And they can, and that they can say whatever they want. No one's gonna judge them. No one's gonna share it outside the group. (Volunteer Peer Supporter)

Both volunteers described experiences of struggling to engage with or accept professional support. They described feeling scared and uncomfortable. Shame, perceptions of low self-worth and incompetence were highlighted. The volunteers explicitly contrasted these concerns against the benefits of a peer support network.

fear or something's holding me back from actually seeking professional help. (Volunteer Peer Supporter)

if I go to see someone [professional], it means I'm incapable of solving my own problems in a way, and maybe the feeling that I'm a little incompetent and am I

still worthless than I can't solve my own issues and I need someone else to solve them for me ..., part of me still thinks that I'll be a little less, I'll be a little less likely to increase my self worth. I guess if I go to a psychologist to help me solve my issues rather than just solving them myself, I think that's the primary reason why I would rather not go. (Volunteer Peer Supporter)

Not feeling alone was an important part of what volunteers thought peer support had to offer

We share our experience so they can feel like. "Ohh it's not just me, I'm not alone. Someone else has felt the same way". (Volunteer Peer Supporter)

Just being there, and just listening were considered key and valuable components of peer support

Supporting them on their journey and helping them recover from it and maybe just listening to them. I'm just trying to be there for them. (Volunteer Peer Supporter)

Even if the professional might have the tools to help me, maybe I just want ultimately at the end of the day, I just want people like me so I can talk to them and just have someone to listen to and someone who will understand me. (Volunteer Peer Supporter)

The staff member brought up her awareness some possible risks of peer support for people with eating difficulties; the possibility of copycat behaviours, unhelpful sharing around restriction behaviours and managing interactions when people may be highly distressed, have experienced trauma or adverse childhood experiences. Nonetheless her research around peer support in other mental health contexts and inspiration from the Mind's Side by Side peer mentoring approach had given her hope that a carefully managed peer support community could offer something valuable that is not available elsewhere.

Most of the professionals that we spoke to absolutely said yes, it's something that's really missing. (Staff Member)

Psychology careers as a motivation to volunteer

Both of the Volunteer Peer Supporters interviewed were psychology students. Both described gaining experience relevant to pursuing Clinical Psychology as being a key motivator for having joined the network. One needed to complete a prescribed number of hours of relevant practice for her Masters course, the other was aware that she would need to build a portfolio of experience and this was a good opportunity.

Being on my CV and for helping me for the future and my job applications. (Volunteer Peer Supporter)

I know how competitive it is to get on [a clinical psychology doctorate], so I kind of thought get as much experience as I can. (Volunteer Peer Supporter)

The work experience and career development available through being part the network had exceeded volunteers expectations, providing rich learning experiences, networking, and perceived access to future career opportunities.

The opportunities that they've actually given us as volunteers and peers has really been amazing. (Volunteer Peer Supporter)

[We met the] lead clinical psychologist at [NHS Trust] who went to [service]. And that is kind of all these little things. (Volunteer Peer Supporter)

Volunteers perceived that their psychology backgrounds in conjunction with their lived experience brought unique benefits in being able to understand mental health conditions and interact with service users and facilitate group sessions.

[studying psychology] you learn about different types of disorders and the different types of mental illnesses that exist and the symptoms and treatment of everything. And it kind of gives you this self-awareness which you might not have otherwise. (Volunteer Peer Supporter)

[because of my psychology background and counselling training plus my] lived experience I can relate quite easily to the group members, so when they're bringing things to the surface, to the group and was obviously group facilitator as well, I kind of take the approach to try and link everything, make it go smoothly and things like that. (Volunteer Peer Supporter)

Being motivated to volunteer for career-related reasons did not appear to detract from more altruistic motivations for involvement. It appeared to sit comfortably alongside wanting to help others and be part of something valuable

I did it originally, did find it more a little bit because of my degree, but it's actually been much more valuable and been more than that because of helping other people, helping myself, making a difference in other people's lives and realising how good peer support networks can actually be for everyone. (Volunteer Peer Supporter)

Career related motivations had different impacts on ability to make long-term commitments to the network; one volunteer currently studying in Southampton was aware that she would move cities for employment or study in the near future and therefore have to cease volunteering at that point. Another volunteer anticipated ongoing involvement with the group, travelling back to Southampton if necessary to remain involved.

In my head I'm solidly committed to this group, and as long as it keeps going. (Volunteer Peer Supporter).

The advisor/expert had mixed feelings about students as volunteer peer supporters. She felt psychology students had unique valuable academic knowledge in addition to their lived experience but was also aware that student circumstances mean their involvement is often transitory. She felt frustrated about investing in people who do not stay long enough to make significant contributions.

if a charity invests in you, they expect something back. And what that sounds a bit mercenary...as a charity it gets rather exhausting if you keep training people (Advisor/Expert)

She highlighted family carers of people with eating disorders, particularly mothers, as being an important group to try to recruit as volunteer peer supporters.

Feeling well trained and prepared

The volunteer peer supporters described the training for the role as having been comprehensive, well-pitched and credible. They felt confident they were in safe hands with the SCIA/Options staff who coordinated the network.

It felt like professionals who did know exactly what they wanted from the peer support network and had researched everything (Volunteer Peer Supporter)

I got a really good sense that both of them know a lot about eating disorders and eating difficulties, and I kind of felt like, ohh, you know, in a good place and this is really good (Volunteer Peer Supporter).

Volunteer Peer Supporters found the staff to be friendly and nurturing and were comfortable making their voices heard and providing their opinions and feedback on the network. The training left the volunteers feeling that they were well supervised and supported. They did not feel 'left in the jungle to fend for yourself' and were relieved to know "there's the support structures there".

Nonetheless, the volunteers described nerves and self-doubt, particularly to start with but persisting to some extent. They were concerned about doing things wrong, particularly if it caused harm or offence.

the first one that we had, I was much more nervous and worried about it. I could barely speak because I was like 'Oh my God, what if I say something wrong and I mess up?'. (Volunteer Peer Supporter).

I don't want to harm anybody and I was like, "ohh what if I say something that you know offends anybody or upsets anybody, or it's taken in the wrong way?". (Volunteer Peer Supporter)

I was worried about triggering somebody like talking about it or, you know, being too open [...] Although that was a worry, one of the worries back then. It currently feels a bit ridiculous now. (Volunteer Peer Supporter)

Meanwhile, the Advisor/Expert was confident that the volunteers had the right skill sets and were able to deliver something valuable through their interactions with service users. She outlined how "they are learning all the time", both experientially as they begin to engage with service users face-to-face, and in terms of their more academic knowledge and understandings about eating disorders and psychology.

They're gradually, they are growing into you know, understanding it more. And of course they're reading around it more. They're doing their courses cause I think three out of four of them are psychologists or something, aren't they? (Expert/Advisor)

The staff member reflected how in the early months the volunteers experience was probably more difficult as the emerging network had yet to acquire a clear structure and the roles were less well defined. Because service users could just turn up those delivering the peer support group didn't know what to expect in early sessions.

We were flying by the seat of our pants! (Staff Member)

Since then, roles had become clearer and the activities more predictable through co-design with service users, so delivering what they wanted and would find useful.

During the group sessions the Advisor/Expert had attended she had witnessed what she felt were “*very appropriate*” conversations and disclosures between volunteers and service users.

The volunteers identified their own tendencies, as people with ongoing mental health problems, to have poor self-esteem or negative thoughts. They thought this was relevant to their performance anxieties and doubts, but felt there was nothing remaining that SCIA/Options could or should have done to address this.

they've done every... I think pretty much everything they can in their capacity. So I feel like it's my own issues that can, but like I need to increase my self esteem a little bit because it's not the best. (Volunteer Peer Supporter)

Witnessing change in service users

Although the service was new when the volunteers were interviewed and there had been a limited number of sessions and service users to draw on, the volunteers thought they had noticed positive changes for some people. This created positive feelings for volunteers new to their roles and struggling a little with self-doubt.

making a difference I think feels really good. (Volunteer Peer Supporter)

It's not like we're wasting our time and effort here or it's not like they feel like their time and effort is being wasted. (Volunteer Peer Supporter)

Everyone was clear that the service was not aiming to treat eating disorders (or difficulties).

The support that we're suggesting is not an intensive programme of any sort. (Advisor/Expert)

We're not the NHS and we're still like students. All three of us are volunteers. We are not qualified health professionals to really be giving them the complete help that they need, like CBT, we can't really provide them with that. But I guess when we say working, we just want to make them comfortable, make things a little easier for them. (Volunteer Peer Supporter)

They had modest aims for what sorts of benefits might be expected. They noted changes in “*All these little things*” (Volunteer Peer Supporter).

Any kind of difference that we can make, even a small one is better than making no difference. (Volunteer Peer Supporter)

Differences noticed included positive body language and increased communication as well as returning to the group sessions more than once

By the end of it, they're smiling, talking. (Volunteer Peer Supporter)

They keep coming back. So that tells me that they're getting something from it. (Volunteer Peer Supporter)

Some service users had made positive comments that allowed the volunteers to know that they were gaining benefits from the activities and tools that had been introduced in the group.

She mentioned that she's been trying to use her Wellness toolbox. And she really likes it. (Volunteer Peer Supporter)

(A service user) is always telling us that, yeah, this is helping me. This is making a difference. (Volunteer Peer Supporter)

The Advisor/Expert was very encouraged by a service user who expressed that she had found a place where she could belong. This feedback inspired hope and confidence that the network has begun to deliver the type of support it aims to provide

So this one girl came and she was very impressed that she had found somewhere she could belong. So I think that the, the, the good thing about the network that will develop is that there will be a sense of belonging and then a sense of ownership and a sense of well, my friends are here now and I've made new friends. And, but actually they're helping me and I'm helping them. (Advisor/Expert)

The staff member recalled a group session where a person with eating difficulties who had arrived at the group in a very heightened state of emotional distress and describe everyone 'rallying around'.

There was a real empathy for a person who was obviously very distressed. (Staff Member)

The staff member had later received feedback that the intense emotions shown during the first meeting had been a mixture, including

Relief that there was something and, uh, a safe place where she could be that she could be herself and supported by lots of other people who kind of understood and somewhat, you know, kind of what she was kind of experiencing. (Staff Member)

This person has subsequently had one-to-one peer support as well as used the online community, and has also returned to the group.

The challenges of getting people talking and sharing

Managing quietness emerged as a consistent theme, with volunteers feeling that it could be difficult to get the right balance of talking. This caused concern and discomfort for the volunteers. There was a tension between knowing that the network was specifically for sharing experiences of eating difficulties and related issues yet ensuring that people were not pressured to share.

It would be nicer there if there was more conversation going about eating disorders and difficulties (Volunteer Peer Supporter)

But sometimes. It's quite it's still quite hard to get a response. (Volunteer Peer Supporter)

I don't want them to come to the group and it's, you know. You share what you want to share. If you don't want to share it. If it's right now, that's fine. If you wanna do it later on. But that's, you know, equally. OK. So it's kind of I don't think we want that pressure. It's there. If they want it and obviously they do because

they're coming. But yeah, there's no, no shoving it down their throats. (Volunteer Peer Supporter).

There was some concern that more outgoing and outspoken service users received more attention than quieter ones.

It felt a little disproportionate. (Volunteer Peer Supporter)

All interviewees were aware of the secrecy inherent in eating difficulties. They described treading carefully, especially with the quieter people and when people were new to the group, and trying to ensure they were not left out if not contributing.

I don't wanna probe too much with them so early on, I think still gaining that like therapeutic alliance. You know, that kind of rapport or type thing (Volunteer Peer Supporter).

It's a bit difficult to toy out the information from people to kind of help them, but at the same time as that, it's being mindful that, you know this is a grouping of people want to contribute what they want to contribute, then that's okay (Volunteer Peer Supporter).

An approach of keeping the spotlight off the service users was adopted, but the volunteers simultaneously tried to keep the spotlight off themselves too, carefully ensuring they didn't make it "more about us than them" (Volunteer Peer Supporter). This meant being very gentle and careful about disclosing personal stories. One approach that appeared to work well was using activities as a way in to starting conversations (see section below).

The staff member highlighted how talking and sharing should happen on people's own terms, describing a good session as 'whatever they want it to be' (Staff Member).

The volunteers had differing views about the ideal number of people in group sessions. While one felt keeping groups small was important for participant's comfort, another anticipated larger groups to be more beneficial.

I just wish more people would come... I think it potentially would mean more conversation. More experience, you know. People might inevitably share more just because there's more people there. Might be easier to engage. And also be helping more people. (Volunteer Peer Supporter)

The Advisor/Expert also expressed some frustration with small numbers so far, although simultaneously expressed how it was unsurprising and natural to start small and that there was a need to begin to 'deliver something' and gain some traction and 'create some energy' alongside publicising the network.

The quietness of the Facebook group was noted with volunteers feeling there were insufficient numbers of users to get much traction. They perceived it as a potentially very vulnerable space where users might 'put something out there and not get anything back' (Volunteer Peer Supporter).

You know, if you're going to kind of write your heart out a bit and you know, and it is an emotional directive thing, and if no one's gonna respond, that could be quite deflating as well. (Volunteer Peer Supporter)

The volunteers speculated that despite the guidance set up around use of the Facebook group, service users could have valid concerns about “*where that information is gonna go*” for example if somebody took a photograph and shared their post and identity.

By the time the staff member was interviewed, the Facebook group had gained members and momentum. This had been facilitated by the appointment of the coordinator. The staff member described engaged users posting and responding to a co-produced self-care themed online advent calendar containing self-care tips and suggestions such as practising gratitude, connecting with nature, and beating procrastination.

So it's a little bit of psychoeducation. So these are all the things that they've been talking about in the last group and pulled together in a plan. (Staff Member).

The multiple roles played by creative activities

All interviewees were positive about the creative activities that took place during group sessions. They mentioned a wellbeing toolbox, journaling and vision boards. They all felt that these activities served various important and beneficial purposes. One was as something that helped people directly. For example, service users had given feedback that they had benefited from the wellbeing toolbox and one volunteer felt the approach was so useful she considered creating a wellbeing toolbox for herself.

In the session after that, one of them mentioned that they actually been using the toolbox very actively, so that was something really nice to hear that the toolbox actually did make a difference. (Volunteer Peer Supporter)

The Advisor/Expert noted that the creative activities were well chosen as they supported wellbeing in a general way without being specific to any type of eating disorder or difficulty. The staff member felt they could be easily tailored and personalised to be relevant to all sorts of members, and that people could choose whether and how to engage.

It would be scoped more towards an interest or what would work for the person. (Staff Member)

Through being in proximity to service users as they engaged in the activities, volunteers were occasionally finding ways to begin conversations about eating difficulties.

People talk when they are doing it...it helps them get into the zone (Volunteer Peer Supporter).

The volunteers also thought the creativity and playfulness of the activities were beneficial in changing mood and focus. Both volunteers felt the activities were a good idea simply because they were fun, and enjoyable and helped people feel at ease. They thought these activities helped people to temporarily feel differently about themselves and their identity.

Focusing on other things and life and realising that it's not just all about the eating disorders and that there are other things in life as well, and that it's just one part of them and that the mental illness does not define them. (Volunteer Peer Supporter)

Maybe the creative activity reconnects them with their inner child and it makes them feel something that you know times when life was better when they weren't suffering from this. (Volunteer Peer Supporter)

The Advisor/Expert and the staff member drew attention to how these small activities build feelings of confidence and competence and hope about the future.

They're proud of what they've created. And they all went saying ohh like this. This is nice. Yeah. Because they've had [an] opportunity to create something and these small wins of self-confidence are like nuggets of gold because they they take people a long way and they start to build where there might have been nothing. (Advisor/Expert)

[A vision board activity] just became about something else other than this thing that, you know, kind of everybody shared and showed aspirations to kind of move forward and give a sense of purpose [...] Everybody was so proud of the fact that they've been able to envision something beyond what they're dealing with at the moment. (Staff Member)

Facilitating engagement with the network

The volunteers had some thoughts about facilitators to service users becoming involved in the network, based partly on reflections of how they might have felt about it when they were experiencing eating difficulties. One felt she would have wanted to 'pilot test' the group, perhaps by observing somehow before properly attending to build trust that 'they really are like me'. Another felt the approach currently being pursued by buddying newcomers and supporting them by email or phone calls on a one-to-one basis before attending was appropriate and drew attention to a range of things that service-users might feel anxious about when attending including knowing where to go, arriving late. By the time the staff member was interviewed, eleven people had engaged in one-to-one support, with much of it addressing the issues raised above.

it generally tends to happen where people say, oh, I'm not quite confident enough to come into the group yet. (Staff Member)

Most one-to-one peer support had been online but in order to make face-to-face meetings easier the staff member was trying to find suitable locations across Southampton; safe spaces which would not be triggering food-wise.

The staff member also felt that a challenge facing the network was meeting a very wide range of needs. The network members so far had a range of ages, different eating disorder/difficulty presentations, lengths of difficulties and status of either person with difficulties or carer. However there had also been a very wide range of co-occurring physical and mental health conditions ranging from multiple personality disorder, chronic illnesses, physical disability (including a wheelchair user) and neurodiversity, some of which was unanticipated and had needed to be responded to 'in the moment', during the group sessions. So far, however, the values underpinning the peer group, the co-produced 'let's be' group rules/agreement and the trauma informed delivery principles appeared to be making the group comfortable and valuable, regardless of this diversity. The members had felt united around a common difficulty - food.

There seems to be this acceptance. It doesn't matter whether it's restriction or binge eating the 'IT' is an unhelpful coping mechanism around food and your relationship with food [...]. The nature of the group is to have empathy for everybody with their own story and their own journey. (Staff Member)

Personal growth and reflection

Volunteer Peer Supporters described gaining personal benefit from being a peer supporter, with 'giving back' and helping others giving the experience a 'feel good factor'.

They also described how hearing service user's stories prompted personal reflection and a different perspective on their own experiences of eating difficulties. Specifically, the volunteers felt that they had become more aware of their own thought processes. This tended to involve noticing that negative thought processes were still present and deeply entrenched.

When I hear their stories, it makes me, have a think again on some of my own thoughts and beliefs and it has helped me maybe have a little more positive thinking than I would have had otherwise. (Volunteer Peer Supporter)

I've noticed and I'm OK with it. That I still have. I still recognise these thoughts, these bad negative thoughts about myself, although I may be able to combat them. And realise that it's not true, it is an inner critic, if you like. (Volunteer Peer Supporter)

Involvement with the network also made them reflect on the meaning of recovery from eating disorders/difficulties which involved recognising that they continue to experience difficulties.

I have done more deep reflection on it. And actually, how it still lives with me today. (Volunteer Peer Supporter).

The Advisor/Expert had an additional perspective on this, drawing on her experiences with volunteers at Tastelife. She anticipated that volunteers will naturally need to move on, leave their roles and their association with an eating-disorder related-identity.

They move on. And they they they move on in their life. And I think it's only fair because when you're when you're dealing with people... It takes you back into where you were as a person with an eating disorder yourself.....is it fair to keep them in that land? (Advisor/Expert).

Growing and keeping a network alive with limited resource

The considerable practicalities and burdens of setting up and sustaining the network were highlighted by the Advisor/Expert as limiting the growth of the network and therefore its reach and impact. These issues did not appear to be on the minds of the volunteers.

The Advisor/Expert was aware of the challenges facing the SCIA/Options staff lead for the network who was undertaking this work with limited time, funds and considerable competing priorities.

[It is] a big piece of work without enough funding! (Advisor/Expert).

Moreover, she felt the lack of dedicated time for co-ordinating the network was preventing the service from growing. In particular she insisted more time needed to be focussed on expanding and maintaining the pool of volunteers, promoting and publicising the network, and establishing effective referrals and signposting from the local eating disorders service and other organisations. She reflected on her related prior experience of running groups and working with volunteers and referred to the sustained effort required to keep the momentum going. She felt that running Tastelife courses was a key route to keeping an 'energy' going, and creating a throughput of people

to join the network as service users and/or volunteers and was disappointed that this hadn't been possible.

Every time I spoke to people about this they said ohh yeah, we're not quite ready yet. We're not quite ready yet. (Advisor/Expert)

She felt that the 'seeds of progress' had been laid down for a successful service but that dedicated resource is now needed to sustain, expand, and make an impact.

It's got great potential. It would be marvellous and the next year I hope we'll really see it flourish (Advisor/Expert)

I just hope that they can find someone who can do that [work around sustaining and growing the network]. That's why they needed this coordinator to, to draw it together (Advisor/Expert)

By the time the Staff Member was interviewed, the co-ordinator role was funded and filled and there was more time and resource available to delivering and extending the network. The staff member reflected that it had been a huge undertaking, particularly delivering the three different modes of support. However, work was already underway to extend the service geographically (Portsmouth/Hampshire/Dorset) and a consultation was being completed around separate support provision for family and caregivers of people with eating difficulties. These service users had been noted to benefit from the current peer support network but had needs that couldn't always be addressed alongside the person with eating difficulties.

Because they can't really talk freely in front of the person that they're caring for about their distress and their concerns, their worries. (Staff Member)

Quantitative findings: survey

The total number of people who completed the survey was 4 out of 56 service users who were eligible to participate (13 emailed directly, the rest receiving the link within the Facebook group). This gives a response rate of 7%. All respondents were people with eating difficulties rather than support people.

Table 3: characteristics of the respondents (n=4).

	N (%) or Mean, range
Gender	
Female	4 (100%)
Age	
25-34	2 (50%)
35-44	1 (25%)
55-64	1 (25%)
Highest level of Education	
University	4 (100%)
Ethnicity	
White British	4 (100%)
Social deprivation (derived from home postcode, Index of Multiple Deprivation decile, 1=most deprived, 10=least deprived)	6.6, 1-10
Length of eating difficulties	

More than 10 years	4 (100%)
Diagnosis of eating disorder	
Yes	3 (75%)
Don't know	1 (25%)
Type of difficulty disorder¹	
Both Bulimia and OFSED	2 (50%)
Binge eating disorder	1 (25%)
Unsure	1 (25%)
Use of psychological/therapeutic services for ED	
In the past but not currently	1 (25%)
On a waiting list	1 (25%)
In treatment currently	1 (25%)
Eating difficulties addressed as part of broader therapy	1 (25%)

¹Where the responder did not have a diagnosis, they responded about which, if any disorders seemed to match with their experiences.

Because SCIA/OPTIONS does not routinely collect demographic or eating difficulties data about people as they begin to engage with the network it is not possible to explore or comment on how the survey responders differ from overall service users.

The respondents had begun using the network in March, April, August and September 2023 respectively (so had been using the network for between 1 and 7 months). The respondents had not made much use of the Facebook group (one had used it once, three had used it 'more than once but not a lot'). The online portal had only been used occasionally (three had used it once, and once had used it 'more than once but not a lot'). They had made more use of the group sessions; three had attended three or more sessions, and one had been to just one session. They all reported being aware of the one-to-one sessions but not having had any.

Participants' hopes and expectations of what the peer support network would be like reflected both the type of experiences they wanted to have whilst using it and what they wanted to achieve:

Get support in a non-threatening environment with people that can relate.

Controlling bingeing.

Finding others experiencing similar problems.

Support me through the final stages of my recovery, help build a supportive community, and potentially be a space I could volunteer to help others when I was ready.

All respondents reported agreement or strong agreement that the network was a safe environment (Figure 3), had allowed them to find people with similar experiences (Figure 4), had allowed them to feel connected with other people (Figure 5). They also agreed or strongly agreed that they had choice and control about how they interacted with others (Figure 6) and were able to be themselves (Figure 7). Most felt able to both give and receive support (Figure 8), and felt the network had helped them learn useful coping strategies (Figure 9) and manage difficult feelings and experiences (Figure 10). In all cases the respondent who reported neither agree/disagree was very new to the network and had attended only one session.

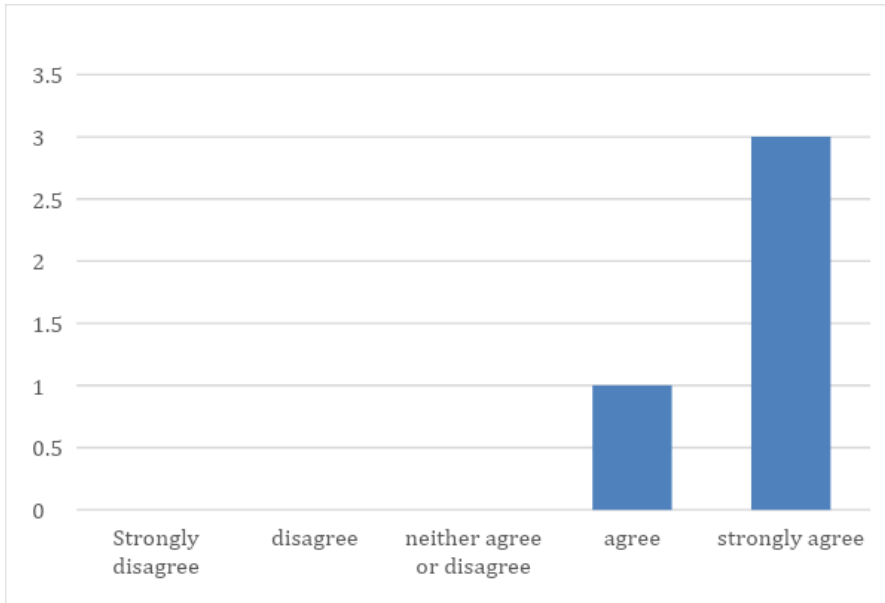


Figure 3 – Responses to “The network feels like a safe environment”

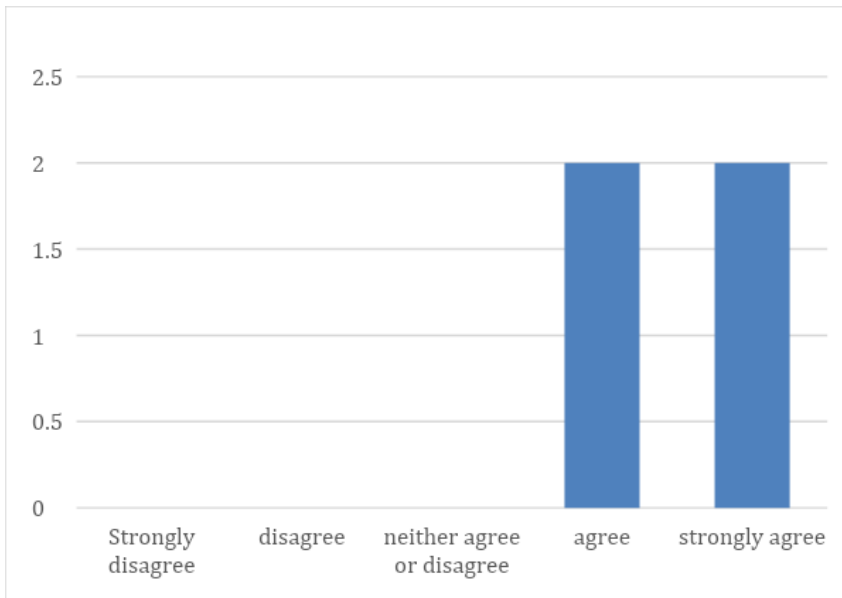


Figure 4 – Responses to “Within the network I’ve found people with similar experiences to me”

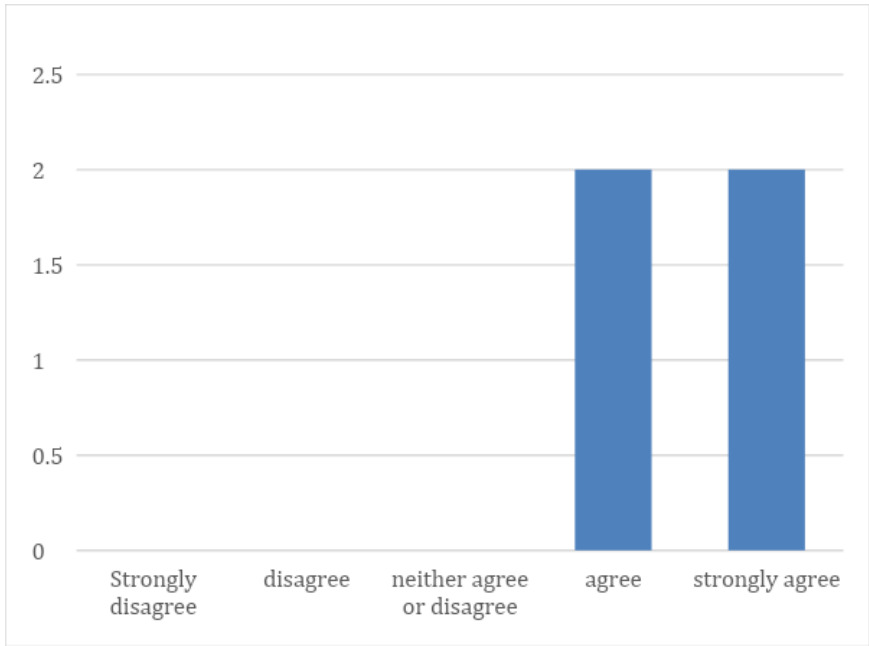


Figure 5 – Responses to “Within the network I’ve felt connected with other people”

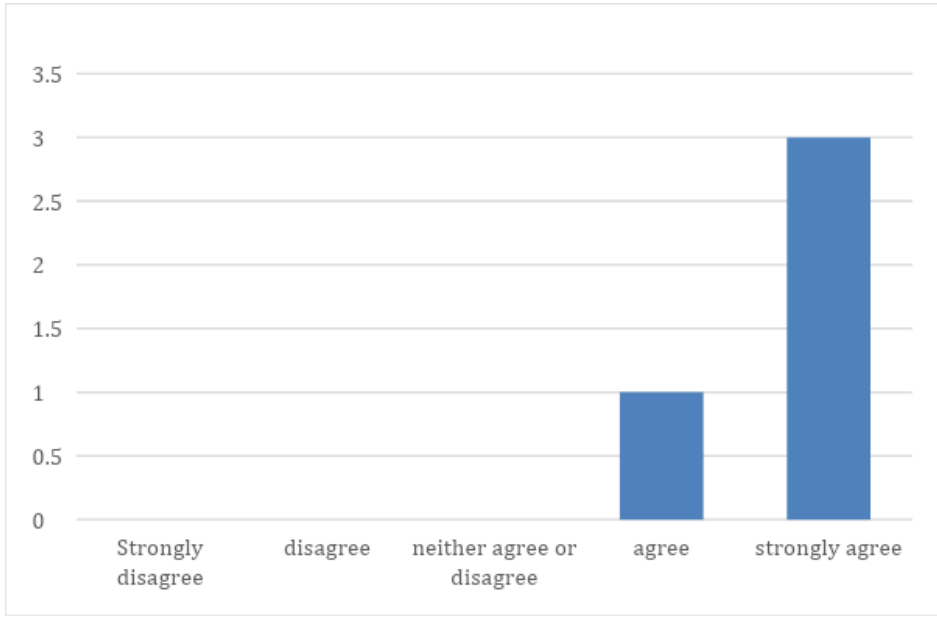


Figure 6 – Responses to “Within the network I’ve had choice and control and how I use peer support”

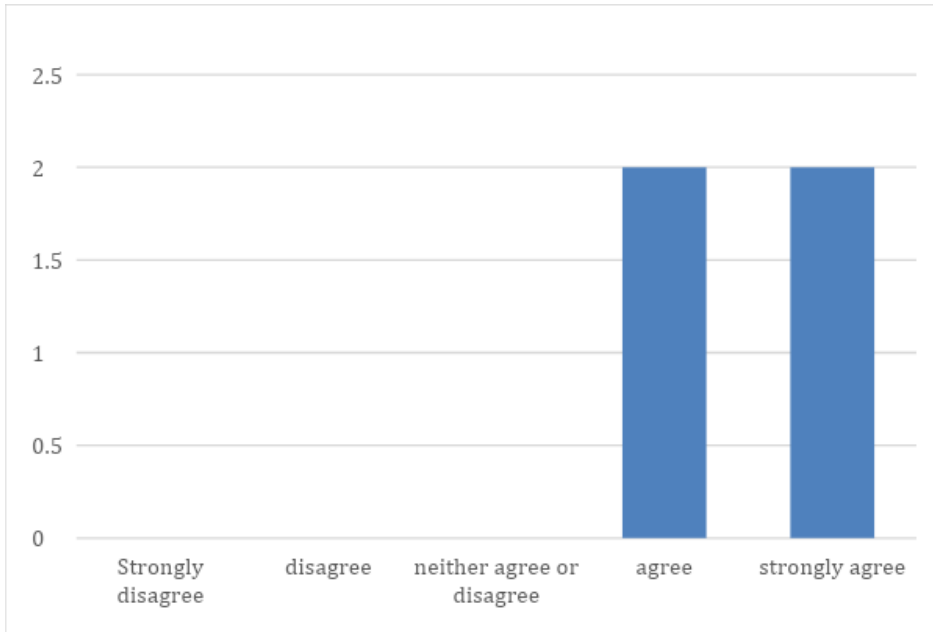


Figure 7 – Responses to “Within the network I’ve been able to be myself”

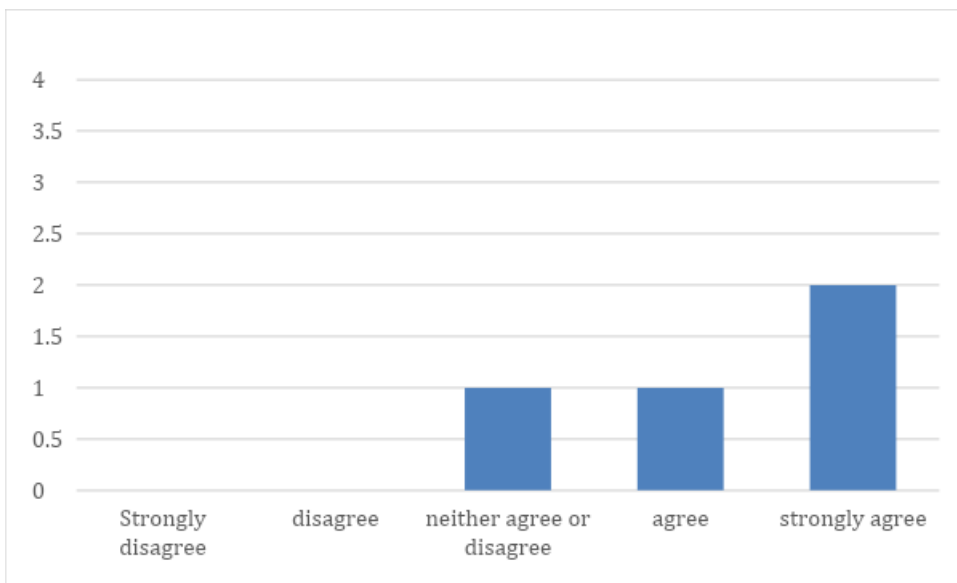


Figure 8 – Responses to “Within the network I’ve been able to both give and receive support”

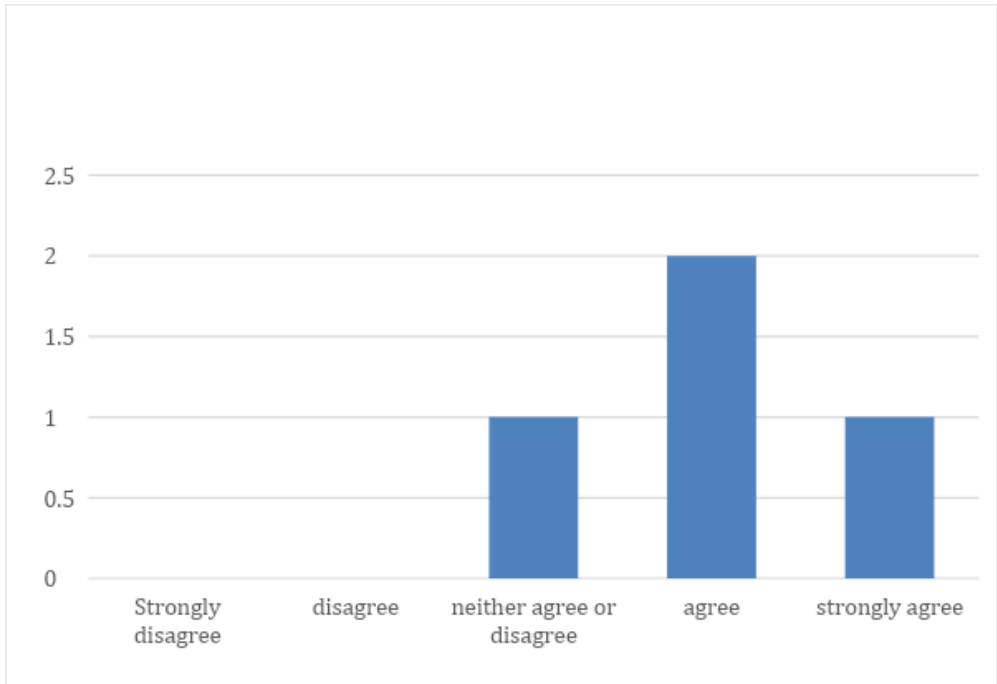


Figure 9 – Responses to “The network has helped me find useful coping strategies”

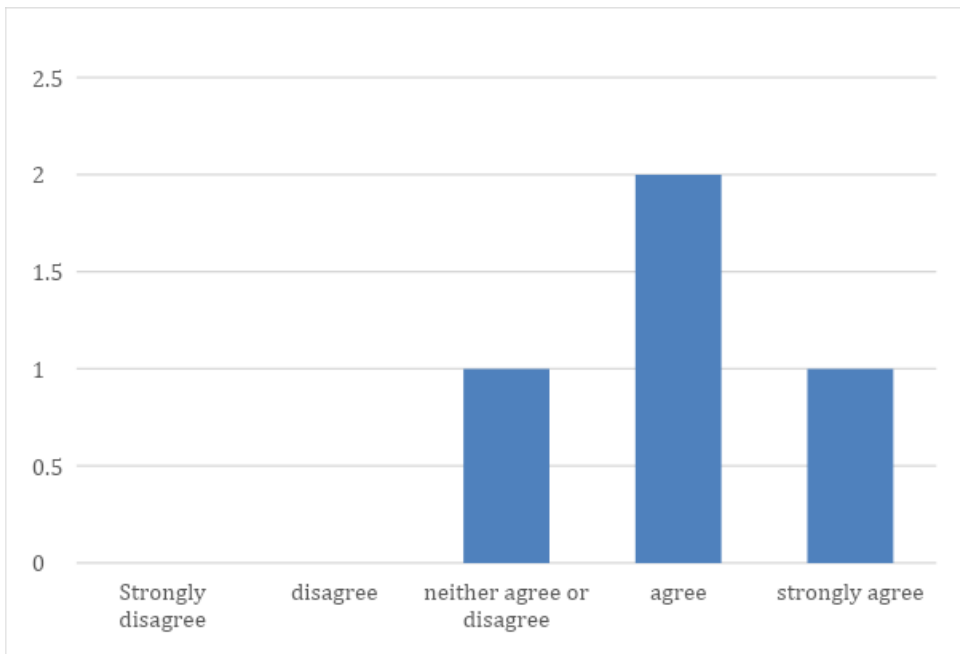


Figure 10 – Responses to “The network has helped me manage difficult feelings and experiences”

Other ways that the respondents reported the network had helped them included acceptance of the problem, confidence, motivation, and achieving a change in eating behaviour.

Encouragement from others gives me confidence in my own skills and ability to manage any difficult thoughts that come up. It also helps keep me motivated and on track with my recovery.

A chance to focus on something else apart from food and body image.

Take action to accept I'm struggling with eating difficulties.

Helped me stop bingeing.

No respondents reported any unhelpful effects of the network. In terms of barriers to accessing the network, one said the start time of the groups did not suit her. One found it difficult to know when meetings were taking place once she had left Facebook. One respondent described concerns prior to attending a group session

Before my first ever meeting I felt nervous to come, I was worried about not fitting in or being triggered or feeling uncomfortable in my body - I worried I would be bigger than everyone else in the room and then feel judged or triggered. These worries were unfounded and the group is lovely but it might be a barrier for people trying their first group... The more information about what to expect from a group meeting and the variety of different people who it is open to the better I think.

Another respondent found contact and support prior to attending made accessing the network easier.

Talking with one of the facilitators before attending the group and being able to attend with a supporter

Another found that “the understanding shown” made it easier for them to engage with the network.

CONCLUSIONS AND RECOMMENDATIONS

Evaluation Limitations

This evaluation captured a developing rather than established network. SCIA/Options anticipated faster network growth and therefore the plan was for the evaluation to be completed during summer 2023. However, slower growth meant the survey was delayed until Autumn. The volunteer peer supporters and expert advisor interviews therefore capture a different (earlier) timepoint compared to the staff member perspective and the service user survey responses.

The survey response rate was disappointing (a total of only 4 service users, 7% response rate). There is no way to know whether these respondents were representative or atypical. Their reported experiences were very positive but it is possible that those who did not respond to the survey may be those who had less beneficial experiences. It is also important to note that none of survey respondents had experienced one-to-one peer support. Furthermore, one-to-one support had not yet been delivered at the timepoint that the volunteers and the advisor/expert were interviewed. Therefore, the staff member’s interview is the only data source available about the one-to-one peer support and does not capture the experiences of either of the service users or the volunteers.

Conclusions

This early and exploratory evaluation captures an innovative peer support network service for people with eating difficulties and their supporters that has gradually developed throughout 2023. The network has welcomed new service users and retained them within the network over time. There has been turnover from the first batch of volunteer peer supporters. Recruitment and training of new volunteers had commenced at the end of the evaluation period.

All three parts of the support network are up and running and are being used; monthly group support, one-to-one peer support and online provision.

Although the data available from service users was limited, it indicates that the network is delivering peer support in the way intended. Users reported that the network feels like a safe environment, allows them to find people with similar experiences, feel connected with other people, have choice and control and be themselves. It helped them to find useful coping strategies and manage difficult feelings and experiences. The respondents perceived it as valuable with a range of hoped-for outcomes that appear well aligned to what the service can realistically provide. They reported some benefits and no negative impacts.

In-depth data from service providers show that volunteer peer supporters are well trained, supervised and supported, and that volunteering is beneficial to them personally and for career development purposes. They report that the volunteer role provides a sense of purpose, allows expression of altruism, social connectedness, sense of belonging, confidence, self-efficacy and self-esteem. Staff and advisors involved in service set up and delivery believe it is operating as planned, with ground rules and routines that ensure it is a safe and appropriate space for valuable peer support. They have repeatedly observed small but encouraging signs that the service users are getting some benefit, including them becoming settled, comfortable, enjoying activities, sharing experiences and changing perspectives and verbally reporting that they have benefited.

Recommendations

Given the findings from the evaluation, the following recommendations are made.

Recommendation 1: Continue to offer and promote the service

- a) Continue to deliver the peer support services to include the group, one-to-one and online elements.
- b) Secure continued and/or additional financial support to ensure co-ordinating, sustaining and increasing the reach of the service is adequately resourced.
- c) Develop a strategy and action plan for raising the network's profile and reaching more people with eating difficulties, including attention to diversity and underserved populations. Continue to develop partnerships with the NHS, third sector, local universities and any other relevant organisations.

Recommendation 2: Develop and optimise the service to address emerging issues

- a) Continue to operate the network combining broad guiding principles (e.g. the Side by Side peer support values, the trauma-informed approach, and the supervision and safeguarding procedures) with encouraging members to co-create network activities and routines. Because this means the network will not consistently deliver a single well-defined programme, future evaluations must be designed to capture broad and overarching peer support processes and outcomes that are consistently relevant despite considerable heterogeneity in members, their presenting problems, and their chosen areas of focus.
- b) Continue to include creative activities during the group sessions. These clearly serve a range of beneficial purposes. As the network grows reflect on how to ensure more mixed (e.g.

mixed gender) groups are comfortable. Consider choice and adaptations to activities to ensure they are acceptable and engaging.

- c) Ensure volunteer peer supporter training and supervision addresses a) doubts and nerves about being good enough at peer support b) skills for dealing with small groups and quiet people.
- d) Continue to be attentive to the ways in which volunteer peer supporters may be affected by their experience of being part of the network, maximising opportunities for benefits and minimising and managing risks.
 - The volunteers interviewed here perceived a wide range of psychosocial benefits. Recognise and communicate to potential new volunteers the wellbeing benefits that volunteering can bring. As the network expands and more volunteers are recruited, organise volunteering opportunities in order to maximise opportunities for positive outcomes. This will include supporting volunteers to develop an enhanced sense of purpose, identity and clarification of values, improved relationships and connection, and opportunities for personal growth and development including the development of confidence and self-esteem. This must be balanced against demands or activities that increase stress, exhaustion or lead to burnout. What Works For Wellbeing briefing⁶ and technical report⁷ on volunteer wellbeing and the associated 'theory of change' covers some useful material.
 - The volunteer peer supporters interviewed for this evaluation felt they were not (and may never be) completely recovered and they still experienced unhelpful thoughts. Be vigilant for negative impact of volunteering on eating disorder symptomology and broader indicators of mental health. There are limited published studies about peer support in eating disorders. Those conducted so far have yielded mixed findings about whether giving peer support for eating disorders/difficulties may be helpful or harmful to volunteers, with most finding evidence for a range of psychosocial benefits and a minority identifying an increase in disordered eating symptomology⁸⁻¹⁰. Previous studies have evaluated interventions that differ to the current network in terms of setting, eating disorder diagnosis, recovery status of supportees/mentors and supportees/mentees, the types of peer support programmes, training, supervision and safeguarding.
- e) Ensure that the network continues to promote and demonstrate the unique value of peer support but achieves this without undermining the importance of accessing professional support where appropriate and available. Beware of a discourse developing that *only* people with lived experience can relate and be trusted. If this point was emphasised there is a risk this could undermine service user's ability and inclination to engage with healthcare professionals. Importantly, this evaluation has not identified that this discourse has developed within the network, only that the interviewed Volunteer Peer Supporters privately held caution and distrust about healthcare professionals.
- f) When recruiting new volunteers carefully consider the pros and cons of students, especially psychology students.

Advantages include;

- 1) psychology students are likely to be highly committed due to their need to gain work experience and they will likely find the network an enriching development opportunity.
- 2) They also come with valuable knowledge and skills relating to psychology in addition to their essential lived experience of eating difficulties.

Disadvantages include;

- 1) the turnover of student volunteers is likely to be high as they typically move away at the end of their degrees (but the training and investment in each volunteer is substantial).
- 2) the inclusion of psychology students who are looking to develop therapeutic skills and experience needs careful management to ensure it does not change the service away from a pure peer support model
- 3) diversity in sociodemographic characteristics and life experiences is likely to be beneficial as the service grows and attracts more service users.

Recommendation 3: Embed evaluation and monitoring into network routines.

- Embed data collection into the routines of the network to support future reporting and evaluation needs, including:
 - a) Where possible, routinely collect sociodemographic data and basic information about the presenting eating difficulties and other support being accessed. The current survey would be a helpful data set to describe who the service is reaching so could be adapted for routine use (Appendix 2 sections 2 and 4/5). However, this needs careful balancing for new members to avoid intrusiveness. Consult with current service users to explore what feels reasonable, at what point, and in what format.
 - b) The items in the online survey developed for this evaluation appear a feasible way to capture the six peer support core values, barriers and facilitators to using the network and some important areas of impact (Appendix 2, section 2). As the network matures and different partnerships with clinical services are built, other valuable processes and outcomes may become apparent and extra questions could be added to the survey.
 - c) A logic model or a preliminary theory of change may be a useful tool to consolidate thinking about what the network intends to deliver and the processes through which this is expected to be achieved. This will help determine what to explore or measure in future evaluations.
- Future formal evaluations of a more established network might consider:
 - a) In depth feedback (via interview) from a small number of purposively sampled service users who are settled into either group or one-to-one support. This sort of data collection was avoided in this early evaluation since all service users were very new to the network.

- b) A paper or online survey of service users, achieving a larger sample size.
- c) Further interviews and/or surveys exploring the experiences of peer support volunteers and others involved in service provision
- d) A survey or interviews with other stakeholders to understand the value the network brings to local services (e.g. NHS services)
- e) Website analytics e.g. the number and types of resources being downloaded from the online portal. Analysis of Facebook posts for evaluation purposes is likely to raise considerable ethical and privacy concerns.

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APPENDICES

- 1a Interview Schedule for Volunteers
- 1b Interview Schedule for Advisor/Expert and Staff Member
- 2 Survey items

Appendix 1a. Interview schedule: Volunteer Peer Supporter

- **Can you start by telling me about how you became peer supporter?**
 - (probe- how found out, why you became involved, what you hoped it would be like)
- **Can I ask you to tell me a little bit about your experiences with Eating Difficulties (or mental health problems). Just say as much as you feel comfortable with.**
 - Probe about - type of problems had, the type of help and support you've had.
- **Can you tell me about what things are like with your eating and/or mental health these days?**
 - Probe about - perceptions of recovery, coping with difficulties
- **Can you tell me about the preparation and training you've had for this role?**
 - Probe about - What did you do? How did you find it?
- **Can you tell me about how you've been getting on in the role?**
 - Can you tell me what you've been doing? Probe – online support, group support, 1-1 support.
 - Use open-ended probes to follow-up on issues raised.
- **Can you talk me through an example of something went well?**
 - Probe - tell me about what happened, how you felt about it?
 - Probe – have you got any more examples of things that have gone well? (Keep probing for different example)
- **Can you talk me through an example of something went less well?**
 - Alternative wording- Perhaps where you didn't feel you could help? Or where things were tricky?
 - Probe – have you got any more examples of things that have gone well? (Keep probing for different examples)
- **Please can you tell me about a user you've helped. Talk me through what happened with them (perhaps use a fake name or if you use the real name, it'll be replaced when we analyse and report).**
 - NB- potentially skip this if detailed examples already given above.
 - Probe- how did you interact with them? What did you say or do? How do you think it affected them? How did you feel about it?.
- **Please can you tell me a time where you are not so sure you've helped/made a difference- talk me through what happened with them.**
 - NB- potentially skip this if detailed examples already given above.
 - Probe- how did you interact with them? What did you say or do? How do you think it affected them? How did you feel about it?.
- **How do you think you help people when working as a peer supporter?**
 - - in what ways? what is it that makes difference to people?

- **Can you tell me about whether there are any people you find it easier/harder to connect with?**
 - Can you tell me whether you've noticed anything about similarity- e.g. backgrounds, age, gender)
- **Tell me about any difficulties or problems you've come across as a peer supporter**
 - What's been hard? What's challenged you?
- **What do you think the strengths of this peer support network are?**
- **Can you think back and tell me about if and how you might have engaged with this service when you were having difficulties yourself?**
 - Probe reasons around engagement/non-engagement. Do you have any ideas about what would have made something like this attractive/unattractive, easy/hard to engage with, for you when you were having difficulties?
- **Do you mind me asking – how has your health/mental health been since becoming involved?**
Probe- can you tell me about if/how anything has changed?
- **In what ways has the experience of being a peer supporter been good for you?**
- **In what ways has it been less good for you?**
- **Can you tell me about what you've learned?**
- **Can you think of anything that might make you feel more confident/competent/happy about being a peer supporter.**
- **Anything you'd like to add that feels important to you and that I've missed?**

General open/ended prompts

- How did you find that?
- What was that like?
- Can you tell me more about x?
- I'd love to hear a bit more about what you were saying about X?
- Can you expand on x?
- Would you be able to give me an example of X?
- What did you mean by x?

Prompts to find out more about specific situations/examples

- Can you tell me more about what happened there?
- Can you talk me through what happened/what happened next?
- What do you think was going on?
- How did you make sense of that situation?
- How did you handle that?

Appendix 1b. Interview schedule: Advisor/Expert and Staff Member

- **Can you start by telling me about how you became involved in the network ?**
 - (probe- how found out, why you became involved, what you hoped it would be like)
- **Can I ask you to tell me about the work you do with Eating Difficulties**
- **Can you tell me about what your role involves?**
 - Probe about - What did you do? How did you find it?
- **Can you tell me about how you've been getting on in the role?**
 - Can you tell me what you've been doing? Probe – online support, group support, 1-1 support.
 - Use open-ended probes to follow-up on issues raised.
- **Can you tell me about how you think the peer volunteers are getting on?**
 - (If you refer to anyone by name I'll remove the name)
- **Can you talk me through an example of something that went well?**
 - Probe - tell me about what happened, how you felt about it?
 - Probe – have you got any more examples of things that have gone well? (Keep probing for different example)
- **Can you talk me through an example of something that went less well?**
 - Alternative wording- Perhaps where you didn't feel you could help? Or where things were tricky?
 - Probe – have you got any more examples of things that have gone well? (Keep probing for different examples)
- **Please can you tell me about a user the network has helped. Talk me through what happened with them (perhaps use a fake name or if you use the real name, it'll be replaced when we analyse and report).**
 - NB- potentially skip this if detailed examples already given above.
 - Probe- how did you interact with them? What did you say or do? How do you think it affected them? How did you feel about it?.
- **Please can you tell me a time where you are not so sure you've helped/made a difference- talk me through what happened with them.**
 - NB- potentially skip this if detailed examples already given above.
 - Probe- how did you interact with them? What did you say or do? How do you think it affected them? How did you feel about it?.
- **How do you think you the peer support network can help people?**
 - in what ways? what is it that makes difference to people?

- **Can you tell me about whether you've noticed anything about people that it easier/harder to connect with?**
 - Can you tell me whether you've noticed anything about similarity- e.g. backgrounds, age, gender)
- **Tell me about any difficulties or problems you've come across with the peer support network**
 - What's been hard? What's challenged you?
- **What do you think the strengths of this peer support network are?**
- **Can you think of anything that might improve the peer support network?**
- **Is there anything that you're concerned about with the peer support network?**
- **In what ways has the experience of being involved been good for you?**
- **In what ways has it been less good for you?**
- **Can you tell me about anything you've learned?**
- **Anything you'd like to add that feels important to you and that I've missed?**

General open/ended prompts

- How did you find that?
- What was that like?
- Can you tell me more about x?
- I'd love to hear a bit more about what you were saying about X?
- Can you expand on x?
- Would you be able to give me an example of X?
- What did you mean by x?

Prompts to find out more about specific situations/examples

- Can you tell me more about what happened there?
- Can you talk me through what happened/what happened next?
- What do you think was going on?
- How did you make sense of that situation?
- How did you handle that?

Appendix 2. Survey Items

Section	Rule. Show to all or show if	Question wording	Response type/options
1. Use of the network	All	Which best describes why you have been involved with the network?	Select from options <i>I'm somebody with eating difficulties</i> <i>I'm supporting somebody else who has eating difficulties</i>
	All	Which month did you start using the network?	Select from options <i>Feb 23</i> <i>Mar 23</i> <i>April 23</i> <i>May 23</i> <i>June 23</i> <i>July 23</i> <i>Aug 23</i> <i>Don't remember</i>
	All	How did you hope or expect the network might help?	Open ended response 500 words max
	All	Have you used the network Facebook group (posting and/or reading)?	<i>I didn't know about this</i> <i>I knew about this but haven't used it</i> <i>I've used this once</i> <i>I've used this more than once but not a lot</i> <i>I've used this a lot</i>
	All	Have you used the online portal?	<i>I didn't know about this</i> <i>I knew about this but haven't used it</i> <i>I've used this once</i> <i>I've used this more than once but not a lot</i> <i>I've used this a lot</i>
	All	Have you been to any group sessions?	<i>I didn't know about this</i> <i>I knew about this but haven't attended</i> <i>I've attended once</i> <i>I've attended twice</i> <i>I've attended three or more times</i>
	All	Have you had any one to one meetings with a volunteer peer supporter?	<i>I didn't know about this</i> <i>I knew about this but haven't had any meetings</i> <i>I have met with somebody once</i> <i>I have met with somebody twice</i> <i>I have met with somebody three or more times</i>
2. outcomes and impact	All	The network feels like a safe environment	LIKERT scale 1. Strongly disagree 2. disagree 3. neither agree or disagree 4. agree 5. strongly agree (arranged with disagreement to left, agreement to right)
	All	Within the network I've found people with similar experiences to me	As above
	All	Within the network I've felt connected with other people	As above
	All	Within the network I've had choice and control about how I use peer support	As above

	All	Within the network I've been able to both give and receive support	As above
	All	Within the network I've been able to be myself	As above
	All	The network has helped me find useful coping strategies	As above
	All	The network has helped me to manage difficult feelings and experiences	As above
	All	Has the network helped you in any other ways? Please give as much detail as possible. It will help us to know if and how we are helping and do more of this!	Open ended. 1000 words (or unlimited)
	All	Are there any ways that the network has been unhelpful? If you can think of anything relevant here it is really important to give this feedback. It may be possible to improve or change things.	Open ended. 1000 words (or unlimited)
	All	Has anything made it tricky for you to use the peer network ? This might include things like time, language barriers, travel, accessibility, other people, feelings, worries or discomfort. Please give as much detail as you are happy to share. This will really help us to understand and improve the service.	Open ended. 1000 words (or unlimited)
	All	Has anything made it easy for you to use the peer network? This is really important as we can do more of this if we know it is helpful!	Open ended. 1000 words (or unlimited)
	All	Is there anything else you'd like to add about your experiences with the network?	Open ended. 1000 words (or unlimited)
3. about you	All	How old are you?	Display numbers from 18-100
	All	What is your gender?	Female Male I define myself another way (please add detail if comfortable)_____ I prefer not to say
	All	What is your postcode? We won't use this to contact you. This is so we can understand more about the locations our service users come from	Open ended – 7 characters max
	All	What is your ethnic group?	White 1. English/Welsh/Scottish/Northern Irish/British 2. Irish 3. Gypsy or Irish Traveller 4. Any other White background, please describe Mixed/Multiple ethnic groups 5. White and Black Caribbean 6. White and Black African 7. White and Asian 8. Any other Mixed/Multiple ethnic background, please describe Asian/Asian British 9. Indian 10. Pakistani 11. Bangladeshi 12. Chinese

			<p>13. Any other Asian background, please describe</p> <p>Black/ African/Caribbean/Black British</p> <p>14. African 15. Caribbean 16. Any other Black/African/Caribbean background, please describe</p> <p>Other ethnic group</p> <p>17. Arab 18. Any other ethnic group, please describe</p>
	All	What is your highest level of education?	No formal education GCSEs or similar A levels or similar University degree Other[please state]_____
<p>4. about your eating difficulties</p> <p>SECTION ONLY SHOWN IF role = person with difficulties</p>	IF role = person with difficulties	How long have you been having eating difficulties? (if you've had difficulties in the past, improved/recovered then started to struggled again please answer this question thinking back to your first problems).	<p>Less than 6 months 6 months to one year Between 1 and -2 years 2-5 years 5-10 years More than 10 years</p>
	IF role = person with difficulties	Have you been formally diagnosed with a specific Eating Disorder?	<p>Yes No Not sure</p>
	IF role=person with difficulties AND yes to diagnosed	Please indicate what disorder you have been diagnosed with	<p>Anorexia Nervosa (<i>trying to control your weight by not eating enough food, exercising too much, or doing both</i>) Bulimia (<i>losing control over how much you eat and then taking drastic action to not put on weight</i>) Binge eating disorder (<i>eating large portions of food until you feel uncomfortably full</i>). OSFED. 'Other specified feeding or eating disorder'. Where symptoms/difficulties don't quite fit with a specific type of eating disorder. ARFID -Avoidant/restrictive food intake disorder. Avoiding certain foods, limiting how much you eat or both. Something else [please state]_____</p>
	IF role=person with difficulties AND No or unsure to diagnosed	In your own opinion do any of these labels/descriptions fit with your difficulties	As above
	IF role=person with difficulties	Have you had any counselling or therapy for your eating difficulties?	<p>I haven't tried to get any</p> <p>I have tried to get some but haven't been referred or accepted</p> <p>I'm on a waiting list</p> <p>I've had some in the past but not currently</p> <p>I'm having some at the moment</p> <p>Other[please state]_____</p>

<p>5 about the person you are supporting's eating difficulties</p> <p>SECTION ONLY SHOWN IF role = supporter</p> <p>Questions are similar to section 4 but just have wording tweaked.</p>	If role=support person	How long has the person you are supporting been having eating difficulties? (give your best guess if you are not sure when difficulties began)	Less than 6 months 6 months to one year Between 1 and -2 years 2-5 years 5-10 years More than 10 years
	If role=support person	Have they been formally diagnosed with a specific Eating Disorder?	Yes No Not sure
	If role=support person AND yes to diagnosed	Please indicate what disorder they have been diagnosed with	Anorexia Nervosa (<i>trying to control your weight by not eating enough food, exercising too much, or doing both</i>) Bulimia (<i>losing control over how much you eat and then taking drastic action to not put on weight</i>) Binge eating disorder (<i>eating large portions of food until you feel uncomfortably full</i>). OSFED . 'Other specified feeding or eating disorder'. <i>Where symptoms/difficulties don't quite fit with a specific type of eating disorder.</i> ARFID - <i>Avoidant/restrictive food intake disorder. Avoiding certain foods, limiting how much you eat or both.</i> Something else [please state] _____
	If role=support person AND No or not sure to diagnosed	In your own opinion do any of these labels/descriptions fit with their difficulties	As above
	If role=support person	Have they had any counselling or therapy for their eating difficulties?	They haven't tried to get any They have tried to some but haven't been referred or accepted They are on a waiting list They've had some in the past but not currently They are having some at the moment Other[please state] _____
		What relationship do you have with the person you are supporting?	Parent Spouse/partner Friend Other [please state]
		In the future we might wish to talk to some network users to get more detailed feedback. If you think you might be interested in being involved with this please write your name and contact details here so we can invite you. If you don't want to be contacted, just leave this blank.	Open ended. 1000 words (or unlimited)