Peer support principles for maternal mental Health Project report

Commissioned by: Comic Relief and Maternal Mental Health Alliance

Undertaken by: Mind and The McPin Foundation

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Outline

As part of Comic Relief's Maternal Mental Health strategy, a need was identified to develop quality assurance principles for third sector organisations running peer support in perinatal mental health. Comic Relief and the Maternal Mental Health Alliance worked together and commissioned the development of a set of good practise principles for local providers across the UK.

Mind and the McPin Foundation were commissioned to undertake this work over a 12-month period. The project leads were Suki Westmore for Mind and Andreja Mesaric for McPin.

Aims of the Peer Support quality assurance principles

The aim of developing bespoke quality assurance principles is to assure the quality and consistency of online and face to face peer support in perinatal mental health. The quality assurance principles are also a key part of wider work to ensure that peer support in perinatal mental health promotes positive outcomes and is:

- Safe for women and babies
- Accessible to all and inclusive
- High quality and evidence-based
- Trusted by clinical services
- Measuring and demonstrating outcomes and achieving maximum impact

Contents

Mental health peer support in the literature

Mental health peer support approaches

Peer support can take many different forms. It can be integrated into formal mental health services (e.g. Salzer et al, 2009) or remain grassroots and community based (e.g. Adame & Leitner, 2008). It can be entirely peer-led (e.g. Doughty & Tse, 2011) or co-delivered with mental health professionals (e.g. Salzer et al, 2009). It can involve trained and paid peer support workers offering support to others (e.g. Sledge et al, 2011) or peers coming together to support each other (Faulkner et al, 2013). It can also take the form of one to one or group peer support and take place in face to face or online settings. Each of these are explored below.

Published research focuses primarily on structured one to one support offered by trained peer supporters in formal mental health services and the voluntary sector (e.g. Sledge et al 2011; Simpson et al 2014). This model is built on a clear distinction between peer supporters and those they are supporting, with supporters normally being at a later stage of recovery (Faulkner et al 2013). Although this approach can bring the roles of peer supporters close to that of professionals, Pitt et al (2013) note that peer support workers offer support differently and spend more face to face time with clients. Not all one to one peer support distinguishes between the giver and receiver of support and in some settings a mutual exchange of support is seen as central to the peer relationship. For example, Faulkner et al (2013) write about peer-led one to one models that emphasise mutual support between two peers where both learn from each other. Peer support groups are more likely to be based around mutuality and reciprocity between group members (Repper & Carter, 2011). They can be entirely user-led without professional involvement (e.g. Barrett et al 2015) or involve varying degrees of professional facilitation (e.g. Gillard et al 2014). While some are informal chat sessions, others take the form of structured courses, for example psycho-education training (e.g. Straughan & Buckenham, 2006).

While much of the history of peer support is based in grassroots, user-led and 'bottom-up' movements developed as an alternative to mental health care (Basset et al, 2010; Faulkner & Kalathil, 2012), many peer support approaches now work closely with and are becoming increasingly integrated into mental health services. There has been some tension around professionalisation in peer support, with some concerns raised in qualitative studies of peer support workers that it could erode the core peer quality of the role (Gillard et al, 2014), in particular undermining equality between peers by establishing power imbalances. People in the survivor movement have also expressed fears that the user-led, informal and friendly approach that grassroots peer support emphasises, and which has traditionally maintained its independence is under threat of being replaced by outcome-driven structured peer support (Faulkner & Kalathil, 2012). However, it has also been argued that integrated and complementary models of peer support may have the opportunity to change the mental health system from within, whereas models outside of the system cannot do so (Adame & Leitner, 2008). Also, interviews with peer support workers have suggested that having a professional identity can be beneficial, particularly in managing multiple identities such as patient, service user, friend and peer (Dyble et al, 2014). There is often a tension in the role of a peer resulting from a blurred boundary between the personal and professional; personal experience is shared while training and integration into services might emphasise objectivity and the maintaining of boundaries (Colson & Francis, 2009). The boundaries that a peer support worker will have cannot be the same as those used by other staff who specifically withhold personal information, and in peer support scenarios boundaries are often blurred (Reidy et al, 2013).

Within formal mental health service roles, there is a distinction between peer support which is integrated into mental health teams and care approaches, and peer support which is separate but complementary to mental health service provision (Pitt et al, 2013). The approach described by Salzer et al (2009), for example, is a model in which the peer worker functioned as a full member of the assertive community treatment team, attending and participating in treatment planning meetings and performing some case management activities. By contrast, some approaches, such as the one described by Sledge et al (2011), involve a role which complements the services that an individual already receives, sitting alongside rather than forming part of services. In this study, peers were paid by mental health services but their role was independent of the clinical system and they did not report to staff within the services. Potentially, this latter model may help alleviate the concern sometimes voiced in the literature that maintaining a distinct role for peer support workers becomes difficult as they are increasingly integrated within the mental health system and adopt the traditional ways of working found in these services (Oades et al, 2012). Some have queried the extent to which lived experience defines the role of a peer support worker as compared to other skills required and how the peer worker identity is distinct from non-peer roles (Berry et al, 2011). Some peer support workers have reported not feeling accepted within the teams they work with as equal partners (Gillard et al, 2013) or have experienced negative attitudes from other staff (Dyble et al, 2014). Despite these challenges, a range of benefits as a result of taking on a peer supporter role have also been described in the literature, such as personal growth and improvements to self-esteem and confidence (Bailie & Tickle, 2015; Armstrong et al 1995; Salzer & Shear, 2002; Bracke et al 2008).

There has been an increase in online peer support, including group platforms providing an opportunity for peers to support each other (e.g. Freeman et al, 2008) and one to one approaches relying on trained peer supporters (e.g. Simon et al, 2011). Webb et al (2008) describe some unique potential benefits of such trusted peer communities, including providing an anonymous space to share experiences that might otherwise be felt to be stigmatising, but also point out the potential dangers in unsupervised forums for young people, particularly around contagion of self-harm and suicide (see also Whitlock, Powers & Eckenrode, 2006). Horgan et al (2013) found that various participants registered and browsed the forum without engaging directly by posting on it. This perhaps suggests that the ability to be an observer, at least at first, is a beneficial mechanism of online settings for peer support, compared to face-to-face settings where people might feel under more pressure to engage earlier. Further, research has highlighted a particular benefit for people living in rural areas who would otherwise find it very difficult to access social and/or professional support for their mental health (O’Dea & Campbell, 2010).

Many people involved in peer support prioritise different identities and experiences over mental health, such as having connections to people who share cultural, ethnic, LGBT or gender identities (Faulkner et al, 2013). A report by O’Hagan and colleagues (2010) identifies peer support as something that often happens informally and naturally within various ethnic minority communities, where individuals might use the support of their family or community, but that the idea of peer support was less well recognised in these communities. The report also points out that identity issues can be complicated for people who have two or more marginalised identities – in this case, that of having a mental health problem as well as a minority ethnic identity – and that such individuals might experience stigma in relation to both their ethnicity and their experiences of mental health difficulties. A related point was made in a report by Faulkner and colleagues (2013) which identified a potential gap in peer support in the UK for ethnic minority communities, suggesting that such groups existed but took on different forms that do not use a mental health label (while providing similar benefits and using similar peer support values and approaches).

Mental health peer support values

There is a growing consensus that value-driven approaches are vital within peer support. An expectation of peer support is often that individuals are honest, intimate and authentic about themselves – their identity and their experiences - in contrast to roles where professional barriers are prioritised over personal connection (Scott, 2011). Without authenticity, much of the benefits of peer support roles will be reduced as the insights and expertise gained from personal lived experiences are what allows people involved in peer support to connect with each other on a deeper level (Mancini & Lawson, 2009). The sharing of identity in an authentic way is not possible without feeling safe. This allows for disclosure of personal experiences in spaces where they know they will not be judged (Repper & Carter, 2011). In these ways, peer support groups both online and offline, can be enabling places that provide a space in which recovery-oriented progress and activities can be undertaken (Duff, 2012).

The transactional nature of peer support is highlighted in the literature, with reciprocal sharing of common experience and provision of support, rather than a one-sided relationship, consistently identified as a central value (e.g. Dyble et al, 2014). This mutual sharing of experience is seen as a unique dimension of peer support which establishes trust, understanding and helps individuals feel that they are not alone (Gidugu et al, 2015). Giving and receiving of support, and working together to find solutions are central components of peer support relationships (Repper et al, 2013). Within the context of online, group or grassroots peer support this reciprocity is likely to be common in practice, but in the context of more professionalised peer support worker roles, there may be a tendency for relationships to be comparatively more one-sided (Faulkner & Kalathil, 2012), albeit not to the extent of traditional practitioner-client relationships. This might be particularly true where – as described above – peer workers are provided training and are further along their recovery than the person they are supporting. However, as we also noted above, in these cases providing support can in itself be therapeutic and rewarding, contributing to the 'helper's' recovery, redefining the peer worker's own distressing experiences into something that has value (Salzer & Shear, 2002). Thus mutual benefit is another aspect of mutuality identified as a central feature of peer support (Solomon, 2004).

Supporting individuals to be in control of their own recovery and increase their own self-efficacy is seen as a central role of one to one peer support (Grant et al, 2012), with individuals increasing their confidence in their own abilities to manage recovery and make decisions (Legere, 2014). This empowering role for the peer worker is a major shift from the traditional marginalisation of people with mental health problems towards an expertise that is valued and given authority (Adame & Leitner, 2008). This arguably differentiates the peer support role from clinical staff; the latter role is more explicitly caregiving while peers support each other to do things for themselves (Paulson et al, 1999). Peer-support is viewed as being non-directive with suggestions, rather than instructions, provided and received (Repper et al, 2013) and has been described as underpinned by a strengths-based, recovery philosophy (Scott & Doughty, 2012). Choice and freedom to decide to participate in peer support are fundamental, as is a person's agency to decide what is best for them (Legere, 2014).

Agency, empowerment and self-determination are also reflected in the fact that many community peer support groups, as well as some of those which are delivered in partnership with formal services, are led by peers themselves. Indeed some have argued that such services must be peer-driven and led in order to ensure their effectiveness and their adherence to other key values (Solomon, 2004). Peer support is often said to involve a collaborative partnership rather than an imbalance of power, which is a defining distinction to traditional mental health care and the unique value that is provided by peer support. Power relations should be openly discussed and open to renegotiation, according to Legere (2014). Another consistent theme in the literature (e.g. Byrne, 2013) is that peer support is under-pinned by a recovery-oriented approach and rejection of medical models which encourage the power imbalances referred to above and have a focus on illness, symptoms, deficits and risks. Recovery approaches, by contrast, emphasise assets, collaboration and self-determination. These avoid clinical language and rather use language based on common experiences (Davidson et al, 1999).

Mental health peer support in the perinatal context

While there is a wealth of literature exploring the nature, effectiveness and values underpinning mental health peer support in general, there are fewer studies focussing on peer support in the perinatal context. Furthermore, most are focussed on postnatal/postpartum depression. Dennis and colleagues studied the effectiveness of telephone peer support in a pilot and larger scale trial conducted in Canada (Dennis 2003b, Dennis et al 2009, Dennis 2014). The pilot study found significant group differences in probable major depressive symptomatology between women in the intervention and control group (Dennis et al 2003b). The larger study found a positive trend in favour of the intervention group for maternal anxiety but not loneliness or use of health services (Dennis et al 2009). Another Canadian study (Letourneau et al 2014) of telephone peer support found that women's depression scores declined significantly. Women's perceptions of having better access to social support increased and higher support was significantly related with lower depression symptoms. An Australian study (Biggs et al, 2015) assessing user satisfaction with a telephone helpline offering a mix of peer support and counselling, established that women found the service helpful. However, recommended improvements included expanding hours of operation to increase accessibility and reduce waiting times, and continuity with the same peer supporter and/or counsellor, suggesting the importance of building relationships over time.

A British mixed methods study on the effects of home visiting by peer support workers on women with elevated risk of post natal depressions (PND) found that peer support had a positive effect on mothers' mental health and their relationship with their baby (Cust 2016). However, a Canadian randomised control trial (Letourneau et al 2011) researching the effectiveness of peer support via home visits focussing on maternal–infant interaction teaching, found that results favoured the control group. A descriptive qualitative study (McLeish and Redshaw, 2017) based on interviews with women who had received peer support from ten projects across England, found that being heard, building confidence, feeling valued, and reducing stress through practical support were important aspects of peer support. Women in this study described how peer support contributed to reducing low mood and anxiety by overcoming feelings of isolation, disempowerment and stress, and increasing feelings of self-esteem, self-efficacy and parenting competence.

Research on the experiences of telephone peer supporters in Australia (Biggs et al 2018) found that although peer support is designed to benefit those who receive support, supporters may also experience personal benefits from the role. These may include emotional impacts including experiences of personal growth and healing as well as developing skills and experience useful in employment in caring professions. Research (Carter et al 2017) on the experience of peer supporters conducting home visits found that for a number of peer supporters the experience aided their own recovery and that some have used their experience of offering peer support as a stepping stone to progress into a professional counselling role. However, some of the perinatal literature (Dennis 2003a; Biggs et al 2018) echoes concerns found in the wider peer support literature regarding professionalisation of peer support via training and highly structured roles, which could lead to peer supporters losing their 'peerness', a defining feature of their role.

While the peer support literature focussing on the perinatal mental health context recognises that the use of online platforms could significantly improve access to peer support, particularly to women from underserved communities and those in rural locations (e.g. Hennig et al 2016), this is an under researched area. One study of online peer support for post-partum depression found that online, women felt safer to reveal negative thoughts about motherhood that they otherwise might feel unable to because of idealised stereotypes about motherhood and being a good mother (Evans et al, 2012).

Research indicates that some women consider peer support the only acceptable support option, as a result of negative experiences with formal services (Abrams et al, 2009; Jesse et al, 2008; Raymond et al, 2014). Several studies have noted the importance of how the peer support context is defined. Anderson (2013) compared general mothers support groups not focused on mental health with support groups focused on PND. The study found that women experiencing postnatal depression found condition-specific support groups to be most helpful as they encouraged disclosure and normalised the experience of PND. Research also shows that peer support interventions need to consider factors such as a mother's age, cultural background, language, and the mother's circumstances and needs (Leger and Letourneau 2015). McLeish and Redshaw (2017) suggest that peer support may have particular salience for ethnic minority women, those who are recent migrants and women experiencing multiple disadvantages. Preyde (2007) found that mothers who received peer support from a trained volunteer, matched for language, ethnicity and culture, felt more confident in their parenting, better understood the medical condition of their child, experienced better quality support, and were able to share their experience. Edge (2011) has explored black Caribbean women's perceptions of perinatal mental health care and found that peer support is given and received informally by family and friends. The women interviewed talked about an ideal service model that was community based and not necessarily delivered by professionals. In studies such as this work with Black Caribbean women, 'peer support' was not always how people describe these exchanges, talking instead about friendship, social support, community support or help from friends and family who have similar experiences.

Methodology

The project adopted a coproduction methodology. Co-production can be defined as

> 'A relationship where professionals and people with lived experience share roles and responsibilities equally in the planning, design and delivery of projects.'

Further exploration of this concept can be found within the Social Care Institute of Excellence's Co-production toolkit.

Women with relevant lived experience known to Mind and McPin were consulted on the bid, they shaped the research design before Mind and McPin were commissioned to do this work. Once commissioned, three facilitators with experience of perinatal mental health problems and perinatal peer support were recruited to design and facilitate co-design events and focus groups, as well as shape the overall development of the project.

The research design included stakeholder interviews with people involved in coordinating peer support (who may or may not have lived experience), three co-design events across England open to anyone with lived experience or working / volunteering in the perinatal mental health sector, and three focus groups for women currently taking part in peer support. These were planned to take place in Wales, Scotland and Northern Ireland to ensure UK-wide representation.

Co-design can be defined as:

> 'A relationship where professionals and people with lived experience share roles and responsibilities equally in the design / outputs of a project.'

The co-design events were intended to progress the research and consultation process at each stage and were not a replication of the same event in three locations. Later, we introduced an online survey, not part of the original research design, to ensure a broader reach when testing a draft version of the quality assurance principles.

Peer support takes many forms, for the purposes of this report we will refer to all formats as projects.

A literature review conducted for an evaluation of Side by Side, a National Lottery funded project to improve access to peer support, was updated in relation to maternal mental health as soon as the project commenced. The Side by Side evaluation had been carried out by St George's, University London and the McPin Foundation 2015-2017. Community based peer support principles and values, identified by the peer researchers delivering the Side by Side evaluation, were drawn upon as a 'starting point' in this maternal mental health research and consultation process.

Four women with lived experience of perinatal mental health problems were recruited to co-facilitate consultation events and focus groups (Lived Experience Facilitators – LEF). We received 44 of applications for these roles which far exceeded expectations. Everyone who applied was passionate about peer support in maternal mental health, the vast majority of applicants were capable of undertaking the role and selection of the final four was made following two days of interviews. An induction day and planning meeting took place shortly following this. At this point one of the women stepped down from the role as she felt that not enough time had been allocated to each woman to fulfill the contract requirements, and that potential additional work would impact on her family life. The remaining women were given the choice of going back to the recruitment pool to find a replacement or to share out the hours. They chose to share the hours.

The women recruited, worked well together with complementary skill sets. They designed the format and content of all the co-design events and focus groups, as well as guiding the promotion and direction of the work overall.

> 'I felt like my input was valued and it helped me to develop my networking and project management skills. It was also a fantastic opportunity to work with the other lived experience facilitators Laura and Katy we brought a wealth of experience and expertise to the project that I felt gave the project added value.'
>
> Nisba, Lived Experience Facilitator

We began the consultation process by interviewing organisations that facilitate perinatal mental health peer support. This involved 13 interviews with staff and volunteers from 11 Comic Relief funded projects and ten interviews with staff and volunteers from seven other organisations (totalling 23 interviewees from 18 organisations).

Event planning started immediately as the first event needed to take place in March, venues for event 1 & 2 were secured through Mind's corporate partnership team. We gained free, good quality venues from DLA Piper for these. Good quality venues were important to ensure people attending felt valued and cared for and therefore more able / willing to share their experiences.

We made the decision to hold the events in cities across England with good transport links (rail and airports) to ensure it was straightforward for people to attend. The focus groups were planned in Northern Ireland, Scotland and Wales.

Event 1 and 2 took place, feedback from participants was good though numbers attending were slightly lower than anticipated. Whilst all tickets for event 1 were allocated only 40% of those who signed up attended on the day, to compensate we offered additional tickets for subsequent events.

Two focus groups took place, in Ireland and Scotland. It was challenging setting up the group in Wales as the service we initially approached were in a startup phase and had only just recruited staff. Discussions continued with them and other groups until September when the decision was made to conduct telephone interviews with women living in Wales, as it was still proving challenging to run a focus group.

Event 3 took place in September and was an opportunity to sense check the draft principles, further feedback was also received via an online survey to ensure people who had attended previous events or were unable to attend could share their thoughts on the draft.

The budget was tightly managed however it became apparent that additional funds would be required when a third sponsored venue could not be secured. Additional funds were supplied by Mind.

The Lived Experience Facilitators reported that they had a positive experience co-producing the principles with us.

> 'My experience of facilitating the co-design process significantly exceeded my expectations. I had anticipated that I would be helping to plan and deliver some consultation events and focus groups, which I did – but I was also treated as an equal partner, which was hugely empowering..'
>
> Laura – Lived Experience Facilitator

> 'I was very impressed with the whole process as this was the first time that I have been involved in co-production where the service users really were in control of the project rather than just consulted which often happens.'
>
> Katy – Lived Experience Facilitator

We prioritised lived experience leadership roles, ensuring the project was shaped and delivered in a meaningful and considered manner for all involved. All facilitators reported a lasting impact on them personally and in their working lives

> The co-design process offered me the perfect combination of autonomy and support, so that I was able to explore and develop my abilities and recognise my own potential. The fact that I was paid fairly for my time made me feel valued and valuable, and enabled me to put in enough time to do this work well.
>
> Laura – Lived Experience Facilitator

> My work on this project has helped me to network and build my contacts. I have been able to access other opportunities as an individual with lived experience.
>
> Nisba – Lived Experience Facilitator

To read more about the impact of leading this work as a Lived Experience Facilitator refer to Appendix 8.

Research summary

The research informing the development of the quality assurance principles included a literature review, 24 stakeholder interviews, three co-design events across England, two focus groups with women currently involved in peer support in Northern Ireland and Scotland, two interviews in lieu of a focus group in Wales, and an online survey open to anyone interested in perinatal mental health. As there was overlap in the timeframe of these different data collection and co-design methods we are not presenting the analysis by type of method but by stage in the research process. In particular, the co-design events cut across different stages of the research process and informed the thinking feeding into various drafts of the quality assurance principles.

Understanding the context

To gain a better understanding of the context of perinatal mental health peer support and how it might differ from other types of mental health peer support we conducted a literature review (see page 4) and conducted a number of phone interviews with people involved in running perinatal peer support projects. Interviewees were recruited via organisations funded by Comic Relief to deliver perinatal mental health projects and from additional contacts suggested by Maternal Mental Health Alliance (MMHA). Interviews were conducted with 13 stakeholders from 11 Comic Relief funded organisations[1] and 10 stakeholders from 7 additional organisations.[2] 23 stakeholders from 18 organisations were involved in this stage of the research. We conducted an additional interview with a representative of an online perinatal mental health peer support platform[3] in August 2018 to gain a better understanding of quality assurance issues from an online peer support perspective.

Interviews were conducted over the phone. The questions asked in the interviews (full interview schedule is available in Appendix 3) were developed around the five priorities identified in the tender document - that peer support should be safe for women and babies; accessible to all and inclusive; high quality and evidence-based; trusted by clinical services; and measuring and demonstrating outcomes and achieving maximum impact. The interview schedule was also informed by the themes emerging from the literature review. Interviewees were asked about their work, their views on what makes good peer support and their thoughts on quality assurance.

Interviewees identified the following ways that quality assurance principles would be useful to their work and to women using peer support:

- Improving own organisational practice
- Induction document for new staff and volunteers
- Addressing concerns about unsafe peer support ‘out there’
- Available to women using peer support to hold peer support organisations to account
- Appearing credible to referrers and funders

Interviewees also expressed some concerns that the quality assurance principles might be too bureaucratic to adhere to in practice and that they might inadvertently drive standards down. This includes the danger of funders not funding anything beyond the minimum standards set out in the principles. There was strong agreement regarding the need for addressing recruitment, training and supervision of volunteers as well as safeguarding. Other suggestions

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[1] All 17 funded organisation were invited to interview but only 11 responded. These included Action on Postpartum Psychosis, Bluebell Care Trust, Community Intercultural Programme, MindWise, MRANG, Quarries, Relate Cymru, The Balsam Centre, The Happy Mums Foundation CIC, The SMILE Group, Maternal Mental Health Alliance (Everyone's Business Campaign).

[2] These included Acacia, Island House, NCT, PANDAS, Parents 1st, Parents4Parents-North Yorks, Tamba.

[3] Netmums.com.

were not consistent across different interviews but included defining peer support (e.g. needs to be peer-led) and the purpose of peer support.

Identifying and exploring tensions

The next stage of the research process identified and explored tensions that emerged from discussions held at the co-design events in Birmingham and London. The events brought together a range of people with an interest in perinatal mental health peer support. At the Birmingham event, held in April 2018, we asked participants to discuss the five priority areas. The discussion was based around prompting questions developed for each priority area and guided by facilitators from Mind and McPin assigned to each discussion table. Discussion notes were analysed using thematic analysis. The analysis identified a series of tensions emerging in the data. These were apparent from ambivalent views contained in the data, themes contained in the data that seemed contradictory or from direct disagreement on certain issues among the event participants. The following tensions were identified, illustrated with quotes from the participants.

1) Peer support should develop its own outcomes vs. peer support should work to achieve clinical mental health outcomes

> "Are we actually expecting people's mental health to improve drastically/at all from peer support? If not, is it without value? Removing stigma and guilt, acceptance of problems and bonding in spite of them."

> "Danger of over professionalising peer support – copying mental health professional services rather than doing something different."

2) It is important for peer supporters to maintain boundaries vs. human connection is a central aspect of peer support

> "How to maintain boundaries if peer support is about breaking them down?"

3) Peer support should remain independent vs. peer support should be integrated into or work closely with clinical services

> "How does working with clinical services affect power dynamics?"

4) Peer support organisations should deliver a consistent 'service' vs. peer support develops organically and is guided by people taking part in the peer support

> "Peer Support needs to develop with the people that join the group and not be a franchise"

5) The importance of safety structures vs the importance of informality

> "Formal doesn't have to feel formal"

> "Safety comes from formal process, effectiveness comes from informal atmosphere"

6) Funders demand evidence on measurable outcomes vs. some outcomes of peer support are difficult to capture

> "Funders want consistent measures which may not match up to family experience."

> "When support is unmeasurable we can't tell if it's effective or safe – can't refer/signpost"

We found that (over-)professionalisation of peer support is a theme that cuts across most of these tensions. Professionalising peer support can help it meet many of the requirements for ensuring quality peer support such as delivering a consistent service, measuring outcomes, and being trusted by clinical services. However, it leaves open the question of how that impacts on the organic, human nature of peer support, and especially of how reliance on professionalised peer supporters influences the equality and mutuality in relationships between peers, highlighted in the peer support literature.

The second event, held in London in July 2018, explicitly focussed on exploring these tensions. Event participants had a range of views on the topics discussed and consensus was not reached on all. What emerged was a need for balancing between the polar opposites of the six identified tensions in order to develop structures and frameworks recognisable to clinicians and other professionals without losing the unique qualities of peer support. This is reflected in quotes recorded in event discussion notes.

> “We need balance between safety structures and a non-intimidating environment.”
>
> “The relationship between peer support and clinical services should be a Venn diagram – overlap but also clear definition of remit. Peer support provides support NHS can’t.”
>
> “It’s more beneficial to be seen as independent but to be on a clinical pathway with those connections and referrals without being seen that way by service users.”
>
> “Different women want a different dynamic from peer support; some want equal and mutual while others want to be “held”, to lean on another’s strength. Peer supporters need to be adaptable and have good communication around this.”
>
> “Peer support is compatible with benchmarking and quality assurance in certain circumstances – quality assurance shouldn’t be too rigid or tick box. It can become too corporate – but if you have flexibility you wouldn’t allow quality assurance/benchmarking to formalise peer support.”
>
> “Funders/commissioners want impact to be targeted – i.e. fewer GP appointments. This is misguided but we have to work within the system.”

During this stage of the research we also conducted two focus groups with women currently involved in perinatal mental health peer support, one in Northern Ireland and one in Scotland. Both took place at projects funded by Comic Relief. In contrast to the interviews in the initial stage of the research were we spoke to people involved in delivering peer support or managing peer support projects, and the co-design events that brought together a range of people with an interest in perinatal mental health, the focus groups aimed to explore the experiences of women who are involved in peer support but have not taken on formal roles. Both projects offered group peer support. The Northern Irish project was aimed at recently arrived migrant women and the Scottish project at women experiencing PND.

In June 2018, we conducted a focus group with women from the Community Intercultural Programme (CIP) in Portadown, Northern Ireland. The focus group was attended by eight participants, including two facilitators and the organisation’s director (who is male). The main themes emerging from the focus group were connected to who can be considered a peer and how that relates to creating a safe and welcoming environment. The project works with women who are recent migrants. Focus group participants compared the experience of this group to predominantly Irish mums’ groups, where they felt excluded and uncomfortable. One of the challenges highlighted in that context was the language barrier. However, given that many of the women also experienced language barriers at the CIP group (which caters to migrants of any background who often do not share a common language), yet didn’t experience the same alienation, points to the importance of considering structural disadvantage and processes of othering in creating welcoming spaces and facilitating peer relationships. This is reflected in the below quote from one of the focus group participants.

> “It’s because we are all different, it’s all different language but you interact, you don’t feel the difference. But if you are in an Irish group you feel like you are neglected, I’m not being

> rude, but it's facing the reality. You feel that you are different from them, they do their space, just only the Irish ones and you feel neglected. Over here is all welcome, you chat, talk, laugh, you can give support, speak. It's like accepted, like a family. It's so genuine."

Focus group participants also raised the importance of additional support available from CIP staff regarding advice on healthcare and housing, suggesting that relationships with services beyond peer support may be beneficial and that these need not be only clinical services. These issues might be particularly relevant in the context of recent migration but most likely have relevance for other perinatal peer support contexts.

In early September 2018, we conducted a focus group with women from Quarriers in Glasgow. The focus group was attended by eight participants. None of the participants had formal roles within the peer support project. Women shared what they feel they had gained from peer support, listing examples such as improving relationships with their family members; feeling more comfortable about having PND and experiencing certain feelings; feeling they can be more open about their PND; learning coping strategies; and recognising signs of when they are not coping better. This resonated with some of the feedback at the co-design events that suggested peer support has a somewhat different purpose to clinical mental health services. Some women in the focus group had negative experiences with psychiatrists and the group as a whole expressed a preference for independently run peer support. Women thought it was important for facilitators to have training to support the safety of the group. However, they considered training not to be enough if the facilitator does not have the right personal qualities or relevant lived experience. Furthermore, they thought it important that facilitators share something about that experience. Women also thought that the group would lose its character if it became open to women who had not experienced PND. They were adamant that they did not want their partners involved in the group.

Developing and testing the principles

The feedback from the first two co-design events and both focus groups informed a first draft of the quality assurance principles. At this stage the principles were formulated as:

1. Peer support should be peer-led
2. Peer support should have a different purpose to clinical mental health services
3. Peer support projects should take steps to ensure accessibility
4. Peer support projects should create a safe and nurturing environment
5. Peer supporters should be properly supported
6. Peer support projects should foster positive relationships with services but maintain their independence

(Full text of the draft principles can be found in appendix 1)

The next phase included testing the draft principles via the third co-design event, an online survey, and interviews with women currently involved in perinatal peer support in Wales (as there was no dedicated data collection in Wales up to that point). These three strands of the research informed the revised version of the principles included in this report.

The third co-design event took place in Newcastle in late September 2018. It used a similar approach of facilitated discussion tables to the first two events. The discussions were focused on the draft principles and how they could be revised and improved. Many of the participants suggested that the principles should include more detail, particularly around training and safeguarding, and clarification around what is meant by peer-led and what constitutes relevant lived experience. There were also some safeguarding concerns around the suggestion that some projects may choose to avoid contact with clinical services to increase accessibility to women who have had negative experiences with services or to assert their independence (included in Principles 3 and 6). There was considerable consensus that peer support should maintain at least a basic relationship with services in case they need clinical backup.

> "Even small initiatives need a working relationship with local perinatal services, if only to be able to raise concerns."
>
> Professional

Some participants suggested that maintaining independence might be more challenging in situations where projects receive NHS funding. The discussions raised interdependence as an alternative approach, where:

> "Peer and clinical roles are equal and must respect one another's expertise – working together at every stage."
>
> Person with lived experience

The event also raised the broader point about the phrasing on the principles. 'Peer support should…' was seen as potentially intimidating and weakness rather than strengths based – especially smaller projects might feel they are being told they are failing. An alternative phrasing, 'Good peer support is' was suggested at the event and adopted in the revised version of the principles.

The online survey was open between September and October 2018 and tested the same version of the principles as at the Newcastle event. The survey was administered by invitation to organisations and individuals who had previously been involved in the consultation process and those who had expressed an interest in being involved. Additionally, we were targeting audiences that had less representation in the consultation process to ensure a balance of views. The survey was also promoted on social media. We received 40 complete responses to the survey. The survey asked about the respondents' interest in perinatal peer support (e.g. personal involvement in peer support, manager of peer support project, commissioner, clinician, etc.), what region of the UK they are based in, and, if applicable, the type and format of the peer support they are involved in, and the demographics represented in their peer support (see Appendix 6). It then asked respondents a series of questions relating to the draft principles and provided opportunities for them to suggest improvements via free text comment boxes. 85% of respondents agreed that they would feel comfortable using peer support or referring someone to peer support guided by these principles and 68% agreed that the proposed quality assurance principles capture the specificity of maternal mental health well enough. Free text comments were broadly similar to the feedback we received at the Newcastle event, particularly around providing more detail regarding training, safeguarding and peer leadership, and safeguarding concerns around deliberate lack of contact with services.

> "Some reservations around relationships with other services, including PMH [perinatal mental health] clinical and other agencies, needs to be robust as the reality is that women being supported by PMH peer support projects are often extremely unwell as thresholds for specialist services are so high, many women will never be offered access to any PMH teams - therefore peer support workers need to be very well linked in with health professionals in both secondary and primary care as they cannot hold women presenting at the more severe end of the PMH spectrum alone."
>
> Professional

> "Access to appropriate channels for any safeguarding concerns is especially important for peer-led groups running in the community. This is where close links with local clinical teams e.g. specialist perinatal mental health services can be invaluable."
>
> Professional

The emphasis on peer support having its own purpose distinct from clinical service and the importance of meaningful opportunities for peer leadership was generally well received, with some suggestions that the principles should provide more detail on this.

> "The outcomes being developed with peers is an important one. People may need more guidance on what this means though."

> "Feedback on principle: 1. Good to see this as a principle in itself. Would be useful to summarise where this is most essential and adds most value? And to make clear that this is only one component of the skills and experience required for implementing a peer support project."

28% thought that the quality assurance principles should be tailored differently to large and small organisations. As this was not seen as a priority for most respondents we decided not to develop two separate sets of principles. Instead, we acknowledge where there might be differences between big and small organisations in the revised version of the principles.

45% of respondents agreed that 'quality assurance principles' was the right term to use in this context. The respondents that disagreed considered quality assurance to be too corporate to be a suitable term in the context of peer support. An additional concern was that peer supporters might feel the quality of their relationships is being assessed, rather than project structures.

> "It is a bit 'corporate' and formal, though well recognised as a generic term. Though principle 3 talks about 'accessible language' so perhaps something like 'what works well'."

> "I'm not sure if another expression would be better as 'quality assurance' relates to a 'product'. Chocolates on a production line are tested for quality assurance. I don't think peer support can be described as a product ...... it's much more personal."

> "I think 'quality' implies that there is good and bad quality peer support and while this may be true in a way, it may lead to anxiety among volunteers that they are being assessed or the 'quality' of their supportive relationships is being assessed.'

Suggested alternatives included guiding principles, good practice principles, and peer support standards.

Towards the end of the data collection process we also conducted two phone interviews with women currently involved in perinatal peer support in Wales. This was to address a focus group not being held in Wales. We unsuccessfully attempted to organise a focus group through various perinatal peer support projects based in Wales. As an alternative, we planned a focus group at the National Centre for Mental Health in Cardiff but could not recruit enough women to attend the focus group (we would need a minimum of 6). We conducted phone interviews with two women who expressed an interest in attending the focus group. As this took place towards the end of the process, the interviews focused on discussing the draft version of the principles, rather than the topic guide used in the focus groups. To protect confidentiality, given the small sample of interviewees, we cannot report on their feedback in detail. We can note that they stressed the importance of peer supporters being properly supported with training and supervision, and considered some connection with clinical services to be beneficial.

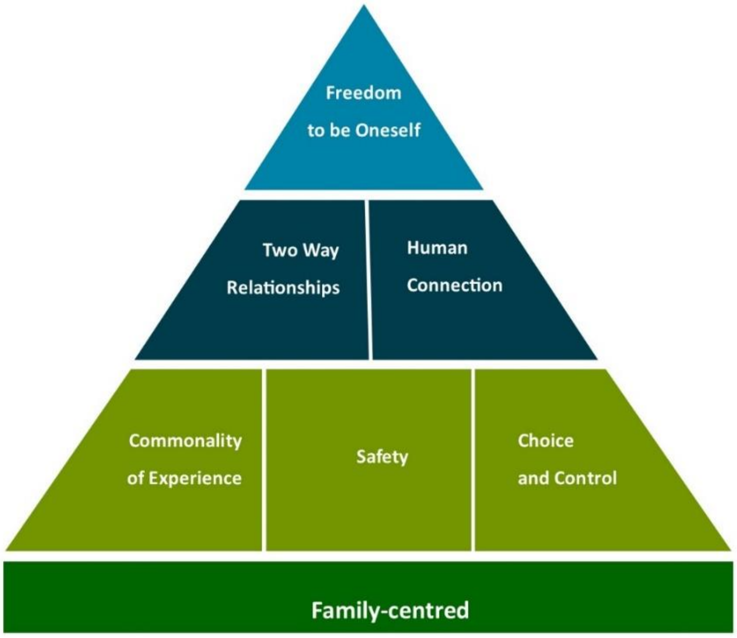
Taking into consideration feedback from the final event, survey and last two interviews, we rephrased the wording of the principles, included more detail on each and modified the sections that many people found concerning, particularly around links to clinical services. In the re-phrasing process what appeared as the second and sixth principles in the draft version sounded very similar. We therefore merged them into one principle, now appearing as Principle 3. The order of the principles has also been restructured to aid flow and to demonstrate order of importance. Refer to appendix 5 for the full wording of the initial principles before revision.

Testing the peer support values pyramid

The research also considered if and how peer support values identified by the McPin Foundation and St George's, University of London team in the Side by Side project (commonality of experience, safety, choice and control, two way interactions, human connection, and freedom to be oneself) should be adapted for perinatal peer support contexts. We thought about this throughout the process but also held an activity at the final co-design event dedicated to discussing the values identified in the Side by Side pyramid. Women suggested additions to the list of values identified in Side by Side that could be grouped into three categories:

- Alternative phrasing of the existing values (e.g. mutuality instead of two-way interactions)
- A desire for information on how to develop effective peer support that does not fit into a values framework e.g. guidance notes, reflective questions, toolkit
- Views which emphasised that perinatal peer support needs to consider women's babies and wider family (partner and other children, and possibly wider family networks).

As concern for the mother and baby as well as the woman's broader family network was considered to underpin the ethos of perinatal mental health peer support, we introduced an additional value into the Side by Side values pyramid framework. The value of 'family-centred' was included in the lowest tier of the pyramid to reflect how this underpins the work perinatal peer support.



The fact that the values pyramid needed little revision as well as that the headline phrasing of the revised quality assurance principles at first glance does not seem to be very specific to the perinatal context reflect that the values of principles of perinatal peer support do not diverge from other forms of mental health peer support. What is specific is the detail of what needs to happen in practice in order to uphold those values and principles. That is why the headline principles revised after several rounds of consultation and co-design sound quite broad, while the text accompanying them highlights the specificities of the perinatal context.

Next steps

At various points in the process, and in particular at the final co-design event, people identified what they would like to see in terms of next steps for the quality assurance principles. We include a summary of their suggestions:

- Plain language resources that promote peer values and highlight perinatal needs
- An open access downloadable resource/toolkit for small informal initiatives that links to the principles, including suggestion on how small initiatives can access training and supervision
- A database and interactive map of peer support projects adhering to the principles
- A formal system of quality assurance accreditation and recommendations on how to gain accreditation
- A self-assessment / how to toolkit
- A platform where peer support projects could quality assure each other

Principles for maternal mental health peer support

1. Good perinatal peer support is safe and nurturing
2. Good perinatal peer support is accessible and inclusive
3. Good perinatal peer support complements rather than replicates the work of clinical mental health services
4. Good perinatal peer support provides opportunities for meaningful involvement of people with lived experience and peer leadership
5. Good perinatal peer support benefits everyone involved, including peer supporters

1. Good perinatal peer support is safe and nurturing

Good peer support fosters a culture of trust, non-judgement and empathy. It enables women to feel safe to share their experiences and difficult feelings should they wish to. This is facilitated by clear guidelines on how to discuss difficult topics safely, for example how much to share and in what way. Good peer support establishes clear ground rules and boundaries at the outset. These need to be revisited and renegotiated periodically as the peer relationship develops or group membership changes. Ground rules and boundaries should be developed within organisational policies but may be unique to each peer relationship as they are co-designed with peers.

Peer supporters and peer facilitators create a friendly and welcoming environment by being warm, demonstrating care and using positive language. Human relationships are crucial to peer support. Peer supporters and facilitators need to be free to share about themselves and have control over how much to share. Whilst the relationship should be nurturing, open and honest, peer supporters should guide conversations and ensure they are boundaried and safe. Therefore, peer supporters and group facilitators should be further along in their recovery. That does not mean that mums that have not been trained cannot offer peer support to each other in a group setting. However, this needs to be managed by a trained facilitator. Group facilitators should encourage group members to think about their individual boundaries and how to maintain them in the group. This includes thinking about how much they are willing to share and hear, and whether they want to maintain contact with other group members outside of the peer support group.

A safe and welcoming environment is supported by robust safeguarding structures that ensure the safety of everyone involved including mums, babies and peer supporters. Peer support organisations need clear child and adult safeguarding policies and procedures, a safeguarding lead and clear reporting systems. These should be understood by staff, volunteers and project members/service users. If relevant, projects or services should also have lone working and home visiting policies and procedures in place. Peer supporters need to be trained in recognising and responding to potential safeguarding concerns. They should be supported to reflect on how to balance maintaining confidentiality and trust with acting to safeguard mums and babies. Online peer support, whether a group-based forum or one to one messaging, should be facilitated through a moderated platform. Moderators should maintain safety by removing inappropriate and triggering posts and reaching out to platform users posing safeguarding concerns. In both face to face and online peer support, safety can be supported by positive relationships with clinical services. These can be useful in addressing safeguarding concerns and signposting of women who need additional support.

Reflective questions

A. What practical steps does your project/service take to create a welcoming environment?

B. What are your safeguarding policies and procedures? Do you have a named lead? Do policies cover adult & child? Who could support you with developing this?

C. How are ground rules and boundaries established and maintained within the project/service?

D. If yours is an online service, what are the additional safety risks this might raise? For example, how is it moderated? What training have the moderators received? What are the limitations around using Twitter?

2. Good perinatal peer support is accessible and inclusive

Good peer support takes proactive steps to ensure accessibility. An important part of this is the option of self-referral and limited waiting times. Practical steps that make it easier for women to attend face to face peer support include holding meetings in accessible locations with good transport links and at times suitable to peer support members. While some projects or services will find they need to provide childcare in order to increase accessibility, others may find that mums want the opportunity to attend a group with their children. Ideally, peer support should address the financial barriers women face in accessing peer support, for example by covering transport costs and not organising activities that will cost women money. Using accessible language women can relate to can also be important. This may include avoiding mental health terminology in favour of more neutral terms like emotional wellbeing.

Maintaining control over what peer support to engage in and when can contribute to accessibility. This includes a choice of different types of peer support including whether it takes place in person or online, in a one to one or group format, and in the form of structured discussions about mental health or informal chats and activities. Choice over how often to engage in peer support (e.g. not being required to attend every session) and to what extent (e.g. not having to share at every session) is also important. The option of phone and online peer support can increase accessibility, especially in rural areas with fewer face to face options. However, this may not be appropriate for everyone as some women might struggle with literacy or have limited internet access. It may be that a range of peer support options cannot be achieved within one project, service or organisation, especially when it comes to small projects based in the community. Therefore it is important for different peer support projects and services to work together collaboratively as the full range of peer support choices on offer will increase accessibility of peer support to individual mums.

What each project or service can and should do is to increase accessibility for the specific group of women it is aiming to support. From this perspective, increasing accessibility might mean defining membership more narrowly. This is important for women who might be reluctant to attend general maternal mental health peer support. This includes women with less common maternal mental health experiences such as postpartum psychosis, perinatal OCD or birth trauma. It could also include women from minority ethnic backgrounds, refugee and migrant women, women with disabilities, lesbian and bisexual women, and women who have experienced homelessness, drug and alcohol misuse, or contact with the criminal justice system. Projects or services will need to consider if there are any specific accessibility issues relevant for women that they support and respond accordingly (e.g. running sessions in languages other than English).

Reflective questions

A. What steps has your project or service taken to increase accessibility?

B. Does your project or service offer a range of different peer support formats and activities? Have you developed links with other peer support projects or services in your area to increase women's access to a variety of peer support options?

C. Have you considered the specific barriers women accessing your project or service may encounter? What will you do to address this?

3. Good perinatal peer support complements rather than replicates the work of clinical mental health services

Good peer support builds on what makes it unique and distinct from clinical mental health services. It offers holistic support that goes beyond mental health. It works flexibly to adapt to the needs of the mum and her family. The work of peer support and clinical mental health services should complement each other. As the outcomes of peer support and clinical mental health services overlap only partially, women need to have access to both forms of support. Depending on the women's circumstances, including the severity of the mental health difficulties they are experiencing, one approach may be more suitable than the other. However, the two should establish relationships of interdependence and equal recognition should be afforded to both approaches. Maintaining positive relationships with local clinical teams can enable peer support projects or services to support women better, for example via mutual referral. A relationship with clinical services can be particularly useful for peer-led groups running in the community. It facilitates access to appropriate channels for any safeguarding concerns and could provide an avenue for accessing clinical supervision for peer supporters. However, peer support should be able to accommodate the needs of women who prefer to avoid clinical mental health interventions because of previous negative experiences. Therefore, good peer support remains one step removed from clinical services. Different models and degrees of collaboration with clinical services advance or hinder different aspects of peer support. Peer support projects or services need to make their own decisions regarding what is suitable for them. Negotiating relationships with clinical services may be more challenging in certain contexts, for example when peer support is funded by the NHS or located within the NHS. In those contexts, encouraging meaningful peer leadership and involvement of mums in making decisions about what the peer support is aiming to achieve can ensure peer support maintains its distinct nature.

While there is likely to be some overlap with clinical mental health outcomes, peer support projects or services should define their own outcomes. These may include things like feeling heard and understood or dealing better with being unwell (rather than focusing solely on becoming well). Not all peer support projects or services will identify the same set of outcomes as relevant to their work. This can vary depending on the focus and context of the peer support and may reflect cultural variation in mental health concepts. Outcomes should be developed in consultation with mums who can identify what feels relevant to them. This can include outcomes specific to individual women (for example, reconnecting with a family member with whom they have a fraught relationship) or outcomes that could be relevant to all women in the peer support (for example, normalising the experience of having mental health difficulties or living with a particular mental health diagnosis). When consulting women, it is important to consider what language to use – for example, asking about what they would like to get out of peer support rather than what outcomes they would like to achieve.

Reflective questions

A. What is your relationship to clinical maternal mental health services? How does this contribute to the support you provide?

B. How is what your project or service offer similar and different to clinical services in your area?

C. What are the outcomes your project or service is aiming to achieve? How did you decide these?

4. Good perinatal peer support provides opportunities for meaningful involvement of people with lived experience and peer leadership

Good peer support involves people with relevant lived experience in its design and delivery. It is essential that all peer supporting is done by people with lived experience considered relevant in a particular peer support context. This on its own does not guarantee the quality of peer support but is necessary for the support to act as *peer* support rather than professional support or voluntary support delivered by non-peers. This is particularly important in one to one peer support but should also be considered in group facilitation.

What can be considered relevant lived experience may differ depending on the context of peer support. At a minimum, this includes experience of maternity and mental health difficulties or struggling with emotional wellbeing. In peer support aimed at women with a particular mental health diagnosis, from a particular demographic or with a particular experience, such as twin and multiple births, disability, migration, drug and alcohol use, or contact with the criminal justice system, relevant lived experience will be more narrowly defined. This will shape who can be considered a peer in a specific peer support context. This may change over time as the project or service develops and should be reflected upon periodically. If an organisation setting up peer support does not have relevant experience among its staff and volunteers, it should consult people who do when developing the project or service. It should recruit staff and volunteers with relevant lived experience to deliver it.

It is important that people with lived experience have a leadership role where they have a voice and can influence the direction of the peer support. This includes involvement at project management level and representation on trustee boards. Peer leadership can take different forms depending on the focus of the peer support, and the size and structure of the organisation running or hosting the peer support. Larger organisations with established structures might find it more difficult to promote people with lived experience into leadership positions, while smaller organisations and informal initiatives might have more flexibility in enabling peers to take the lead. While peers who have taken on additional responsibility need to be supported in their roles, this support can be offered by people who have both lived experience and professional skills. If these roles cannot be filled by people who possess both relevant lived experience and professional skills, it is preferable to skill up people with lived experience to take on management positions rather than recruit trained professionals without lived experience. If this is not possible, peers should at a minimum be involved in the co-production and co-design of peer support projects and services as equal partners.

Reflective questions

A. Who has been involved in the design of your peer support? Who is responsible for decision making?

B. What aspects of lived experience are important in the context of your peer support? How do these experiences inform the shape of your project or service?

C. Which leadership positions within your project or service are held by peers? Do you have relevant lived experience representation in management positions and if applicable senior positions at trustee level?

5. Good perinatal peer support benefits everyone involved, including peer supporters

Good peer support enables peer supporters to benefit from their involvement in peer support. People with lived experience in supporting roles, whether one to one supporters, group facilitators or online moderators, are not merely ‘providers’ of support. They should have the possibility of benefiting from peer relationships. While they may not benefit from their involvement in peer support in the same way as the mums they are supporting, peer support organisations should recognise that offering peer support has an impact on supporters’ mental health and wellbeing. Some of the benefits they might experience are increased confidence, a sense of purpose and feeling helpful. Peer support organisations should recognise this as valid outcomes of peer support. This will guard against over-professionalisation of peer support where peers in supporter and leadership roles fill the position of ‘service providers’ rather than that of people engaging in peer relationships.

Peer support organisations need to provide peer supporters with training that will support them in their role. This should address how to engage in peer support relationships including how to enable a safe and nurturing environment, listening skills, facilitation skills, communicating and negotiating boundaries, safeguarding, and when to share confidential information. This should also include training on maternity specific topics such as feeding and sleep, and training on a range of maternal mental health conditions and experiences that they may encounter such as postnatal depression, postpartum psychosis, perinatal OCD, baby loss, and birth trauma. Peer supporters should be trained on understanding the remit and recognising the limits of their role and where to signpost women who are in crisis or in need of additional support. Where smaller organisations lack the capacity to provide training in house they may seek external support, for example through external training courses, engaging independent consultants or developing relationships with larger organisations.

Peer supporters need to be provided with regular opportunities to debrief and reflect and identify additional training and support needs. This can take the form of supervision meetings. In larger organisations this will form part of organisational management structures. Small peer-led initiatives without a formal organisational structure can develop relationships with larger organisations that might be able to provide them with supervision and support. If they are unable to access this support from larger organisations, peer supporters should debrief and reflect in pairs or in group reflection sessions. Peer supporters should ideally also have to access clinical supervision. In larger organisations and NHS affiliated peer support, this could be provided in-house. Smaller initiatives could develop relationships with local clinical mental health services, such as a local perinatal mental health team or a hospital mother and baby unit, to provide them with clinical supervision.

Reflective questions

A. How does your project or service impact the mental health and wellbeing of peer supporters?

B. What training do you provide for your peer supporters and peer facilitators? How is this training relevant for your specific peer support context?

C. What training and support do you provide for peers progressing into leadership roles?

D. What kind of supervision & clinical supervision do your peer supporters have access to? Who could you approach to support you with this?

Appendix 1 – Self-reflection Grid

To be used alongside the principles document and with the women giving and receiving peer support and other relevant resources

Principle and accompanying reflective questions	Use the boxes below to note down how you have or are planning to achieve each principle. Think about how you will demonstrate how you have achieved each principle	What actions do I need to take? If you have identified gaps or areas, you need to take action what will this be?
Principle 1 – Good perinatal peer support is safe and nurturing A. What practical steps does your project/service take to create a welcoming environment? B. What are your safeguarding policies and procedures? Do you have a named lead? Do policies cover adult & child? Who could support you with developing this? C. How are ground rules and boundaries established and maintained within the project/service? D. If yours is an online service, what are the additional safety risks this might raise? For example, how is it moderated? What training have the moderators received? What are the limitations around using Twitter?		

Principle and accompanying reflective questions	Use the boxes below to note down how you have or are planning to achieve each principle. Think about how you will demonstrate how you have achieved each principle	What actions do I need to take? If you have identified gaps or areas, you need to take action what will this be?
Principle 2 – Good perinatal peer support is accessible and inclusive A. What steps has your project or service taken to increase accessibility? B. Does your project or service offer a range of different peer support formats and activities? Have you developed links with other peer support projects or services in your area to increase women's access to a variety of peer support options? C. Have you considered the specific barriers women accessing your project or service may encounter? What will you do to address this?		

Principle and accompanying reflective questions	Use the boxes below to note down how you have or are planning to achieve each principle. Think about how you will demonstrate how you have achieved each principle	What actions do I need to take? If you have identified gaps or areas, you need to take action what will this be?
Principle 3 – Good perinatal peer support complements rather than replicates the work of clinical mental health services A. What is your relationship to clinical maternal mental health services? How does this contribute to the support you provide? B. How is what your project or service offer similar and different to clinical services in your area? C. What are the outcomes your project or service is aiming to achieve? How did you decide these?		

Principle and accompanying reflective questions	Use the boxes below to note down how you have or are planning to achieve each principle. Think about how you will demonstrate how you have achieved each principle	What actions do I need to take? If you have identified gaps or areas, you need to take action what will this be?
Principle 4 – Good perinatal peer support provides opportunities for meaningful involvement of people with lived experience and peer leadership A. Who has been involved in the design of your peer support? Who is responsible for decision making? B. What aspects of lived experience are important in the context of your peer support? How do these experiences inform the shape of your project or service? C. Which leadership positions within your project or service are held by peers? Do you have relevant lived experience representation in management positions and if applicable senior positions at trustee level?		

Principle and accompanying reflective questions	Use the boxes below to note down how you have or are planning to achieve each principle. Think about how you will demonstrate how you have achieved each principle	What actions do I need to take? If you have identified gaps or areas, you need to take action what will this be?
Principle 5 – Good perinatal peer support benefits everyone involved, including peer supporters A. How does your project or service impact the mental health and wellbeing of peer supporters? B. What training do you provide for your peer supporters and peer facilitators? How is this training relevant for your specific peer support context? C. What training and support do you provide for peers progressing into leadership roles? D. What kind of supervision & clinical supervision do your peer supporters have access to? Who could you approach to support you with this?		

Appendix 2 – Core values of peer support

Experience in common

Peers have experiences in common. In a mental health context, these are common experiences of social and emotional distress. This can form the basis of their connection to each other, regardless of the extent to which this experience is openly discussed. Peers can share experiences of broadly defined social and emotional distress or experiences linked more narrowly to a particular mental health diagnosis. In some peer support, specific additional aspects of personal experience or identity shaped by gender, ethnicity, age, sexuality, disability, and migration are critical to people recognising each other as peers.

Safety

The process of creating peer support involves developing structures to provide physically and emotionally safe spaces. Safety building is essential and can include creating guidelines or 'ground rules' to address confidentiality and how peers can behave respectfully towards each other. It also includes reviewing meeting locations for privacy and accessibility, role modelling the way peers can share (or not share), and clarity over how peers may discuss particular topics (for example, the level of detail peers give about self-harm may be limited). The knowledge that 'what is shared in peer support, remains in peer support' helps to create trust that allows peers to be able to express themselves without fear of judgement. In some forms of peer support, the responsibility for creating safety in peer support may rest with online moderators, group facilitators, or supervisors. In other forms of peer support, peers collectively take responsibility for creating safety.

Choice and control

It is up to the individual peer to decide how they will participate in the peer support environment. This includes control over when they attend or take part in peer support, what they choose to share, what support they want to try, what role they take in a group or interaction, and how long they access peer support. Peers can withdraw from peer support for a period of time and return to it later on without being penalised.

Two-way interactions

The interactions between peers are two-way, and involve both giving and receiving support. This type of two-way interaction may be called 'reciprocity' or 'mutual support'. At different points in time, peers may give more or receive more or less support depending on their circumstances. What is given and received may vary, but there is always the potential in peer relationships to both give and receive support.

Human connection

Peers actively acknowledge that they have a connection with each other based on having experiences in common. These common experiences provide a basis on which peers feel they may have a better understanding of one another than other people in their lives. Previous negative experiences can be put to a positive use through this connection. Peers work together to create a warm, friendly, welcoming environment for all peers, and act with intentional kindness towards each other online or face-to-face. Peers understand, emotionally support, and care for each other. This generates a culture of companionship and belonging. Through the connection with each other, peers may come to feel less isolated and feel that they are part of a supportive community.

Freedom to be oneself

The ability to express themselves freely – without fear of judgement – is necessary for peers to be able to share difficult issues, not all directly about social and emotional distress, and to feel comfortable in doing so. The experience of feeling heard and understood in peer support is powerful. For this to happen, peers need a space in which they can be vulnerable and talk about difficult experiences. Structures need to be in place to create this safe space, which means having ground rules to address the way peers behave towards each other. For many peers, peer support allows them to feel like they are normal, and are just like any other person in their peer support. This is in contrast to having felt different, stigmatised, or excluded in other aspects of life.

Appendix 3 – Stakeholders interview schedule

1. Can you tell me about your role in the organisation?
2. What kind of support does your organization offer to pregnant and postnatal women?
   - What does the project look like in practical terms? What kind of services/activities do you run?
   - In your experience, what approaches work particularly well in engaging women?
   - How does your work with pregnant and postnatal women fit with the broader work of your organisation?
3. Can you tell me about the women that you support?
   - Do you work with a particular demographic/group of women?
   - What kind of concerns do women approach you with?
   - How would you say the needs of pregnant and postnatal women are different to needs of other women/people?
   - Are you aware of any barriers that women experience when trying to access support for their mental health (or other support) during this period of their lives?
4. How does your work involve peer support?
   - How are peers involved in your work?
   - Who is considered a peer in the context of your work/project?
5. What role would you say peer support can play in mental health recovery of pregnant and postnatal women?
   - How would you define peer support?
   - How is peer support different to other types of support?
   - How is maternal mental health peer support different from other mental health peer support?
6. How can we ensure quality peer support? What needs to be in place to make sure that:
   - It is safe for women and babies?
   - It is inclusive and accessible to everyone?
   - It results in improved mental health for women?
7. What do you think of the idea of having quality assurance principles for maternal mental health peer support?
   - How could a document like that help you in your work?
   - What areas/topics would you like it to address?
   - How can we make quality assurance compatible with peer support as an approach?
   - What alternative approach could be used to make sure peer support is safe, inclusive, and leads to improved mental health?
8. Is there anything else you would like to say?

Appendix 4 – Focus group topic guide and Demographics

Experience of the project

1. Can you tell us a bit about the group?

- What happens when you meet?
- What do you get from coming to the group?

Views on peer support

2. How would you define good peer support?

- Who would come?
- Who would lead it?
- What would happen in the sessions?
- What else would need to be in place?

3. What should peer support be aiming to do?

- What is the purpose of peer support?
- How is peer support different to other support? (e.g. health, social services, friends, family)

4. How does the presence of babies change peer support?

- How is peer support for mums with babies different to other peer support?
- What difference does it make if babies are in the room or not?
- How does it impact accessibility, safety, nature of conversations and activities, and effectiveness of peer support?

5. What should be the relationship between peer support and health, social care and other services?

- Should peer support organisations work closely with health and social care services or should they work independently?

Peerness, leadership and boundaries

6. Who do you consider to be a peer?

- Which experiences are important? (e.g. motherhood, mental health condition, living in the local area, profession, being a migrant, etc.)
- Do you think it would change the group if people without those experiences joined? (inclusion of fathers; friends and family; women with other conditions, etc.)

7. What is the role of facilitators and volunteers?

- What should the role of the group facilitator be?
- Could any member of the group step into the facilitator role if needed?
- Is there a difference between talking to a trained peer supporter and a non-trained peer (another mum from the group)?

Safety

9. What makes the group a comfortable, safe space?

- What needs to be in place to ensure safety?
- How does/can everyone in the group contribute to that?
- How does the presence of babies affect safety?

Accessibility

10. How could peer support be more accessible and inclusive?

- Is there anything that makes it difficult for you to come to the group?
- What do you think could make it difficult for other women who don't come to the group but could benefit from it?
- Is there anything that makes it difficult to take part when you are here?
- Is there a time limit to how long you can attend? Is that important?

11. Is there anything else you would like to say that we haven't asked about?

Participant demographics

Ireland

Ethnicity: White Irish - 3 White Eastern European – 3Arab 1 Black - other 1

Gender: Male – 1 Female – 7

Scotland

Ethnicity: White British – 6

Gender: Female – 8

Age: 18-24 – 2 25-34 – 5 35-44 – 0 45-54 – 1 65+ - 0

Appendix 5 - Peer Support principles – Early initial draft

Note: This version of the principles was drafted using feedback from events 1&2, interviews, focus groups and some early online feedback. They were taken in this format to event 3 for feedback and refinement, further refinement took place within the MMHA operational group.

1. **Peer support should be peer-led**

   Maternal mental health peer support projects should be designed and delivered by people with relevant lived experience. At a minimum, this includes experience of both maternity and mental health difficulties. The exact nature of relevant lived experience may differ depending on context. It may include but is not limited to the type of maternal mental health difficulties, ethnicity, sexuality, drug and alcohol use, contact with criminal justice system, and migration status. If an organisation setting up a maternal mental health peer support project does not have relevant experience among its staff and volunteers, it should consult people who do when developing the project and recruit staff and volunteers with relevant lived experience to run the project.

2. **Peer support should have a different purpose to clinical mental health services**

   Maternal mental health peer support should be flexible and adaptable offering personalised holistic support that goes beyond mental health. Peer support projects should define their own outcomes. While there is likely to be some overlap with clinical mental health outcomes, peer support projects should build on what makes peer support unique and distinct from mental health services. Outcomes need to be developed in consultation with mums, who can identify which outcomes feel relevant to them. These may include things like normalising mental health difficulties and dealing better with being unwell (rather than just improving). Different peer support projects may identify different sets of outcomes as relevant to their work, depending on the nature and context of their peer support. This includes how outcomes are shaped by cultural variation in mental health concepts.

3. **Peer support projects should take steps to ensure accessibility**

   This includes practical steps that enable women easier access to peer support such as accessible venues, providing crèche facilities and covering transport costs (resources permitting) as well as using accessible language women can relate to. Increasing accessibility could also mean limiting membership to people with specific experiences that would be reluctant to attend more generic groups – e.g. women with less common diagnoses such as postpartum psychosis, women from minority ethnic backgrounds or refugee and migrant women. In some cases, a deliberate lack of contact with services could ensure accessibility to women who avoid services due to previous negative experiences or fear of negative consequences.

4. **Peer support projects should create a safe and nurturing environment**

   This includes safeguarding as well as creating a friendly and welcoming environment where women feel comfortable to spend time and share their experiences. Peer support projects should have clear safeguarding policies and procedures that should be communicated to staff, volunteers and project members. These need to take into account mums and babies. Peer support needs to foster a culture of trust, non-judgement and empathy, which will enable women to feel safe. Ground rules and boundaries need to be established clearly at the outset, and revisited and renegotiated periodically as the peer relationship develops or group membership changes.

5. **Peer supporters should be properly supported**

   Peer support projects should provide staff and volunteers with training that will support them in their role. This should include safeguarding, communicating and negotiating boundaries, when to share confidential information, where to signpost women in crisis, and any other topic area relevant to the nature of the specific peer support. Peer supporters need to be provided with regular supervision that will offer them an opportunity to debrief and reflect. Peer support projects should take steps to ensure that not only women being supported but also peer supporters benefit from peer support. They should not be seen merely as ‘providers’ of support but rather as equal partners in the peer relationship. This will guard against professionalisation of peer support where people with lived experience in leadership roles take up the role of ‘service providers’ rather than that of peers on an equal footing.

6. **Peer support projects should foster positive relationships with services but maintain their independence**

   Maintaining positive relationships with clinical and other services can enable peer support projects to support women better, e.g. via mutual referral. However, peer support should not act merely as a part of the ‘perinatal pathway’ and should strive to retain its independence and peer-led nature. This requires good communication and clarity on both sides regarding responsibilities, including what peer support can and cannot do. Different models and degrees of collaboration with services advance or hinder different aspects of peer support. Peer support projects need to make their own decisions regarding what is suitable for them. Some projects may decide that a direct relationship with services is not appropriate if it would deter women from seeking support.

Appendix 6 – Online feedback data

Format of peer support

65.52% - One to One
65.52% - Group
20.69% - Other

Relationship to maternal mental health peer support

I have personal experience of giving / receiving peer support – 45%
I work or volunteer as a peer supporter / group facilitator – 27.5%
I manage a peer support project – 45%
I commission/ am interested in commissioning peer support – 5%
I am a clinician who refers/ is interested in referring clients to peer support – 12.5%
I am a non-clinical practitioner who refers/ is interested in referring clients to peer support – 12.5%
I am a friend or family member of someone who has used or could benefit from using peer support – 10%
I am considering using peer support but have not been involved in peer support before – 7.5%
Other – 17.5%

Region of respondents

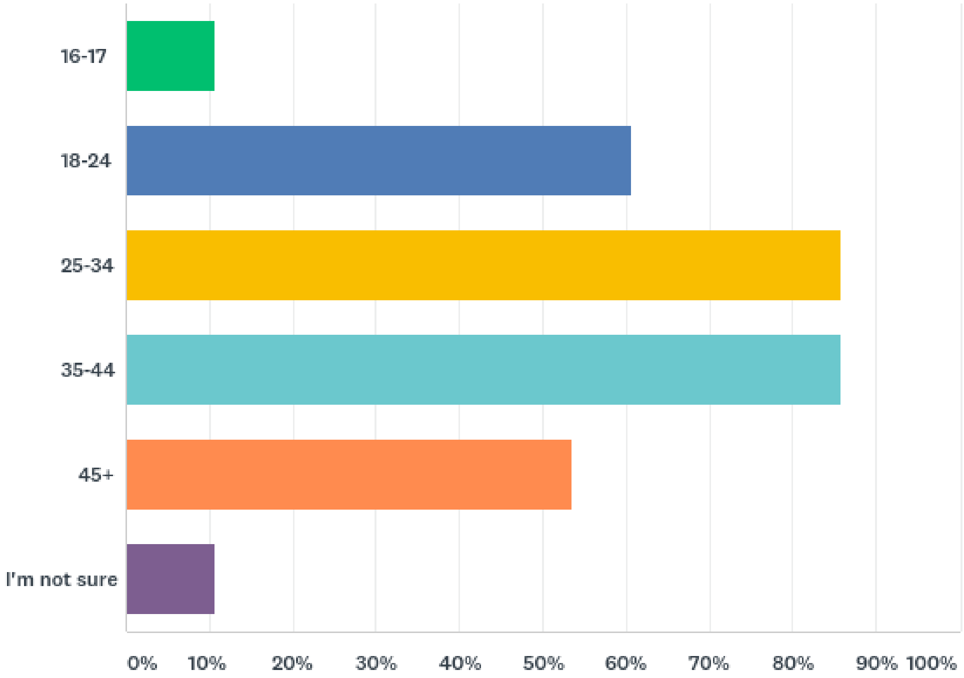
Greater London – 20.7%
South East – 0%
South West – 17.2%
East of England – 0%
East Midlands – 0%
West Midlands – 10.3%
Wales – 6.9%
Yorkshire and the Humber – 3.5%
North East – 0%
North West – 13.8%
Scotland – 17.2%
Northern Ireland – 0%
England wide – 0%
UK wide – 24%

Organisations running peer support

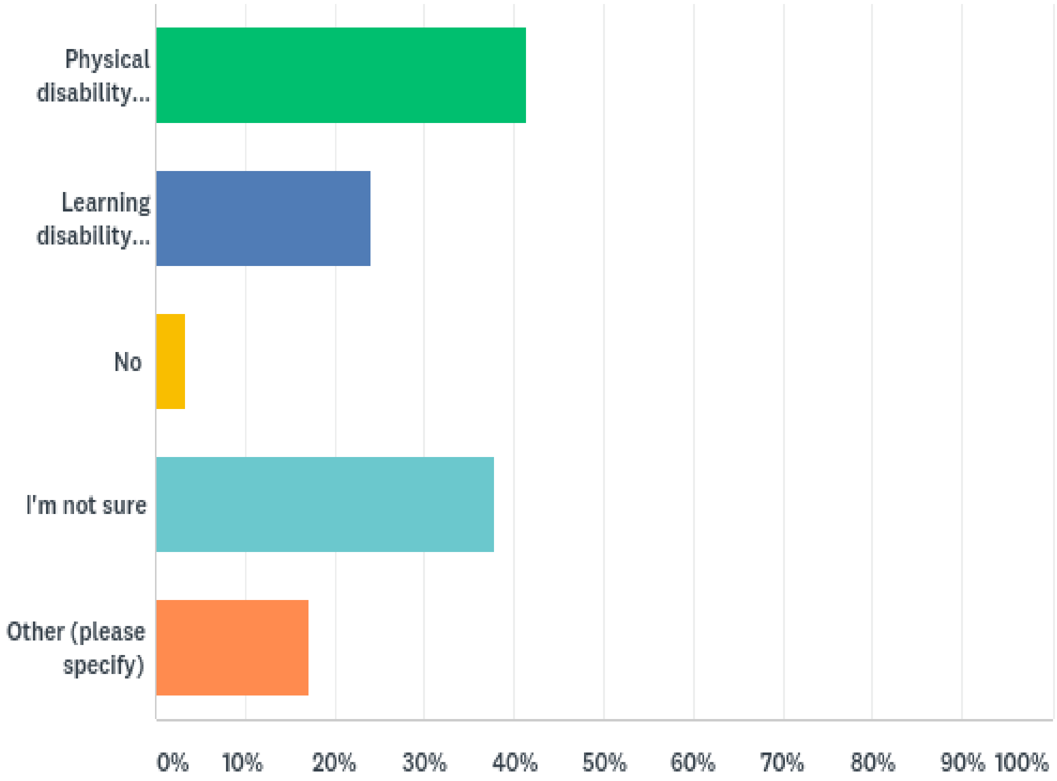
Maternal mental health organisation – 40%
Mental health organisation – 0%
Women's organisation – 0%
Parent support organisation – 50%
Refugee or migrant organisation – 0%
Unconstituted peer support group/network – 0%

Other – 10%

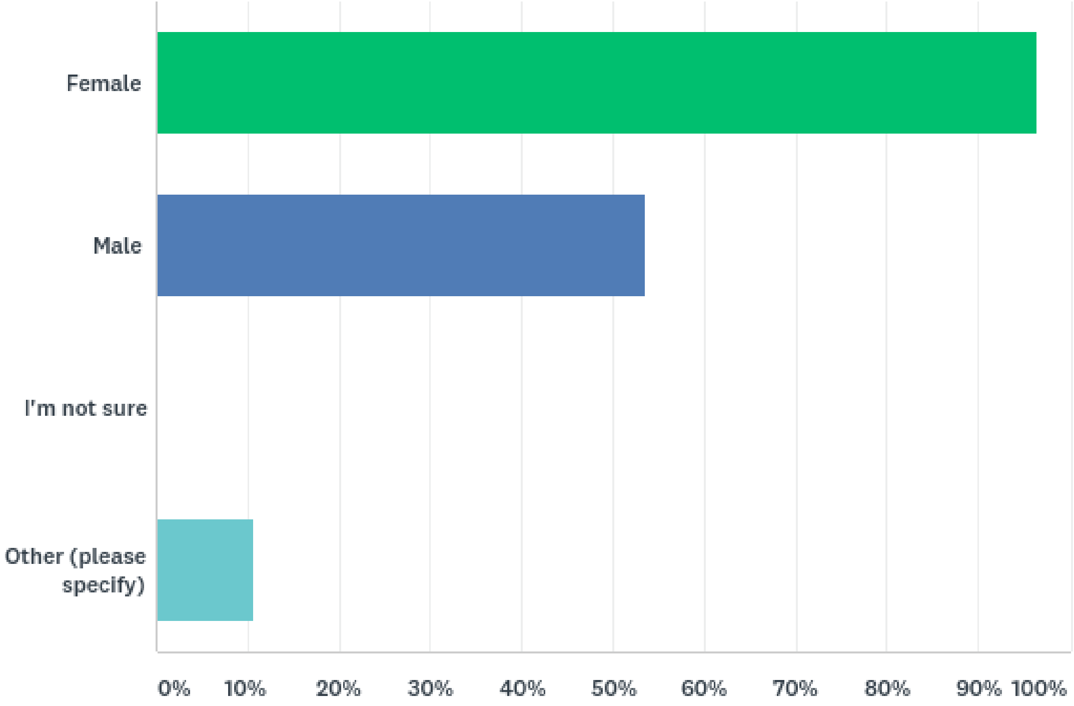
Q7 People from which age categories are represented in your peer support?



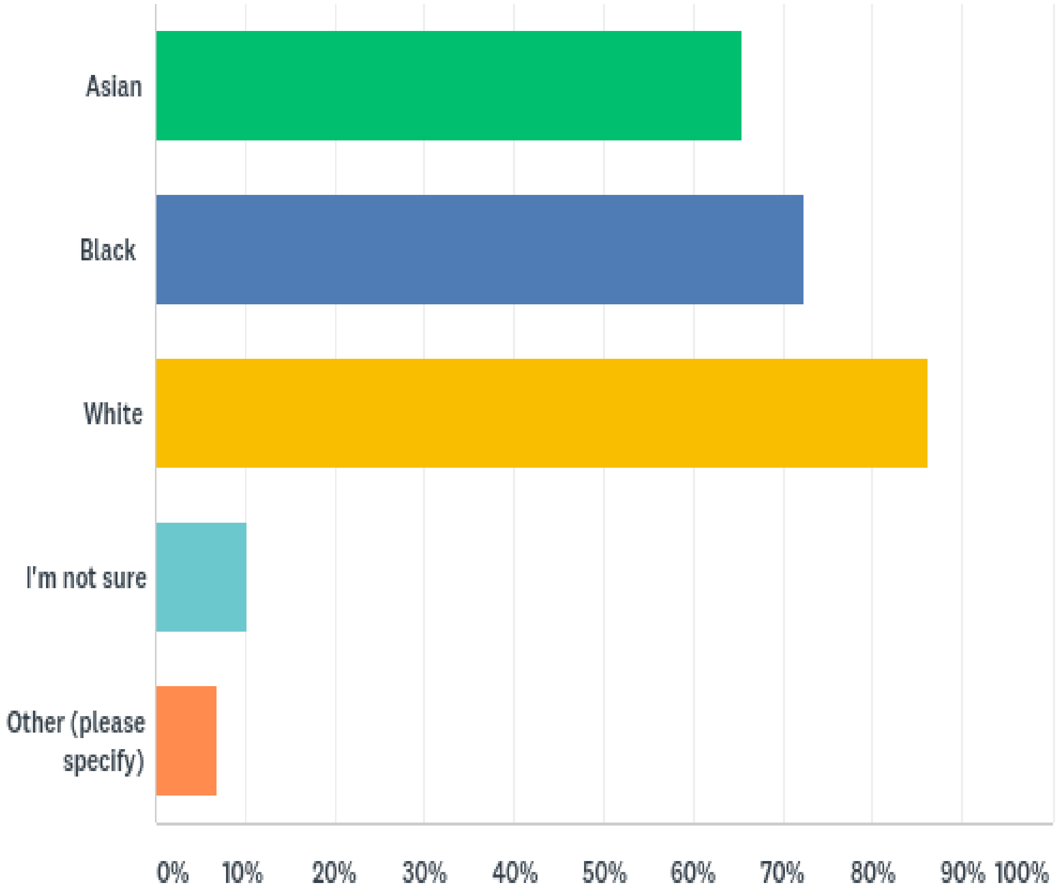
Q11 Are people with disabilities represented in your peer support?



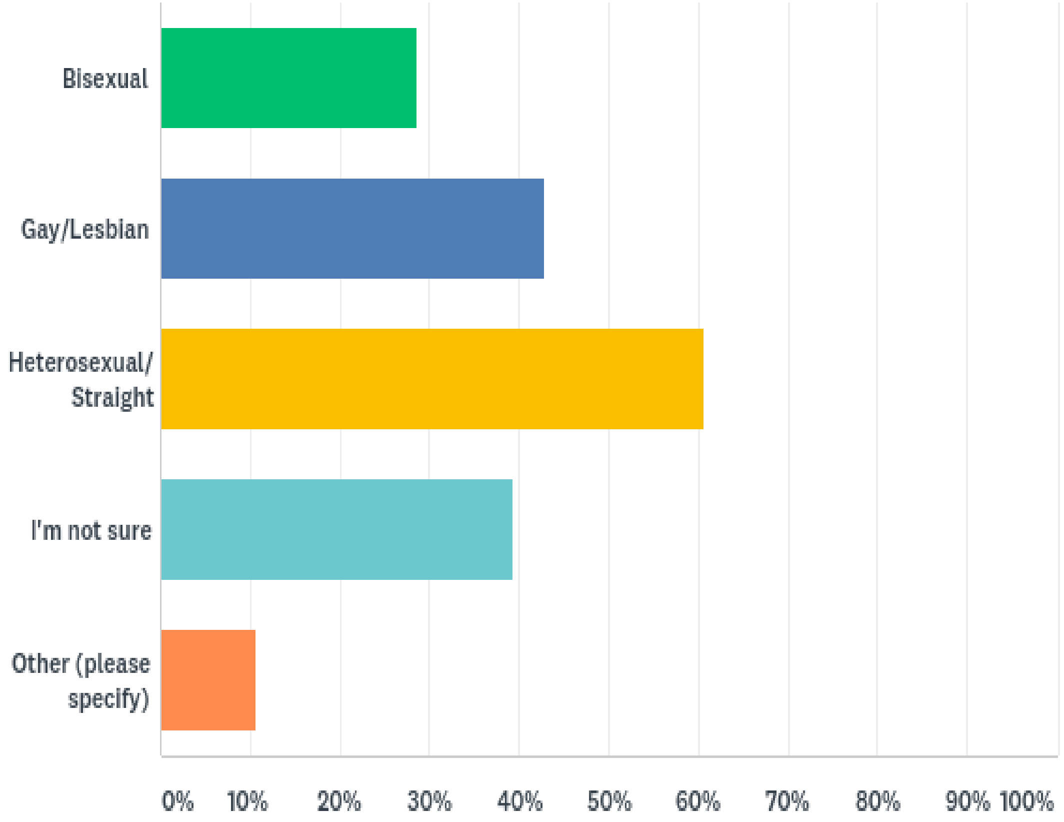
Q8 People of which gender are represented in your peer support?



Q10 People from which ethnic categories are represented in your peer support?



Q9 People of which sexual orientation are represented in your peer support?



Appendix 7 – Demographic data of event participants

Mailing list:

45 Organisations signed up to mailing list

35 people signed up to mailing list

Number of event attendees: Event 1 – 28 Event 2 – 27 Event 3 - 24

Organisations attending event 1

IAPT
RSVP
Birmingham City University
Northamptonshire Health care NHS
Balsall Health Children's Centre
The Pinks N Blues CIC
Thrive Network
Action on Postpartum Psychosis (APP)
NHS/ beyond birth trauma
MRANG
NHS
MRANG
Thrive Women’s network
Approachable Parenting
Mind
Student Minds
Smile Group
Only Human Therapy
NCT
Acacia Family Support

Organisations attending event 2	Organisations signed up to event 2
the Eritrean Women's Network	Executive Assistant Randstad CPE
NCT - Research and Evaluation Manager	Probation worker and midwife
NHS - Senior nurse practitioner	Essex CRC
Director - APP	Assistant team manager /social worker
Specialist Mental Health Midwife	Hampshire
The Foundation for Mother & Child Health - Founder/Co-Chair	CEO Bluebell Care Trust
NCT - Newham coordinator	PMH Peer Support Lead Bluebell Care
Parents first - CEO	Office Manager - Association for Postnatal Illness
Business Transformation Lead	Communities Officer - Mind
Manor Gardens	Peer Support Project Worker Solent Mind
Peer support worker	Solicitor
Shoreditch Trust/ Bump buddies	Freelance
Netmums - Head of Support	Recovery & Wellbeing Coordinator Darlington Mind
Maternal OCD/MMHA	Peer support worker Sutton Mental Health Foundation
Clinical Psychologist	Mindfulness Teacher Breathe Mumma
Bluebell care - PMH Peer Support Lead	Founder Honest parents club
Cocoon Family Support - Director	CEO Parents 1st
Bluebell Care Trust - CEO	Head of Support Netmums
Consultant Psychiatrist	Wessex Clinical Lead for Perinatal Mental health NHSE
Association for Postnatal Illness - Office Manager	Volunteer Peer Support Parents 1st
Solent MindPeer Support Project Worker	NCT Research and Evaluation Manager
Sumaq Capital Consulting Director	Midwife - Freelance
Equalities Manager - Mind	Researcher UCL
	Birth and postnatal Doula New Mums Help
	Project Director and Development Office Parents4Parents-NorthYorks
	Founder/Co-Chair The Foundation for Mother & Child Health

	Director - Cocoon Family Support CEO UKPEA Founder - Dorset Parent Infant Psychotherapy Director - Sumaq Capital Consulting RESEARCHER - Freelance Consultant Psychiatrist West London Mental health Trust Clinical Psychologist West London Perinatal Mental Heath Service Clinical Director - MumsAid Business Transformation Lead London Business School Specialist Mental Health Midwife - Queen Alexandra Hospital Portsmouth Senior nurse practitioner - Sheffield health and social care trust Perinatal service Founder / Practitioner - Tranquil Birth Peer support worker Training & Development Manager - Mind in Mid Herts Psychotherapist

Organisations attending event 3	Organisations signed up to event 3
The Halo Project charity	The Halo Project charity
Action on Postpartum Psychosis	Family Action
Best Beginnings	Oxford health foundation trust
Action on Postpartum Psychosis (APP)	Action on Postpartum Psychosis
Mummy cycle	Best Beginnings
Parents in Mind	Shining stars community group
Light	Action on Postpartum Psychosis (APP)
Northumberland Tyne and Wear NHS Foundation Trust	Little owls children's cafe
HealthWORKS Newcastle	Mummy cycle
Young Women’s Trust	Parents in Mind
Children North East	Light
Northern England Maternity Network	Northumberland Tyne and Wear NHS Foundation Trust
NCT Runcorn and Widnes	Snowdrops
	HealthWORKS Newcastle
	Sheffield City Council
	Young Women’s Trust
	Queens MVP
	Children North East
	Action on postpartum psychosis
	Oxford health Foundation Trust
	Light
There were major problems on the rail network on this date which impacted on travel plans	NHS
	Northern England Maternity Network
	NCT Runcorn and Widnes
	Raindrops to Rainbows
	Surrey & Sussex Healthcare NHS Trust
	Parents4Parents
	Shelter
	Tees Esk and Wear Valley NHS Foundation Trust
	HEY Mind
	Oxford Health

Event demographics

NB: Completing demographic forms was optional, numbers listed reflect those happy to give this information. It is not reflective of all event participants

Age	Event 1	Event 2	Event 3	Total	Percentage (of total across all events)
18 - 24	0	0	0	**0**	**0%**
25-34	10	8	0	**18**	**21.1%**
35-44	7	25	3	**35**	**41.1%**
45-54	2	22	1	**25**	**29.4%**
55 - 64	0	4	1	**5**	**6%**
64+	0	1	1	**2**	**2.35**

Gender	Event 1	Event 2	Event 3	Total	Percentage (of total across all events)
Female	19	27	9	**46**	**98%**
Male	0	0	1	**1**	**2%**
Identifying as Transgender, now or in the past?	0	0	0	**0**	**0%**

Sexuality:	Event 1	Event 2	Event 3	Total	
Heterosexual/Straight	19	24	10	**53**	**94.6%**
Gay	0	0	0	**0**	**0%**
Lesbian	0	1	0	**1**	**1.7%**
Bisexual	0	2	0	**2**	**3.5%**

Ethnicity	Event 1	Event 2	Event 3	Total	Percentage (of total across all events)
Asian or Asian British	0	0	0	0	0%
Chinese	0	0	0	0	0%
Indian	0	1	0	1	1.5%
Pakistani	1	1	0	2	2.9%
Another Aisian background	0	0	0	0	0%
White Asian	0	1	0	1	1.5%
White & black African	0	0	0	0	0%
White & Caribbean	0	1	0	1	1.5%
Another mixed background	0	2	0	2	2.9%
White British	16	28	10	54	79%
White Irish	1	1	0	2	2.9%
European	0	0	0	0	0%
Another white background	0	2	0	2	2.9%
Caribbean	0	0	0	0	0%
African	0	1	0	1	1.5%
Another Black background	0	0	0	0	0%
Arab	0	0	0	0	0%
Gypsy or traveller	0	0	0	0	0%
Another background	0	2	0	2	2.9%

Religion	Event 1	Event 2	Event 3	Total	Percentage (of total across all events)
No religion	9	28	4	**41**	**53.2%**
Christian	0	27	5	**32**	**41.5%**
Buddhist	0	0	0	**0**	**0%**
Hindu	0	0	0	**0**	**0%**
Jewish	0	0	0	**0**	**0%**
Muslim	0	2	0	**2**	**2.5%**
Sikh	0	0	0	**0**	**0%**
Another	0	1	1	**2**	**2.5%**

Event 2		Categories representing experience of mental health problem	Event 3	
Booking	On day		Booking	On day
32	10	I have personal experience of mental health problems	0	7
26	4	I use / have used mental health services	0	4
6	1	I use / have used the services of a local Mind	0	0
19	5	I am a family member of somebody who has experienced mental health problems	0	2
19	4	I am a friend to someone who has experienced mental health	0	2
7	1	I care or look after someone who has mental health problems	0	0
21	10	I work in the mental health sector (e.g. nurse, social worker, psychiatrist,)	0	5
1	0	None of the above	0	1
0	0	Prefer not to say	0	0

Appendix 8 – Lived experience facilitator feedback

Facilitator A

How did facilitating the co-design process meet your expectations?

I was pleasantly surprised when we were actually given full control and treated as equal partners in the project. I thought we would just be facilitating a couple of sessions and we would just be consulted upon in terms of co design. It was liberating to see that the project was a blank canvas and guided by Suki and Andreja we delivered on the outcomes for the project. It was truly a co-produced project which was very exciting as not many organisations including statutory do this with people with lived experience.

Personally, I have not been involved in a project like this coming from a lived experience perspective and I wasn't sure what to expect. It took me a long time to come out of my comfort zone to apply for this post. I am passionate about making a difference in this field because of my own personal experiences of perinatal and maternal mental health. Suki and Andreja are brilliant and have been really supportive throughout the whole process.

What did you learn as a Lived experience facilitator?

I learned about the positive work that is being undertaken throughout the country about maternal mental health. The experience helped me to build my self-confidence and self-esteem. It was great to work on a UK wide project and manage the project as part of a team from design to evaluation. I felt like my input was valued and it helped me to develop my networking and project management skills. It was also a fantastic opportunity to work with the other lived experience facilitators Laura and Katy we brought a wealth of experience and expertise to the project that I felt gave the project added value. I also found out more about the work of Mind and the Mcpin Foundation and how research is conducted to inform the project.

What impact has taking part had?

On you personally:

- It has helped me to conquer my fears and not let my physical disabilities be a barrier in accessing opportunities that I can make a difference in. This project has changed my life as I was stuck in my comfort zone wanting to do more but feeling not able to as a vulnerable disabled individual (Sight impairment due to stroke). My mental health and physical health are really unpredictable but I applied and the experience has liberated me and given me the confidence to go for other opportunities. I also felt I was making a difference in a field that I would love to work in. This project gave me back 'me' that I had lost six years ago when I suffered my stroke.

On current/further work:

- My work on this project has helped me to network and build my contacts. I have been able to access other opportunities as an individual with lived experience. It has also given me a chance to self-reflect and sometimes saying no to opportunities so that I can manage my own personal health. I would love to be involved in other maternal mental health projects.
- I am proud to be associated in the development of the principles and it is a valuable piece of work that is very much needed. I have had people approach me to find out what is happening to the principles as there is need for them to be disseminated throughout the whole country.

Facilitator B

How did facilitating the co-design process meet your expectations?

My experience of facilitating the co-design process significantly exceeded my expectations. I had anticipated that I would be helping to plan and deliver some consultation events and focus groups, which I did – but I was also treated as an equal partner by Suki and Andreja in designing and delivering the project as a whole, which was hugely empowering. This enabled me to explore and develop my own strengths, to take the lead in some areas, and to be passionate about the work we were doing.

I felt very supported throughout: the other facilitators became friends as well as colleagues; Suki and Andreja were fantastic to work with and always mindful of the wellbeing of the whole team; and I was encouraged further by enthusiasm for the project amongst the wider maternal mental health community. Everyone who participated was so passionate and invested in good peer support for mums; many went above and beyond, emailing me resources to inform the work and checking in regularly to ask how it was going. It was a privilege – and very validating - to be their point of contact, to be associated with a piece of work which they recognised as so important and so needed.

I enjoyed my facilitation role immensely, far more than I had expected. The team were great fun to work with, and I felt that I had finally found my 'niche' in that I was using my skills and abilities in a way that was meaningful, energizing, and effective.

What did you learn in the role of lived experience facilitator?

Much of what I learned in this role was from the other members of the team. Andreja taught me a lot about research methods and the importance of keeping lived experience at the heart of the research agenda. Suki has a gift for making other people feel cared for and valued, and for passing on her own expertise whilst maintaining space for others to explore theirs. I benefitted from this personally, and also learned from her some very practical ways in which I can ensure that influence and participation activities are conducted to truly care for and respect everyone involved. Both Suki and Andreja showed me how the third sector 'works' in terms of funding and managing a project, and this all feels far less daunting as a result. Nisba taught me about resilience and persevering through difficult circumstances, and about how to engage with Muslim communities in the context of mental health. Katy deepened my understanding of peer support and is skilled at balancing everyone's needs, even when those needs conflict. I feel very fortunate to take such a wealth of new knowledge away from this project and new skills to practice.

What impact has taking part had?

On you personally:

- As mentioned, I've made some wonderful friends and learned a great deal - it's also built my confidence tremendously. The co-design process offered me the perfect combination of autonomy and support, so that I was able to explore and develop my abilities and recognises my own potential. The fact that I was paid fairly for my time made me feel valued and valuable, and enabled me to put in enough time to do this work well. I used to feel that as a lived experience practitioner rather than a clinician or someone from a third sector background that I was a bit second-rate, that I was seen less skilled and as only really useful for rehearsing my own story, when actually I have always wanted to contribute more. My facilitation role showed me that I am quite capable of doing so, that I can make things happen, take the lead, that my expertise can be recognised and valued by others. It has left me with a new sense of purpose, a sense that this is the kind of work that I want, and am able to, pursue.

On current / further work

- My role in this project has broadened my horizons and my network of contacts, and subsequently it has already brought new opportunities my way. In the few months since my contract ended, I have been asked by around a dozen individuals and organisations to contribute my expertise on peer support, on influence and participation activities, or both, as a result of my association with the principles. I have also learned to value myself more highly, which has meant sometimes saying no for self-preservation. My role in this project encouraged me to consider more seriously the need for representation from marginalised communities and to actively learn more about how to reach out and engage well. My lived experience work is wide-ranging and various, and I feel that I am more effective in all of it as a result of the confidence and the new skills I developed in this role.

Facilitator C

How did facilitating the co-design process meet your expectations?

I was very impressed with the whole process as this was the first time that I have been involved in co-production where the service users really were in control of the project rather than just consulted which often happens. Suki and Andreja were very supportive throughout and it worked really well.

What did you learn in the role of lived experience facilitator?

I learnt that as part of a team I could design an event, run it, evaluate it and then use that to design the next event. It made me appreciate how much my lived experience is valued as well as being able to use some of my other skills. At all of the events we had a mixture of professionals and women with lived experience and everyone really valued each event.

What impact has taking part had?

On you personally

- It gave me a lot of confidence and I have met some wonderful people on the way!

On current / further work:

- As a peer support worker in maternal mental health it has made me very aware of what needs to be done for effective peer support by following the principles that have been developed. As for future work I have made a lot of connections which has led to other work opportunities.

Anything else you would like to say?

The principles need to be released now so that they can be used to help women.

References

Abrams, L. S., Dornig, K., & Curran, L. (2009). Barriers to service use for postpartum depression symptoms among low-income ethnic minority mothers in the United States. Qualitative Health Research, 19(4), 535–551.

Adame, A. L., & Leitner, L. M. (2008). Breaking out of the mainstream: The evolution of peer support alternatives to the mental health system. Ethical Human Psychology and Psychiatry, 10(3), 146-162.

Anderson, L. N. (2013). Functions of Support Group Communication for Women with Postpartum Depression: How Support Groups Silence and Encourage Voices Of Motherhood. Journal of Community Psychology, 41(6), 709–724.

Armstrong, M.L., Korba, A.M. & Emard, R. (1995). Of mutual benefit: The reciprocal relationship between consumer volunteers and the clients they serve. Psychiatric Rehabilitation Journal, 19 (2), 45-49.

Bailie, A.H. & Tickle, A. (2015). Effects of employment as a peer support worker on personal recovery: A review of qualitative evidence. Mental Health Review Journal, 20 (1) 48-64.

Basset, T., Faulkner, A., Repper, J., & Stamou, E. (2010). Lived experience leading the way: Peer support in mental health. London: Together for Mental Wellbeing.

Berry, C., Hayward, M. I., & Chandler, R. (2011). Another rather than other: Experiences of peer support specialist workers and their managers working in mental health services. Journal of Public Mental Health, 10(4), 238–249.

Biggs, L. J., Shafiei, T., Forster, D. A., Small R., & and McLachlan H.L. (2015). Exploring the views and experiences of callers to the PANDA Post and Antenatal Depression Association Australian National Perinatal Depression Helpline: a cross-sectional survey. BMC Pregnancy and Childbirth, 15, 209.

Biggs, L. J., McLachlan H.L., Shafiei, T., Small R., & Forster, D. A. (2018). Peer supporters' experiences on an Australian perinatal mental health helpline. Health Promotion International, 1–11

Byrne, L. (2014). A grounded theory study of lived experience mental health practitioners within the wider workforce. Central Queensland University.

Carter, R., Cust, F., & Boath, E. (2017). Peer support workers' experiences of supporting women with postnatal depression: a constant comparative exploration. Journal of Reproductive and Infant Psychology, https://doi.org/10.1080/02646838.2017.1416336

Colson, P.W., & Francis, L.E. (2009). Consumer staff and the role of personal experience in mental health services. Social Work in Mental Health, 7 (4), 385–401.

Cust, F. (2016). Peer Support for Mothers with Postnatal Depression. The Journal of New Writing in Health and Social Care, 2 (2), 21-31.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. Clinical psychology: Science and practice, 6(2), 165-187

Dennis, C.-L. (2003a). Peer support within a health care context: a concept analysis. International Journal of Nursing Studies, 40, 321–332.

Dennis, C-L. (2003b). The effect of peer support on postpartum depression: A pilot randomized controlled trial. Canadian journal of psychiatry, 48 (2), 115-124.

Dennis, C-L. (2014).The process of developing and implementing a telephone-based peer support program for postpartum depression: evidence from two randomized controlled trials. Trials, 15, 131.

Dennis, C-L., Hodnett, E., Kenton, L., Weston, J., Zupancic, J., Stewart, D. E. & Kiss, A. (2009). Effect of peer support on prevention of postnatal depression among high risk women: multisite randomised controlled trial. BMJ 338:a3064 doi:10.1136/bmj.a3064

Doughty, C., & Tse, S. (2011). Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries. Community Mental Health Journal, 47(3), 252-266.

Duff, C. (2012). Exploring the role of 'enabling places' in promoting recovery from mental illness: A qualitative test of a relational model. Health & place, 18(6), 1388-1395.

Dyble, G., Tickle, A. & Collinson, C. (2014). From end user to provider: Making sense of becoming a peer support worker using interpretative phenomenological analysis. Journal of Public Mental Health, 13 (2), 83-92.

Edge, D. (2011). 'It's leaflet, leaflet, leaflet then, "see you later"': black Caribbean women's perceptions of perinatal mental health care. Br J Gen Pract, 61(585), 256-262.

Evans, M., Donelle, L., & Hume-Loveland, L. (2012). Social support and online postpartum depression discussion groups: A content analysis. Patient education and counseling, 87(3), 405-410.

Faulkner, A., & Kalathil, K. (2012). The freedom to be, the chance to dream: Preserving user-led peer support in mental health. London: Together for Mental Wellbeing.

Faulkner, A., Sadd, J., Hughes, A., Thompson, S., Nettle, M., Wallcraft, J., Collar, J., de la Haye, S. and McKinley, S. (2013) Piecing together the jigsaw: Mental health peer support in England. London: Mind Publications.

Freeman, E., Barker, C., & Pistrang, N. (2008). Outcome of an online mutual support group for college students with psychological problems. CyberPsychology & Behavior, 11(5), 591-593.

Gidugu, V., Rogers, E. S., Harrington, S., Maru, M., Johnson, G., Cohee, J., & Hinkel, J. (2015). Individual peer support: A qualitative study of mechanisms of its effectiveness. Community mental health journal, 51(4), 445-452.

Gillard, S.G., Edwards, C., Gibson, S.L., Owen, K. & Wright, C. (2013). Introducing peer worker roles into UK mental health service teams: a qualitative analysis of the organisational benefits and challenges. BMC Health Services Research, 13 (188).

Gillard, S., Edwards, C., Gibson, S., Holley, J., & Owen, K. (2014). New ways of working in mental health services: A qualitative, comparative case study assessing and informing the emergence of new peer worker roles in mental health services in England. Health Services Delivery & Research. doi:10.3310/hsdr02190.

Grant, E.A., Reinhart, C., Wituk, S. & Meissen, G. (2012). An examination of the integration of certified peer specialists into community mental health centers. Community Mental Health Journal, 48 (4), 477-481.

Hennig, S., Stone, K., & Nicholson, J. (2016). Into the Light: Using Technology to Develop a Mother/Family Centered Peer Support Network. Journal of Parent and Family Mental Health 1 (2) Art. 1.

Horgan, A., McCarthy, G., & Sweeney, J. (2013). An evaluation of an online peer support forum for university students with depressive symptoms. Archives of psychiatric nursing, 27(2), 84-89.

Jesse, D.E., Dolbier, C.L., & Blanchard, A. (2008). Barriers to seeking help and treatment suggestions for prenatal depressive symptoms: focus groups with rural low-income women. Issues in Mental Health Nursing, 29 (1), 3–19.

Legere, L. (2014) The Provider's Handbook on Developing & Implementing Peer Roles. http://www.psresources.info/images/stories/A_Providers_Handbook_on_Developing__Implementing_Peer_Roles.pdf

Leger, J. & Letourneau, N. (2015). New mothers and postpartum depression: a narrative review of peer support intervention studies. Health and Social Care in the Community, 23(4), 337–348.

Letourneau, N., Secco, L., Colpitts, J., Aldous, S., Stewart, M., & Dennis C.-L. (2014). Quasi-experimental evaluation of a telephone-based peer support intervention for maternal depression. Journal of Advanced Nursing, 71 (7), 1587–1599.

Letourneau, N., Stewart, M., Dennis, C-L., Hegadoren, K., Duffett-Leger, L. & Watson, B. (2011). Effect of home-based peer support on maternal–infant interactions among women with postpartum depression: A randomized, controlled trial. International Journal of Mental Health Nursing (2011) 20, 345–357.

Mancini, M.A., & Lawson, H.A. (2009). Facilitating positive emotional labor in peer-providers of mental health services. Administration in social work, 33 (1) 3-22.

McLeish, J. & Redshaw, M. (2017). Mothers' accounts of the impact on emotional wellbeing of organised peer support in pregnancy and early parenthood: a qualitative study. BMC Pregnancy and Childbirth, 17, 28.

O'Dea, B., & Campbell, A. (2010). Healthy connections: Online social networks and their potential for peer support. Studies in health technology and informatics, 168, 133-140.

O'Hagan, M., Cyr, C., McKee, H., & Priest, R. (2010). Making the case for peer support. Calgary: Mental Health Commission of Canada, 1-92.

Oades, L. G., Deane, F. P. & Anderson, J. (2012). Peer support in a mental health service context. In R. King, C. Lloyd, T. Meehan, F. P.Deane & D. J. Kavanagh (Eds.), Manual of psychosocial rehabilitation (pp. 185-193). United Kingdom: Wiley-Blackwell.

Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutler, D., & Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental service providers. Community Mental Health Journal, 35 (3), 251–269.

Pitt, V., Lowe, D., Hill, S., Prictor, M., Hetrick, S. E., Ryan, R., & Berends, L. (2013). Consumer-providers of care for adult clients of statutory mental health services. Cochrane Database Syst Rev, 3(9).

Preyde, M. (2007). Mothers of very preterm infants: perspectives on their situation and a culturally sensitive intervention. Social Work in Health Care, 44, 65-83.

Raymond, N. C., Pratt, R. J., Godecker, A., Harrison, P. A., Kim, H., Kuendig J. & O'Brien, J. M. (2014). Addressing perinatal depression in a group of underserved urban women: a focus group study. BMC Pregnancy and Childbirth, 14, 336.

Reidy, H., Webber, M., Rayner, S., Anthopoulos, S., & Doue, P. (2009). Evaluation of the Peer Support Scheme in Southwark. https://www.york.ac.uk/media/spsw/documents/cmhsr/Peer%20Support%20Final%2015.5.13.pdf

Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. Journal of Mental Health, 20(4), 392-411.

Repper, J., Aldridge, B., Gilfoyle, S., Gillard, S., Perkins, R., & Rennison, J. (2013). Peer support workers: Theory and practice. London, UK: Centre for Mental Health and Mental Health Network, NHS Confederation.

Salzer, M.S. & Shear, S.L. (2002). Identifying consumer-provider benefits in evaluations of consumer-delivered services. Psychiatric Rehabilitation Journal, 25 (3), 281-288.

Salzer, M.S., Katz, J., Kidwell, B., Federici, M. & Ward-Colasante, C. (2009). Pennsylvania certified peer specialist initiative: training, employment and work satisfaction outcomes. Psychiatric Rehabilitation Journal, 32 (4), 301-305.

Scott, A. (2011). Authenticity work: Mutuality and boundaries in peer support. Society and Mental Health, 1(3), 173-184.

Scott, A. & Doughty, C. (2012) "Confronted with paperwork": information and documentation in peer support. Journal of Mental Health, 21 (2) 154-164.

Simon, G. E., Ludman, E. J., Goodale, L. C., Dykstra, D. M., Stone, E., Cutsogeorge, D., Operskalski, B., Savarino, J.,& Pabiniak, C. (2011). An online recovery plan program: can peer coaching increase participation?. Psychiatric services, 62(6), 666-669.

Simpson, A., Flood, C., Rowe, J., Quigley, J., Henry, S., Hall, C., Evans, R., Sherman, P.,& Bowers, L. (2014). Results of a pilot randomised controlled trial to measure the clinical and cost effectiveness of peer support in increasing hope and quality of life in mental health patients discharged from hospital in the UK. BMC psychiatry, 14(1), 30.

Sledge, E., H., Lawless, M., Sells, D., Wieland, M., O'Connell, M.J. & Davidson, L. (2011). Effectiveness of peer support in reducing readmissions of persons with multiple psychiatric hospitalizations. Psychiatric Services, 62 (5), 541-544.

Solomon, P. (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. Psychiatric rehabilitation journal, 27(4), 392.

Straughan, H., & Buckenham, M. (2006). In-Sight: an evaluation of user-led, recovery-based, holistic group training for bipolar disorder. Journal of Public Mental Health, 5(3), 29-43.

Webb, M., Burns, J., & Collin, P. (2008). Providing online support for young people with mental health difficulties: challenges and opportunities explored. Early intervention in psychiatry, 2(2), 108-113.

Whitlock, J. L., Powers, J. L., & Eckenrode, J. (2006). The virtual cutting edge: the internet and adolescent self-injury. Developmental psychology, 42(3), 407.

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