



Cheshire East Joint Strategic Needs Assessment

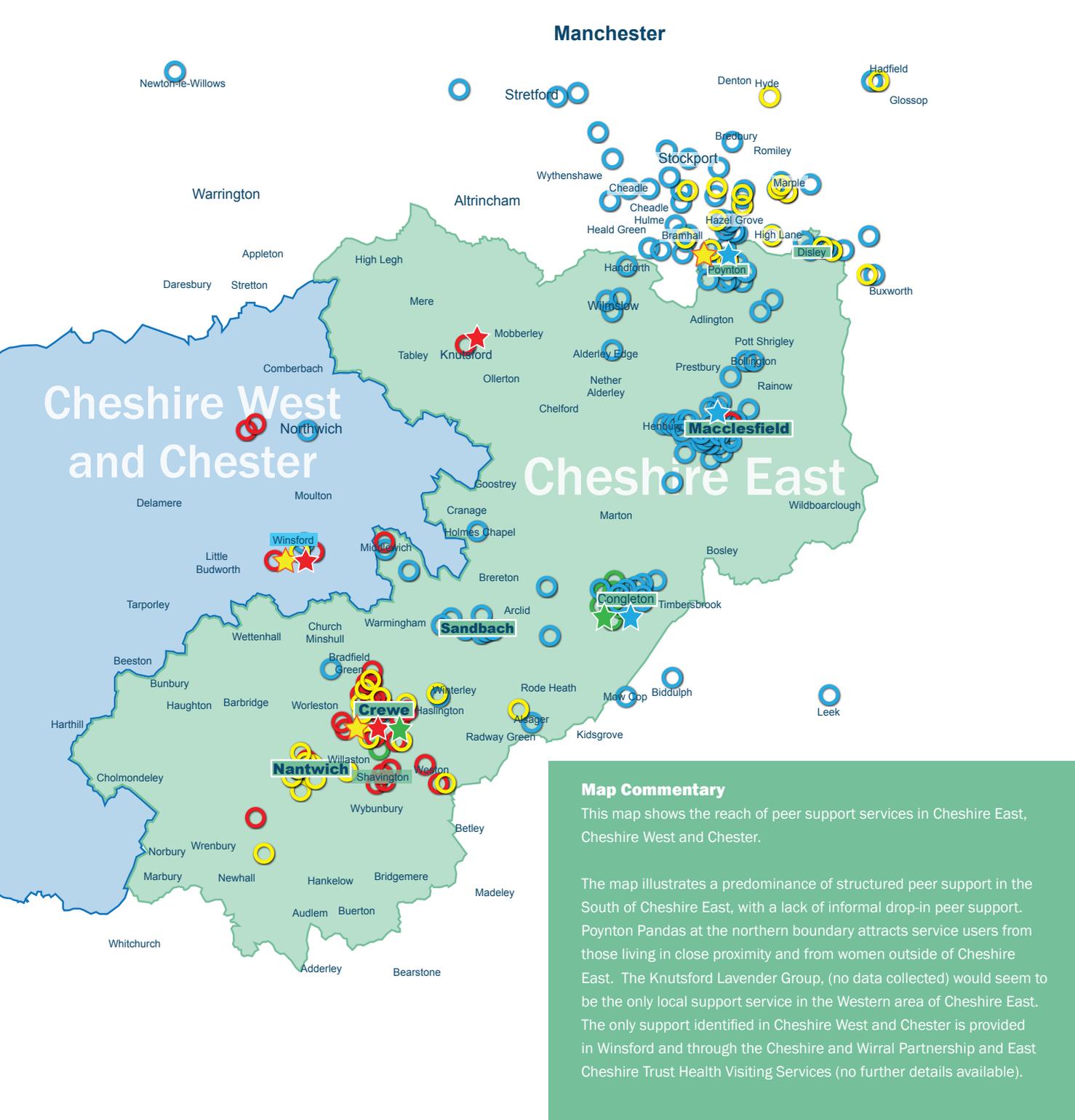
Perinatal Mental Health Report
Full Report - Section 2
The Experience Of Mums
February 2017

Section

2

Delivered by





Perinatal Mental Health Report: Geographical Mapping of Reach of Service

- Service users who accessed:**
- Structured peer support programme**
93 Attendees
 Delivery locations:
 ★ Crewe, Knutsford (service user data not available)
 ★ Winsford
 - Informal drop-in peer support**
Approximately 200 attendees
 Delivery locations:
 ★ Congleton, Macclesfield, Poynton
 - Informal activity-based support**
Approximately 60 attendees
 Delivery locations:
 ★ Crewe, Poynton, Winsford
 - Family peer support activities**
Approximately 20 attendee families
 Delivery locations:
 ★ Congleton, Crewe

A changing picture

The SMILE group will be establishing a new informal drop-in group in Sandbach from the end of November, and will also be providing 1-2-1 home visiting sessions in Macclesfield, Congleton and Sandbach.

What we don't know but would like to know

- Postcode data of service-users from the Knutsford Lavender Group.
- Postcode data from the yet to be established SMILE initiatives.
- More detail on the types of peer support facilitated by health visitors across Cheshire West and Chester, their delivery locations and service user postcode data.

Approximate figures taken from service provider data available.

Map Commentary

This map shows the reach of peer support services in Cheshire East, Cheshire West and Chester.

The map illustrates a predominance of structured peer support in the South of Cheshire East, with a lack of informal drop-in peer support. Poynton Pandas at the northern boundary attracts service users from those living in close proximity and from women outside of Cheshire East. The Knutsford Lavender Group, (no data collected) would seem to be the only local support service in the Western area of Cheshire East. The only support identified in Cheshire West and Chester is provided in Winsford and through the Cheshire and Wirral Partnership and East Cheshire Trust Health Visiting Services (no further details available).

The experience of mums

The user experience survey

An online survey was created for mums who had experienced, during their pregnancy or up to one year after birth, any mental health issues within the last two years. The online link was widely distributed throughout the Cheshire region, using a variety of networks, contacts and social media outlets. The link was also publicised through national forums, clearly stipulating that the survey was for Cheshire residents only.

The survey was made available in paper format with reply-paid envelopes and was distributed through local contacts, organisations and Children's Centres within Cheshire East to enable those with limited access to the internet to respond.

26 responses were received for the survey and all of these were from the Cheshire East region. It may be the case that responses were not received from CWaC residents due to very limited peer support provided in this area. 3 of the 26 responses were received through the post.

Where mums have sought support

In many cases women approached their GP or Health Visitor prior to attending a peer support group. Some of these mums had already been referred for IAPT by their GP and were waiting to start the sessions, others had already completed their IAPT referral.

"I felt very alone. Baby cried non-stop and my husband moved into another room. I had no other friends with babies, my pregnancy was terrible and so was the birth. My husband became uninterested in 'us' and angry with a crying baby. I have never felt so horrible, it was just not what I thought it would be..."motherhood". I hated it."

- Survey respondent.

The mums had had different experiences of IAPT with some finding it very helpful and others having negative experiences. Health Visitors were a significant source of support and where good links existed between peer support groups and the Health Visiting service, referrals were regularly made to the groups.



Two mums described their experiences before they attended a VCFS peer support group:

"I was put on antidepressants by my GP. I had CBT every other week for half an hour. There were lots of worksheets and I felt guilty that I couldn't do the tasks. So I paid for weekly private counselling which was helpful but so expensive. Now I go to... [peer support group]"

"I've not had the best experience with Health Visitors... They handed out leaflets but wouldn't engage with me otherwise. I was referred by my GP for CBT which was very good."

Some mums commented that a combination of support available had made the difference to their recovery, with one mum crediting; medication, Health Visitor support, and attendance at a peer support group, as the 'formula' that had worked for her.

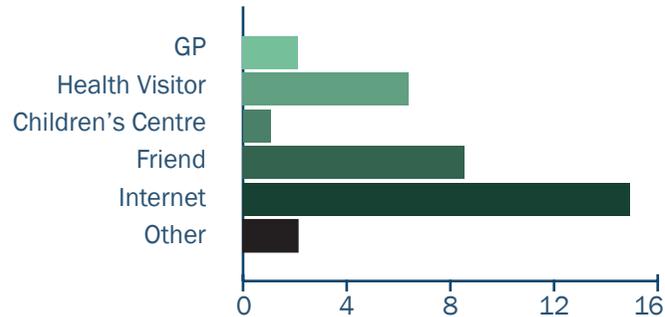
How mums had found out about available peer support

The survey asked the mums how they found out about available peer support within the area. Two of the VCFS service providers have strong links with Health Visiting teams and this is represented in the responses.

However, the internet/social media came through very strongly as the first place that women visited to find out information, and several mums mentioned that they discovered the peer support groups through using Google or Facebook. The second most popular route to the groups is through word of mouth/friends who are aware of the group's existence.

Of the 26 respondents to the service user survey, 54% of the mums had found out about their local peer support group provision through the internet/social media. This was followed by:

- 31% through a friend/word of mouth.
- 23% through a Health Visitor.
- 8% by their GP.
- 8% through Private Healthcare providers.
- 4% through their local Children’s Centre.*



*Survey respondents returned multiple responses to this question so figures do not add up to 100%

Service promotion and communication channels

The research suggests that promotion of the groups within GP surgeries could be improved. Although there is understanding that statutory providers need to be assured that any service they refer to is a safe and appropriate service, some of the VCFS support groups have not had the opportunity to promote their services as they can struggle to make contact with relevant staff at GP Practices. There is an instance of one VCFS group with strong links, but this is a single instance rather than the norm. A number of mums felt that peer support groups should be promoted within GP practices:

“...I was just lucky that my friend in Warrington went to one [a peer support group], she recommended it to me. But I didn't know anything about it which is a shame, because I think if they had, in the doctor's waiting rooms or something like that, notices about [them], you know, you can subtly look and then take a leaflet and think about it.”

Although a number of the groups had strong links with Health Visiting services, often it was felt that these could be improved.

There are a number of communication channels that don't currently feature details of the groups, and this could be a missed opportunity for mums who would benefit from the services. These include:

- Promotion through ‘Local Offer’.
- Promotion in the pregnancy folder given to all pregnant women.
- Leaflets listing local perinatal mental health peer support provision in GP surgeries.
- Promotion through midwifery services for women who develop PMH issues during pregnancy.

Lived experience/health professionals

Project staff were only able to collect responses from mums who attended VCFS peer support, therefore the following comments are from mums who have not experienced the Health Visitor led groups.

When mums who responded to the survey were asked who they would rather run the groups, 88% stated that they would rather the peer supporters had lived experience of perinatal mental health issues themselves:

“I actually think that the Health Visitor issue is quite important, that it should remain volunteers and people that have gone through it themselves really. And then they might feel brave enough to come to a face to face group which has added benefits.”

It's worth noting that for one of the VCFS groups (that started out with health Visitor involvement) that this issue of lived experience versus professional led sessions, was something that they considered when creating the group:

“...and what mums were strongly saying to us, and what we were noticing in the group, was that mums were a lot more open and honest when it wasn't the Health Visitor there. So we didn't really pursue that kind of side of it and just thought, well, you know, we'll do it as [lived experience] peer support.”

When asked about this issue, the Lavender Group Leader (statutory, Health Visitor-led) said that this had not been raised as a problem by the mums who have gone through their programme:

“I've found them [the mums] very open. I mean something that's raised quite a lot ...if people admit to feeling very depressed or very low, or not able to bond with the baby, that there's a risk that the baby might be removed. And that's why a lot of mums don't come forward.”

However, the Lavender Group has received course completion feedback from women attending the group commending the friendly and supportive atmosphere created by the Health Visitor and Family Support Worker:

“Group leaders were so friendly and made me feel so at home.”

“Very friendly and helpful group leaders.”

Formal/informal support

It became clear during the research process that there is no ‘one size fits all’ regarding the peer support group session structure. The drop-in nature of the informal peer support sessions is valued by those group mums as there is less pressure to arrive on time, and mums feel they can come and go without disapproval, and can attend on weeks when they feel they need the support without a formal commitment. Conversely, the structured approach from the formal peer support programmes is also valued by those group attendees and provides an incentive to attend and complete the programme.

The supportive and mindful nature of the groups is something that is not specifically promoted to the users by the groups, it is something that seems to occur within each group naturally. And as one group leader explained:

“ ... she started our group on a Friday and she said ‘that’s the first time that I’ve ever spoke and I haven’t been judged’. I was like, my god, that’s terrible. And she stuck with it [the programme] and she doesn’t stick with anything.”

The forging of new support networks with women who shared experiences

One outcome for women who attend the peer support groups is that in many cases women have continued to meet, either continuing as a group once structured programmes have ended, or individuals have started to meet outside the informal drop-in sessions. This is something that apparently happens quite regularly and without group facilitators’ input. There have been instances of mums setting up private Facebook groups and arranging outings as a group. In the words of a survey respondent:

“I’ve made new friends and we meet up over the Summer break and go to soft play places which I might not have gone to on my own. I’ve felt better being part of a group.”

In some cases, group leaders have spoken about mums who have made new connections from the peer support groups that have proven to be long-lasting in nature and very much appreciated:

“I’ve just been to see a mum now who was on my last cohort and they all went out to dinner last week. They have been forming nice friendships, meaningful friendships because they can really be themselves with each other. Because they’ve opened their hearts out in the group really.”

“I’ve made friends with other mums here, you can’t talk to your other friends as they can’t understand.”

Shared experience appears to be the most powerful connector for women attending these groups, and the peer support groups can facilitate the forging of new support networks for women to continue with once they feel they no longer need to attend group sessions.

Peer support is not for everyone

Whilst it is clear that the informal peer support group drop-in sessions are highly valued by the mums attending those groups, it should be noted that not everyone feels comfortable in an informal, sharing environment. There are instances where groups may see a mum for a single session and they do not return. Due to the nature of the sessions, it is not possible to contact those mums to ask why they felt the group was not for them.

“...because this isn’t for everyone you see, this kind of environment. We have plenty of people who come one week and we’ll never see them again. And I think that’s based on the fact that, where they are at the moment a lot of people are in denial about what they’re going through and they don’t want to come to a support group for that, you know that sort of thing. So you can tell pretty much within the first ten minutes of meeting someone whether this environment will suit them at this stage in their lives or not.”

Barriers to accessing peer support

There are also barriers to attending peer support group sessions which may result in fewer women attending support sessions. Three out of the four service providers surveyed, and 55% of service users who responded to the survey, said that anxiety and associated stigma is the biggest of these barriers.

These anxieties were addressed by some of the VCFS groups through the use of social media and online communication to build up a rapport with potential new mums. The Lavender Group in Crewe addresses this

barrier by visiting at home all mums who have been referred to the programme along with the Family Support Worker before the course begins. This means that the mum will know at least two people before attending a group session.

When women stop attending

With the structured programmes, mums will stop attending the core peer support group sessions once the programme has ended. Those mums who have been required to attend by social care services will often end their connection with the service providers at this point, whereas those who have been referred by health visitors will often continue to meet as a group externally.

As previously mentioned, women tend to create their own personal ‘journey’ through the menu of services offered by the voluntary service providers. This can vary from mum to mum depending upon their needs and the length of time their recovery takes. A common pattern with the drop-in service providers is for mums to ‘step-down’ to one of the activity-based peer support sessions or family support sessions when they stop attending the weekly support. This way the link is maintained with the group and informal online communication is also often maintained. Providers have also explained that mums will tend to stop attending weekly sessions when they finish maternity leave or go back to work on a full-time basis.

It is not always possible to know why mums have stopped attending due to the nature of the drop-in sessions, as the peer supporters will not necessarily know that it will be the last session that a mum attends, and so will not have the opportunity of speaking to the mum to gain feedback.

The use of language and terminology

It should be noted that the language and terminology used to promote and develop perinatal mental health services should be considered carefully. The term ‘perinatal mental



Online Resources

General perinatal mental health resources

“Perinatal Mental Health Toolkit”, Royal College of General Practitioners website (featuring two contributions from the SMILE Group). Aimed at Primary Care Professionals, the Toolkit includes a section on Peer and Online Support and was launched in July 2016:

<http://www.rcgp.org.uk/clinical-and-research/toolkits/perinatal-mental-health-toolkit.aspx>

“Postnatal Depression and Perinatal Mental Health”, MIND website:

<http://www.mind.org.uk/information-support/types-of-mental-health-problems/postnatal-depression-and-perinatal-mental-health/#.WA4PIGcVDIV>

Cheshire perinatal mental health peer support providers

Motherwell CIC:

<http://www.motherwellcic.com>

Poynton PANDAS:

<https://en-gb.facebook.com/PoyntonPANDAS>

or

<http://poyntonpandas.blogspot.co.uk>

The SMILE Group:

<http://www.thesmilegroup.org>

Campaigns

Maternal Mental Health Alliance’s ‘Everyone’s Business’ campaign. Hosted by Action on Postpartum Psychosis (APP) and funded by Comic Relief, the campaign was launched in January 2014:

<http://everyonesbusiness.org.uk>

National Childbirth Trust’s #BeyondBabyBlues campaign. Launched at the end of 2015:

<https://www.nct.org.uk/get-involved/campaigns/beyond-baby-blues>

National Childbirth’s Trust’s ‘Parents in Mind’ campaign.

Launched in 2016 and funded by the Department of Health, this campaign centres upon trained, local volunteers delivering 1-2-1 and group peer support within community settings:

<https://www.nct.org.uk/professional/parents-in-mind>

Benefits of peer support supporting information

“Peer Support”, The Mental Health Foundation website:

<https://www.mentalhealth.org.uk/a-to-z/p/peer-support>

“Peer Support Directory”, MIND website:

<http://www.mind.org.uk/information-support/guides-to-support-and-services/peer-support-directory>

Perinatal mental health national bodies and organisations

Action on Postpartum Psychosis (APP):

<http://www.app-network.org>

Association for Post Natal Illness (APNI):

<https://apni.org>

Maternal Mental Health Alliance (MMHA):

<http://maternalmentalhealthalliance.org>

PANDAS Foundation (National):

<http://www.pandasfoundation.org.uk>

Perinatal Mental Health Network (PMHN):

<http://www.pnmhnetwork.org>

Social media resources

“#PNDHour” on Twitter, run by PND&Me:

<http://www.pndandme.co.uk/pndhour>

Netmums online information:

<http://www.netmums.com/support/pre-and-postnatal-depression>

Netmums forum:

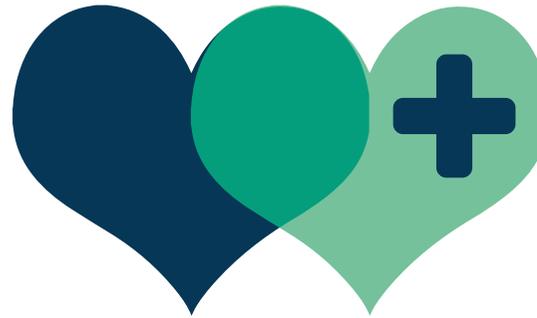
<http://www.netmums.com/coffeehouse/advice-support-40/antenatal-postnatal-depression-55>

APPENDIX 1: Summary of service provision

Question	SMILE	Poynton PANDAS	Motherwell		Lavender Group	
			Crewe	Winsford	Crewe	Knutsford
Types of support provided:						
1-2-1 support	> 10 users	x	21-40 users (estimation)		x	
Peer support groups	100+ users	65 users	44 users	6 users	20-25 users each p.a.	
Online support	x	100+	Figures not available		x	
Telephone support	x	x	x		x	
Family support	8-9 families per monthly session	x	x		Figures not available	
Delivery location	Macclesfield, Congleton and Sandbach at the Children's Centres	St. George's Church Hall, Poynton	Everybody Lifestyle Centre	Everybody Lifestyle Centre	Children's Centres at Crewe (Brooks) and Knutsford	
How often regular peer support groups meet	Weekly, all year round	Weekly, term-time	6 week structured programme, 1 day per week 9-5		6 week structured programme, 1 morning per week	
What days/times?	M: Friday am C: Wednesday am S: Tuesday pm	Monday 10:45 - 12:15	Thursday	Wednesday	Varies	
Any additional regular sessions?	Monthly Saturday family day (Ruby's Fund, Congleton)	Monthly evening session in Adlington	#Riseandshine (Buggy Fit & Baby Yoga); and Mum Shine creative group		A dad's session in week 7 at Crewe	
Length of time regular sessions established	1-2-1 as a 3 month pilot, peer 5 years+	2-5 years	Less than 12 months		2-5 years	
Potential barriers cited to accessing support	Anxiety and transport	Anxiety	Agencies not knowing how to refer to them		Anxiety	
Can women attend sessions with:						
Child/children	✓	✓	Very young children only		✓	
Friend	✓	✓	x		x	
Relative	✓	✓	x		x	
Can users attend on a drop-in basis?	✓	✓	Not for the peer support group session		x	
Do users have to commit to a certain number of sessions?	x	x	Yes for the peer support group		✓	
Mode of referral	Self-referral or professional referral	Self-referral or professional referral	Self-referral or professional referral (social care, Health Visitors)		Referral by Health Visitor, GP or IAPT	
How is the group funded?	Eastern Cheshire CCG, fundraising activities, Cheshire Community Foundation, Peaks and Plains	Donations and fund-raising	Big Lottery funding, donations and fund-raising activities		Venue provides refreshments, funded as part of service level agreement with Eastern Cheshire CCG	
Is your service quality assured?	✓	✓	✓		✓	
	Portfolio of policies	Varied training programme	Working towards GRIPP		Care Quality Commission (CQC) and Ofsted QA'd	
	Part of the Perinatal Mental Health Partnership	Disclosure & Barring Service (DBS) training	Uses HAD Scoring (Health, Anxiety and Depression scale)			
	Works to encourage best practice in peer support with network of perinatal mental health charities	Range of policies and procedures	Working towards becoming a charity			
	Clinical supervision	Clinical supervision	Clinical supervision			
	Has become a Charitable Incorporated Organisation (CIO) with 8 trustees	Has a Board and constitution	Has a Board and constitution			
Mode of impact measurement	CORE10	No specific mechanisms	HAD Scoring		Pre-course and post-course evaluations	
	Anecdotal evidence	Anecdotal evidence	Anecdotal evidence		Stepping Stones activity (Crewe)	
When can service be accessed?	Antenatal and up to 3 years	Antenatal and up to 3 years	Antenatal and up to 2 years		Up to 1 year after birth	

Health Visitors deliver Baby Matters Groups in Vale Royal Children's Centres and Peer Support Groups are also being developed in West Cheshire CCG area but further details are not currently available.

Perinatal Mental Health Peer Support In The Cheshire Region



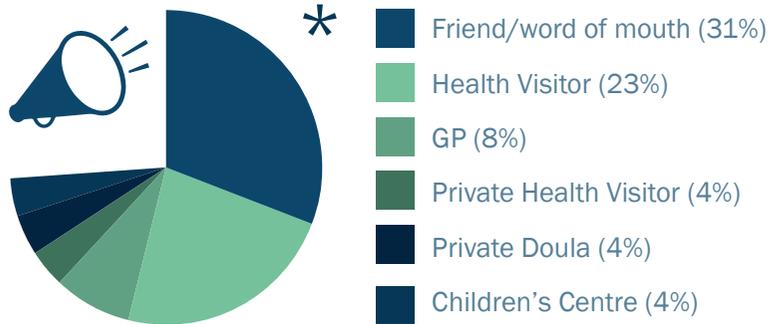
Just under **7,200** maternities in Cheshire (Cheshire East and CWAC). An estimated **15-20%** of women develop depression or anxiety within a year of giving birth which could mean between **1,080 women (15%)** and **1,440 women (20%)**.

The four providers worked with:

Peer support: up to **300 women**
 Counselling: up to **50 women**
 Online support: more than **100 women**

Still leaving a large shortfall of women who have not used their support but who could benefit from it.

54% of mums found out about the peer support group through the internet/Facebook followed by (in order):



100%

of survey respondents had used a **peer support** group.

96%

of survey respondents said the **peer support** group had made the biggest difference to them out of all the support given.

*Does not add up to 100% as some respondents ticked more than one option.



17 out of 20 (85%)

said they felt lonely and isolated while waiting for support.



Up to **69%**

of survey respondents had used online support (1-2-1 and forums).

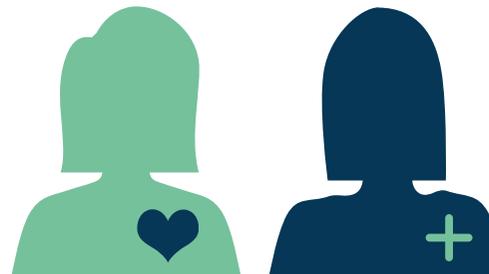


3 out of 4

service providers and **55%** of service users said that **anxiety** is the biggest barrier to attending a **peer support** group.

88%

of mums using VCFS services said they wanted someone with **lived experience** to run the groups.



100%

of survey respondents said it had a positive impact on them – 'normalising', 'reducing isolation', 'sharing'.



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