healthwatch Norfolk

Maternity and Neonatal Voices Partnerships

An independent review

February 2025

Contents

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.
The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.
Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.
We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

We were asked to undertake an independent review of the Norfolk and Waveney Maternity and Neonatal Voice Partnerships (MNVPs). These partnerships play an important role in getting people's feedback of their experience of using maternity and neonatal services and using this feedback to improve the safety, quality and experience of these services. NHS England produced guidance in November 2023 to ensure Integrated Care Boards (ICBs) meet their responsibilities in making sure that MNVPs can do the job they are meant to do and put feedback from service-users at the heart of service improvement. We structured our report around this guidance to help show where the MNVPs met the guidance or whether changes were needed.

We interviewed the MNVP Leads, Midwifery and Neonatal Senior Staff from the Norfolk and Norwich University Hospital, the James Paget and the Queen Elizabeth Hospital, representatives from the Norfolk and Waveney ICB, regional Maternity and Neonatal Leads and representatives from Kernow MNVP, which is seen as a model of excellence.

We found out that the neonatal work is less developed, as it has only recently been included in the work of the MNVP. There are concerns that the "maternity voice" tends to dominate and there is some frustration about this. We also heard that it is important that the Neonatal Lead is someone with lived experience of neonatal care, but it can be hard to recruit people with this. Engagement with regional groups, such as the Parent Advisory Group (PAG) for parents with lived experience of neonatal care, the Regional Neonatal Leads Group and the Regional Maternity Voices Leads Group could be improved with better clarity around roles and responsibilities. This could increase support to the Neonatal Leads.

The MNVPs are very good at engaging with their local communities, including bereaved parents and the voluntary, community and social enterprise sector. Feedback and other data are used to make changes to services. They undertake the processes for reviewing services outlined in the guidance – Fifteen Steps and Walk the Patch. The MNVPs are valued by the Trusts and the MNVP Leads are expected to attend key meetings.

MNVP Leads should be service users with lived experience of maternity and neonatal care. However, they are expected to have leadership skills that will enable them to lead a complex programme of work. They should also be paid at an appropriate level for the role and should not be volunteers. The guidance suggests they should either be employed by the ICB or through a third party organisation, or be self-employed. This is not the case for the Norfolk and Waveney MNVP Leads.

The funding for the MNVPs was a key issue; the MNVP Leads do not feel they have sufficient hours to undertake the role that they are now being asked to do, especially engaging with diverse groups and attendance at key meetings. The rate of pay is not seen as adequate for the role. The fact that the MNVP Leads are not employed leaves the Trusts vulnerable and the Leads unprotected.

From our findings we have made four recommendations:

- The ICB should reconsider the level of funding needed to properly undertake MNVP work
- The MNVP Leads and key team members should be employed
- Consideration should be given to the Neonatal Leads working together across the system
- Seek ways to improve engagement with region and across the system

Why we looked at this

> Yeah, it's really tough, you know, people's experiences of maternity right now. Maternity is in a really difficult place.

There have been a number of high-profile inquiries that have identified systemic issues relating to poor-quality maternity care that have resulted in the death and disability of mothers and babies.

A key feature in these inquiries was the failure to listen to people who used the services. In response to this NHS England produced a three-year delivery plan for maternity and neonatal services (NHS England, 2023) to look at how services can be made safer, better meet the needs of people using the services and ensure that all people have equal access and are treated fairly. At the heart of this is the importance of hearing the voice of those who have used these services, through representation from Maternity and Neonatal Voices Partnerships (MNVPs).

We were asked by the Local Maternity and Neonatal System (LMNS), which is part of the Norfolk and Waveney Integrated Care Board (N&WICB) to undertake an independent review of the three Maternity and Neonatal Voices Partnerships in Norfolk and Waveney; specifically to look at how they are currently operating and identify areas for improvement or change that may be needed to meet the requirements for MNVPs outlined in the delivery plan.

Maternity and Neonatal Voices Partnerships (MNVPs) are set up to find out about the experiences of women, birthing parents* and families of their maternity and neonatal care, and to use the learning from this to improve the safety, quality and experience of maternity and neonatal care.

MNVPs will have one or two Leads, who are members of the public with previous experience of using maternity and neonatal services. These Leads meet with the

relevant staff from the hospital trust, such as the Head of Midwifery and Neonatal Senior Staff members to work together to improve maternity and neonatal services.

There is an MNVP at the Queen Elizabeth Hospital King's Lynn NHS Foundation Trust, the James Paget University Hospital NHS Foundation Trust and the Norfolk and Norwich University Hospital NHS Foundation Trust. Each MNVP is part of the Trust, but they are commissioned by the Norfolk and Waveney Local Maternity and Neonatal System (LMNS), which is part of the Norfolk and Waveney Integrated Care Board (N&WICB).

As well as reporting to the hospital Trust, Maternity and Neonatal Voices Partnerships also report to the LMNS. The LMNS uses the information it receives to gain assurance that local maternity and neonatal services are providing safe, quality care, taking a proactive approach to learning from incidents and sharing lessons across maternity providers.

The NHS England November 2023 National Guidance includes the following commitments for Maternity and Neonatal Voices Partnerships:

- Ensuring local Maternity and Neonatal Voice Partnerships (MNVPs) have the infrastructure they need to be successful and put service user voices at the heart of service improvement. This includes funding MNVP workplans and providing appropriate training, and administrative and IT support.
- Listening and acting upon issues raised by staff or service users through Freedom to Speak Up (FTSU) Guardians, the complaints process, or MNVPS.

To help Integrated Care Boards and Trusts put these plans into practice and meet their responsibilities, NHS England produced Maternity and Neonatal Voices Partnerships (MNVPs) guidance in November 2023. A previous review in 2022 looked at what were then, Maternity Voices Partnerships (MVPs). This review identified a high degree of variation in MVPs across England and the support they had. It also recognised that the role had changed and there were increased expectations on MVPs, but inconsistency in resourcing, training and support meant that there were challenges to how the MVPs functioned. The November 2023 guidance aimed to address the variation and challenges.

**The CQC Maternity Survey (2022)* (Care Quality Commission, 2022) *found that 0.65% of respondents stated their gender was not the same as their sex registered at birth.*

How we did this

We were provided with a list of the Maternity and Neonatal Voices Partnership (MNVP) Leads, relevant Trust staff and Norfolk and Waveney Integrated Care Board (N&WICB) staff contact details by the Local Maternity and Neonatal System (LMNS) Senior Programme Manager. The Senior Programme Manager emailed all the contacts to inform them that this project had been commissioned and outlined the aims of the project. The email informed them that they were a key stakeholder and that a member of the Healthwatch Norfolk team would be in contact to arrange an interview with them.

We set up a form on MS Forms which allowed people to select the dates and times that they could be available for interview. All stakeholders were sent an email in early November, confirming that Healthwatch Norfolk had been commissioned to undertake a review of the Maternity and Neonatal Voices Partnerships and that we wished to arrange an interview. The email included a link to the form.

We asked if people could select as many dates and times they could do, so that we could give those with limited availability priority. As people responded we emailed them within a week to confirm the time and date of their interview and providing a calendar request with a link to an MS Teams meeting.

We regularly updated the form to show which interview slots were no longer available.

Interviews

Interviews were booked for November, December and January. We had hoped to complete all the interviews by the end of December 2024, but five stakeholders could not identify a convenient date and time until January 2024, despite a wide offer of days and times.

All interviews took place over MS Teams. The interviews were semi-structured, with a series of questions that were adjusted according to the role of the interviewee. The interviewers also asked supplementary questions to gain a

deeper understanding of issues. The key interview questions can be found in Appendix One.

Who we interviewed

We interviewed 23 people for this project. Interviews were undertaken with people in the following roles:

Norfolk and Norwich University Hospitals NHS Foundation Trust
- Maternity and Neonatal Voices Partnership Lead (maternity)
- Maternity and Neonatal Voices Partnership Lead (neonatal)
- Divisional Midwifery Director
- Deputy Divisional Midwifery Director
- Quality Improvement Lead Midwife
- Neonatal Intensive Care Unit (NICU) Matron

Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
- Maternity and Neonatal Voices Partnership Lead
- Acting Head of Midwifery
- Deputy Head of Midwifery
- Neonatal Ward Manager

The James Paget University Hospital NHS Foundation Trust
- Maternity and Neonatal Voices Partnership Lead (maternity)
- Maternity and Neonatal Voices Partnership Lead (neonatal)
- Head of Midwifery
- Deputy Head of Midwifery
- Consultant Midwife
- Neonatal Senior Sister

Norfolk and Waveney Integrated Care Board
- Senior Programme Manager (LMNS)
- Lead Midwife
- Senior Project Officer (LMNS)
- Director, Children, Young People and Maternity
- Consultant Obstetrician

Regional Team
- Regional MNVP Lead

- Neonatal Service User Voice Representative for NHS England Maternity and Neonatal Programme

We also spoke to representatives of Kernow MNVP (Cornwall) and Evolving Communities CIC, which hosts Kernow MNVP. Kernow MNVP in Cornwall is recognised as a model of excellence and highlighted in the NHS England guidance. The supporting documents for the guidance were developed within Cornwall and the Isles of Scilly LMNS.

Ethical Considerations

We accepted that we had consent to contact the stakeholders directly as the Norfolk and Waveney Integrated Care Board copied us into the email from the LMNS Senior Programme Manager, informing the stakeholders that we would be in contact by email.

At the start of each interview we confirmed the purpose of the interview and what the review aimed to achieve and asked if the interviewee had any questions. We sought consent to record the interview and outlined how the interview recording would be used and that it would be deleted once the project has been completed. All interviewees gave their consent to be recorded.

It was bought to our attention that the cohort of interviewees was small and therefore it would be unhelpful to attribute quotes, even by the person's role, as it would be easy to identify the individual. It was important to reassure people of confidentiality when being interviewed and therefore we confirmed that all quotes would be anonymous.

Analysis

All interviews were transcribed and then analysed using Nvivo, a qualitative data software which is used to identify themes.

Limitations

We do not have expertise in the provision of maternity and neonatal services and we had to learn about how the systems relating to the services worked together as the interviews progressed. However, it was of interest to discover that there was a variation in understanding the role of the Trust, the MNVPs, the LMNS and the regional groups and their responsibilities.

What we found out

> To make sure we get the full range of voices we really need the MNVPs.

It is important to say that the MNVP Leads were enthusiastic, committed and knowledgeable. The role of an MNVP Lead is complex and requires a broad set of professional skills. As the role develops in response to the new guidance there will be increasing demands on those undertaking the role and yet the main requirement for this role is that the individual is someone who has previously used the services and is not a clinician. This is a difficult balance to meet.

The value of the MNVP Leads and their work was also recognised by those in the system:

> *"We are very fortunate to have our neonatal MNVP and as both leads, they are so proactive and so responsive to and so knowledgeable of the up to date and current situation alongside the thing that actually made them come into this field in the first place".*

Meeting the demands of the new guidance

The NHS England Maternity and Neonatal Voices Partnership Guidance, November 2023, is for Integrated Care Boards and Trusts on how they can:

- Meet their statutory obligations for involving people and communities in the planning, proposals and decisions for NHS maternity and neonatal services.

- Respond to the actions and responsibilities laid out in the three-year delivery plan for maternity and neonatal services (NHS England, 2023).

The guidance sets out two key areas to be addressed:

- The addition of neonatal voices
- Commissioning effective MNVPs

We have structured our findings around the guidance, using the headings from the guidance, with a brief explanation of what the guidance says and what we found out through our interviews. We have also highlighted in these sections some of the work undertaken by the three MNVPs. This does not reflect all the work undertaken by the MNVPs but is intended to give a flavour of the work they undertake.

The addition of neonatal voices

> I always just make the clear point, that to make sure they consider neonatal leadership, when they are deciding whatever they do.

Responsibility for commissioning neonatal critical care moved to the Integrated Care Boards from 2024/25 and guidance for the LMNS states that service users should be coproduction partners in improving quality of maternity and neonatal services. Parents who have experienced neonatal care should be represented through the MNVP or Parent Advisory Group (PAG).

In Norfolk and Waveney this has resulted in a change from Maternity Voices Partnerships (MVPs) to include the experience of Neonatal services, changing to MNVPs. This has also resulted in the appointment of two Neonatal Leads for the Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH) MNVP and the James Paget University Hospital NHS Foundation Trust (JPUH) MNVP. The MNVP of the Queen Elizabeth Hospital King's Lynn NHS Foundation Trust (QEH) does not have a separate Neonatal Lead, instead responsibility is picked up by the Maternity Lead and her Deputy.

Through our interviews we heard that the Neonatal Leads are still developing their role and are still trying to establish themselves in the role. *"...so they moved away from just being maternity, it's now Maternity and Neonatal Voices. So they're probably, as far as MVP, 18 months, two years behind", "So I think now is not the moment to assess it, to be honest, because I think it hasn't had its chance to kind of grow its wings."* and *"I would say our neonatal voice is not as developed".*

People also told us that there is a risk that the neonatal voice work gets subsumed by the maternity work because the maternity voice work is better established *"However, the focus it's, I would say, probably 95% of maternity and the rest is neonatal"*, *"We have included the neonatal voice, however, I feel the maternity voice is very strong"* and *"I was told 'well at the minute we're focusing on maternity, there isn't really anything neonatal, but there is work planned for the future'".*

This is not just an issue for the MNVPs but is also felt within the Trusts *"But I think historically within the trusts there is a separate maternity and the neonatal are seen as very separate, which is a challenge in itself but that's really hard for the MNVPs as well".*

> *I think us not being on par with maternity, and I know we won't, maybe we'll never be, on a par because we haven't got as many people experiencing neonatal. But I think even meetings and things, it is maternity heavy because that is the focus and (it's) not that we're forgotten, but it feels like it's maternity and then it's neonatal.*

There was recognition with those we spoke to that there are challenges with establishing this work *"I think the challenges are the same in that maternity is more established than neonatal and because of that it's harder, it's more difficult at the moment to work with neonatal because they're not used to it as much as maternity. They're not as embedded as they are in maternity. But also the governance, the priorities are separate"* and *"And the other challenge we have is, is getting our neonatal colleagues on board as well".*

People suggested that dedicated time should be given to focus on neonatal experiences and feedback *"So as an example....the various LMNS forums, make sure that there is enough time allocated to neonatal as it is for maternity,*

because I know that often we just take over with maternity" and *"It's a whole different team of people that are having to engage for neonatal, and because it's not so well established, I think they have challenges as well. So, I think that is another area of where it's difficult for them (MNVPs)".*

The hope is that the neonatal voice work will become much more developed *"it would be lovely to have someone whose complete focus was on neonatal"* and *"But it's sort of a ripe area for feedback and because it's such an intense experience for those parents and there definitely is an opportunity there to learn and improve things from the parent perspective".*

The experience of Kernow MNVP has been slightly different as they had included neonatal voices before the changes *"I think we've been very lucky here that Cornwall has always, since the very start of the LMNS back in 2017, included neonatal in that. So, we've always had neonatal feeding through it, which I think makes that transition a little bit easier because it is already sort of normal for people to talk about maternity and neonatal".*

There are also challenges in creating appropriate opportunities to speak to parents *"I think it's hard to pick your moment and to get engagement because they're automatically those parents going through quite a traumatic event or have been through a traumatic event"* and *"People have then had really traumatic experiences, which makes it harder to engage"*.

> *"It depends what's happening with their baby at the time. If it's a sick, unstable baby, obviously that's not the time to get feedback. But if it's a baby that's been with us for a while and is stable and on the way towards going home, then I think that perhaps is a good time to have the discussion and get some feedback. And then sometimes I think perhaps there's a group of parents, maybe after discharge is a good time, when they've had time to reflect and things".*

For some the Neonatal Intensive Care Unit (NICU) felt less accessible *"NICU is quite insulated in terms of their working and how they work and they're very sort of closed door sort of things"* and *"But I feel like on the NICU, I still feel very much like an outsider. I feel very much like I can't just rock up. I need to make sure it is all planned out in advance"*. But for others this wasn't an issue *"she goes and sits in the parents' room and has tea and coffee and brings cake for families and*

chats to families…. she's very welcome to come… She's got her picture up on the board, she's got her own board on NICU…. We have quite an open door". We asked one unit if there were any challenges to people visiting the NICU; they didn't think there were "*I'd say as long as it's planned and we're aware…I'd like to think we were always welcoming and welcome the input because the parent perspective is obviously really important".*

There was some frustration that the neonatal work was not progressing as expected "*I just find it that the maternity teams shout about the MNVP, how great they are, all this, that, and the other. But I can't say that we get that from our neonatal".* We also heard that there was some misunderstanding about where the barriers were "*I think the neonatal leads perspective was that staff weren't engaging and the staff perspective was that the neonatal lead wasn't engaging. So something had broken down there*".

We also heard that having a Neonatal Lead who has lived experience of neonatal services makes undertaking the role easier "*So she's there as the parent's voice and she's an ex-NICU parent. She's got that insight of how she felt at the time. I think that's really useful as well*" and "*I think they would automatically, having been through that themselves, have quite a passion for the role and for improving things where they need to be improved".*

For some, having lived experience of neonatal services is essential "*I think just that level of understanding of what those parents on the unit are going through or have been through, I think they'll just be able to pitch those conversations better and have the confidence to initiate those kind of conversations with some understanding, that I think as someone that hasn't been through it perhaps wouldn't be able to do. I think it definitely should be a requirement*", "*having lived it, having that neonatal experience as a Lead is really important*" and "*It was my understanding that the neonatal representative needed to have neonatal lived experience*". However, it is not always possible to find someone with lived experience to fill this role "*We were only able to pay a day or two per month. So, we didn't have enough people; we had some people interview and then turn it down*".

Regional groups have been established to ensure that service user voice for parents and carers who have used neonatal services within the region are represented. These groups are Parent Advisory Groups (PAGs). PAG members are service users who are representing their own experience "*they're people that come with just their own lived experience.*" Whereas although MNVP Leads are

service users, they are expected to seek and represent the views of their communities. There is an expectation within the guidance that MNVPs and PAGs will build a relationship and work together. The Neonatal Family Engagement Lead and Chair of the PAG, would like representation at the PAG from the region's MNVP Neonatal Leads "*I tried to encourage any neonatal leads at the MNVPs are PAG members, so they get that link between regional work and local work*". However, those who do not have lived experience of neonatal care cannot be members "*PAG is for people that have had a neonatal experience and we have to make sure it's a psychologically safe space*". One of the Neonatal Leads in Norfolk and Waveney is the Vice Chair of the PAG and in this role is representing her own experiences, rather than that of her community.

There is also a Regional Neonatal Leads Group, which aims to provide support for the Neonatal Leads "*we have like WhatsApp groups for peer support, but then we also have quarterly neonatal lead meetings which are in addition to the regional MNVP lead meetings*." Until very recently, there has been limited involvement from two of the Norfolk and Waveney MNVPs, but this is changing and at the last meeting there was attendance from both Neonatal Leads. "*the neonatal leads do engage with me…*".

There is also a Regional MNVP Leads group, which meets bi-monthly "*we hold a bi-monthly MNVP group for MNVP Leads and system MNVP Leads, and we support the local systems to share their learning, local involvement information and to develop themselves in terms of their engagement, functioning and the way that the MNVP have developed in line with the MNVP guidance*". The LMNS Project Officer attends these meetings and reports back to the Norfolk and Waveney MNVP Leads.

We found that there were misunderstandings between the regional and local teams about how they should work together and of the expectations around roles and responsibilities, which has led to frustration about engagement on both sides. This is a gap in the wider system for hearing the voices of those who use maternity and neonatal services and ensuring safer services. It is also a loss of potential wider support.

> It's a whole section of the region that we're not really penetrating in terms of support.

Commissioning Effective MNVPs

Much of the guidance is focussed on how the MNVPs should be functioning effectively to involve service-users and meet the commitments of the Three-Year Plan for Maternity and Neonatal Services. We have looked at each of the areas below.

Engagement and listening to families

This is the main role of the MNVP – to engage with families and seek their feedback about their experiences. The challenge for MNVPs is to reflect the diversity of their local population and to engage with seldom heard groups, such as those who are most likely to experience health inequalities, parents who have experienced neonatal care and families who have been bereaved.

> Our role is to really represent the service user experience, because in maternity and neonatal care, it's just so nuanced and as soon as you become qualified as a midwife or have responsibilities to the NHS, your perspective is very different to somebody who's actually using the services.

We heard of excellent methods of engagement from all three MNVPs and there was unanimous praise for the efforts made to engage with families and seek their feedback. The MNVPs have regular engagement with existing groups in their patch, such as parent and baby groups. They also attend local events and make visits to the maternity and neonatal wards. Feedback from Trust staff was positive about the efforts made by the MNVP team to engage with families.

> I think really celebrating how creative and trailblazing our MNVP is, in terms of the kind of work that they undertake to get as many of our staff as possible to hear the voices of as many of our communities as possible; I would want that to be one of the kind of standouts of the report.

According to the Office for National Statistics (ONS), Census Data from 2021 (Norfolk County Council, 2021), Norfolk's non-white population is 5.3% of the

overall population and in Waveney it is 3%. Asian people are the largest minority group in Norfolk accounting for 2.1% of the population and in Waveney it is mixed or multiple ethnic groups, which accounts for 1.3% of the population, with 1.1% of the population identifying as Asian (Office for National Statistics, n.d.).

95% of the Norfolk population have English as their main language. 2.7% of the Norfolk population selected "other European Language" as their main language, with 0.6% selecting Portuguese, South Asian or East Asian were the main language for 0.8% of the population (0.4% each) and Russian is spoken by 0.2% of the population (Norfolk County Council, 2021).

The data for languages spoken in Waveney from the 2011 census data showed that 98.4% of people living in Waveney speak English. The other top languages spoken are 0.3% Portuguese, 0.3% Polish, 0.1% all other Chinese, 0.1% Romanian, 0.1% Turkish (Qpzm Local Stats UK, 2025).

The MNVPs have made efforts to find ways to engage with their ethnic minority groups. The JPUH MNVP were keen to engage with their non-English speaking population and have had their surveys translated into the three main languages, Portuguese, Lithuanian and Polish. *"We're really proud the trust paid for our surveys to be translated into our top three languages…. we have translated surveys available in those languages for maternity and for neonatal".* This work was valued by members of the Trust "*she has got a real focus on underrepresented and outreach communities. She has assisted a lot, in terms of all the work around ensuring the information poster was available in different languages. She has done a really good job and she always has in her mind the underrepresented people and families coming through the service. I would say she's doing very well on this".*

The QEH MNVP has identified future plans to translate all their resources into the top seven languages spoken in their area. They are also planning a listening event for the Gypsy, Roma and Traveller population.

The NNUH MNVP has developed links with their local Bengali population through connections made by the NNUH Community Midwife Team. The MNVP Community Engagement Facilitator was able to meet with and get feedback from this group. It is hoped to build upon this link.

The challenges of engaging with those groups who are seldom heard were recognised by the MNVP Leads "*We struggle to get service users engaged.*

Obviously we are in a lower education area and area of deprivation". One person told us that they would like wider representation on the MNVPs "*We'd still like more representatives that are a diverse cross section of our population. It is still very much white middle class that are representatives. We'd like a lot more volunteers from diverse ethnic backgrounds*".

Each of the MNVPs have targeted opportunities to attend groups that are held in those areas where their more vulnerable communities are, based on data from the Index of Multiple Deprivation (IMD). The QEH MNVP has worked with a group of parents who mainly live in the IMD1-2 areas (most deprived) and who have had neonatal experiences. This group has contributed to a neonatal poster and have other projects underway.

Figure 1: An image of a poster with ideas of activities to do with your baby in NICU.

The neonatal poster gives suggestions of things that parents of babies who are in Neonatal Intensive Care can do with their baby. *"(one thing) the MNVP Lead worked on was actually a poster for our parents; kind of suggesting things that they can do with their baby. And those suggestions came firstly from parents, things that they've enjoyed doing, and then she asked for input from the staff as well. That is out and on display on the unit, which is a nice thing, because it's things like reading to your baby and playing music, that kind of thing, bringing in teddies and toys. Things that some parents almost feel they need permission to do".*

The JPUH MNVP helped to produce a video that highlighted the challenges of service users who are neurodivergent, which has been a valuable tool for use within the Trust *"although we've had pre-existing pathways around support for people who might be neurodivergent and have additional care needs… For those families where there might not be a formal diagnosis or someone might not choose to disclose everything about what they're going through in terms of diagnosis, we didn't really have a good way of understanding those experiences and understanding the challenges that maternity care might pose to anyone coming through the door"*.

There was a frustration expressed by the MNVP Leads that the lack of hours restricted opportunities for engagement, especially with those groups who are seldom heard, as there is recognition that to do this well takes time. This was seen as one of the biggest challenges *"The additional resource and skills and expertise that are required for addressing health inequalities and the time and resource to speak with vulnerable women and the special approaches that you need to make for young parents, Gypsy Roma and Traveller families, homeless people… I'm really cautious about approaching those groups and doing that work because my resource is so limited"* and *"Potentially there are some people who don't want to engage with anyone trust related at all, but I think if I had enough time and budget I would be able to get around them because there are so many different ways to reach people"*.

However, it was also identified that the changes in the guidance will need a different approach:

"I think that we've got a lot of deprivation, we've got more travelling communities. We've got more harder to reach sort of communities, particularly those that are moving into the area, that we really need to make sure that their voices are represented. I think that's where our lead is now starting to do some of that work and pick that back up again. But I think it's about supporting her to do that, maintain that, and we've got some work to do for making sure that somebody from the trust is supporting her with that because she can't do it alone. I think that's where that true co-production comes together. I think we haven't got necessarily that element of us working hand in hand quite right at the minute".

Others identified the need to look at the work of the MNVP Leads *"I think that we need to have a look at a lot, what are the models we've got out there. I think that we could be doing a lot better with our co-production than we currently are.*

And I think that's part of the representation that we don't have… I was having conversations the other day with some of my counterparts and the way that they really are conducting their model, literally they'll have all these different events set up and actually a member of the trust staff will go with them to these events and they do things together and I think that we need to work towards that and how we do that".

Within the guidance there is recognition that when reaching out to parents who have suffered a bereavement, this should be done sensitively and done in a way that protects parents from being retraumatised by sharing their experience. Suggestions for this are training for MNVP Leads, separate engagement opportunities and working in partnership with local Voluntary, Community and Social Enterprise (VCSE) organisations that have experience of this.

The MNVP Leads told us that they had requested training around trauma from the LMNS Project Team as they recognised the importance of this *"with all the highlights on the reports and everything like that, it's a really important area to make sure that we're not causing harm"* however there was a sense of frustration about the training on offer and the expectation of when it should be completed *"We have all recently asked for training, but we've been told before we're allowed to access some of the training, we have to do the free versions on EFHL or whatever it is, whatever the NHS point… It's not the education that we wanted and none of us have got the headspace. I certainly haven't had that time to do the free training so that I can potentially access the funded training that I wanted in the first place because the free training won't be as good"* and *"I said that I would like to develop my skills around birth trauma and that because of the recent birth trauma inquiry, which obviously everything has to be linked and justified, that that's something that I would like some training on. So they (the LMNS Project Team) sent me a link to an NHS England webinar thing to click through on and have asked me to do it when I have time, which isn't really in the spirit of things…".*

The JPUH MNVP Lead talked about linking with TimeNorfolk, a Norfolk-based VCSE organisation, which provides wellbeing support to anyone in Norfolk and Waveney who experiences mental health challenges due to pregnancy loss at any stage *"I keep in contact with work with TimeNorfolk, they're a great organisation".* Building on the success of a video project to highlight the needs of people who are neurodivergent, the JPUH MNVP have worked with the bereavement team to find people with different experiences of bereavement care who were willing to be filmed. It was important to capture the voices of

those who had a bereavement, in a way that was sensitive to their situation but could be used with different groups of midwives "*We're not traumatising a service user by asking them to continuously repeat their experience or say it in front of a lot of people*".

The NNUH MNVP has a bereavement subgroup that includes representatives from local bereavement charities. The QEH MNVP has a bereavement working group, which meets regularly and this working group of parents who have experienced stillbirth contributed to the butterfly garden and a bereavement poster.

Hospital to unveil Butterfly Garden for those affected by baby loss

The Queen Elizabeth Hospital King's Lynn (QEH) is set to officially open a Butterfly Garden, a dedicated space for reflection and remembrance for families who have experienced the devastating loss of a baby.

Taking place during Baby Loss Awareness Week, the opening ceremony is set for Wednesday, 9th October, following a two-year project to create a tranquil sanctuary for all in the hospital community.

The Butterfly Garden, fully funded by the hospital's own QEHKL Charity, has been thoughtfully designed to offer a peaceful environment where families, staff, and visitors can find solace and connection.

It features hand-forged butterfly sculptures with some bearing the names of babies lovingly remembered by their families. This space will serve as a poignant reminder of the brief yet impactful lives that have touched many hearts.

Some of the families involved in the project visited the garden recently for a symbolic release of butterflies.

Hospital CEO Alice Webster expressed the importance of the garden ahead of its unveiling: "This garden is much more than just a physical space. It is a sanctuary – a place for peace, where anyone who has experienced the unimaginable pain of losing a baby can come to find comfort and support.

"The Butterfly Garden stands as a lasting tribute to the lives of the babies we have lost and a testament to the strength and resilience of the families and our hospital community."

The project has been a collaborative effort involving families, staff, and community partners, co-produced with specialist bereavement midwives from the Butterfly Suite, who provide essential care and support to families navigating baby loss.

The QEH (King's Lynn) Maternity & Neonatal Voices Partnership (MNVP) has also played a crucial role in shaping the garden, ensuring it meets the needs of those who will use it.

Emily Lunny, Lead for the MNVP, said: "I am so privileged to have been involved in the creation of the garden. We have been able to bring service users voices to all design aspects from the species of butterfly to the specific shades of purple chosen.

"Whilst nothing can take away the pain of losing a baby, the team at QEH have ensured we have the resources and facilities to best support women and families on this difficult journey."

Figure 2: Excerpt from the QEH King's Lynn charity website (QEH King's Lynn Charity, 2024)

The guidance states that the MNVP Lead has responsibility to ensure that appropriate risk assessments, safeguarding procedures and training are in place for anyone who is engaging in the community or within the maternity and neonatal services. The Norfolk and Waveney role description for MNVP Leads and Co-Leads includes the following responsibility (the role description states that all the responsibilities listed may be included and therefore none of them appear to be mandatory):

- Put in place appropriate risk assessments, safeguarding procedures, escalation processes and training including trauma-informed approaches for all MNVP members undertaking outreach and engagement activities

The MNVP Leads told us that they currently do not undertake risks assessments for volunteer community visits, however one Lead stated "*We do complete risk assessments when requested for one off events such as Pride*".

Each Lead was clear about how to escalate safeguarding concerns within their Trust and had undertaken appropriate safeguarding training through the volunteer training programme.

Fifteen Steps

Fifteen Steps is a process of visiting neonatal and maternity settings with a small team of service users and staff to observe the setting and identify if any improvements could be made. Clear guidance on how the Fifteen Steps visit should be set-up and undertaken is set out in the Fifteen Steps for Maternity Toolkit (NHS England, 2018).

The guidance states that findings from the Fifteen Steps visit should be shared with the LMNS Board, trust governance and safety champions. In Norfolk and Waveney, the Fifteen Steps visits are fed back to the LMNS via the quarterly meetings, unless there is anything that requires feeding back sooner.

The NNUH MNVP undertook a Fifteen Steps visit with young parents from MAP, a local VCSE organisation. The visit was arranged with the Young Parent Advisors from MAP, who helped to make the guidance more accessible to the young people. The visit was felt to be a success and it is hoped that this will be the start of a continuing collaboration with MAP.

Figure 3: An image of the report from the Fifteen Steps visit with young people

The QEH MNVP also conducted Fifteen Steps visits in 2024.

Walk the Patch

This is a way to collect direct feedback from people who are currently using maternity services and on the maternity unit. The aim is to have a snapshot of care on one day. Guidance for this can be found on the National Maternity Voices website (National Maternity Voices, 2022).

All the MNVP Leads talked about visits to the maternity unit. The NNUH MNVP annual report identifies that Walk the Patch visits are one of the methods of gathering feedback.

Surveys and digital feedback mechanisms

There should be mechanisms to collect ongoing feedback that are easily accessible. Each of the MNVPs has an electronic survey, which can be accessed via the MNVP website.

Each of the MNVPs had electronic surveys which were available to the public via the website. We looked at the surveys and websites for each MNVP and this is what we found.

Norfolk and Norwich University Hospitals NHS Foundation Trust MNVP

NNUH MNVP links to an NHS survey for maternity services, which could be off-putting for service users as it may not be seen as independent. Some responses are required, which means it is not possible to scroll through and see what is involved in the survey before deciding whether to complete it. However, the NICU survey is independent, and it is possible to see all the questions before completing the survey.

A link on NNUH website maternity section takes you to a section on the NNUH website, which explains what an MNVP is, but there is not a link to the MNVP website or the survey. The NICU section on the NNUH website is hard to find – once found there is no mention of the MNVP and no link to the neonatal survey. You have to find the NNUH MNVP website by searching for it online.

Queen Elizabeth Hospital King's Lynn NHS Foundation Trust MNVP

The QEH MNVP has an independent survey, which is well designed. It allows for detailed responses, and you can review the questions before completing it. However, there is no neonatal survey available.

The MNVP is shown on QEH website, but there is no link to the survey. The MNVP is not mentioned in the neonatal section of the QEH website at all.

James Paget University Hospital NHS Foundation Trust MNVP

The JPUH MNVP is known as "Birth Voices East", which helps to give a sense of the independence of the MNVP but may mean that people struggle to find it if they are looking for "their local MNVP".

The JPUH MNVP survey looks independent but there is little opportunity for narrative response. You can look at all the questions before completion. The survey has a lot of scaling questions, which could be off-putting. There is a survey for both maternity and neonatal.

The MNVP is not clearly identified on the JPUH website – it would be easy to miss. The link to the MNVP takes you to a flyer and not the website and there is no link

to the survey on either the flyer or the JPUH website. There is no link on the neonatal section of the JPUH website.

None of the regular surveys of the three MNVPs addressed baby loss / bereavement. Although each MNVP has a targeted approach around bereavement, some people may find it preferable to complete an anonymised survey to share their experience.

We also looked at other relevant websites and found that the listing on the National Maternity Voices website does not include a link to the NNUH MNVP website, but there are links for the JPUH and QEH MNVPs. We also found that there are good links to the MNVPs websites on the Just One Norfolk website and wondered whether they could host the surveys on the MNVPs behalf as a way of extending their reach.

The guidance states that those who coproduce the surveys should be aware of trauma informed language and accessibility requirements and may need additional training around this. Trauma-informed language emphasises empathy, support and respect for the individual's experiences.

Some aspects of accessible survey design that could be considered include:

Clear and Understandable Language:
Utilise plain and simple language, avoiding jargon or complex terminology. This allows participants with varying levels of literacy or cognitive abilities to comprehend and respond accurately.
Multiple Response Options:
Offer diverse response formats (text, audio, or visual) to accommodate participants with different communication preferences or disabilities. Ensure compatibility with screen readers for visually impaired individuals.
Appropriate Visual Elements:
Employ high-contrast colour schemes and provide alternative text for images to aid participants with visual impairments. Avoid relying solely on colour to convey information.
Navigational Simplicity:
Create an intuitive and straightforward survey layout. Clearly label sections and use a logical flow to make navigation easy for all participants, including those using assistive technologies.

Outreach

The guidance states that an indicator of an effective MNVP is the engagement within the community, which should take place across the whole patch served by the trust. This is a challenge in Norfolk and Waveney as it has a large geographical footprint. The JPUH serves a population from Norfolk and Suffolk, which is a challenge for the MNVP Lead especially as service users in Norfolk and Suffolk have different support structures for parents or parents to be "*my biggest challenge, and I even wrote this in my annual report, is that I can often be found sat in a meeting going, what about Suffolk? Because for example, the antenatal education offer that's just coming out, they're linking it with Pathway to Parenting, which is a Norfolk offer, which is not allowed to touch Suffolk. So immediately, 50% of my population are at an absolute inequitable offer".*

Each of the MNVPs have tried to extend their reach in their geographic area. The NNUH MNVP mapped out their engagement activities in their annual report showing their geographic spread.

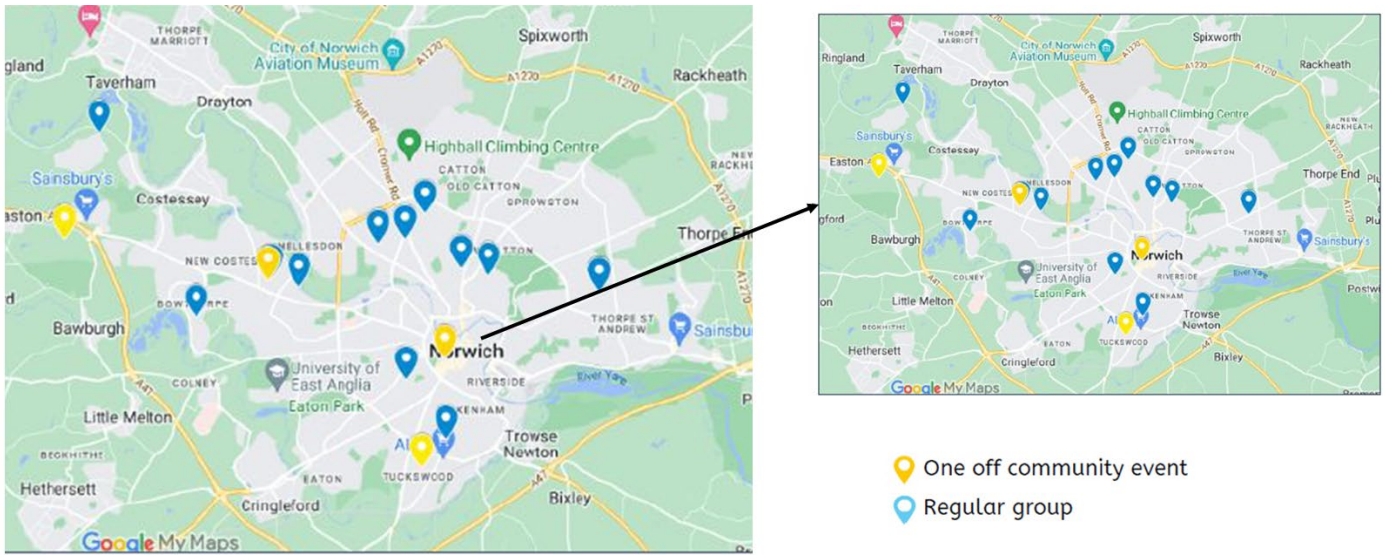

Figure 4: An image of a map showing where the NNUH MNVP have undertaken engagement visits

The engagement should also take place with neonatal families, bereaved families, marginalised groups and those who are more at risk of health inequalities and adverse outcomes, which we have looked at in the section on engagement and listening to families.

Partnership working with voluntary, community and social enterprises (VCSE)

Working in partnership with VCSE organisations can help with effective engagement with neonatal and bereaved families, but also with vulnerable and seldom heard groups.

There is evidence of partnership working with the VCSE. MNVPs told us about a range of organisations that they had engagement with.

The JPUH MNVP recognised the value in using their local VCSE organisations to act as a voice for those they worked with who might not be willing or able to speak for themselves "*Because of the level of deprivation and vulnerability I have within the Paget, sometimes it is more appropriate for me to work with a staff, or a professional representative than it is for me to work directly with the service user because they're vulnerable or they don't engage or they don't understand and things like that. For me, it's been really important to have the voice of those organisations*"

The JPUH MNVP set up a professional's event to explore the experiences of those using maternity services who had English as a second language and those who are neurodivergent.

The event was seen as a success "*there were like 30 people in the room and there was a range between charities, staff from the hospital, from both neonatal and maternity*".

Figure 5: An image of the JPUH MNVP poster for professional's forum

Social Media

The guidance states that social media can be a way of engaging with families and getting feedback from them. The strength of social media is that it can be on an independent account (from the Trust). We looked at the MNVPs' social media accounts.

Norfolk and Norwich University Hospitals NHS Foundation Trust MNVP

The NNUH MNVP has a Facebook page and has 3.1k followers. The page is mainly used to advertise events, but there are also links to surveys. The Facebook pages are kept up to date.

Queen Elizabeth Hospital King's Lynn NHS Foundation Trust MNVP

The QEH MNVP Facebook page was harder to find. We were unable to find it through a search of groups on Facebook and eventually found it through a link on the website. The page has 642 followers. In the introduction section of the page (which remains at the top of the page) there is a link to the maternity survey. The pages are mostly used to advertise events and engagement opportunities. There are fewer posts than on the other MNVP pages. The QEH MNVP also has an Instagram account.

James Paget University Hospital NHS Foundation Trust MNVP

The JPUH has a Facebook page with 1.8k followers. The pages are used to advertise engagement opportunities and provide opportunities for feedback. The pages are kept reasonably up to date.

It is important to acknowledge that the MNVPs do not have any external support with managing their social media and this has to be undertaken within their existing resources and hours.

We felt there was more of an opportunity to use the Facebook pages as a tool to gain more volunteers to support the work of the MNVP and also for recruitment of MNVP Leads in the future.

Thematic analysis of feedback

By reviewing the feedback and other sources of data, the MNVP is able to report on findings and use this to influence service improvement and decision-making.

All three MNVPs reviewed the data they had received along with other sources of data and used this to develop work plans or identify areas of concern with their Trust colleagues. *"I have a quarterly feedback meeting with key staff at the*

Paget led by our Consultant Midwife, where we talk about all the themes of complaints, debriefs, what I'm seeing, what they're seeing directly, what they're feeling and (we) come together and go, so this is what we're all saying collectively is a problem" and *"I meet with the maternity leadership, so it's the Deputy Director of Midwifery, the Quality Improvement Midwife. An Obstetric Consultant also has responsibility to my MNVP, and the Patient Engagement and Experience team. We meet once a month or once every other month and review all of those feedback themes together. Then from that we have subgroups. So that's our way of getting the feedback to the staff on the ground and getting actions out of it".*

We were given numerous examples of how data had been used to improve services from each of the Trusts and MNVPs. An example of this was feedback from parents who had experience of neonatal care *"we had a lot of feedback about the rooms on NICU, the bedroom spaces. People said they were quite clinical, which they have to be to a certain extent, but when you're living on a unit, these are the bedrooms that the parents obviously are in on NICU, some parents are in there for months at a time".* The feedback was acted upon and as a result new furniture and lighting was introduced, some rooms had TVs and a family room established with facilities for siblings *"they've really improved it from what parents said, it's really lovely".*

The MNVP should also liaise with the regional Parent Advisory Group (PAG) to understand the experience of neonatal service users, which we have covered earlier.

Strategic influence and decision-making

According to the guidance the key role of the MNVP is involvement in decisions on local strategies and policies in maternity and neonatal care. This should be carried out at Trust level and at the LMNS.

Within the Trust an MNVP plays a role in contributing to the quality and safety of maternity and neonatal services. This is done through the Perinatal Quality Surveillance Model (PQMS) an NHS model that aims to increase the oversight of the clinical quality of perinatal services and support the integration of perinatal clinical quality into the structures of the Integrated Care System and ensure clear responsibility and accountability for addressing any concerns about quality.

By ensuring that MNVPs are part of local governance structures and activities, such as safety champion activities, mortality audits, serious incident response groups and guideline committees, they will be able to provide both the critical friendship and supporting oversight needed for the PQSM. MNVPs should also be involved with the ICB-level PQSM.

There was a lot of feedback about expected attendance at meetings outlined in the guidance. The LMNS Project Team had sought clarification about whether attendance at some meetings were mandatory "*We have checked on that, because some were less comfortable with (the meetings) and essentially they're saying no, they have to do it and you have to facilitate it*".

Attendance at the Perinatal Mortality Review Tool (PMRT) meetings are a cause for concern "*the PMRT meetings, I absolutely fundamentally disagree with that. However, that is national guidance. We are having to work towards that; so we are working towards it. But fundamentally, I sit in PMRT meetings regularly and I find them tough going and I'm a midwife of many years and sometimes I sit there and I could cry and you think, how could you support an MNVP through some of this stuff?".*

One MNVP Lead also felt strongly that it was not appropriate to attend these meetings "*I do not believe that they are appropriate, and I know that we've had a lot of support for that from within our Trust and within the ICB. I don't believe they're an appropriate place for an MNVP to be at all".*

The MNVP Lead should have relationships with senior leaders in maternity and neonatal services within the Trust and be supported in developing and maintaining these relationships.

The Trust staff we spoke to, talked about the positive value senior leaders placed in the MNVPs and their role in improving service user experience and safety "*my relationship with our Chair, our Lead MNVP is really strong. I go to their monthly meetings, their quarterly meetings, I liaise with them. I allocated my own deputy to be the liaison person. I see the real importance of having the MNVP"* and "*she is increasingly sort of, if not quite, one of the key members at some of our meetings*".

At LMNS level there should be strategic influence from service users and a clear pathway developed to ensure the work of local MNVPs can influence and feed into the LMNS. This can be achieved by ensuring that the MNVP is part of the

membership of the LMNS and that feedback and coproduction from each of the MNVPs is coordinated and, along with other service user feedback, use it within LMNS activities and decision-making.

The guidance identifies the value of having MNVP leads as quorate members of Trust strategic meetings and at LMNS Board and Maternal and Neonatal Quality meetings.

> All of the system has to have ownership and they have to understand themselves, each trust, what their roles and responsibilities are within that.

We encountered some confusion about the LMNS. The Three-Year Delivery Plan for Maternity and Neonatal Services (NHS England, 2023) outlines the various parts of the maternity system:

"Integrated care boards (ICBs) commission most maternity services. Each ICB will be a partner in an integrated care system (ICS). ICSs are a partnership of organisations that plan and deliver joined up health and care services. *The local maternity and neonatal system (LMNS) is the maternity and neonatal arm of the ICS.* ICBs commission maternity and neonatal voices partnerships (MNVPs) which are designed to facilitate participation by women and families in local decision-making."

The LMNS should consist of representatives from each of the three Trusts as well as the MNVPs and ICB staff, but it was often seen as something separate *"I do think the trust themselves refer to the LMNS as that organisation over there and they are all part of it, it's the local maternity and the neonatal system".* People sometimes confuse the LMNS Project Team with the LMNS.

The Project Team are viewed as helpful at times *"we had a member of the LMNS come and support as well. So the three of us did this event. So they will come along to help us capture the feedback. It'll help with projects as well"* and *"I've found the LMNS a really valuable resource",* but others have felt this is not always the case *"the line that we've kind of tried to tread between or that they've been treading between being supportive and being challenging, it hasn't always felt like the balance is right with that".* However, the expertise within the LMNS is valued *"we've got colleagues with expertise in the LMNS that we don't have in the Trust"* and *"I think of all the LMNS is I've come in contact with this one works the*

best. They're very open and honest and supportive. They've been really proactive and supporting that drive, really willing".

The increased demand for MNVP Leads attendance at meetings does have an impact on the time they can spend engaging with service-users. "*I think it's gone from being talking to service users in a trust and feeding into a much more formalised requirement around what they report, the meetings they attend, how they engage with their trusts. So it is shifted from a, we'll just go and talk to some parents and feed that in, to much more, you must do this*" and *It takes more from their time that they should be having with the service users, doesn't it? That's the battle that we're having and we've always been that link from the MNVP to the meetings and things with interest. But like I say, there's more of a push now for them to actually attend themselves".*

Someone suggested that this calls for a different way of thinking about the role "*the MNVP lead shouldn't be doing the engagement. You should have like engagement officers, so really the MNVP should be a team. You should have an MNVP lead, a neonatal lead, and then you should have engagement officers…. because that's the thing, one MNVP Lead can't do all the strategic work, all the meetings, all the quality assurance and engagement and social media and all that*".

Leadership

MNVPs should have a lead who is a service-user, with lived experience of maternity and/or neonatal services. They should not be an existing employee of the trust or system. The guidance suggests a separate strategic lead for neonatal care, to support the shaping of neonatal services. All of Norfolk and Waveney's MNVP Leads are people who have used maternity services. Some of the people we spoke to recognised the importance of a Neonatal Lead:

> Somebody with lived experience of neonatal who has more hours and the drive to work independently within the MNVP, of maternity. So focus on the neonatal side rather than just working alongside them. Obviously they'd need to do things together, but as the neonatal lead, I would think you would be the one that'd be coming to the neonatal unit, finding out what I'll be wanting, what I am offering, this is what I'm doing, do you think that works well? What would you expect from me? And that's not what we've had. We've had to go out and ask for it and are still not feeling very

reassured by what we've had back. It still feels very, oh, maternity focus and we'll think about neonatal when we've got the opportunity to.

The guidance also suggests that there could be a leadership team, with different people taking on responsibility for different areas of the MNVP programme, such as engagement with seldom heard groups or parents who have been bereaved.

Our Maternity (and Neonatal) Voice Partnership are a working group made up of a team of women, people and their partners that work very closely with us as Midwives, Nurses, as care professionals, and Doctors and Commissioners to really work together to contribute to a better local maternity and neonatal care. We do work very closely with our Maternity and Neonatal Voice Partnership and with the other LMNS leads. And really for me their role is to provide an independent voice and co-production for our maternity and neonatal services. Their role is very key in bringing the user voice at the centre of all that we do and looking at some of the great achievements made in the last year, in terms of service development, providing a better access to care, especially to those parents and family living in the most deprived areas, has really made a difference.

Each of the three MNVPs has a small team of people who play a role in engaging with service users and getting their feedback.

MNVP	Team and hours
QEH	Lead: 4-7 days per month Deputy Lead: 1-3 days per month
James Paget	Maternity Lead: 4 days per month Neonatal Lead: 3 days per month Volunteer Lead: 1 day per month Community Engagement Lead: 1 day per month
Norfolk and Norwich	Maternity Lead and Neonatal Lead: 8 days per month in total

	Community Engagement Lead: 3 days per month Community Engagement Volunteers
Kernow	MNVP Lead – 24 hours per week Project and Coproduction Lead – 24 hours per week Engagement Lead – 22.5 hours per week Volunteering Project Officer – 15 hours per week

Figure 6: A table showing the roles and hours of each MNVP. The information is taken from the 2024 annual reports and from information provided by Kernow MNVP.

It is recognised that MNVP Leads will need to have leadership skills that will enable them to lead a complex programme of work and contribute to quality and surveillance work. "*from a lead perspective, it's really important to recognise that it is a senior professional role that they are being asked to do, and actually, if you look at the job description in the guidance, it's really clear that it's a senior professional role that we need these people to do*".

> I know funding is a is a big issue, but you can't expect people to work in highly strategic senior professional roles and not get paid.

The November 2023 guidance outlines the key responsibilities of an MNVP Lead and includes a role description from the Kernow MNVP. (See Appendix 2). Norfolk and Waveney ICB have developed their own "charter" which includes the roles and responsibilities of an MNVP Lead and the Trust. (See Appendix 3). There is a disparity between the Kernow job description and the Norfolk and Waveney Charter because the Norfolk and Waveney MNVPs are not employees. We asked about the charter but the feedback we had was that people were struggling for time to read it "*I think they made one not long ago, but I've got to be honest, I've not really looked at it because I haven't had the time*" and "*it's called a SOP,*

which was standard operating procedures, so I couldn't tell you the last time I read it, but I know I'm doing my job".

The guidance states that the role of the MNVP should be suitably paid for the demands of the role and leads can either be employed by the ICB, be self-employed and contracted in or employed by a contracted third party. We heard mixed perspectives about whether the MNVP Leads should be employed or continue as volunteers.

In Norfolk and Waveney the MNVP Leads are seen as volunteers of their Trust and therefore paid under Patient and Public Voice (PPV) Policy through honorary contracts. Whilst this is also the case in some other MNVPs it is an issue "*I know that some MNVPs nationally are saying that they're not compliant with the NHS England guidance if they're still on PPV rates because PPV is only for volunteers*" others were much clearer that using PPV was not compliant with the guidance "*I mean obviously to be in line with the guidance they shouldn't be doing PPV because it does state that it's not for volunteers*".

People we spoke to were clear that the MNVP Leads should not be employed by the Trusts "*I don't think they should be employed by the trust because I think they have to maintain that independence from us to be able to keep that impartiality with the service users, to ensure that they feel they are open to reach out to the MNVP"* and "*I suppose my view is if for example they were employed by the trust, then they lose their independence and they just become the trust".* We did not hear of any reservations from people about the ICB employing the Leads.

"*My suggestion is, if it's the way that it's going, that they're going to have to sort of have very specific requirements around a very big financial gain through CNST (Clinical Negligence Scheme for Trusts) and to be part of our governance, and they need to be employed probably through the ICB, but employed properly, not just volunteers……I think that if we're looking at having some sort of independence and being very open and transparent about this, I think it needs to stick with the ICB".*

Some saw advantages to a third party employing the Leads "*If you're an independent organisation that's working collaboratively with system partners, the value and the fact that you can have those real honest conversations with individuals without the fear of 'is my care going to be affected if I tell you the*

truth or if I'm open and honest with you?' So absolutely independence is always one of those is top of the list for me".

There are also risks to having the MNVP Leads as volunteers both for the Trusts and for the MNVP Leads. "*at best it's the gig economy; it does exploit service users when it's a prolonged engagement that way"* and "*But it's also quite unnerving for us. Obviously we are volunteer status and that's quite unnerving in itself. So yeah, it would be a bit nicer to know your job's stable for another year*" The fact that the MNVP Leads are not employed does mean that they can decide to stop doing the role and leave the MNVP in a difficult position "*the MNVP lead can go, actually I don't want to do this anymore, I'm gone and there's nothing you can do".*

We also heard of historic issues that highlighted the vulnerabilities of using volunteers, which have since been addressed by the LMNS Project Team *" She ticked the boxes, but I don't think she did much at all. I certainly didn't see her on the unit. It was post COVID, but even post COVID, she wasn't coming in, she wasn't coming to the meetings.."* and "*despite having the annual payment for the website having just been taken out, she took the website offline, wouldn't give anyone access, took access to absolutely everything, including all of the documents we have, all of our posters, absolutely everything*".

For the MNVP Leads, not being employed means they miss out on employment rights and benefits "*for MNVP Leads who have no employment rights, no support in terms of not being able to take maternity leave when they have their babies"* and "*there's no security in these roles and you can just be gone, and two, if anything happens, to yourself or your family member, there's no annual leave or no sickness or compassionate leave or nothing".* There was also concern that this meant that people might be unable to access training "*MNVP Leads like in Norfolk and Waveney are not employed, so you can't access anything. You can't even access sometimes mandatory training, whereas if you're then employee, it opens up a lot of those".*

The expectations as an ICB that you can have on an individual that you don't have on any sort of contract, that you're not giving any sort of actual professional accountability to, it's unfair to have expectations on that person if you're not going to pay them an appropriate contract and you're not going to equitably support them with things like pension, annual leave, sick pay, supervision, career development and line management and all

of those things that you would expect in a professional role, to then force professional expectations on them.

We also heard that because the leads were not employed that there was confusion about where responsibility for the support and oversight of the MNVP Leads should sit, with some Trust staff feeling it should sit with the ICB and ICB staff feeling that it should be with the Trust "*I would probably say it would sit with the ICB from my perspective*" and "*I think it should sit within the Trust*". The Trusts have put in support should the Leads struggle with some of the things they hear "*they have access to our PMA* (professional midwifery advocate) *service…We also have clinical psychology which we can refer our staff to and we would include them within that if required".* But there was not clarity about how they should be line managed "*We may have interviewed but we are not like an employer. We don't pay for them as such. And then you think, so who is the best person to then line manage? Is that the LMNS who are that little bit sort of further away who have the purse strings if you like, of how they set the budget? Are they the best people to line manage*?"

However, the MNVP Leads themselves appreciated the flexibility that comes with not being an employee "*I don't ever want to be employed. I like the way we work because the flexibility works for me. It means I can work my hours when I want to, and I can flex around my own job*" and "*I personally don't mind the volunteer status and I think the flexibility is really key. So for me it works quite well".* All the Leads fitted their role around other, paid employment, which had to take priority "*it's hard in the sense that this is volunteering and my other job has to come first because obviously that is my security, that is my security job, that's my pension*".

People we spoke to recognised that the MNVP Leads appreciated the flexibility they had with their roles but noted some caution "*They like the freedom that they've currently got with the role, although they don't like some of the volunteer status, they like some of the freedom. And that is going to be the challenge going forward. Because once they become much more formalised roles with more governance and from an employment (whatever that looks like) perspective, they're not going to have that freedom. And that freedom is an advantage to them. But some of that might get lost"* and "*in some areas there have been very long lived MNVP Leads who don't particularly want an employed*

role, prefer it to be a voluntary role, and that's very nice, that's very good, but it's not what the role needs right now".

One person identified that if the roles were employed roles this could be a barrier to some, even though it could make people feel more valued *"I guess if this was a role for people to have where it was more secure, then that would be lovely…. and I think maybe people would feel possibly more valued if it was more shown that we are actually employed. But at the same time, I like the flexibility. I couldn't do the role if it wasn't flexible. So I guess if it was employed and it was more strict, I perhaps couldn't do it and I think a lot of people wouldn't be able to".*

Payment through PPV is also a problem as individual hours cannot be claimed *"PPV has to be paid in full days or half days. It can't be broken down into hours, so they can't be making us do individual hours".* There was also frustration expressed that although they were being paid through PPV the parts of the NHS guidance for reimbursing expenses and paying involvement payments (NHS England, 2021) are not being followed *"the PPV things say to pay the day rate, plus travel, plus childcare. They're paying us the day rate plus travel but have made an agreement with themselves to not pay childcare. So we aren't even paid what the PPV says".*

Levels of renumeration were also flagged as an issue for the MNVP Leads.

> I find it quite uncomfortable when we're told by someone who's getting a big pay rise, paid an 8B (Band) or an 8C (so they're getting that big pay rise) to tell us that we don't need a pay rise. I find that really difficult, for them to try and say that we don't need one. And actually, fair enough, a few years ago when this job was a voluntary role, but now it's a role with a lot of responsibility where we actually have to do things like it's a proper job now, so it does need to be paid appropriately in line with that.

This was also recognised by others *"it's difficult when you've got a meeting and you've got some that are volunteers but on PPV and then you've got others that are employed Band 7"* (NHS pay banding) and *"So they can obviously get access*

to the trust, but the way in which they're paid seems to be a really contentious issue because I think that when they've talked about their responsibilities, they feel like their equivalent might be on Band 7 or Band 8 or whatever", "I absolutely see her as part of our team, but she's not remunerated like we are, no. And the ask is massive. And I don't think it's fair. No, I really don't think it's fair what we're asking" and *"But in terms of, I think the biggest rub that she has, the biggest issue is around the remuneration and the time that she gets to do the job she's doing".*

One person felt that the pay was good but recognised that MNVP Leads were often working more than their hours *"I feel that the rate of pay is very good and I think it depends how much work they do, because if they do a certain number of days, I think that the pay is really good, but I know that they do a lot outside of those hours. So is it fair? I'm not sure"*.

It is the responsibility of the ICB to make sure that there is service user involvement and engagement at both system and trust level. The guidance suggests that for larger systems that there should be separate LMNS and MNVP Leads.

Infrastructure

The guidance refers to the systems and structures that need to be in place for the MNVPs to work effectively, these include operational and logistical support, workplans, and budgets, remuneration and expenses.

Operational and logistical support

Operational support will be needed to support the MNVP Leads in carrying out their role. This support can include support around managing the finances of the MNVP, administrative support, IT, project management, communications, HR including grievances and complaints, managing volunteers, research and data analysis, data protection and training. This can be provided by the ICB or commissioned through an external provider.

The MNVP Leads told us that they did get some support from their Trust, mainly around IT *"the trust digital team help me"* and *"they've (the Trust) given me a laptop, which I haven't had time to get connected because they just handed it to me, and it's not set up for homeworking, so I need to go to the Trust to get it sorted".* Some admin support was mentioned *"I do have someone within the Trust who may help minute stuff, but it's not like I have someone I can always*

guarantee". The Trust staff are aware of this "*They don't have a desk. They don't have a spot, so they can't just pop in and come and see us. It's really difficult*" and "*Very limited admin support I would say because I should have three admin support, now we are down to under one…but we have made sure they've got the right support if they've asked for it, they've got all of the access to their IT equipment we've given them and the training needs that they've sort of gone through with us".* The difficulty of limited resources within the Trust was echoed elsewhere *"I mean we've got our Lead who is doing a lot of the work but we don't have admin support for her. We don't even have admin support in our hospital for a lot of things we do, so we can't provide her with it".*

The guidance states that the ICB will have to make the decision, in partnership with maternity and neonatal stakeholders whether the operational and logistical functions of the MNVPs should be provided by the ICB, or whether to commission an external organisation to host the MNVPs. It is recognised that there are advantages and disadvantages to both options, which was acknowledged when we spoke to the team at Kernow.

"*When an ICB is trying to make a decision as to whether they want to manage their MNVP in house or contract out, these are the sorts of things they need to think about. So, while they will pay that MNVP Lead more if they manage it in-house, some of the other costs they will be able to save on by using existing resources within their ICB and splitting it across areas. Whereas when you contract it out, there are other costs to think about as an initial upfront where you're paying a fee to the company to provide that support. You're paying MVP leads less, but it's a much easier, clearer sort of arrangement because it's there and it's distinct and you know what you're doing. So I don't think there is a right answer; I think there are pros and cons to both options and I think it very much depends on your setup as well, how big an ICB you are*".

Workplans

MNVPs should have workplans in place that are flexible, allowing them to respond to needs of the local services and community and deliver the work programme that is required of them; to listen and represent service user voice, along with meeting the responsibilities from national reports, guidance and policy.

> She's very good at work planning and so we've got a very clear work plan for the next year.

Each of the three MNVPs have stated in their annual report what they hoped to achieve in the following year. Each MNVP appears to have a different approach to planning. *"I also think there is an element of certain areas they're really interested and invested in because they have that personal interest"*

"We (MNVP Leads) tend to have a look at what we've been doing this past year, see what's been working. Obviously the odd thing you do, might not get much or any uptake and then we would look at trying to do something around that, but change the process of what we've done to try and get a bit more engagement. We have certain things that we're given from the LMNS that we need to work on. So those things would be sort of on the list".

"I think in terms of focus, there's a big element of what she wants to do and what she thinks is right and then meeting me, I try and pull her back a little bit because she's quite keen. I'll try and say to her realistically, what is it we can do with the time that we've got with you? What is it we actually need from you that's more important than anything else? So that's where those conversations are with me and my MNVP".

The guidance states that workplans should be coproduced in partnership with representatives from service user voice, the provider trust and LMNS and there should be a commitment to sufficient resource and time to ensure the work plan is of high quality.

The workplans should meet the requirements and responsibilities of the MNVP and use local data from key sources. The workplans should align with the trust and LMNS strategies, along with the ICB Five-year Joint Forward Plan and Integrated Care Strategy and the National Three-year Plan. This can be achieved by coproducing the plan with senior stakeholders from the system.

A Trust member told us about the planning process of their MNVP:

"Our planning is usually based on, we look at the CQC maternity survey, that's a really key sort of informer of our plan, and we pick up the themes through the feedback. So what we do is usually every nine to 12 months get together. I mean, we obviously see each other more, but we usually set aside a whole day to bring some of these different, it will be things that are local and specific to us as well as national drivers such as the Ockenden report or Saving Babies Lives or CNST and bring all those things together. And it is quite a sort of free flow brainstorming session and then come up with some themes, for example, informed decision making and consent, and then some more specific actions as well".

A staff member from a different Trust told us "*I think it goes into their annual reports, what their plans are…, so that's come through as a draft, to look at and then our Head of Midwifery has got a meeting with the MNVP Lead to go through that. So feedback happens in that way".*

The NNUH MNVP used their sub-group approach to manage their workplans "*That's our subgroup approach. We consider that our work plan. So as a multidisciplinary team, we agreed our subgroups in line with service user feedback, priorities, trust improvement priorities, and essentially what we felt we had capacity to work on. We'd have limitless subgroups and limitless projects if possible, but we needed to hone it down. So those areas of priority each have a subgroup; we consider that our work plan*".

The workplans should be reviewed and kept updated in response to the work of the MNVP, thinking about any work that may be outstanding or ongoing, but also responding to local feedback from outreach and engagement activity. Trust staff told us that they thought the work plans were flexible and that the MNVPs could be responsive "*it doesn't seem like there is a set work plan, but it's much more responsive and subgroups are set up, but also that things are sort of thrown in at the last minute*" another told us "*it's really dynamic, but it will be kind of in partnership, and in response to feedback really".* Another Trust staff member told us how the work was monitored "*She puts the minutes of our meetings together and she puts actions of what we are doing. She puts it in green just to say that we're actioning this, what we are doing about it and if there's an action that's been highlighted and we haven't done anything with it, she sort of brings it to the group, we can say we haven't done anything with this one, what are we planning to do? So we've got an action plan of what we've discussed… what we're planning to do and a timeframe for those kinds of things".*

The ICB has a responsibility to provide funding for the delivery of the workplan, therefore the funding and workplan will need to be aligned. MNVPs should seek agreement from the ICB on the content and activity in the workplans. The guidance sets out what should happen if agreement is not reached.

A Trust staff member told us "*I think there is a work plan in place and it went through the LMNS committee, etc. It was actually quite prescriptive in terms of hours, what they will be attending, etc…The planning is very clear*". Another was concerned that the plans were not appropriately funded or realistic "*I think if it's properly funded with a proper work plan, a proper set of objectives for the whole year that actually are realistic…they do a work plan with the LMNS and sometimes it really is not as realistic as it could be".*

There was frustration expressed that planning was hindered by changes in personnel and late confirmation about the levels of funding "*because I am often continuously losing senior staff, it makes it really hard to plan anyway. But when our funding is never (agreed) the ICB can be very slow to confirm it*" and "*we have to plan, so we have our forward plan, which isn't really included in there, at least I haven't included it in there because I don't know how much of a forward plan we can even make not knowing our budget".*

There were some concerns expressed about planning "*foremost of these are the issues from the Trust perspective, can you plan over the next three months, share with us what your plan is to try and engage on those? Then actually we know what feedback we should be expecting and what they want to do on a monthly basis or whether that's after each (listening) event. I feel like then at least we'd have in a plan of what to expect and how we would expect it. But we don't have that at the moment"* and "*We are lacking in forward planning. That's an issue. It's a very much fighting fires approach, and it's, oh, we're doing this project on pelvic health. Can you join the meeting next week?"* The latter concern expressed about demands from the LMNS.

Budgets, remuneration and expenses

The ICB has to provide the funding to deliver the workplan and support the provision of the operational and infrastructure support along with the engagement activities of the MNVP. The budget setting for this should ideally be carried out with the key stakeholders.

We found that the MNVP Leads were asked to set their own budgets, which people were uncomfortable with "*The budget thing in particular is horrible because nobody has any oversight. They ask me to set the budget for myself*" and "*I had to write a budget based on what we could do with what we had*".

One Trust member expressed concern that the budget included time for people who had been paid through unallocated hours in the previous year, but would not be covered in the next year's funding allocation. The potential impact of this was that the level of service previously provided would not be able to continue "*they are now in fear that they won't be able to provide that level of service anymore"* which was a concern for the trust staff member.

The ICB has a number of ways in which they can make the funding for the MNVP available, such as providing it to the MNVP Lead to manage (where the MNVP Lead is an employee), through a contract with a third party organisation, providing in-house services or paying individuals directly. The ICB can use one or a combination of these methods. The MNVP Leads should be able to easily access funds that cover the basic expenses that allow the MNVP to operate.

Budgets should include the leadership roles, operational support and membership expenses. There should also be funding for engagement activities and reasonable expenses for MNVP members, such as travel, accommodation and subsistence and childcare.

> I just think it needs to be funded properly so that they can take the time to do the things.

We looked at the issue of employment and payment of the MNVP Leads in the Leadership section. The issue that has frequently arisen is the budgets for the MNVPs only allow for limited hours of the MNVP Leads. Given the increasing demands of the role, the budgets are likely to need to cover more hours *"I think one of the challenges is the remit and the expectations on their time…they've been a victim of their own success, and I don't mean our people specifically, but the MNVPs (nationally), the Ockenden Report recognises the importance of*

them, therefore there are essential actions related to them. And actually, if you add up all of the essential actions that far exceeds the time that they have allocated and are paid".

The MNVP Leads told us about the pressures of trying to manage their limited hours "*That will be bullet point number one on your findings for all of us, I could tell you that now, and it's actually I do need more than four days a month*" and "*If I was appropriately paid and paid for all the hours that we needed to do for the job, it would be much less frustrating. But knowing that we're having to not do everything that needs to be done is really difficult*". One lead told us "*I have hummed and hawed whether I'll be able to keep going for ages if it does keep upping and there's more and more meetings…I think we've got fourteen additional meetings we need to try and fit in or something crazy like that".*

One person told us that they thought the budget did cover what it needed to "*I believe most of the time it does. I think our budget has been, last year's was a good amount and there's also a little bit of scope if I do three days instead of four and then we've got that extra money to be able to, so that really helps because of the flexibility".*

Trust staff recognise the pressures that the MNVP Leads are under in respect of their hours "*she's very proactive within the communities trying to get feedback, I think the rub comes from her perspective is that she's doing an awful lot of hours and expected to do an awful lot. She comes to as many meetings as I can get her on. Realistically, it's very hard, isn't it, when they're only paid for a certain amount of hours to do the kind of work that we're asking them to do*" and "*I think the leads work well from my perspective, the leads work well together. I just think that they need to have the resources around them to do that lead role. It probably takes more hours than what they're being funded for, so they probably need to have that paid time increased so that they have the hours they need to do that*"

One Trust staff member felt that the difference in funding between the three MNVPs did not take into account the amount of work the MNVP Leads had to do "*But actually when we then look at the hours and the attendance requirement, which is very clear from the framework and from the LMNS, actually the input is more or less should be very similar. So despite their bigger unit, the input should be the same. They should be attending the same meetings, they should be delivering the same amount of listening events and things like that*".

> *I think their portfolio is huge…They are underfunded, and it's not just the financial recompense for doing things. It's the time.*

People also recognised that there are limitations on the funding available "*Well, we don't have the bottomless pit of money. Actually, we want to pay. We want to pay you for the work that you do. We don't have that and the LMNS don't have that"* and *"I think that the ask that we have in terms of the meetings, it's so useful to have their input at lots of our meetings. But actually, if she came to every meeting that it might be potentially useful for to have her input in, that would be all of her hours for the MNVP. I think that balance is really, really difficult and we need to kind of constantly look at that to get it right"*.

There was also acknowledgement that MNVP Leads often work more hours than they are being paid for "*We've already done all of our hours this month and we're still doing other things; we just don't have the people at the moment*".

The fact that there is no guidance about appropriate levels of funding for MNVPs does not help "*no one has ever allocated or said it's going to cost X amount of money for an MNVP and neither will we get that from the central team. So, you know, ICBs will allocate what they feel is appropriate for those roles. I suppose everyone always, everywhere, is going to say we don't have enough money because we generally don't*" and this lack of guidance has created large variance in funding "*there is a lot of variance in funding across the country, indeed in fairness into what being allocated to MNVP*" and *"I feel like there's pressure now to sort of look at our budget and look at how we work. Because a lot of other ICBs have put a lot more money into it. And I'm not saying that's the answer"*.

There was also concern expressed about the lack of funding for neonatal work "*there's a lot less, there's no funding. LMNS don't think of the N in the LMNS and a lot of the funding and the support goes to the maternity, not to neonatal. So we are trying our best in shouting as much as we can at every meeting that we go to, but it doesn't always get heard"*.

National models

Kernow MNVP is highlighted as an example of excellent practice within the guidance. We spoke to the MNVP Lead of Kernow and the host organisation to find out more about the way they work and what they consider to be the features of their success.

Unlike Norfolk and Waveney, Kernow MNVP has one ICB and one provider Trust "*Cornwall and the Isles of Scilly is the ICB. Geographically the mainland is about 3,500 square kilometres and then we have the offshore islands, the Isles of Scilly, but we only have one acute provider. We have one ICB, one provider and one local authority, which makes it easier. All the boundaries of those sort of align*".

The provider Trust has a number of maternity services "*we have one obstetric unit, which is in Truro at our main acute hospital and we then have three freestanding midwifery-led units, one of which is on the Isles of Scilly and two on the mainland, but they're all run by the same provider Trust*".

Kernow MNVP was established in 2018 following the publication of Better Births (National Maternity Review, 2016) "*it launched officially in April with a chair and was very much that sort of traditional model of a separate committee that was chaired by a service user voice chair and brought service users and professionals together and would meet on a quarterly basis*". The difference in Cornwall was that the Chair was funded "*at that point Cornwall was already a little ahead of the game because when they launched that they launched it with a £10,000 honorarium is what they called it at the time. So the Chair was contracted to do up to 10 hours a week for £10,000 a year*". The Chair was hosted in the then CCG (Clinical Commissioning Group, which were in place before ICBs) but for operational reasons this wasn't working well and so the post was moved into Healthwatch Cornwall under a Memorandum of Understanding.

The pandemic had a huge impact on the work of MNVP. The current Chair came into post in December 2020. At this time, she was being paid through the PPV policy. Healthwatch Cornwall also employed other staff to support the engagement work "*we had some engagement and project officer support that were employed through Healthwatch to deliver those sort of support functions*". Following the pandemic it seemed appropriate to review the work of the MNVP and what it was trying to achieve

"Once we sort of came out of all of that COVID crisis, that's when we started that review work. We all recognised that the current situation that we had and how we were delivering the MVP, wasn't accessible, wasn't sustainable, wasn't equitable, wasn't fair. We needed to do that sort of review of actually what is it the ICB wants the MVP to be? What is it they want them to do? What is it they want them to deliver? And then what do we need to be able to effectively do that? So, we did that work with the ICB, with the provider, with Healthwatch, sort of worked through it, kind of pulled together job descriptions, worked out what we think we need and then were able to secure some funding from the ICB initially. I became employed in the lead position with Healthwatch Cornwall in May 2023".

This work took place before the NHS England guidance was published and this is why Kernow features in the guidance as they had already undertaken a thorough review of their work.

The MNVP has a team to deliver the services "*we have what's called a Project and Coproduction Lead; she does a lot of , as it 'says on the tin,' project work. I do a lot of the strategic stuff, the governance, the quality surveillance work and she takes the lead on a lot of that infant feeding work, the mental health, the pelvic health work streams, the sort of public health work with the local authority, all of that kind of work. Then we have an Engagement Lead who is out in the community every week talking to families. And we have a Volunteer and Project officer who does a lot of that volunteer management and a lot of that sort of admin and project-based support. That is our sort of core employed team that we have now.*

When we spoke to the MNVP Lead, there was not a Neonatal Lead, however plans were underway to address this "*we're out to recruitment; the advert closes on Sunday and we've got interview set for the 4th of February. We have been including neonatal in our in our work for a while. I am currently covering maternity and neonatal; going to all the neonatal governance meetings and guidelines meetings and everything, which is in no way sustainable. With the spring budget funding obviously that came down last year, we were able to coproduce a plan with the ICB on how to spend that money, and that has been to go out to recruitment to employ a neonatal lead who will sit alongside me and be able to lead that neonatal programme of work*".

Following a procurement process the MNVP became hosted by Evolving Communities CIC. The contract is in place until March 2026.

The Kernow MNVP team are all part-time but have over two fulltime equivalent posts in hours "*my contract is 24 hours a week, I obviously have my Project and Coproduction lead who is also 24 hours a week. I have my engagement lead who's 22½ hours a week and my Volunteering Project Officer who's 15 hours a week. And then the Evolving Communities team provides things like comms support, there's some research support, some extra like business management, the budget management, that signing off of invoices, you know, all of those kinds of things".*

We asked the MNVP Lead for Kernow what she felt had been key to the success of their MNVP. She told us that "*I think initially, if we think right back to the very beginning of when, you know, we were starting MVPs, in all honesty, it came down to one person. It came down to a maternity commissioner that felt really passionate about the work of Better Births and saw the value in Better Births around bringing the user voice in and was able to make that initial decision that they were going to invest in that*". But she also said that:

"You know if you asked the Director of Midwifery or the Clinical Director or the Chief Nurse at the provider or you know the senior managers within the local authority, they would all tell you, they absolutely could not imagine functioning without a really well embedded MNVP now, because it is just business as usual for one of us, or a representative, to be in all of that work. They don't make any decisions without that user voice being considered. But it's taking that the first step, which is always the hard bit. And I think often in with MVPs historically, what we have found is we have an expectation for MVPs to do the work and prove their value before somebody will actually invest in them and pay them appropriately.

What this means

All the MNVPs showed great commitment and passion for the work that they do to engage with their local service users. There is almost a reliance on this commitment as the hours that they are paid for do not cover the increasing demands of the role, causing some MNVPs to work hours that are not paid.

The MNVP Leads are knowledgeable about the local area and needs of the service users, through the good engagement with the local communities. There is a desire to engage more with vulnerable groups and those who experience health inequalities, but these efforts are hindered by the limited hours available.

The Neonatal Voices work is still developing and the Neonatal Leads are less confident in their roles. There is a risk that the voices of neonatal service users can get swamped by the stronger and greater number of maternity service user voices. Having a Neonatal Lead with lived experience of neonatal care is an important factor.

There is a lack of clarity about the roles and responsibilities between the regional and local teams and this could lead to a silo approach and blocks off a potential source of support, especially for the Neonatal Leads. Solutions to some of the issues that are being grappled with in Norfolk and Waveney could be found through discussion with colleagues from the region.

The MNVPs have contributed to some excellent pieces of work that have led to positive changes in services. The need for these projects were identified through feedback obtained through outreach, other forms of engagement and the use of data.

The role of the MNVP Lead is rapidly changing and with these changes come increasing demands, including more attendance at meetings and an increasing need for a strategic approach. Currently the MNVP Leads are trying to meet most aspects of the work of the MNVP, but there is potential to develop more of a team approach, with a clearer separation of responsibilities.

The current allocation of funding for the MNVPs barely covers the hours required to do this important role. The level of pay, through the PPV rates, does not match the level at which some MNVP Leads expect to be paid.

The fact that the MNVPs are not employed does not appear to be in line with the guidance. Whilst the flexibility of this may suit the current MNVP Leads, it poses risks to the Trusts and leaves the MNVP Leads in a vulnerable position. The guidance clearly identifies employment through the ICB or a third-party organisation as the options. Employment by the Trust is not an option.

By not employing the MNVP Leads there is no mechanism for ensuring that the role requirements are met or that any potential issue around performance cannot easily be addressed. It also means that the MNVP Leads do not receive adequate or appropriate support for the difficult tasks they can undertake. It would also allow for more consistency with reporting and work plans.

The variation in the funding allocated to MNVPs is a reflection of the priority given to this work – we heard that part of the reason for the success of Kernow MNVP is due to the commitment to funding the work. The ICB must decide what priority this work is given in Norfolk and Waveney and then decide on the budget to support the work.

Recommendations

From the findings of this piece of work we have made several recommendations

1. The existing good work of the MNVPs should continue

- The MNVPs engage well with their communities and this is their strength. The recommendations below should support their plans to grow their engagement with more vulnerable groups and widen their reach.
- The MNVPs use data well to support the need for change and this should be supported.

2. The ICB should reconsider the level of funding needed to properly undertake MNVP work

- Consideration needs to be given to the number of hours needed to meet the requirements of the guidance, in particular attendance at key meetings and the continuing engagement with service users.
- The roles of the MNVP Leads should be looked at in response to the demands of the NHS England guidance, with the role becoming more focussed on representing service users' views, which are gathered by others, and leading the work of the MNVP.
- Additional roles should be developed that have responsibility for leading the engagement with service users.

3. The MNVP Leads and key team members should be employed

- The Maternity and Neonatal Leads should be employed posts within the ICB or a third-party organisation. They should be remunerated at a level that is appropriate for the leadership requirements of the role.
- Any roles that are developed around leading engagement with service users should also be a paid role, but this should be at a lower level to the Maternity and Neonatal Leads.
- There should be an appropriate recruitment process for any future staff, with opportunities advertised through the MNVP social media, websites and through wider stakeholders.
- All MNVP staff and volunteers should receive appropriate training for the roles they are undertaking.

4. Consideration should be given to the Neonatal Leads working together across the system

- Helping the Neonatal Leads to work as a team across the three Trusts could support their development and allow a stronger neonatal voice. This would be easier if Recommendation 3 is actioned.
- Work that has to be undertaken could be given to one of the Neonatal Leads to lead on, reducing duplication and sharing the workload.

5. Seek ways to improve engagement with region and across the system

- The guidance is clear about the need to engage outside of the individual Trust. Local MNVPs and Regional colleagues should continue to develop their relationship.
- Working with colleagues from the region and across the system will enhance learning.

Response from Norfolk and Waveney Integrated Care Board

NHS Norfolk and Waveney Integrated Care Board (ICB) would like to thank Healthwatch Norfolk for their valuable work in engaging with our Maternity and Neonatal Voices Partnership (MNVP) Leads, staff, and stakeholders across our Local Maternity and Neonatal System (LMNS).

This report showcases the outstanding work our MNVPs do to connect with local communities, tackle health inequalities, promote inclusivity, and co-produce solutions that support the delivery of safer, more compassionate, and personalised care.

While the core purpose of our MNVPs remains to ensure that service user voices and experiences are used to shape the development of maternity and neonatal services, their role has evolved considerably in recent years. MNVPs are now recognised as strategic partners, actively embedded within trusts' governance and quality improvement frameworks.

In 2023, NHS England issued guidance for ICBs on commissioning MNVPs that are fit for purpose. This presented an ideal opportunity for the ICB to undertake a comprehensive review of the current MNVP model to ensure it aligns with national expectations and ensures long-term sustainability.

The ICB has developed a set of options to deliver against the above recommendations. The options paper considers recent national developments relating to the revised model and footprint of ICBs. The next step is to consider the options and agree the best way forward. We will then update everyone involved in the Local Maternity and Neonatal System, as well as Healthwatch Norfolk, on the actions we will take in response to this report.

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Appendices

Appendix One – Interview Questions

MNVP Lead questions

Thank you for your time today, we appreciate your help with this especially knowing the pressures that you will be under.

As you are aware Healthwatch Norfolk have been asked to undertake an independent review by the Senior Programme Manager of the Local Maternity and Neonatal System (LMNS) of the of the three Maternity and Neonatal Voices Partnerships, to see what is working well and what the challenges are in meeting the NHS England's November 2023 guidance.

Our approach to this is to interview key stakeholders to assess strengths, challenges, and potential solutions and to undertake research about current national models to see how they compare.

Do you have any questions?

Would you be happy to give your consent to me recording this interview? It would make it easier for me to ensure that I am accurate in reflecting our conversation – it will also help me to capture direct quotes. The recording will be transcribed and then deleted. All transcripts will be destroyed once the project report has been completed and published.

Do I have your consent? Thank you.

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1. Could you please start by confirming your name, which MNVP you are part of / link with and your role?

2. Are you remunerated for the work you do and how is this calculated and paid? (contracted hours, timesheets etc).

3. Could you give me a bit of an overview about your role and how you go about reviewing and improving maternity and neonatal care?

4. How do you ensure that you are meeting your roles and responsibilities as an MNVP Lead?

5. What data do you use and / or collect and how is this used to support your work and how is it reported?

6. Can you tell me about the planning process of your MNVP, how often plans are made and what happens to those plans?

7. Does your MNVP produce and publish an annual report, which highlights your work and what has been achieved? If so, where is this published?

8. What resources do you as an MNVP have to support you? (Training, budget, admin support, etc)

9. What steps does your MNVP take to hear the experiences of women and families that use your maternity and neonatal services? (the practical steps to do this?)

10. What does your MNVP do well in getting the views of women and families?

11. What are the challenges to this and how could this be improved?

12. How do you use the views that you gather to improve maternity and neonatal care? Could you give me a recent example of how something has changed in response to feedback?

13. What is the relationship between the MNVP and the Trust? Do you as a group feel heard and valued and your recommendations implemented?

14. What would you say is working well in your MNVP in addressing health inequalities? (ethnic minority groups, most deprived, disabilities including LD and LGBT+) Are you able to give me any examples of success/ good practice in these areas?

15. What is not working so well? How could this be improved?

16. How does your MNVP engage with the wider community, including engagement with the VCSE? (HV clinics, ante-natal groups etc)

17. What do you feel works well with community engagement and what are the challenges?

18. How do you communicate the work and achievements of the MNVP within the trust and to the general public?

19. What would you say is working well with communication?

20. What is not working so well and how could it be improved?

21. Who is responsible for the content of and updating the MNVP website?

22. What do you see as the key challenges of your MNVP and the barriers to your work?

23. Is there anything that you think could make a real difference to the work of your MNVP and its success?

24. Is there anything you would like to add?

Thank you so much for your time.

Appendix Two – Kernow MNVP Lead job description and person specification

Job description

Job Title: MNVP senior lead (expert by experience)

Salary: £48,526 - £54,619 (NHS Band 8a) per annum for 35 hours, pro rata for hours worked

The lead for MNVP is responsible for delivering the agreed objectives of the partnership and is expected to use their influence to drive the delivery of highly effective and visible outcomes.
The senior lead will represent the MNVP at local and national maternity and neonatal meetings and events and provide independent challenge and scrutiny based on evidence gathered from parents/carers and professionals from the projects.
As the senior lead for service user voice, you will lead the organisation to identify and engage with pregnant women, parents and their families at every level of change to enable authentic co-production. You will lead and enable the MNVP to deliver projects focused on improving the quality of care provided for maternity and neonatal service users through the lens of lived experience; you will use your lived experience to identify key strategic barriers to providing high quality care as defined by women and families and co-create solutions.
This will include the co-production, with other team members and experts both within and out with the team to produce supporting guidance, tools, and technologies. We are particularly keen to consider how we can best reach groups who are marginalised and how we can co-produce with these communities in a way which is meaningful and authentic to them.
Main responsibilities of the role include:

Leadership

- Build strong influential relationships with providers, commissioners and local system partners at all levels, including cross border working, to break down barriers, ensure the voices of families are heard and the programme priorities reflect the views of the community.
- Support the system to recognise and understand the voices of families and use the intelligence gained to significantly influence quality, safety and productivity.
- Act as a leader for change ensuring that all activities and plans are effective and fresh, in line with current evidence, thinking and practice and reflective of intelligence gained through engagement.
- Recruit and manage a team to deliver on specific the agreed workplan.
- Represent and promote service user voice at board level within the local system, regionally and nationally.
- Chair relevant multi professional meetings.
- Use intelligence gained through the work of the MNVP to support senior leaders to develop operational and strategic plans that contribute towards the agreed transformation and quality surveillance deliverables.
- To build robust networks regionally and nationally to feed into regional and national training and engagement events.

- To be fully up to date with national reports, guidance, and policy to ensure work locally aligns and delivers the required outcomes.
- Lead on responding to statutory, national reports and guidance, ensuring KMVP and service user voice contribution is centred.
- To influence national and regional policy and represent the voices of the local population and services at national level.
- Champion the voices of marginalised and disadvantaged groups at all levels and influence strategic plans to ensure equity and accessibility of services.

Planning, development and delivery

- Manage and deliver on time and within budget, complex multifaceted engagement and transformation projects for maternity, through a standardised system wide methodology process including setting goals, objectives, resources, milestones and measures of success which deliver significant change and sustainable improvement.
- Enable transparency across the quality and safety surveillance agenda by attending and meaningfully contributing to local governance, audit and safety meetings. Bringing the voice of the service user to the heart of the quality and safety agenda.
- Using the information and intelligence gained through engagement to influence and provide critical friendship.
- Work collaboratively across the system and with VCSE organisations to ensure your team are able to engage with diverse groups of families so you can present an accurate and representative view of the local population, including voices from those communities that are disadvantaged or marginalised.
- Develop and support an ongoing plan for engagement that is responsive to the needs of the system and ensures coverage of the whole geographical area.
- Ensure that the relevant boards and committees are presented with regular updates and reports as required to provide assurance on the function of the MNVP.
- Report regularly on the intelligence gathered within the community, sharing the voices of those using the service and ensuring feedback is heard by senior leaders across the system.
- Ensure that all transformation projects and safety initiatives are built on a solid foundation of engagement, transparency, and support.
- Work with project managers and research analysts to develop relevant, timely actionable metrics and measures to track performance.
- Ensure that evidence-based practice is fully and effectively deployed where possible in all projects and is informed by diverse, recent feedback and involvement of service users.
- Apply creativity and innovation techniques to the projects including learning from non healthcare sectors especially to ensure accessibility and diverse representation.
- Through supporting others, ensure efficient management of projects of work ensuring the maximum return on investment and the delivery of excellence, in line with the values of the integrated care system.

- Ensure a focus on objectives which deliver the agreed deliverables of safer, kinder, more personalised care for all.
- Ensure alignment of projects with the wider transformation and quality surveillance agendas, locally, regionally, and nationally.
- Scope and support the development of business cases as and when required to secure investments required to achieve sustainable change.
- Lead the development of an organisational timeline of improvement projects which will deliver over the next 12 months.
- Participate in board level governance and safety meetings as appropriate in order to comply with NHS guidance.

Communication and engagement

- Identify, involve, and incorporate the views and needs of patients, the public, NHS staff, stakeholders and ensure their voices influence all stages of work.
- Liaise regularly with system partners including NHS providers, local authorities and VCSE partners to maximising co-operation and multi-agency working.
- Support the development of ongoing communications for social media, website and printed materials to engage and inform diverse communities.
- Lead on exploring innovative engagement tools and techniques to reach and communicate with diverse communities.
- Communicate and present highly complex information to a wide range of internal and external stakeholders using formal reports and data analysis to track and communicate trends and themes.
- Where necessary, have robust and challenging conversations with providers, championing the voices of families and using this intelligence to positively challenge where appropriate.

Health and care workforce development

- Develop and enable, involvement of MNVP and service user voice in staff training programmes and culture development in line with core competency framework.
- Lead the ongoing improvement of the MNVP through staff engagement
- Working with the senior team within the provider trust to develop the capacity and capability of the organisations to deliver on the required transformation and safety agendas.
- Maintain an understanding of, and contribute to, best practice nationally and internationally to support the strategic development and improvement of maternity and neonatal services.
- Provide leadership and development to Transformation, clinical leaders and project management staff working on projects as required.

- Develop and promote best practice for involving and valuing service user voice in both transformation and quality surveillance across the organisation. Supporting continued culture development to embed a safe learning culture.

System governance responsibilities

- Report to governance committees and support effective governance to support learning from risk management systems, investigations, reviews, processes, and audits to be shared, embedded and used to continually improve practice, mitigate risks and improve patient safety.
- Provide independent transparency and critical friendship at senior level to support system assurance that learning is shared and governance processes are robust.
- Support and champion a safe reflective culture with all organisations. Creating a psychologically safe space for everyone to speak openly and feel heard.

Accountability and project governance responsibilities

- Ensure compliance with information governance, confidentiality, and data sharing requirements.
- Hold responsibility for finance and budget reporting for the MNVP.
- Maintain professional relationships and positively challenge where appropriate, while functioning in a sensitive and responsive climate.
- To create an inclusive working environment where diversity is valued, everyone can contribute, and ensure we meet our duty to uphold and promote equality.

Person specification

Senior lead (KMVP)

	Essential	Desirable
Education qualifications:	Educated to degree level in a relevant subject or equivalent level of qualification or significant relevant previous experience.	
	Commitment to continuing professional development.	
Experience/ knowledge:	Expert by lived experience in maternity support services from ante-natal to two years.	Experience leading and facilitating co-production and involvement in healthcare settings, social care, or voluntary/ third sector organisations using innovative, inclusive tools
	Extensive experience of national, regional and local drivers for transformation and quality surveillance across Maternity and neonatal services	
	Experience of leading on partnership working together with a wider range of people from different backgrounds and organisations to influence, plan and implement a programme of transformation and quality surveillance work.	

	Essential	Desirable
	Understanding of how care and support is delivered via maternity, neonatal and parenting support services across the pathway.	
	Understanding and experience of leading on multifaceted programmes of work	
	Proven ability to work under pressure, prioritising workloads and meeting deadlines	
Skills/personal attributes:	Excellent planning and organising capabilities.	
	Excellent time management and problem-solving skills.	
	Ability to develop an inclusive, team-based approach to problem solving and decision-making	
	Ability to support and manage a team of people to work effectively and achieve agreed outputs	
	Ability to respond to changing demands and able to identify a need to reprioritise	
	Ability to work on own initiative, organising and prioritising own workload to tight deadlines	
	Knowledge of Microsoft software applications (outlook, word, excel and PowerPoint etc.)	
	Ability to understanding the link between strategic decisions and direct patient experience of care	
	Ability to understand complex clinical information and policy and translate into accessible discussion to support diverse involvement	
	Attention to detail and accuracy with the ability to transcribe accurately	
Interpersonal skills:	Works well with others, is positive, compassionate, and helpful, listens, involves, respects, and learns from the contribution of others	
	Well-developed delegation, people and workload management skills Well-developed verbal/written communication skills	

	Essential	Desirable
	Ability to prepare and produce concise, insightful communications for dissemination to senior stakeholders and a broad range of stakeholders as required	
	Ability to communicate complex information to different stakeholders internally and externally	
	Experience in managing challenging conversations with a variety of stakeholders	
	Demonstrate willingness and ability to challenge existing practice	
	Ability to hold space for multiple, contrasting opinions and worldviews while maintaining safety for marginalized groups	
Values and behaviours:	Commitment to improving quality and the outcomes and experiences of women and families who use maternity services	
	Recognises and understands the benefits of co-production and involvement in improving the quality of care received by women and families	
	Champions and actively encourages diversity and difference in the workplace	
	Ability to make a connection between their work and the benefit to patients and the public	
	Actively develops themselves and supports others to do the same	

Appendix Three – Norfolk and Waveney Roles and Responsibilities

MNVP Leads and Co-Lead

MNVP Lead and Co-Lead role and responsibilities

Role:

To lead the MNVP in seeking out and engaging with local families about their experiences of maternity and neonatal services, sharing learning with Trusts to influence improvements and support the co-production of services to meet the needs of the population they serve.

Responsibilities may include:

- Act as the main point of contact for the MNVP
- Lead and manage the annual MNVP programme of work, work plan development and budget allocation
- Actively encourage the involvement of all communities, including bereaved families, and populations most at risk of health inequalities including those living in areas of deprivation, from black and minority ethnic backgrounds and with protected characteristics.
- Conduct regular outreach and engagement into the community, reflecting the Trust footprint
- Organise and lead regular formal MNVP meetings, ensuring all stakeholders can contribute
- Manage regular communications to support engagement and share information with local communities
- Recruit and induct volunteer service users
- Ensure the MNVP is compliant with GDPR and local governance systems
- Contribute to relevant Trust, LMNS and other maternity and neonatal meetings to gain oversight of maternity experience, improvement projects and ensure service voice representation.
- Share regular feedback learning and outcomes with Trusts to influence improvements in safety, quality and experience and support the co-production of services to meet their needs.
- Put in place appropriate risk assessments, safeguarding procedures, escalation processes and training including trauma-informed approaches for all MNVP members undertaking outreach and engagement activities
- Attend Trust inspection visits such as CQC and Fifteen Steps
- Support neonatal service user representation by developing relationships and sharing regular feedback with the East of England ODN PAG

Core meeting responsibilities

- Clinical governance
- Safety champions
- Maternity senior leadership
- CNST
- CQC
- PQSM
- Local projects according to Trust need
- MNVP/ LMNS
- LMNS Programme Board (on rotation)

Useful information

- MNVP email address
- MNVP website address
- Social media accounts
- Trust website
- LMNS website
- ICB website
- MNVP (national) website)

Key contacts and support

Contact	Contact details	How they can help
Director/ Head of Midwifery Name	**Email/ telephone**	• Introduction to the maternity team • Meeting attendance • Support with new projects/ initiatives
PMA midwife Name	**Email/ telephone**	• Supervision
MNVP leads Name Name	**Email/ telephone**	• Collaboration on overarching projects / shared working • LMNS Board updates • Processes and procedures
Volunteer Office Name	**Email/ telephone**	• Recruitment queries • Mandatory training • IT queries and equipment • Expenses • ID badge
Trust Comms team Name	**Email/ telephone**	• Out of hours queries and issues
LMNS Name	**Email/ telephone**	• Invoicing and budget queries • Support with new projects/ initiatives • Training requests

Trust Roles and Responsibilities

Trust role and responsibilities

Trusts should ensure:

- MNVPs have appropriate administrative support and access to adequate IT equipment
- MNVPs are embedded in decision-making and have strategic influence
- MNVPs are involved in quality, governance and co-production when designing and planning the delivery of maternity and neonatal services
- Learning and feedback collected by MNVPs is acted upon and themes and actions are monitored by the senior leadership team.
- Meeting minutes and action logs can demonstrate evidence of service development resulting from co-production between service users and staff
- Service user voice is embedded in training by consulting with and involving MNVPs in the co-design of training programmes and delivery of educational activity.
- MNVPs are supported to develop and maintain relationships with senior leaders within maternity and neonatal services
- MNVPs are invited to attend key strategic meetings to bring together intelligence and influence decision-making
- MNVPs can be "critical friends" to the Trust's quality and safety agenda through governance structures including safety champions, guideline committees etc.

MNVP core meeting involvement/ updates

- Clinical governance
- Safety champions
- Maternity senior leadership
- CNST
- CQC
- PQSM
- Local projects according to Trust need
- MNVP/ LMNS
- LMNS Programme Board (on rotation)

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