

**One Year of the
Maternity and
Neonatal Independent
Senior Advocate Pilot
in the North East and
North Cumbria**



Your Maternity and Neonatal Independent Senior Advocates

As we come to the end of the first year of the Maternity and Neonatal Independent Senior Advocate Pilot we have taken some time to reflect on how things are progressing, what we have heard and learnt and how our time has been spent.

The service was launched in March 2024, after a six month period of recruitment, training and preparation.

Headline messages

- We have a team of three advocates, Annette, Ellie and Jan
- We are working with 6 families (7 referrals, 1 non-engagement, 1 ineligible)
- We have referrals from 50% of Trusts in our region
- Hundreds of eligible families have not been referred to our service
- We share what families have told us and what our advocates have observed
- We make suggestions for increasing referrals
- We outline the work our advocates have undertaken.

Who we have worked with

Since the service launched six months ago, in March 2024, we have had contact with 7 families. One referral did not meet the adverse incident criteria for inclusion in the pilot. We were able to provide them with independent advocacy from elsewhere in our organisation.

Of the 6 families who our advocates are currently working with, 3 relate to neonatal deaths, 1 to stillbirth, 1 to a neonatal brain injury and 1 to a critical care admission.

Whilst it is early days for the service, feedback has been positive and one family whose baby died before the service was launched have fed back how useful the support would have been to them earlier on.

Given the small numbers involved we will not provide detail in relation to each case and have worked to ensure people's experience is reflected in this report, whilst maintaining their anonymity. Consent has been sought for the inclusion of direct, anonymised quotes.

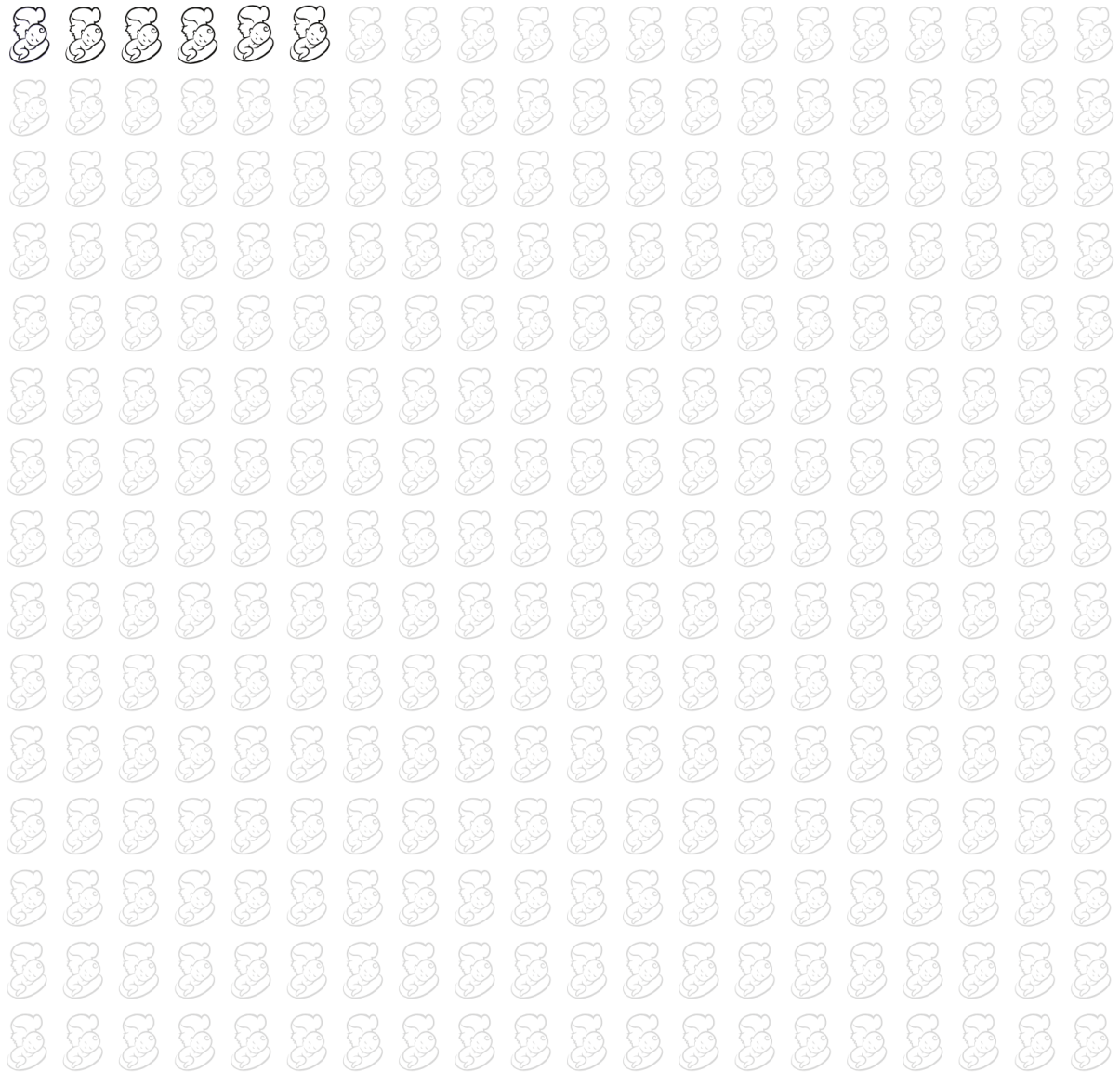
We can report that the 6 active referrals cover care provided by 4 Trusts. This means there has not been a single referral from 50% of Trusts in our region.

Families have spoken about the benefits of having someone whose purpose is only to be on their side. Practically, they felt having the advocate present in a meeting reassured them that staff would be transparent and honest.

We have also heard that families are overwhelmed with the number of people they need to communicate with. Having an advocate to help navigate and take on some of this communication was helpful.

"Thank you again for all your hard work. It makes a huge difference" [Family member]

Where are the referrals?



We have extrapolated Q1 2024-25 data for this diagram (see below). There were 60 families eligible for referral to our service in Q1, this diagram combines those numbers with the previous calendar year (assuming 60 families per quarter).

Of a possible 300 families, only 6 have been referred to our service.

In terms of eligibility, there is no cut off period for when an adverse outcome has occurred, we could therefore assume the number of families eligible for our support is even greater.

Q1 data 2024-25

Adverse outcome	Potential referrals	Family declined referral	Referrals received
Stillbirth	27	0	1
Neonatal death	18	0	1
Maternal death	5	1	0
Unplanned hysterectomy	1	0	0
Unplanned ITU admission	5	0	1
Neonatal brain injury	4	0	1
Total	60	1	4

Our service went live at the end of 2023-24 and therefore all the families who suffered an adverse outcome in Q1 of this year were eligible for our support.

One family declined a referral being made, 4 families were referred into the service and are now working with our advocates. The remaining 55 families, or 92% of those eligible for support, have not been referred.

All Trusts in our region experienced adverse outcomes in Q1. Due to the small numbers we have not broken down referrals by Trust, but we have only received referrals from half of Trusts.

Why are referral numbers low?

It might be the case there is little or no uptake by families because they have been informed of the service but decided that it is not for them. Although, if that were the case we would anticipate those choices being reflected in the data collected relating to families declining a referral.

We anticipated that referrals would be low at the start of the pilot, however we have growing unease that families are not being supported to access our service.

"In one case, there was a lengthy delay in receiving full referral information. The care crossed two Trusts, and there was a significant delay in gaining family consent. We waited a month for this referral after initially being notified which could have been avoided" [Advocate].

We have identified a number of possible explanations for the low referral rate. These include:

- issues of awareness (e.g. families not being informed; staff not aware of the role)

- staff reluctance to refer (e.g. concerns of duplication with Family Liaison Officers; concerns referrals will increase complaints or litigation)
- barriers to access (e.g. families are just handed a leaflet and not supported to make a referral)
- confusion about the referral process (e.g. staff waiting for approval to make a referral; staff assuming others had made the referral).

How can we increase referrals?

We will continue to raise awareness of the pilot, the eligibility criteria and what independent advocacy is.

The LMNS has recently sent correspondence to the perinatal leadership team (QUADs) at each Trust stating the following:

"Please can I ask that you inform every single family (maternity and neonates) who are eligible to access the Maternity and Neonatal Independent Senior Advocacy Service about the service and offer to make a referral on their behalf if they so wish" [David Purdue].

We hope that this direct request to the perinatal leadership teams will result in an increase of referrals and provide our advocates the opportunity to proactively contact families and explain what support they can offer.

We wish for this process to be as easy and accessible for families as possible. In one instance, a family were asked their consent to have their contact details shared with us so that we could call them. They agreed, an advocate was able to contact them and explain the support available and that is how the referral was secured. They have since commented that they feel they were unlikely to have made the call themselves if they had just been given a leaflet.

"I was so glad that the staff member offered to pass my details onto you. If I'd just left the hospital with your leaflet in amongst all the others I don't think I would have reached out" [Family member]

Addressing staff concerns and misunderstanding

We are keen to address staff concerns about potential increase in complaints and litigation. Our service is there to inform people of their rights and options, so, if they have the right to complain or seek litigation, they will be informed. However, advocacy is impartial and does not lead people one way or another. It allows them the opportunity to decide.

We are not driven by targets to reduce litigation claims or complaints but if we are able to support families' concerns to be heard and acted upon, it may be that these claims and complaints decrease.

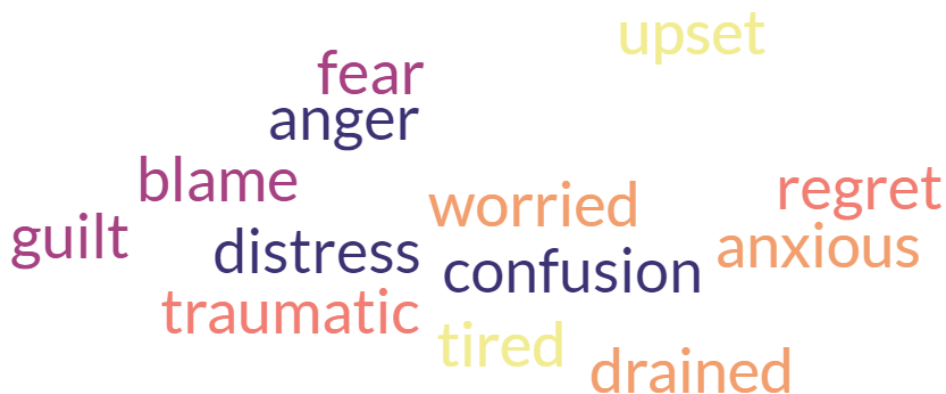
We have received mixed responses from hospital staff regarding the perceived benefits of the advocate role. A common concern was whether the role merely duplicates what already exists in the Family Liaison Officer Role. This role was launched after the initial planning stage of the pilot, but before the service was launched, meaning the existence of both roles may have not been foreseen.

One advocate spoke directly with the Family Liaison Officers at a Trust, and they shared this concern. However, we strongly feel that the roles are different. Although both are there to support families through investigations, ensuring they are treated with compassion and respect, the advocate role sits outside of the Trust and can support families for a longer time and through more diverse situations.

Our advocates have ensured to state their role clearly and ease concerns that it is a duplication. Following this explanation, the FLOs appeared far more receptive to the role and could see the differences, acknowledging the limited time they have with families.

What families have told us

Families have told us that they feel a wide range of emotions, which are often conflicting. Some of these are reflected in the word cloud that follows:



This emotional experience, sometimes on top of grief and loss, is obviously tiring. Many of the families who we have worked with are drained and have commented on the length of time the investigation processes take. We have heard directly that people get to a point where they just don't feel they have the energy to worry about it anymore.

Families have also commented on the lack of consistency in the care they have received, especially if it has come from multiple Trusts or care providers. It seems to suggest that different Trusts can approach things differently, despite national guidelines and policy.

Some families report problems with communication, where they feel they have received mixed messages from staff. This has left them feeling confused and distressed, this was despite them experiencing the conversations themselves as gentle and compassionate. A lack of consistency, and a lack of updates, has heightened anxieties for families, leaving some to consider information was being hidden.

Some families have shared that they experienced staff as not listening to them, and not understanding their wishes and concerns. Some families draw a direct link between not being heard and negative health outcomes they have experienced.

Several families we are working with have raised their concerns around consent processes and the information they were given.

"During labour I vaguely remember signing something, what was it?" [Family member]

One family reported being given a consent form and not understanding what it was for. Another family felt that the risks of pregnancy were not properly explained.

One family felt that staff were talking around the risks, being hesitant and unclear, perhaps to avoid being seen as insensitive. Although such a response may come from a place of not wanting to worry or upset people, it tends to do the opposite, and people just want to be told the facts no matter how hard they are to hear.

We have of course also heard positive feedback from families about the care they received. In one instance, they could not be more satisfied with the bereavement care they received. This was true for them, alongside concerns around other aspects of care they had received, showing that both can be true at once. Having two experiences that are so vastly different can be conflicting for families.

This is the context in which we share what families have told us about the support we have provided. Given the small number of families we have been able to work with so far, this feedback about our service is very much anecdotal and small scale. Nevertheless, we think it is worth sharing.

Timing of support

As mentioned at the start, one family whose baby died over a year before the service was in existence stated how valuable the support would have been earlier on. Another family commented similarly that they wished they had the support of an advocate whilst their baby was in intensive care.

Independence

We have received positive feedback around the independence of the role and how reassuring it is for families to know that there is someone there whose purpose is only to be on their side. This became even clearer when families requested an advocate's presence at meetings with hospital staff. The family had concerns around openness and accountability and felt having someone independent present provided a level of reassurance that staff would be transparent and honest.

Supporting family members to share their experiences

Other advocates elsewhere in the country shared that families had provided statements to be read aloud, or videos to be watched, in meetings such as PMRTs. We informed families we work with about this and one parent created a video statement outlining their experiences and feelings around the care they had received. This was highly emotive and met with thanks by the staff attending the PMRT. It was the first time a statement had been shown that way in a PMRT in that Trust.

Streamlining processes

The healthcare landscape is vast and can be confusing to navigate. One benefit of having the support of an advocate is that they can work across multiple issues a family may be facing, and multiple processes they are going through, acting as a point of contact for the family. We have heard people are overwhelmed with the number of people they must speak with, and services involved. As advocates, we can be a consistent support to help the family navigate all these steps.

A further example is a family that knew they were entitled to and wanted to make a PALS complaint but found they were unable to face completing this. This caused a delay in filing the complaint. An advocate is now working with the family to support with this. ...

What our advocates have observed

In the course of conducting their roles our advocates have both witnessed, and reflected upon, a number of interactions between healthcare providers and families. Some of their initial observations are provided below.

The profound impact of poor communication

One advocate witnessed how poor communication, characterised by delays and inaccuracies lead to a family worrying that staff were trying to cover something up and were intentionally withholding information.

The individual has been visibly worried and upset due to the responses from the Trust and has shared these concerns with the advocate directly. Poor communication has also created worries in families that excuses are being given.

It may be that staff have simply forgotten to keep families informed or have not felt there any important updates to share. What we have learned from families is that being told that there are no updates is important to hear, as silence can be taken to mean something other than “no news is good news”.

Limited information given to families

Following a serious incident, although processes are in place and usually followed, our advocates have observed that families are not always properly informed about what is going to happen and why.

For example, one family were told there would be an investigation but given no further details. They did not know that the name of the tool being used was the Perinatal Mortality Review Tool, or PMRT. This removed their ability to conduct their own research around this or learn more.

Lack of attention to detail

Small mistakes and inaccuracies in recounting events can have profound impacts on families. A document was shared with an advocate that incorrectly stated the date the baby was born. The advocate corrected the author of the document to ensure it was corrected. Fortunately, the family were not copied into the email and so did not see.

In other instances, the term “stillbirth” has been used incorrectly and has caused great upset to families we are supporting.

Lack of compassion from Trust staff

Families have expressed their upset at a lack of compassion from some hospital staff, one describing them as “cold” and that one member of staff laughed whilst giving evidence. Some have commented that their

interactions with the Trust have been traumatic right from the point of accessing care.

Our advocates have observed differences in how staff members from the same Trust have greeted family members and offered their condolences (or not done so) on the same occasion.

A siloed approach to investigations

Obviously, many pregnant people will access health services outside of the maternity/neonatal wards, such as Ambulance Services and GPs. Feedback on the interplay of hospitals with these other services has not always been positive with some families commenting that there seem to be communication issues, specifically, a lack of proper communication.

When concerns were identified in the handover between services e.g. the ambulance service and a maternity unit. Each service conducted their own review into what had happened, separately. Our advocate observed that this approach did not work for the family. The separation made little sense and created confusion around knowing who to go to for what.

For the family, this was their holistic experience, and they wished to get answers in a simple way. They witnessed a lack of understanding between the two services around how the other operates and how their respective investigations were run. Consequently, our advocate has seen the attempts for answers taking twice the amount of work, time and distress.

Lack of understanding of advocacy

Just as midwives and consultants know best how to explain their role, so do our advocates know best how to explain what advocacy is, its benefits and limitations. However, given the adverse outcomes link to our eligibility criteria, hospital staff are responsible for informing families of their options, including the advocacy role.

Our advocates cannot be there on the ward to have these conversations. As such, we are heavily relying on these staff to present the role objectively and accurately.

"I don't think that staff have a good understanding yet and perhaps that's why we haven't had any referrals yet" [NHS Manager].

If staff do not feel confident explaining the service, then families are not properly informed. There are two approaches we could take to address this issue. The first, speak to staff again about advocacy and hope that they come to understand it better. The second, take the ownership off

staff to explain the role and have our advocates do this. Whilst we have taken both approaches, the second feels to be more beneficial.

As mentioned earlier in the report, we have spoken with potential referrers in hospitals and asked them to make the referral process as easy as possible. Feedback from families using our service has been that hospital staff asking for their consent to share their number with the service, and the advocate to call them directly was helpful. Not only does this mean that our advocates get to explain the role directly, but it also takes pressure off hospital staff to do this and to complete a referral form (which requires getting consent for more personal data) and for them to do any follow up after information is first given to families.

Staff surprise they did not know an advocate was working with a family

When people self-refer into our service, we are under no obligation to inform the Trust at which they received their care. This seemed to come as a surprise to a member of staff who met an advocate at an inquest. This person presumed the advocate was observing the inquest for their personal development, rather than supporting the family, as they were unaware of the referral. During discussion with the advocate the Trust staff member acknowledged the importance of maintaining the independence of the role.

Maternity and Neonatal Teams in the same Trust working in silos

Across the region, our advocates have observed a clear division between Maternity and Neonatal Departments within the same Trust. This has resulted in staff verbally apportioning blame to the department that they do not work in.

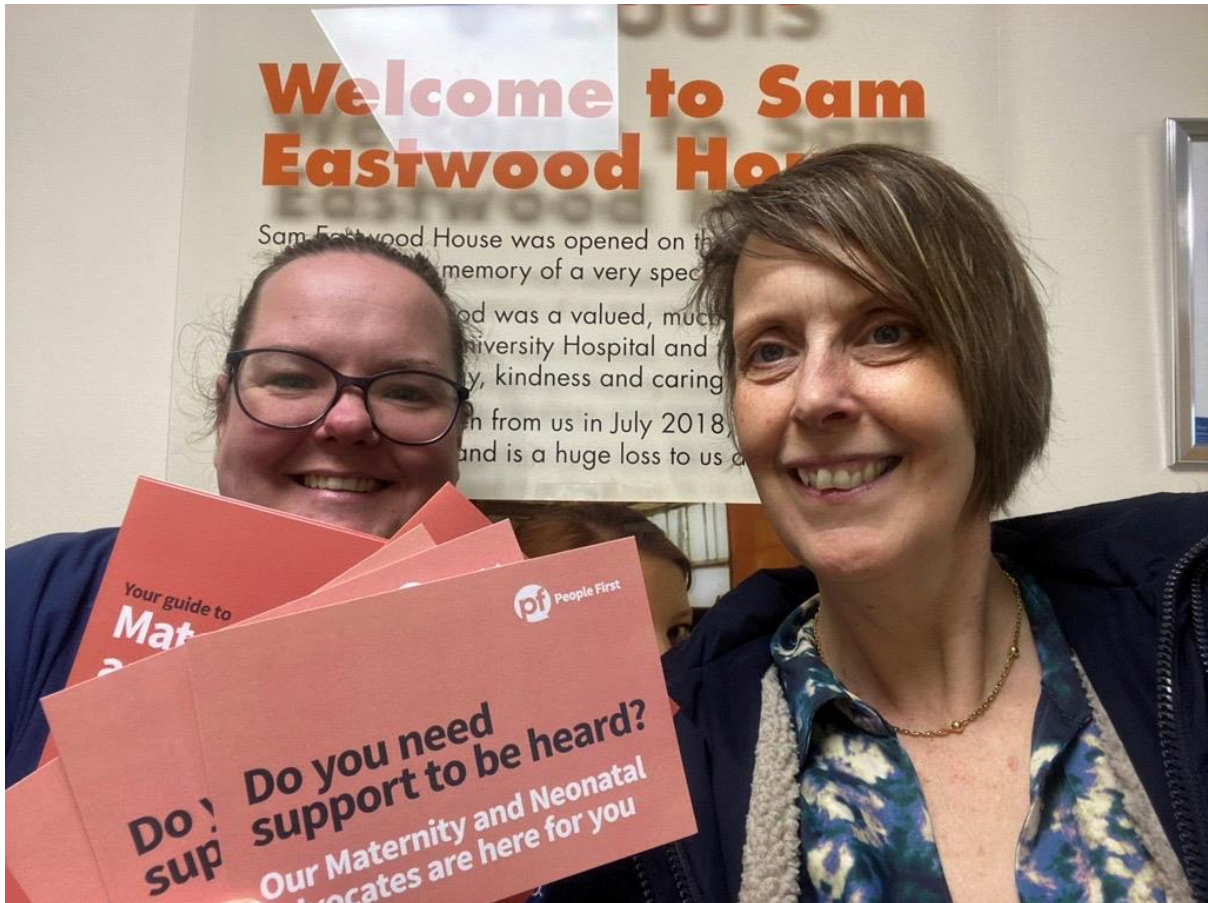
Hesitancy when advocates present

An advocate attended a PMRT meeting on a family's behalf and noticed that the Meeting Chair had written on their case notes "careful talk – advocate present". The words "careful talk" had been crossed out but was still clearly visible. The advocate felt welcomed into the space, but this comment suggests the Trust was on high alert to their presence.

Setting up the pilot in our region

As mentioned previously in the first six months of operation the focus was on recruitment, training and preparation for our team of advocates.

We have also spent considerable time on outreach work with Trusts and community groups, meeting with key stakeholders across the region. The focus of this has been to explain the purpose of the pilot, understand their roles and identify how we can work together to support families.



Annette meeting Victoria from 4 Louis

In this section we will outline the other activities we have engaged with.

Baby Lifeline training

Our advocates were enrolled into Baby Lifeline training which aimed to equip them with the knowledge and skills to effectively and sensitively advocate for families. A large part of the training looked at the maternity and neonatal healthcare systems to ensure advocates knew what people are entitled to, policies and processes, and where to signpost. Baby Lifeline also offered sessions around cultural and psychological safety as well as personal safety and well-being advice. There was a total of 6 modules which were a mixture of online and face-to-face:

1. Introduction, roles and responsibilities
2. Understanding the perinatal/maternity system and landscape
3. Signposting, escalation and interdependencies
4. Communication skills
5. Equality, diversity and inclusion
6. Personal well-being

Advocacy training in-house

As an established independent advocacy provider, People First were able to offer our advocates further training. We found that the Baby Lifeline training lacked advocacy specific training so felt that giving our advocates

a more in-depth induction was necessary. This looked at advocacy principles and practices. Our advocates were also able to start working under our non-statutory remit before the service went live, giving them relevant experience.

Re-working communications documents

NHS England provided a communications toolkit with pre-written promotional pieces for NHS Trusts, the press, and those that may use the service. We found that the language and style of these pieces did not match People First's culture. The LMNS approved changes given that the content itself was not changed. Our marketing team and advocates put a lot of time into re-drafting the promotional materials. We also developed easy read versions and had our experts by experience offer feedback on these. We have been able to share our easy read version with advocates working on the pilot elsewhere in the country.

Social media outreach

Our marketing team have given our advocates training around social media and communications. They each have access to People First's Facebook and Twitter (X) accounts.

Initially, they were used to post information about the pilot launch and how to get in touch. Now, they are used to share information around the work we are doing such as our advocates' visit to the charity 4Louis, and the volunteering they have undertaken.

Being the only independent organisation

Sitting as an independent charity within the wider pilot has been challenging. We are operating differently, and it is easy to feel isolated.

However, as an established advocacy service, we have also found it easier to connect with other services. Our organisation holds several NHS complaints advocacy contracts in the region so we work closely with our colleagues here. We also have established connections with local Healthwatch services so had links to share information about the pilot.

Our advocates have also accessed opportunities offered by the North East and North Cumbria Advocacy Network.