

Value of Community Nursing: Engagement with Patients, Carers and Families across the East of England

To understand public perceptions on the value of community nursing, Community Nurse Fellows in the East of England commissioned local Healthwatch to engage with patients, families and carers about their experiences of accessing community nursing, the value of the service, and how it could be improved.

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Background and Aims

Community nurses provide invaluable care to people in their own homes, care homes, or close to where they live, in clinics, GP practices across every village, town and city in the country. They also provide outreach services to those who may not have a secure home¹.

Community nurses support patients with a wide range of mental and physical health needs, often operating alone or in small teams. They deliver and coordinate the complexity of 24/7 care and supervise the management of multiple long-term conditions to ensure people can maximise their independence, avoid complications associated with immobility, disability and existing illness, and where possible, minimise the risk of going into hospital or a care home.

The care community nurses provide extends all phases of life. This includes²:

- Safe and healthy birth and early years development
- Maintaining population health and wellbeing
- Avoiding hospital admission and delivering acute care at home
- Enabling rapid hospital discharge
- Long-term care
- End-of-life care

There are more than 86,000 nurses across England. The diagram below illustrates the different types of community nurses that exist across the NHS.

¹ [NHS England » Community nursing](#)

² [NHS England » Community nursing contribution](#)

More than
86,000
nurses in the
community



The NHS Long Term Plan published in 2019 outlines a renewed focus on investing in greater community care, of which community nurses play an integral role³. The successful implementation of the NHS Long Term Plan is dependent on having a strong workforce of community nurses delivering care throughout England, particularly as the country recovers from the Covid-19 pandemic. As such, it is important that community nurses are able to demonstrate their value to ensure their roles and the services they provide are appropriately resourced and funded by NHS England and other commissioning bodies.

To support this, the NHS is developing a National Community Nursing Plan 2021-26 which will set out how the NHS can ensure the success of community nursing⁴. Potential themes for the National Community Nursing Plan have been established through initial engagement with more than 4,000 community nurses and other stakeholders. However, it is important to note that these themes are a starting point and will be adapted in light of wider engagement and as the needs of the community nursing workforce changes over the years to come.

The themes and specific action areas are presented in the diagram below.

³ [NHS Long Term Plan v1.2 August 2019](#)

⁴ [NHS England » Potential community nursing themes](#)



How community nursing is seen and valued is recognised by the NHS as a key area for improvement, and is a listed priority within the National Community Nursing Plan.

Evidence shows that the work of community nurses is often misunderstood, undervalued and overlooked by others – whether that be the public or the NHS. Community nurses are often referred to as the ‘invisible workforce’ as they tend to work in settings that are not necessarily seen by others. This evidence was further highlighted in research by The Queen’s National Institute (QNI) which found a lack of awareness regarding the range and the complexity of care community nurses provide, as well as the economic value community nursing brings to the NHS and to local communities⁵.

Demonstrating the value of community nursing is what Action Area 7 (as shown in the diagram above) intends to achieve. To do this, Community Nurse Fellows in the East of England region looked to gather research and evidence to understand how the public perceives community nursing and the value of this service.

Community Nurse Fellows commissioned local Healthwatch across the East of England to engage with patients, carers and families about their views towards community nursing, and their experiences of accessing this service⁶. Local Healthwatch involved in this engagement included: Healthwatch Essex,

⁵ [2020 vision five years on.pdf \(qni.org.uk\)](#)

⁶ Healthwatch England is the independent national champion for people who use health and social care services in England. There are over 150 local Healthwatch across England, all working towards the same goal of enabling people to have a voice about health and social care. Healthwatch England and local Healthwatch were established under the Health and Social Care Act (2012).

Hertfordshire, Cambridgeshire & Peterborough, Central Bedfordshire, Bedford Borough and Suffolk. It is worth noting that Healthwatch Norfolk tried to recruit participants but did not have any representation. This could be an indication of a harder to reach or disengaged cohort.

The aims of the engagement were to:

- Hear the positive impact community nursing has had for patients, carers and families.
- Understand the challenges patients, carers and families have experienced when accessing community nursing.
- Explore what community nurses are doing well, and what could be improved.

Methodology

Community Nurse Fellows worked with local Healthwatch across the East of England to develop questions for a series of focus groups. The questions explored:

- How patients, carers and families have been supported by community nurses.
- Barriers and challenges in accessing community nursing.
- Experiences of using out-of-hours support from community nurses.
- Experiences of providing feedback and/or making a complaint.
- The value of community nursing and how the service could be improved.

Local Healthwatch in the East of England carried out online and face-to-face focus groups. Three focus groups were held and in total 19 people participated. Participants included parents, carers, family members and friends who have either personally used community nursing, or supported a loved one who has accessed this service.

Each focus group was transcribed, and thematic analysis was used to code the similarities and comparisons in experiences of community nursing.

Key Findings

All participants with the exception of one individual, had accessed NHS community nursing. The findings below outline very positive experiences, as well as areas for improvements which should be taken forward. The findings also include a selection of patient stories. Please note that pseudonyms have been used to protect their identity and to anonymise their feedback.

1.1 Communication and Information

Communication with Community Nurses

The majority of participants had very positive experiences when communicating with and contacting community nurses directly, with many community nurses even sharing their personal contact details with participants and/or their loved one. Having a specific phone number to contact should they have any questions or require urgent support made participants feel reassured and supported.

“I have not experienced any barriers. The nurse contacts me and I have not experienced any change through Covid-19.”

“I was given the nurse’s number to contact if I had any concerns or questions. This was my first time having care from community nurses so this really helped in reassuring me.”

“The nurse gave me their personal number so I could contact them directly if I needed anything.”

The ability to contact and speak to the community nurses directly was seen as particularly valuable by parents whose child is under the care of the community nursing service. By enabling parents to have their specific contact details should they have any questions or concerns about their child’s condition(s) or symptoms, parents felt that the community nurses were not only looking to support their child, but them as well.

“My child was receiving nursing at home for five years for hypoxia. This was a good experience. I could always get in contact.”

“With my child I knew I could contact the nurse whenever I wanted to. I felt that the nurse understood my child and they were not only looking out for my child but they were looking out for me as well.”

Across all of the focus groups, participants also shared that the community nurses communicated with them, and/or their loved one, with kindness, dignity and compassion. Being treated with respect was very important to all of the participants, with many noting that they found community nurses to be more caring and empathetic than other healthcare professionals they have engaged with.

“I think they’re very underappreciated in comparison to doctors for instance, they’re more compassionate than a lot of doctors.”

“The nurses that visit are all very good, very friendly and do a good job.”

“The community nurses I’ve had have always been professional, kind and so pleasant.”

“I’ve never had a negative experience. Some will even take the time for a quick cup of tea and will shed a tear with you. They show that empathy and are so caring.”

One participant has a child who is non-verbal but despite this barrier, the community nurses made great efforts to communicate with their child in a way they could understand, and treated their child with both dignity and respect.

“As a parent, they do tend to try and make sure they treat my child with respect and dignity, even though they can’t verbalise or communicate with them. They will always try to make sure my child is aware of what’s going on, and the nurses are actually better than I am at making sure they’re talking through what they do before they do it.”

Similarly, another parent shared that their child is under the care of community nurses and during the peak of the Covid-19 pandemic, the community nurses regularly contacted the parent and their child and even provided care within the home during this time, so the parent and their child did not have to travel into London.

Patient Story: Emily* caring for her child with complex health needs during the Covid-19 pandemic

Emily has a child who is under the care of community nurses. During the Covid-19 pandemic, the community nurses made great efforts to contact both her and her child to ensure they were safe, and to check if they needed any additional support.



“During Covid-19 we had quite a positive experience in that the community nurses contacted us once a week when they knew we were kind of stuck at home and to check whether we had everything we needed and if we needed any support.”

On one occasion, Emily and her child needed to travel to London for her child to have annual blood tests. Emily was hesitant to travel, given the risk of Covid-19 and her child being clinically extremely vulnerable. To accommodate and to ensure their safety, the community nurses carried out the blood tests at their home and sent the samples to Great Ormond Street.

“At one point my child needed her annual blood tests for her kidneys and we didn’t want to have to go down into London to do it amongst the pandemic, so the community nurses came and did the blood tests at home and sent them to Great Ormond Street. I found that quite positive that they were trying to minimise our exposure to too many people.”

Communication with Community Nursing Administration Teams

As highlighted above, participants often had a positive experience when communicating with and contacting the community nurses directly. However, across all of the focus groups, participants had problems when trying to make contact with the administration team – whether this be to reschedule an appointment, raise a query or to discuss their care.

Participants said that they found that the administration teams tended to be inefficient and unresponsive, with participants having to wait hours or even days for a call back or response from the administration team, or for their care to be reallocated or

rescheduled. For many, this resulted in their care, or their loved one's care, being significantly delayed.

"I fell in July and broke my hip and when I was discharged from hospital I was told that I would be under the care of community nurses because I had to do a particular injection every night. I had no contact details for the community nurses and the administration team did not get in contact with me. Eventually we managed to get through to the ward and ask what the phone number was."

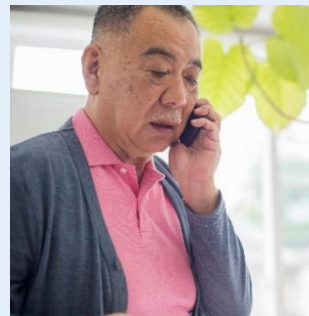
"My main problem was with communication. There were numerous occasions where I was told by the admin person that they would pass on my message. The community nurse then rang me back 48 hours and said they were terribly sorry to be so long replying but the message hadn't come through the right channels. One time I phoned and never got a reply."

"I have been receiving nursing at home since 2014. The problems I have experienced are getting through to the administration team if I need to reschedule an appointment. Often having to wait on the phone for a long time."

One participant has community nurses come to replace their catheter on a monthly basis. On several occasions, their care has been delayed due to errors and poor communication from the administration team.

Patient Story: Toby's* experiences of poor communication with the administration team

Toby receives ongoing care from community nurses, who come on a monthly basis to replace his catheter. On numerous occasions, Toby has not had his catheter replaced in time due to errors and poor communication from the community nursing administration team.



“Just last week I was due to have my catheter replaced on Tuesday and at 8:00am the community nurse rang me and said they were sorry but they couldn’t make it and would put the job back to the triage unit. I rang the triage unit and asked if they could ring me back to confirm the job had been reallocated and when someone would be coming and they said they would.”

The next day, Toby had received no communication from the administration team, and a community nurse had not arrived to replace his catheter. This situation reoccurred over the next few days, meaning Toby’s care was now significantly delayed.

“The following day nobody came. I rang back and the person who answered didn’t know anything about the conversation. They said again that someone would ring me back to confirm the job had been allocated. Once again nobody rang me back. Each time you’re promised someone will get back to you but they don’t.”

Although Toby is very grateful for the care he receives, and thinks the community nurses themselves provide an excellent service, he is frustrated with the consistent inefficiency and disorganisation of the administration team.

“The administration team is generally poor and often a problem. You don’t get through to the person you need to and regularly they do not ring you back or the message gets lost. You can never fully trust that you’re going to get a response to the question you’re raising. The admin around the service seems relatively poor and inefficient.”

Given that this issue was raised across all of the focus groups, it is important that NHS England and other commissioning bodies look to improve the efficiency and organisation of the administration team, as well as the communication they provide.

Accessible Information and Communication

Most participants were given a leaflet when they first started receiving care from community nurses, which included all of the information they needed, including key contact details and who to call if they had any concerns or questions.

“I have never had a problem getting hold of a community nurse. I was given a booklet with all their contact details.”

“I was given a leaflet with all the information and phone numbers I might need.”

However, some participants felt that patients with additional communication needs might struggle to understand the information provided, often because leaflets are not shared in different languages or in accessible formats such as Easy Read. Some participants also said that the information given is quite complicated, and could be made more simple to understand.

“The information I was given was overwhelming and there was a lot of information that could be quite hard to understand. It is also not clear how to get the information in a different format should you have any communication needs.”

“Information and leaflets in Easy Read and different languages needs to be offered.”

“A pack of information would be helpful, including contact information. This needs to be simple, easy to read information and provided in various accessible formats.”

For example, one participant shared how their partner is deaf, meaning the participant has to contact the community nurses on their partner's behalf, as there are no other means for their partner to communicate or make contact with the community nursing team.

“My partner is deaf so if he needs support I would have to make contact. He would not be able to do this himself.”

Language Barriers

Similarly, participants had concerns for those who do not speak English, or English is not their first language. Participants felt that these groups are likely to experience communication and/or language barriers, and problems accessing community nursing as a result. This is particularly because most of this communication takes place over the phone rather than face to face.

Participants also felt that these groups are likely to face challenges when trying to communicate directly with community nurses. Participants emphasised how addressing and accommodating for language barriers is essential for ensuring patients can understand the information they are given, and can consent to the care or treatment they are receiving.

Accommodating for language barriers is also important for building trust and in ensuring that they feel comfortable and confident in the care they are receiving.

“Seldom heard communities might have language barriers. People are often scared and may not understand the treatment that is being delivered or why it is necessary. And they might not be able to say if they do not understand.”

“There needs to be awareness of cultural and language barriers. Community nurses need to overcome them so the patient can understand what they are saying and so they can consent to the care they are being given.”

“Some people who are not English speakers would struggle to contact the teams especially if there was a problem or a concern around a person’s condition due to difficulties in making themselves understood over the phone.”

“Translation is needed for some communities who don’t understand or struggle with English.”

This was emphasised by one participant who shared that English is not their first language. The participant stressed how important it is that community nurses explain

information in an accessible way, so patients with a language barrier can ask the right questions and understand the care or treatment being given.

“I am a non-English speaker. I do not mind being given lots of written information as long as it is explained to me at the time so I understand what it is about and have the chance to ask questions.”

Participants also felt that in light of recent events, information and communication needs to be made accessible to refugees in particular, so they are able to understand how to access community nursing, as well as other NHS services.

“The barriers were lack of information, how to contact, how to find information. Afghan and Ukraine refugees need to know how to access different services and understand the treatment or care they are given.”

Positively, one participant shared that their partner does not speak English, however the community nurses caring for their partner made great efforts in ensuring their partner was communicated with and presented information in a way they could understand and engage with.

“My partner had community nurses in 2018. There was good communication even though my partner is a non-English speaker. They received care for a short time over a small number of visits following a hospital stay and the standard of care was good so we felt looked after and respected.”

Cultural Competency

Likewise, participants said it is important that community nurses are aware of different cultures, religions and ethnicities, and exercise cultural competency when delivering care to patients.

One participant had a particularly positive experience with their community nursing team. The community nurses respected their culture and took the time to learn about their culture and ethnic background. They also built a strong relationship with the family, which the participant and their loved ones very much appreciated.

“The nurses that come to us have known us for a long time and have a good understanding of our culture. They always take their shoes off at the door. They give us information on what is happening and the procedure. The nurses that come have an awareness of Kurdish culture and have built a relationship with our family.”

1.2 Continuity of Care

Receiving continuity of care and seeing the same group of community nurses was very important to all of our participants, across all of the focus groups. Participants who saw a team of community nurses said they could build trust, rapport and relationship with them, and noted that having this consistency meant they did not have to keep repeating their story or health needs to different community nurses.

“The nurses that come to my house are fantastic. They have got to know me. I cannot fault them.”

“At the moment I seem to just see one community nurse who I talk to quite a lot. I’m pleased about that because it’s nice, because it’s a bit of continuity that I didn’t get before.”

“My partner sees the same nurse and the nurse communicates with the GP and the consultant.”

“I see a handful of nurses that seem to rotate as they travel to different counties. Most of them know me quite well. They do tend to communicate amongst the team.”

One participant said that their friend had early stage dementia, and that receiving continuity of care and seeing the same group of community nurses was very valuable to that individual, and gave them the support and reassurance they needed during a difficult and challenging time.

“My friend had early stage dementia and they used to regularly have the community nursing team going round and doing her diabetic checks. I remember how valuable that was to them, having the consistency of the same recognisable faces.”

Continuity of care was particularly important to parents with a child who is cared for by community nurses. Seeing the same nurse, or the same team of nurses, was essential in both the parent and their child building trust and a relationship with them.

“My child sees three different nurses who know us well. They will feedback to the GP regarding medication and the communication is good.”

“We saw the same nurse and that was really good for me and my child. We got to know the nurse and they got to know us.”

However, there are clear inconsistencies across community nursing services, with some participants receiving continuity of care and only ever seeing the same group of community nurses, while others will frequently receive care from a range of different community nurses, and have experienced inconsistency for a number of years. Those participants said that they would prefer to see the same group of community nurses, primarily because they would like to build a relationship with a team of community nurses, and receive greater consistency in their care and treatment.

“It’s always a different person. I never feel like anyone is getting to know me. You never get the feeling that you’ve got any individual who is caring for you as an individual and providing that continuity of care.”

“It was always someone different that came in.”

“At the start of their care, my partner never saw the same nurse twice and communication was not shared.”

“I would prefer to have the same nurse. I could build a rapport and ring them directly.”

One participant has used community nursing for a number of years, and during this time they have very rarely seen the same group of community nurses.

“I’ve used community nurses since 2013, so that’s nine years. It’s because I have a catheter and they need to do things for that, change it, sort out problems. Rarely I see the same nurse and every time I would have to explain how long I’ve had it, how many infections I’ve had, every single time.”

1.3 Quality of Care

Across all of the focus groups, participants expressed their gratitude and appreciation for community nurses. The majority of participants shared very positive experiences of the care either they, or their loved one had received, and noted that community nursing often went the extra mile to ensure they were both physically and emotionally supported.

“I think they’re amazing, they’re so dedicated and they’re really trying. They are doing the best they can with the service and they are doing the main part of their job which is to look after patients.”

“We’re really lucky because our community nurses are so dedicated.”

“They do an excellent job, they are fantastic and provide such good care.”

One participant said they joined the focus group primarily to share how excellent their experience has been. The participant has now been discharged by the service, but noted that the care and support they received was invaluable.

“The service has been first class as far as I’m concerned. I’ve got heart failure and my community nurse has been coming on a very regular basis to effectively adjust my medication. I’ve just seen the nurse for the last time because they’ve now discharged me. But they gave me their phone number if I’ve got any queries or questions then I can use that number. My experience was very good and I’m very grateful for the service.”

Participants also shared that the community nurses involved them in their care, or their loved one’s care, and ensured that they had their agreement in any decisions made regarding their treatment. Parents in particular said they felt included in any

decisions made about their child's care, and felt that the community nurses respected and supported them in their caring role.

"I feel fully involved in decisions about my child's treatment and I am treated with respect and dignity. I feel listened to. The nurse cared for my child but also really looked after our whole family, making time for us to ask questions and to make sure we were all involved."

"My child has complex needs. We needed some training on different equipment and they were excellent. They came in and taught us and involved us straightaway."

One parent had a child who was born premature, and shared that they were very grateful for the care and support both they, and their child received from the community nurses during this difficult time.

Patient Story: Gabriella's* experience of caring for her premature baby

Gabriella's son was born premature at 28 weeks. Her son had to stay in hospital for awhile due to having a number of complications. Gabriella remembers feeling very scared to bring her son home after being under the care and support of the hospital for such a long time.



"My son was born at 28 weeks with a lot of complications so spent a long time in hospital. When we took him home it was quite scary and the community nurses played a huge part in supporting us. For months you've had people around you, and your son is hooked up to machines, and all of a sudden that's gone and you've come home and it's this great big world that you're alone in."

A community nursing team was put in place to care for her son. Not only did the community nurses support her son, but they also supported Gabriella and proved to be her lifeline.

"A community nursing team were put in place and they were my lifeline. I was incredibly grateful to them for that and it really helped us through a difficult time. They used to always let me know when they would be coming and I really needed that."

However, a few participants did occasionally have a poor experience with community nurses. For example, some participants said they did not always feel involved in decisions around their care. One participant said that their medication will often be changed without them being informed or consulted about that decision.

“I do not always feel involved with decisions about my treatment. Sometimes the dose goes up without me knowing and I don’t know why.”

Other respondents felt that the care they received was rushed, and that the community nurses did not always have enough time to provide sufficient care and support to their patients. Participants recognised that this is probably because community nurses are very stretched and have high case loads, and felt this was the greatest barrier preventing community nurses from providing better quality care.

“One nurse seemed rushed and inexperienced and did a poor job replacing a dressing.”

“Sometimes I’ve felt that they’re not really taking in what you’re telling them. They’re in a rush, they’ve got to get to the next person.”

“I understand they are under pressure and have big workloads but being in a rush is not an excuse for poor service or poor care. It would be good if the quality could be assessed.”

“You want to feel supported but unfortunately these people are on the ground, they’re hitting the ground running. They need more time to see each patient. They just know they’ve got to get onto the next patient and can’t be with you for long.”

One participant had a particularly poor experience with community nurses. The participant shared that their parent had Chronic Obstructive Pulmonary Disease (COPD) and the participant felt that the care they and their parent received was inadequate.

Patient Story: Matthew* caring for his mother with Chronic Obstructive Pulmonary Disease (COPD)

Matthew was caring for his mother who had COPD and was receiving regular care under the community nursing service and felt that the care him and his mother received was inadequate.



“I’ve had an experience with the community nurses for my mum who has sadly just passed away a few months ago actually. She suffered with COPD and I didn’t have the best of experiences with the community nurses.”

Matthew felt that the communication him and his mother received from the community nurses was often poor, rushed and at times, insensitive.

“It was clear they had a job to do, they came and did the job and then very much disappeared. They left me in some very awkward situations, like mentioning that they would refer to a hospice, and to call the ambulance because she needs to go back in.”

On one occasion, Matthew’s mother became very unwell and her oxygen levels had depleted. Matthew felt that the communication from the community nurses could have been better, and that him and his mother could have been better supported during this crisis.

“One day my mum said she was very unwell and she needs to speak to someone. She had a case of white coat syndrome so I knew it was serious. I phoned the team and had to wait four hours for a call back from them. When I eventually did get that phone call I was asked if we had an oximeter. I put that on her finger and her oxygen levels were 50%. She didn’t stay on the line, she said she’d call back in 10 minutes. When she called back she said to put the phone down and to phone an ambulance. I had paramedics here within three minutes because she went on red alert because of her oxygen levels.”

Matthew felt that the community nurses should have provided him with greater support and reassurance, particularly as this was a traumatic situation for both him and his mother.

“We shouldn’t have been left in that position. They knew she was in a critical situation and I was left thinking is my mum going to die on the spot while I’m waiting for ambulance? I would have liked them to be by my side, almost holding my hand saying it’s okay.”

Out-of-Hours Support

Most participants have not required out-of-hours support from community nurses, though they did have the contact details should they, or their loved one, ever require this support.

“I have never used the out-of-hours service but I have the contact details should I ever need to.”

“I have direct numbers for out-of-hours support.”

For those who had used out-of-hours support, their experiences were mixed. Some participants received good quality and timely care, while others had to wait a long time for the community nurse to arrive, by which point they were already in a lot of discomfort.

“A nurse came out at 7:00pm at night on a Saturday and was very helpful and said someone would come back the next night to supervise me doing the injection.”

“They took ages to come. I understand they have big workloads but by the time they arrived I was already in a lot of pain and uncomfortable.”

1.4 Specialist Community Nurses

Participants shared the importance of having a range of specialist community nurses, as they have a thorough understanding of particular health conditions and can therefore deliver tailored and personalised care to patients.

Specialist community nurses also tend to have expert knowledge and in many cases, participants felt that they provided more specialised care than the doctors and consultants they had engaged with. Participants also said they could build a good relationship with the specialist community nurses, usually because they would see them on a regular basis, which they found highly valuable.

“I seem to have been fortunate as my community nurse was a specialist in cardiology, heart failure. They are trained particularly in those aspects of care.”

“They are brilliant. They’ll do whatever they can and nobody knows more about Multiple Sclerosis (MS) than they do. Including all the consultants I’ve seen over the years.”

“They know what the patient needs more than a doctor because they spend more time with them and they understand the situation. Doctors only see an overview of the patient, but they don’t really know that patient.”

One parent has a child who received care from an epilepsy community nurse who they felt was invaluable, and played an important role in supporting their child, as well as the family.

Patient Story: Fergus* caring for his child with complex health needs and epilepsy

Fergus has a child who has been under the care of community nurses since they were one and a half years old. His child is now 12 years old. His child needed a great amount of support when he was younger, and he was given an epilepsy community nurse who Fergus felt was invaluable in providing not only high quality care for his child, but for the whole family as well.



“I have a child who has quite complex health needs so they’ve been under the community nursing team since they were about one and a half. They are tube fed so the nurses have supported with helping with changes of tubes and stuff like that. They are also catheterised so they’ve come and helped with training and things too. They had quite severe epilepsy so the specialist epilepsy community nurse was a God-send when they were younger. You could ring the nurse and they’d help you if you couldn’t get hold of medication and stuff like that, they would be there to help you.”

Fergus noted that for years, there was not an epilepsy community nurse in their area. He shared the story of a family whose child was having severe seizures, but they did not have access to an epilepsy community nurse who could have provided this support.

“There wasn’t an epilepsy nurse for years. When there was one they were brilliant and you could ring them and if you needed a tweak to medication they could do it without you having to see a consultant. You need that immediate action and that’s what they could help with. I know that one family had no epilepsy nurse and their child was having really bad seizures so they had to be rushed to hospital as they couldn’t get hold of anybody. If there was an epilepsy nurse they could have handled that and prevented the trip to hospital.”

A number of participants shared their concerns regarding the shortage of specialist community nurses and felt that recruitment and retention of specialist community nurses was essential, particularly given the high quality of care and expertise they can provide patients. There seems to be a specific shortage of Neurology nurses across the East of England, with this issue raised in all of the focus groups.

“There needs to be more specialist nurses. You need those nurses like MS nurses, epilepsy nurses, who really know those conditions.”

“It seems there are simply not enough nurses to provide specialist care.”

“This gentleman was desperate for a dedicated Parkinsons nurse. They had been promised one for so long but it never materialised.”

“I was really chuffed when eventually we got a MS community nurse. It must have take years of campaigning and there was never any funding.”

One participant shared that their area has been without a Parkinsons Nurse for over a year, meaning people who are newly diagnosed are not getting the support they need.

Patient Story: Rose's* concerns about the provision of Neurology Services

Rose has Parkinsons and shared her concerns about the lack of Parkinsons nurses across her area. Rose feels she is not getting the support she needs, but is most concerned about the lack of care those who are newly diagnosed with Parkinsons are receiving.



"I'm a bit concerned about the Neurology Community Services provided by the Trust. We've been without a Parkinsons nurse in our area for over a year now, so newly diagnosed people don't have the opportunity to actually speak to a nurse when they have been diagnosed and of course it's really important that you learn how to manage your Parkinsons and the community nurses are the ideal people to do this."

Rose has been working with Parkinsons UK to speak with the Trust to discuss how local people living with Parkinsons can get the support they need, given the shortage of community nurses.

"Through Parkinsons UK we are trying to talk to the Trust about what we need and how we can improve the service together with them. We had a meeting in the past with some of people from the Trust to discuss how we might improve the service for people with Parkinsons. We're trying to get another meeting with them."

1.5 Feedback and Complaints

Across all of the focus groups, no participants had ever made a formal complaint about community nursing, and the majority had never provided any negative feedback. Participants were aware of how to make a complaint or provide feedback, but most said they would be reluctant to do this, as they know the service is under pressure and they feel that overall, community nurses are doing an excellent job and provide high quality care to their patients.

"I would only make a complaint if an action was detrimental to myself but this has never happened."

"I know how I would make a complaint or give feedback but I don't think I'd ever need to. The service I get is great."

"I've never made a complaint or given any negative feedback, the care I receive is fantastic."

Most participants felt confident that if they did make a complaint or provide feedback, it would be listened to and taken forward by the community nursing service. However, a small number of participants had concerns that providing feedback could affect the care they, or their loved one receives, as well as their relationship with the community nurses they see on a regular basis.

“I’d be concerned about saying something because of the repercussions of what it could mean for my child.”

“I know the feedback is probably anonymised but I imagine it’s quite easy to join the dots. I’d be worried that it’d affect my care.”

A few participants did provide some informal feedback. This was either related to poor communication from the community nursing administration team, or inadequate care provided by a community nurse. However, all of the participants felt that their feedback was recorded and taken forward.

“I was unsatisfied with a particular nurse so I discussed this with my regular nurse.”

“I informally mentioned to the administration team that their attitude and failure to deliver messages or feed messages back to me needed to get sorted.”

“I said can I just give some feedback as I don’t think this should be happening. I don’t think they were that happy but I think they listened and took it back.”

1.6 Improving the Service

Areas for improvement have already been listed within the above findings, however participants also shared other suggestions which they felt should be addressed within the National Community Nursing Plan.

Pressures on Community Nursing

One of the main concerns participants had was the pressures on the community nursing service. Participants felt that community nurses are severely unsupported, short staffed and working with unmanageable and unsustainable caseloads.

“I worry about them. They’re so unsupported to be honest.”

“The nurse was obviously really under it. They all are because they’re understaffed and too busy.”

“Community nurses are considerably stretched and it’s an issue that I think should be at the top of priorities.”

“Shortage of resource and staff. We need more staff.”

One participant spoke to a community nurse who had received 29 calls which they needed to get through that day.

“One of the main problems is the workload. One of the nurses I spoke to said that is the problem for them. Sometimes in one day she gets 29 calls. That’s got to be hard. And they weren’t all simple things like giving medication some of it was really complex care. And then you have to think about all the travelling too.”

Signposting and Integrated Care

Participants said that community nurses could provide signposting information, particularly to families and carers. Participants felt that community nurses could offer information about other NHS services available, but also within the Voluntary,

Community, Faith and Social Enterprise sector who can offer care and support. This was particularly important, as often patients, families and carers are not aware of what support services are available, particularly within the voluntary sector.

“I think being aware of other things and support within the community. Being able to signpost effectively to other services that may be able to help us as families, and being aware of how, and what that referral process is.”

“Sometimes as a parent or carer your own mental health and wellbeing can be on the floor, so knowing where to go and how not to feel isolated is important and I think community nurses could help with that.”

Participants also noted that community nursing could be more integrated and joined up with other services across the NHS. Participants felt that this would enable a more holistic approach to be taken when providing care and supporting patients, carers and families, particularly as community nurses tend to be the initial point of contact for many.

“It would be nice if they were able to look after the whole family and look at the holistic approach to the family.”

“The community nurses might be your first point of access and they could be that point of access to make it easier in general. The NHS is siloed. I don’t know who to contact if I’m having difficulties.”

Training

Linked to the above, participants felt that community nurses could receive greater training around mental health. Participants said that community nurses would be well positioned to spot the signs and symptoms of ill mental health, given that they will see the same patient on a regular basis and get to know their personality and behaviours.

“I don’t know how much training community nurses get but I think mental health is something that needs to be massively looked at. The community team are the people who are on the frontline and the people that may be able to refer patients to the right places. They are in a position to notice when people are at risk and could refer them to places to get the support they need.”

“With my child, I was never ever offered any support with my mental health. At that time, I didn’t even know that I was suffering with mental health after the trauma I went through and now I know to have Post Traumatic Stress Disorder (PTSD) but that was 18 months in. I think if people asked the right questions they would have possibly seen the signs before even I did.”

Conclusion

It is evident that the majority of participants engaged with had very positive experiences under the care of community nurses. Many participants shared that they received high quality care and support, involvement in decisions around their care, timely communication from community nurses, and being treated with kindness, compassion and dignity. Participants also noted that community nurses made great efforts to communicate with their patients in ways they could understand, particularly with those who have additional communication needs, and also exercised cultural competency when delivering care to their patients.

As with any service, there are clear areas for improvement, with some participants receiving inadequate care from community nurses. Participants acknowledged that their poor experiences were a product of systemic issues and the pressures on the service, such as high caseloads and lack of staff. NHS England and other commissioning bodies need to ensure community nursing is appropriately resourced and funded, and need to look to recruit to and retain the community nursing workforce, particularly specialist community nurses.

Across all focus groups, participants noted that communication from the community nursing administration teams was often poor, with participants not receiving a response for hours or in some cases days, resulting in their care being delayed. Administrative errors and incompetence were also seen as common, and highlights how the administration around community nursing must be a priority for improvement.

Participants also recognised the key role community nurses play in supporting patients, carers and families. Participants felt that this could be expanded by community nurses offering more signposting information, and receiving training, such as mental health training, to spot the signs for ill mental health.

Overall, participants are very satisfied with community nursing, and have great gratitude and appreciation for the service. Participants are keen for community nursing to get the recognition they feel it deserves, and would like to see this reflected in greater resource and investment.

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