London Ambulance Service NHS
NHS Trust

Insight Project

Background

The London Ambulance Service (LAS) recognises the continuous improvement of services is essential. It also believes this can be best achieved by working together with patients and carers. Co-production provides a model of working together as equals. Whereby the LAS can establish effective working relationships with patients and carers to understand their unique perspectives, experiences and ideas. Using this insight LAS can work together with patients and carers to agree better ways to deliver care.

The Patient and Carer Communities

Three patient and carer communities were identified as being regular users of the service; people with respiratory disease such as COPD and Asthma, people with Sickle Cell Disorder and people living with a Personality Disorder.

Following initial enquiries, three groups were identified and were willing to work with LAS to explore how services could be improved, these were:

- **The Lewisham Breathe Easy Group**
- **The Merton Sickle Cell & Thalassaemia Group**
- **The Oxleas Trust ResearchNet Peer Support Group**

The Methodology

The patient and carer groups were very helpful in supporting the arrangement of focus groups which took place in December 2016 and January and February 2017. Working with existing groups enabled access to a higher number of service users. The Sickle Cell group was particularly well attended.

Groups were attended by patients, carers and London Ambulance Service staff. This model of co-production was an important feature of the work.

Each focus group was independently facilitated by Jessie Cunnett of Patient and Public Involvement Solutions, this was an essential aspect of the methodology, ensuring the facilitator had no real or perceived stake in the service as a user, carer or provider. This neutral role proved important to balance discussion, ensure staff from LAS weren't defensive and enable service users to speak freely.

The location of focus groups on 'home turf' in community venues where groups already meet was also key. Creating a safe and familiar space for groups to interact with LAS staff.

The layout of the rooms ensured staff and service users were mixed so as to avoid any sense of 'them' and 'us'. A social element was included, with time for refreshments to share and speak informally as well as in the focus group set up.

The Breathe Easy Group met twice and was attended by 10 group members, 2 local respiratory nurses and 4 members of LAS staff (including one note taker) at the first session and 11 group members, 2 local respiratory nurses and 8 members of LAS staff (including two note takers) at the second session.

The Sickle Cell & Thalassaemia Group met twice and was arranged and co-facilitated with, Eulalee Valentine a Well Being Consultant with a specialism in Sickle Cell Disorder. The first focus group was attended by 12 group members and 5 members of LAS staff (including one note taker) and the second focus group was attended by 15 group members and 5 members of LAS staff (including one note taker).

The ResearchNet Peer Support Group met twice in total, with an initial focus group in 2015 and a follow up group that was attended by 9 group members, an art therapist who co-ordinates the group and 7 members of LAS staff this year.

Each group followed a slightly different approach depending on the group. The facilitator and staff were careful to ensure group members could participate as equals and to lead discussion on the issues and topics that were most important to them.

At the first discussions, broad question areas were used in each group as a starting point for discussion including; Have you used the LAS in the last two years? What was good about your experience? What would you want from your experience if you had to call LAS in the future? What could be different or better? What advice would you give to the LAS about caring for people with your condition?

The second discussions were used as an opportunity to clarify what had been heard at the first discussion, agree themes and look at themes in more detail. The conclusion of each discussion involved an agreement about next steps.

During the course of the focus groups, participants shared their powerful and sometimes emotional experiences and stories. To do this takes great courage and appreciation is extended to people for being so generous with their time, energy and spirit. Examples are included within the report to provide a flavour of what people had to say in their own words. **Blue speech bubbles represent a service user or carer view** and **green represents a member of LAS staff.**

The proposals are often cross-cutting with other agencies and many are patient led initiatives. LAS will need to consider the proposals and look at whether and how they can be implemented or shared with others, such as CCG colleagues and NHS England for further consideration. A continuing discussion and relationship with the groups to develop the proposals further would be advised.

Respiratory Disease

Respiratory disease is a term that encompasses conditions of the upper respiratory tract, trachea, bronchi, bronchioles, alveoli, pleura, and pleural cavity, and the nerves and muscles of breathing. Respiratory diseases range from mild and self-limiting, such as the common cold to life-threatening like bacterial pneumonia, pulmonary embolism, acute asthma and lung cancer.

From the two focus group discussions a number of themes were identified, agreed and discussed in more detail with the group. These themes were: **Communication, Response, Access and Care/Treatment.**

Steve's Story
"If they weren't there, I wouldn't be here. I had a respiratory arrest. It was the first time I had ever called an ambulance for me. They seemed to talk forever on the phone but I couldn't breathe. The female I spoke to tried to keep me on the phone while she authorized a rapid response unit. I was the only one in the house. I knew they would get in but I told the operator I would open the door so I had to get downstairs. That's all I remember. From there I don't remember but I was in ICU for 12 weeks. I owe everything to the LAS, otherwise I wouldn't be here"

Lillian's Story
"My husband had to call twice for me. They asked him, 'is she breathing and conscious?', I called out 'yes!', When the ambulance came I had a temperature of over 40 and had to go to hospital. I could have died that night. I have never used an ambulance since; the car is quicker. My husband takes me now; I couldn't be bothered to wait for an ambulance"

Gloria's Story
"The last time I went to the doctor it was with a headache. By the time I got in to see the doctor I couldn't breathe. If I had gone by car I would have died. The ambulance crews know to think about the breathing rather than the headache"

Respiratory Disease: Comments from the group

Patient and Carer comments are shown in blue
LAS staff comments are shown in green

I'm the one with the emphysema and I know what it's like, and what's best for me

I have an ICE contact on my phone with information about me and my condition

I don't want to call 999 as they will take me to Lewisham and I want to go to King's as that's where my treatment is done

We respond to acute problems and our priority is to get you the correct treatment or to the right department. Every A&E can do bloods and check your gases, so we must get your immediate problem under control and then can refer you once you are stable. Sometimes this means going to the nearest A&E to find the problem.

I've had many ambulances and have no complaints.

They made me feel like I wasn't wasting their time

If someone knows their own condition and feels it is severe they should call an ambulance.

Ambulance crews should ask people which hospital they normally go to, so they can be taken to the place that holds their notes, Unless the situation is life threatening, in which case the ambulance will take the patient to the nearest hospital.

If you go by car you still have to wait.

The following suggestions and ideas were generated from the group discussions and are proposed for further consideration:
• Patients supported to develop a personal emergency plan. A 'what to do in a crisis' information card to be kept by the phone at all times. The card might include, key words and phrases to use when speaking is difficult, important numbers, people to contact, tips to reduce panic and things to remember to do and say.
• Support patients in a crisis to make informed decisions about when to call an ambulance. What will happen when the ambulance arrives including how decisions are made about going to a preferred treatment centre or to the nearest hospital. Why patients might be asked to lie down briefly whilst being transferred from a carry chair to a stretcher.
• Exploring the consistent use of a system to allow patients to communicate non-verbally. For example, tapping the phone to give basic, yes and no answers to questions.
• More consistent use of the 'message in a bottle' containers kept in the fridge that hold specific personal preferences and medical information.
• Use of mobile phone apps and technology solutions such as, ICE (In Case of Emergency) information such as date of birth, next of kin, medications taken. This is possible using the most basic mobile phones. Also the ICE App, a more advanced option for smart phones.
• Providing information about the value and use of key safes.
• Personal Information Cards kept at the patient's home or in their wallet.
• Looking at Patient Specific Protocols for some patients and providing information and advice on how to set one up.
• The value of good communication between the crew, the patient and the carer and how to help patients to feel confident to communicate with staff around their preferences and needs.
• Training for LAS staff in what it feels like to not be able to breathe.

Sickle Cell & Thalassaemia Disorder

Sickle Cell and Thalassaemia are inherited blood disorders in which the red blood cells are sickle shaped [Sickle Cell]; the blood cells are normally round in shape, a bit like a 'ring'-donut. In Thalassaemia the cells are smaller in size and are paler in colour. Because of their shape, sickled red blood cells can't squeeze through small blood vessels as easily as the almost donut-shaped normal cells. This can lead to these small blood vessels getting blocked which then stops the oxygen from getting through to where it is needed. This in turn can lead to severe pain and damage to organs.

The following themes were generated by the discussions at the two focus groups: **when to call, understanding sickle cell, managing pain, use of Entonox or morphine, choice of hospital/treatment centre and care plans and handover.**

Zaina's Story

"I called the service once and the call taker stated that I needed to answer a questionnaire. My 13yr old daughter was screaming in pain… I told them it was Sickle Cell Crisis and I was begging her to send an ambulance but they continued to ask questions… the call taker said they are not taxi drivers and she needed to continue with the questionnaire. I cried and cried. I was told to wait 10-15mins for an ambulance, I felt this was unnecessary and was told I could take a taxi. I ended up taking my daughter to hospital in a taxi. On another occasion I had to carry my daughter down the stairs on my back while the crew stood with their hands in their pockets. 98% of staff are brilliant, it's just these two occasions"

Osei's Story

"The call handler, the ambulance, now I'm older I'm more aware. In the ambulance they may give you an opiate, in hospital they may delay your next step. Then A&E. The ambulance takes back the Entonox but the hospital won't give Entonox or continue it when you go in. The service feels disjointed. Now you have to deal with the nurses who treat you differently, then taken to a ward. Each part is separate."

Daniel's Story

"I don't want to put myself through that agony which is why I boycott the ambulance service and get myself to hospital. I have a treatment plan. Speaking too many words multiplies your pain. My consultant made it easier for me by putting a care plan on the hospital computer which means I can bypass A&E. This has made it easier for me. I sometimes drive myself and get a priority service"

Norecia's Story

"I called an ambulance a couple of weeks ago and was told the wait would be up to one hour. I have kidney problems and had several fits. It's not good enough. I have epilepsy and had a stroke when I was five years old, the first woman (call taker) hung up on me because she didn't understand me"

The groups took place just before a BBC News article on the growing calls from patients, experts and the Royal College of Nursing for better understanding of Sickle Cell Disease, so that patients get treatment and the care they need as rapidly as possible. One of the case studies involved a patient of LAS. The news item can be viewed at the following link http://sicklecellsociety.org/watch-bbc-breakfast-gaps-in-sickle-cell-care-and-awareness/

Sickle Cell & Thalassaemia Disorder: Comments from the group

Patient and Carer comments are shown in blue
LAS staff comments are shown in green

I can't get a breath, I can't say, I'm … a … sickle cell …patient… and answer lots of questions

There isn't a nice way of putting it, people are called addicts

I've plucked up the courage to call 999 for help

I am a cancer patient, I have epilepsy – we are human beings as well

They should be asking if you need assistance. There is a bit of a misunderstanding about the condition.

I'm just shocked and overwhelmed by these guys response. I made the choice to boycott the ambulance in the early 2000s and I'm surprised all this is still going on. I haven't used an ambulance since 2008

I get a great service for my daughter

Some people are really caring, others are just earning their salary. How can you teach empathy?

A lot of us will try to manage our pain at home. We've tried everything by the time we call

The care plan is very important. Mine was done in Kings and says exactly what happens to me in hospital. This needs to be given to the ambulance service so the care is the same

Not all vehicles have a paramedic on them and only they can give controlled drugs such as morphine

We talked about all of this 4 or 5 years ago – something needs to be done

The following suggestions and ideas were identified through the discussion and are proposed for further consideration:
• Staff education and training on sickle cell disorder. Co-designed and delivered with sickle cell patients. Specifically, to address the tough issues of pain relief and the link with the problem of perceived and actual racism of care givers.
• Co-produce information about key words to use in a crisis, including, 'sickler', 'pain', 'crisis', 'chest'.
• Patient information and support to develop and follow patient held care/crisis plans in partnership with the clinical teams.
• The development of and/or use of an existing App to support people with sickle cell disorder to share information including with consultants, to plan and to empower decision making.
• Support sickle cell patients in a crisis to make informed decisions about when to call an ambulance. What will happen when the ambulance arrives including how decisions are made about going to a preferred treatment centre or to the nearest hospital.
• Ensuring gas and air is always available.
• Co-produce information on the different roles and requirements of paramedics, technicians and other types of LAS crew to share with patients.
• Follow the patients need and always carry a person with sickle cell to the ambulance unless they wish to walk.
• A focus on handover to A&E, the handover of pain relief and the engagement of patients in the handover process.
• Sharing the clinical guidelines for sickle cell with patient groups so that everyone is informed of protocol.
• Always say, 'I can see you're in pain, how can I help you?'
• Always ask, 'Do you want pain relief? What works for you?' 'Shall we get the chair?'

Personality Disorder

Personality disorders are conditions in which an individual differs significantly from an average person, in terms of how they think, perceive, feel or relate to others.

Themes generated by the focus group include: **Communication, Response, Treatment and Care, Validation**

Comments from the group

Patient and Carer comments are shown in blue
LAS staff comments are shown in green

It made me feel like my condition is not serious, invalidating how I feel.

What is said impacts on how you're seen at the next place. If there are discrepancies, or the language used, can lead to the patient not being taken seriously and make the condition worse.

We try to give help and advice over the phone, we also support ambulance staff when required.

Fridays, Saturdays, Sundays and Mondays are busiest, we can call back 20 calls a day depending how long each call takes

I had a care plan that Oxleas have on their system but they close at 6pm, so there is no access if I need help out of hours.

It can be very hit and miss as to whether patients have a Crisis Care Plan in place. Most care plans will say go to A&E but this is not always the best place to be. It would be useful to have a more detailed plan in the Hub.

Telling your story over and over again is difficult and tiring

Some crews are more personable, others just run through their set of questions

It's frustrating if you can't find the words, distressing if you can't communicate what's wrong with you

The following were put forward for areas for further discussion; peer support, training (co-produced and co-delivered), crisis plans, pain score/physical/emotional pain.
The group suggested questions to ask and to include in LAS Training Module including:
• How did you end up calling us today? • I can hear you are distressed - what do I need to do right now to help you?
The group also suggested some principles and statements that could be used to inform the delivery of care to people with personality disorders:
Providing affirmation - "It's never anyone's fault" • "It's good that you called" • "You have done the right thing" • "It sounds like you are really hurting"
• More consistent roll out and development of patient held crisis care plans that include things that should/shouldn't be said and the patients' preferences rather than treatment.
• Explore the viability of Crisis Care Plans (or parts of them) being available to crew on the way to a call, so as to be more prepared on arrival.
• Review the personal crisis plan after each crisis with the patient, to reflect on what they would like to happen next time or things they don't want to happen.

Conclusions and Next Steps

Co-production means delivering public services with people rather than to them. Dealing in, what matters to people not, what is the matter with them. The focus groups have established a way of engaging with patient groups that support this idea. It will be important to continue to develop and build relationships, both with the groups that have already met but also with new groups of patients.

Alongside the residents and visitors to London who rely on LAS, the staff are the most important part of the services delivered. They hold the key to service improvement and their views and ideas in collaboration with patients and carers are vitally important.

There is much to be learned and done following the focus groups and their true value will only be felt in the quality of the actions taken as a result. LAS will need to be realistic and honest about what is possible and engage with other partners and stakeholders in how to do this. It will be important to keep patients and carers involved and informed along the way.

A number of the ideas generated by the groups are similar and are worth noting;

- The value of on-going collaboration and discussion
- Learning, education and training
- Empowering patients and carers to make the best decisions in a crisis
- Better understanding by LAS staff of the unique aspects of certain conditions
- Co-produced patient information
- Better use of technology
- Patient and carer led initiatives
- Valuing people as more than their condition
- Recognising and valuing the role of carers
- Better use of existing resources
- Sometimes it’s the simple things that matter most

LAS will need to draw on these as they move forward and look at how they can inform their approach to improving services. Continuing to work with patients and carers to become recognised as a learning organisation. Actively listening and engaging with people, to hear their experiences, their ideas and their challenges and using these in practice and in partnership to improve the services they deliver.

Feedback

Both service users and staff gave feedback following the events and the following provides a snapshot of what people said:

I would like to thank Eula for taking the time to organise these 2 sessions with Jessie and the LAS crew for taking their time to hear us strong warriors to express and discuss our concerns that we have got with the ambulance service – it was interesting and productive and it was great that we got to all vocalise what has been happening …

Things have greatly improved, though I feel there is a stigma attached with sickle cell by some of the ambulance crew

Today was very educational and productive as I learnt a few things about the ambulance service

… I do hope the outcome of the information given by both the service users and providers help to improve the quality of the service given and received as this is a very daunting moment for service users and carers

I was surprised that this patient group (respiratory) were unaware of some key words to use during a 999 call

I got to see another insight into patients we see but not in emergency conditions, what an eye opener

It really brought home to me the experience of people with sickle cell disease, and the appalling impact on individual and families.

I wondered if the 'addiction' narrative and the way it links with the problem of perceived and actual racism of caregivers has been confronted head on in the training provided?

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Jessie Cunnett
Patient and Public Involvement Solutions
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