



555 Neurology Project

Capturing the lived experience of people being diagnosed with a neurological condition in Essex

Spring 2016



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Acknowledgements

Thank you to all of the people in Essex who gave up their time to attend the 555 neurology focus groups.

By sharing your experiences of being diagnosed with a neurological condition to affect change, you have already made a difference.

Special thanks to MS-UK and the Essex Neurological Network.

Please note that all names have been changed to protect identities.

Foreword

In October 2014, Healthwatch Essex celebrated its first '555' project, after conducting a series of focus groups across Essex to listen to the voices of Essex mental health patients, service users and carers. Commissioners, mental health service providers and voluntary sector professionals came together to listen to these voices, and the impact was astonishing.

This award-winning 555 model of engagement was recognised both locally and nationally as an innovative, and yet simple, means of capturing the lived experience of people throughout the county and giving them the opportunity to share their stories, face-to-face, with professionals who deliver care in Essex.

This year, Healthwatch Essex has been working in partnership with MS-UK and the Essex Neurology Network to capture the lived experience of people who have received a diagnosis of a neurological condition. It has become clear, through Healthwatch Essex's engagement work and films, that the point of diagnosis for those living with a neurological condition is a pivotal moment in their lives.

This 555 report is directed at those professionals responsible for designing, commissioning and delivering neurological services. Listening to people living with neurological conditions is the first step to shaping services that are fit for purpose, financially sustainable, and above all, in the best interest of the patients.

To many patients, the neurologists that deliver the diagnosis conversation play a vital role in the journey of people with neurological conditions.

'Have they ever really listened to people who are on the receiving end, like us, and how people are affected? They need to sit and listen to the people.'

Louise, woman living with MS

This project confirms that quite often, due to the complex nature of neurological conditions, people spend a long time trying to get to the diagnosis stage. They may have lived with a range of symptoms for a while, and could be experiencing depression.

The information and support offered during a diagnosis conversation can make a real difference to the patient's journey. A good experience can mean the difference between seeking instant treatment and ignoring reality. It can mean the difference between taking positive steps towards managing their conditions and reducing the impact on secondary services such as mental health services and GP time.

This report brings together the voices of real neurology patients living in Essex and shines a light on their diagnosis experience. It offers patient opinions and suggestions on their own diagnosis conversation, how they felt, what worked well and what could have been improved.

We hope that this qualitative mode of engagement is the beginning of a journey that will see better support for people in the county living with neurological conditions. There is further work to be done in the region to enable people to speak about their experiences to ensure continuous improvement of neurology services, and to facilitate communication with neurology services.

On 08 June 2016, we invited neurologists to attend an event in Essex, to launch this 555 report.

Collectively, we asked local neurologists and health commissioners to take the time to reflect and to learn from the kind of insight that can only be gained through understanding people's lived experience. We wanted to reach neurology professionals on a personal level by sharing lived experience testimonials with them, and to offer them some suggestions to take on board about both what is working well, and where improvements could be made.

Together, we hope that patients being diagnosed in Essex will feel secure in the knowledge that their diagnosis conversation is not the end of their life, and that with the right information and support, they can continue to live life to the full.

Living with any condition puts the patient in a unique position - they become the expert of their own experiences.

Now is the time to listen to the experts.

Dr Tom Nutt

Chief Executive Officer, Healthwatch Essex

Amy Woolf

CEO, MS-UK

Gina Rutterford

Regional External Relations Officer (East of England) MS Society
Chair of the Essex Neurology Network

What we did

Using the 555 model, MS-UK hosted a series of focus groups to listen to the voices of patients diagnosed with neurological conditions in the past three years.

We wanted to listen to people diagnosed with a range of conditions, including brain injury, epilepsy, Huntington's Disease, motor neurone disease, multiple sclerosis, Parkinson's, Progressive Supranuclear Palsy and stroke.

Anyone over the age of 18 and living in Essex could attend the groups and we met and listened to 29 people over the course of the groups. Nineteen of these people were patients living with a neurological condition, and ten people offered support or care to these patients in a significant way.

This report sets out the findings of our 555 Neurology Project. The sample of people is intentionally small, so we can approach this project from a qualitative perspective. Although not strictly generalisable, we are nonetheless able to present a rich tapestry of experiences.

Our findings were taken to a meeting with commissioners and providers of neurology services in Essex on 08 June 2016. As the '555' model of engagement requires, **five** people from **five** focus groups had **five** minutes to tell their story to neurologists at the Chelmsford City Racecourse.

Method

We held five focus groups across Essex between February and April 2016, engaging with 19 neurology patients and 10 carers. We then held an additional two groups at weekends. The focus groups were held in:

- Chelmsford
- Harlow
- Rochford
- Basildon
- Colchester

Participants experienced a range of neurological conditions. The majority of attendees lived with multiple sclerosis (8 people) and motor neurone disease (6 people). People living with Parkinson's also attended (3 people), 1 person with epilepsy, and 1 person who had survived a stroke.

The group attendees were fairly evenly split between male and female (8:11) and of all the attendees, 16 people considered themselves to be disabled.

Located in the Clinical Commissioning Group areas across Essex, each focus group lasted two hours. We asked attendees what was positive about their diagnosis conversation and what could be improved. We also asked what they would like to say to a neurologist, and what matters most to them about their interactions with neurology professionals as a whole now.

Several carers and family members attended the focus groups, although this was not an exercise to specifically capture their views.¹ Many supported their loved ones with prompting and encouragement.

¹ But note that Healthwatch Essex has undertaken a significant amount of work on the experience of carers, which is readily available at healthwatchessex.org.uk.

What we found

The people who attended our focus groups described their diagnosis conversation to us, with a range of themes emerging. Some had been guided through the diagnosis conversation expertly by neurology professionals, and some felt steps had been missed out and the journey could be improved.

Themes in the conversation included the possible prognosis and advice on what to do and when to do it. Participants wanted to know about symptoms, about national and local support available to them, and where to go for trusted information about their condition. News and research were mentioned by several participants, and many also wanted to learn about clinical trials and medications.

*'Every individual is different, aren't they?
Everybody has got different needs.'*

Sophie, wife of man living with Parkinson's

Participants wanted to be guided by their neurologist, and they also wanted a full picture of the team they will be working with going forward in terms of rehabilitation and coping in the future, including any information available about specialist nurses or support services, such as physiotherapists and speech and language professionals.

'It's a strange situation to be in. No one is the same. No two people are the same but they must have maybe a more standardised set of things you could get, [a list]...Even if you don't give it to the person that's had the condition, if you gave it to family or carers that are round you because you'd know then what to expect.'

Roger, man who has survived stroke

For all of the themes, participants spoke about the importance of trusted information, a caring and considerate approach and how vital it is for people being diagnosed with a neurological condition in Essex to know what the next steps are following that initial diagnosis conversation.

'I've got Parkinson's disease. The positive thing was actually getting a diagnosis after quite long time.'

Judy, woman living with Parkinson's

Participants spoke of the time it can take to reach diagnosis, and how this differs dramatically depending on what condition you live with. For example, diagnosis of a stroke usually happens instantly upon presenting at Accident and Emergency, while motor neurone disease can take a long time to diagnose, time which is often of the essence.

'[A positive was] finding out what was wrong with me. So in other words, getting a diagnosis. And that was kind of finally, because - well, the symptoms started around about this time last year, had to be taken into hospital around about June, thinking it was a stroke and then it went on.'

Sarah, woman living with MND

Quite often, participants have undergone a series of tests and may have waited years to receive a diagnosis, so that conversation is a pivotal moment for them, and very much represents a new journey beginning.

'If somebody had got that on a computer somewhere and could have put all the other things together... I could have had an earlier diagnosis.'

Laura, woman living with MS

Developing a more personable manner, and engaging with people as individuals when delivering the diagnosis conversation is something that neurologists could do in the future. No two people living with any condition are the same, and participants would like neurologists to recognise this.

'If you don't fit their criteria they don't want to know.'

Maria, woman living with MS

The five key themes

Five key themes emerged from the focus groups around the diagnosis conversation.

These are:

1. Delivering a diagnosis
2. Questions and answers
3. Treatments and choice
4. Referrals and signposting
5. Making the most of future appointments

While there are five key themes, participants felt strongly that these are not mutually exclusive, and that each needs to be acknowledged at the same time - during that diagnosis conversation. It may seem like a lot to fit in to one appointment, but by recognising the impact of exploring these themes during the diagnosis conversation on the individual and how neurologists can implement a new approach from today, it is an achievable goal.

'It's about also being honest about illness.'

Oliver, husband of Sarah, woman living with MND



1. Delivering a diagnosis

Delivering a diagnosis of any neurological condition takes expertise and empathy. Neurological symptoms may have been present for a while before someone seeks help, and participants in the groups had been formerly diagnosed with a range of conditions such as carpal tunnel syndrome and depression.

'He was down to earth. I think that's what people need.'

Matt, man living with Parkinson's

It was apparent that the initial delivery of a neurological diagnosis was received in a number of ways.

'He was just so uninterested in me...even his tone...

I came out and I was just like, was that me?'

Charlotte, woman living with MS

It was thought that being human, empathetic and recognising people as individuals would make a difficult task easier.

Well I suppose it was his mannerisms and his knowledge really.

For me that was positive.'

Henry, man living with MS

Participants had very mixed experiences of how their diagnosis conversation unfolded.

'When he gave me that diagnosis he came in out of another clinic that he was in and he was calm, he listened to me, which is what the most important thing is. We had the time.'

Maria, woman living with MS

Many of the participants of the groups recognised that it may be an unpleasant task, and they also recognised that professionals have a limited amount of time with each patient.

'I know it's a difficult job trying to explain to someone, you've got something and you've got it for life. There's no cure, as such, at the moment. You've got it for life. Each individual is different.'

Matt, man living with Parkinson's

However, participants believe that small things can make a big difference. Taking a bit of time to explain the diagnosis and 'being honest' about the circumstances was greatly valued by attendees at the groups, as well as a kind and caring approach.

Neurologists should not simply describe inevitable loss of independence, but honesty and sincerity is essential during the diagnosis conversation.

'I felt I'd trusted the health professional and she was really - she had the right tone of language, sort of said the right things. She was comforting.'

Judy, woman living with Parkinson's

Receiving a level of empathy from neurologists was valued by some, and having time to ask questions and talk 'one to one' was important to others.

'He told me the diagnosis, and it was, "Well, where do I go from here?" sort of thing.'

Matt, man living with Parkinson's

Trust was mentioned by many participants. This can be built by being honest from the outset, focusing on the patient and including family members in the conversation if they are present.

'Feeling that the consultant has got time, especially when you get diagnosed. I really felt - one of the things that made it positive was that I didn't feel rushed and she took her time and she - you know. Having faith in the consultant as a clinician. So you get that. And also, that they are people-people, they know how to talk to you and that they - everyone is going to be different, but they pick up on how you react and react to you accordingly.'

Judy, woman living with Parkinson's

Listening is a skill that some neurologists practiced well, and this made a huge difference to the overall experience of the diagnosis conversation. Participants mentioned neurologists who had looked them in the eye. This reinforced trust between neurologist and patient.

'When I had my diagnosis... he pulled his chair closer to me, he lent forward and he looked at me...'

Jane, woman living with MND

This experience differed to other participants' experiences, where neurologists turned to their computer screens a lot or conferred with colleagues instead of focusing on the patient.

Case study

Ben was diagnosed with Parkinson's by a neurologist. He was accompanied by his wife, Sophie, at the hospital, and he felt very rushed during his appointment.

Ben said 'it was, "Come in, sit down, shut up, get out." Ben and Sophie were both concerned about the lack of information he was given about his diagnosis, but more importantly they hoped neurologists could develop more tact when dealing with patients. 'It's as though they haven't got time for you. You're just another person to sort out and get rid of,' he said.

Ben hoped for better things in the future. 'What do I wish he'd done? He was a little bit more caring I would say. He was very hard.' When asked how neurologists could do this, the man said 'I think I'd use the word 'understanding' because when you're poorly and you're in pain you just need that, "Hello mate. You alright?" For them to be nice to you. I know it sounds stupid.'

Ben acknowledged that the neurologist sees a lot of people, but he felt more care could have been taken during his diagnosis conversation. He hopes people will be treated differently by simple steps being taken. 'If you say to somebody, "Are you okay?" That's three words, and they go, "Cor, that was good. They're asking how I am."

Participants felt that honesty was a big element of a positive diagnosis conversation. People struggle when their diagnosis is yet to be confirmed and are seeking a name for the symptoms they have experienced. But once they know what condition they have, they appreciate open discussion about the possible prognosis.

'Don't hide anything.'

Grace, woman living with epilepsy

Case study

Louise was diagnosed with primary progressive MS. Her diagnosis was a shock. Louise really valued the honest approach of the neurologist who diagnosed her.

She said, 'Seeing this neurologist who I found was very honest up front, looked me straight in the eye when I asked her to and told me the truth, and she did, which I found pretty good and which helped me at the time.'

Immediately after receiving her diagnosis, Louise found she became very emotional. 'When I left that room, after about 20 minutes of her, after I told her to look me straight in the face and tell me because I don't beat around and I like to know, it was no good saying, "You might..." I went out the door and went to book the lumbar puncture and I turned round, for some unknown reason, hit the floor and cried my eyes out. Whether that was relief or shock I don't know.'

Louise feels this was handled well by staff at the hospital. She said, 'They took me to a side room and then a nurse sat and explained what they were going to do with the lumbar puncture and everything. But the fact that I knew I had an answer, that they were going to treat me for this 'long word' at the time it was just the relief I think of what's been going on in my mind and being told by someone who should know what they're talking about.'

However, upon leaving the hospital after her diagnosis conversation, Louise waited quite a while to seek further support. She was offered no information from the hospital, and she feels if she had been, she would have accessed support in her local community sooner.

'I'd have liked to have spoken to someone or known where I could go to speak to someone. What do I do? How do I come to terms with what I have and meet people that have got what I've got?...I knew nothing about MS, as such. That was a word that I didn't want to associate with myself. I opened a cupboard and stuck it in there, I didn't want to know.'

Taking time, approaching circumstances honestly and openly and delivering a diagnosis is perhaps one of the hardest things to do, but the value it has to the patient if it is delivered well is life changing and long lasting.

2. Questions and answers

Discussing the prognosis of complex conditions is, as might be expected, sometimes problematic. Everyone is different, and what each person faces will be unique to them. However, participants agreed that hypothesising about what they may face in the coming weeks, months or years was something they wanted neurologists to do.

'I said, "Can you tell me what I can expect?" and they said, "No, because you're all so different."'

Jane, woman living with MND

Some participants said that receiving a diagnosis was a relief, and they finally felt like they had an answer to why they were living with a range of symptoms. Yet this answer generated many further questions for patients.

'My big one is, "What's next?'"

Maria, woman living with MS

Participants wanted to hear about possibilities from neurologists, and examples of what symptoms may occur in the future. Those who met with neurologists who did not want to offer any possible scenarios felt in a position of no control, and unprepared for what the future may hold and what to do when 'the worst' happens.

'He wouldn't answer any question directly.'

Charlotte, woman living with MS

Some participants reflected on their diagnosis conversation, and although they were positive about the tone and approach of their neurologists, the lack of information about the next steps left them disheartened.

'He explained things: "I want you to do this, because I want to see this," and what have you. We did the feedback thinking, "Well, that was a good consultation." But afterwards, carrying on, when we joined the Parkinson's group and what have you, and found out what was available, we thought, "Well, we should've been told this in the first place."'

Anna, wife of Matt, man living with Parkinson's

Discussion about possible future symptoms was highly valued, even if the outlook was negative.

'If they'd said to me, "You're going to get tired. It's going to come from either one of two things. If you walk five miles, you're going to be tired. If you fill out a form or something that you need to think about," like PIP forms, "You're going to be tired from that." If they told you that... That needs to come right at the beginning somewhere.'

Roger, man who has survived stroke

Participants did not expect neurologists to have all the answers, and they empathised with the neurologist's position of delivering this news.

'At the time of diagnosis it would be nice for someone to sit them down and say, "Look, you might experience this, you might not. Everybody is different."

Sophie, wife of Ben, man living with Parkinson's

Case study

Matt received a diagnosis of Parkinson's when he was fifty-seven years old. He had many questions about what may happen to him in the future, especially the physical side effects of the condition. He felt there were not enough answers during his diagnosis appointment.

'Parkinson's is a bit awkward. I don't think, really, he explained to me what was going to happen in the future. My concern would be the future: am I going to end up in a wheelchair, or what? Then again, I didn't ask the question, really. Because when we went there, I didn't know what to expect. I half knew what to expect. You get the diagnosis; then what's going to happen? You just don't know.'

Matt gleaned most of the information that helped him later on through a peer support group. By contacting the local branch of Parkinson's UK, he was able to get a picture of the different ways Parkinson's can develop.

'I think I found out more from talking to other people with it, because when you're in the group, you see the various stages. Some have had it years.'

Matt and his wife, Sophie, were keen to find out the next steps and look to the future. He said, '[The neurologist] could've explained that everyone is different along the path. Because that's not explained...what he could've explained was that you learn to live with what you've got, rather than worry about it.'

'I think more information right from the word go, because I didn't have a clue what Parkinson's was, did we?...We had to look it up on the web.'

Ben, man with Parkinson's

Some participants felt that their neurologist was either friendly, or knowledgeable, yet rarely both when participating in the diagnosis conversation. Participants found this frustrating.

'[The last one I saw] she was friendly and she asked me loads of questions, but she didn't give me any answers. She didn't give me any suggestions when I said, "What might it be?" She seemed really nice and helpful, but I just didn't - she had no answers on these questions or anything.'

Judy, woman living with Parkinson's

People in the focus groups felt sympathy with neurologists who were delivering 'bad news', but hastened to add that they didn't expect the neurologists to fix everything. Even bad news would be better, some felt, than no news.

'I know they should tell you the worst case scenario for lots of things but this was never mentioned. They only really concentrate on the things they can see.'

Roger, man who has survived stroke

Engaging with patients as individuals and reacting accordingly to them is something all participants in the 555 focus groups hoped to see neurologists do in the future. They felt that this would help patients ask and answer more questions initially, and leave their diagnosis conversation knowing what is next and where to turn.

Case study

Paul had a positive experience of being given lots of information during his diagnosis conversation. He was diagnosed with motor neurone disease. He said, 'I think to be perfectly frank, we've been very lucky. The folk we've keyed into in [our town] have organised lots of visits from physios, nutritionists, occupational therapists. The whole network seems to have fallen into place and we were quite lucky.'

Paul and his wife, Jo, have found a lot of support from a local branch of a national charity as well. Jo said, 'The MNDA has been absolutely brilliant,' and he agreed, 'They were superb.'

Paul believes one of the most positive parts of his diagnosis experience was that the neurologist explained the different types of motor neurone disease. The neurologist explained that everyone experiences MND differently, and gave lots of information.

He says, '[The neurologist] set out all the possibilities and he also said - because I've got the lower form, whatever that is, it's a longer term thing than the other form. And he was very positive wasn't he about it? He said, "It's good that you know about these things." And so I thought that was really helpful, because if someone is giving you the bigger picture from someone you know who is the main man then that really sort of boosts you...'

However, Paul recognises that neurologists have a judgement call to make every single time they diagnose a person. He said, 'They're giving you this diagnosis you've got a terminal illness, which it is because there's no way of curing it at the moment. But he doesn't want to overload you with a whole load of other stuff. And some people like us want as much information as you can be given. Other people just freeze and think, 'Oh, bloody hell, what's going on here. Whatever, whatever.' So I think, to be fair, they have to make a very quick decision as to whether you're the sort of person who could take a lot of information or it would just make you really seriously depressed, something like that...But that can't be easy.'

For Paul, posing and answering lots of questions during the diagnosis appointment was the right approach. 'This early explanation of the journey that you're going to be on and what might happen and might not happen and...Then you're left feeling a little bit more in control.'

3. Treatments and choice

There were several elements of treatment that participants discussed, including diagnostic tests, medication management and the choice and access of treatment depending on the area you live in.

Undertaking diagnostic tests to determine treatment were seen by some as a difficult experience, however necessary. Participants felt that neurologists could work towards supporting them to understand the reasoning behind tests, and also set expectations of what tests involve.

'I was in the tunnel and you're completely closed in. It's awful.'

Ben, man living with Parkinson's talking about an MRI scan

The time it takes to test a wide range of symptoms was frustrating for many participants, especially those living with life-limiting conditions.

'Getting the tests done together not one after the other to draw it out. I think that's really important.'

Jo, wife of Paul, man living with MND

Some participants felt that prior symptoms and scans could be taken in to account to deliver a diagnosis, and they wanted to be able to trust the recommended treatments presented by neurologists as the most up-to-date options.

Medication was mentioned by several participants, and they felt it was an important element of treatment which needed to be explained.

'The problem with these sorts of tablets is, you can't, all of a sudden, stop taking them, because that could have bad effects.'

Matt, man living with Parkinson's

Participants felt that neurologists may offer medication without explanation of side effects, or without considering the person holistically in terms of other conditions they may be living with.

Case study

While living in another county, Charlotte went to her GP and then saw a neurologist, who mentioned the possibility of having multiple sclerosis to her. However, after having an MRI there was nothing conclusive, and Charlotte was discharged.

Five years later Charlotte moved to Essex, and experienced a relapse. Her walking was severely impaired, and she visited her GP who referred her to the neurologist in July. It was a scary time, and she was coping with moving to the area in addition to being unable to walk. She said, 'You just think, is this it? Is this my legs gone forever?'

When the referral appointment to the neurologist was confirmed, it was for October, which Charlotte felt was too long to wait. She decided to seek private medical advice, and the consultant she saw mentioned MS. The consultant subsequently got in touch with the NHS neurologist and recommended the woman undergo MRI testing. However, the NHS neurologist did not want to carry this out before the appointment scheduled for October. There was no explanation for why this happened.

Charlotte decided to undergo private MRI testing, at her own expense. She did, however, keep her appointment in October with the NHS neurologist. She found the experience to be very negative. The neurologist asked the woman if she had the MRI results, and when she said she hadn't received them yet, he said there was nothing he could do without them.

Charlotte found the neurologist to be rude, and left the appointment without having any of her treatment questions answered. She specifically asked if she would be able to have access to a drug treatment, if her diagnosis was in fact MS. 'He said, "Well it's on the NHS. All drugs are available on the NHS" ...it turns out it is not available in Essex. So he did not answer the question.'

When Charlotte returned home from this appointment, she received a letter from the private consultant confirming a diagnosis of MS. Charlotte then asked her GP to re-refer her to a new NHS neurologist, and the GP was helpful and agreed to do this.

Case study

Martin was diagnosed with multiple sclerosis in 2015. Martin found living with more than one condition had an impact on his overall wellbeing, and even put him at serious risk when his asthma was not taken in to account when treating his MS.

He said, 'The biggest problem that I had with the neurologist is checking what tablets I'm on, because I'm on 22 different tablets for my asthma. I was put on [a particular medication] and within two days I was in intensive care because they reacted and I shut down and didn't breathe.'

His primary concern is that his neurologist may ignore his asthma complications in future when prescribing medication. 'I've had several tablets that I've been put on for my MS and it's affected other tablets.'

Support from other services, such as his asthma nurse, have been critical to maintaining his health and managing his medication since he was diagnosed with MS.

He said, 'I've now actually got a very good asthma nurse who if I'm put on a tablet I can say to her, "Look, I've been put on this, is it going to affect anything?" But I am always concerned about what tablets, after just going on one tablet and everything shutting down within a day of being on it.'

By taking a holistic approach, neurologists may be able to offer treatment, and specifically medications, that do not interfere with pre-existing conditions. This would save not only time and money in the future by limiting presentation to a range of services, but possibly lives.

'The side effect of some of the tablets I take is really bad heartburn. Nobody mentioned that to me. I phoned the paramedics three times in a month...'

Roger, man who has survived stroke, and lives with an ongoing heart condition

Many of the groups discussed the need to explain what the medication is and the possible side effects.

'You start the course and its two weeks later. "How do you feel?"
You go, "Whoa." They're quite strong tablets.'

Ben, man living with Parkinson's

Prescriptions after the diagnosis conversation were also seen to be an issue for some of the participants, and many felt neurology services could work more closely with GP services to support patients to manage their medication.

'You've got to remember that my GP won't change my medication.
If I want something changed, I need to go to the consultant.'

Roger, man who has survived stroke

The diagnosis conversation is often the beginning of a new course of treatment, and yet some participants felt that only the symptoms that were presented at the appointment were considered, rather than neurologists taking a holistic view of the person's condition and medical history.

'I was supposed to have a follow-up to see how I was getting on with the medication, and that was after three months. Then that became six months. Then, after chasing the, that took about nine months in the end... Well, it is one of the most important things, because some of these medicines, you can have really bad adverse side effects, really bad.'

Matt, man living with Parkinson's

Many participants in the groups wanted to have confirmation from neurologists that their medication and treatment options would be regularly reviewed on a continuous basis.

4. Referrals and signposting

As professionals, neurologists need to be 'filling in the blanks' for patients once they have delivered a diagnosis, during that diagnosis conversation. Participants felt strongly that signposting to trusted sources of information was crucial, and many felt it made the difference in terms of how long it took them to seek further support.

'[The neurologist] knew not to overload me. She warned me not to read too many - go on to too many websites because it would scare me.'

Judy, woman living with Parkinson's

Researching conditions online was seen as a scary prospect, but something many participants felt they had to do because they were not signposted during their diagnosis conversation to a trusted resource.

'Daunting because you look at your computer and it's full of Parkinson's. There's not just one type, is there?...It's full of side effects, which I'd experienced, like headaches, shaking, anxiety...'

Ben, man with Parkinson's, talking about researching his diagnosis online

It was felt that delivering a diagnosis, especially one that was not positive, without then offering further resources to digest was not a good approach. Participants felt it could leave people without the confidence to seek support.

'I was told, "Sorry to give you that information, we think we've got some leaflets, go home and Google it."'

Abigail, woman living with MND

Referrals, and even awareness raising, of specialist nurses was seen as a 'lifeline' by many participants who subsequently connected with nurses. Accessibility to nurses was a key consideration, and many people wanted to be able to contact nurses frequently and easily and be confident that they would be heard and supported by nurses.

'I've got an amazing specialist nurse. So I think that really helps.'

Judy, woman living with Parkinson's

The support that nurses offered to participants was highly valued, and many wished they had been told about and referred to the nurse immediately during their diagnosis conversation.

'Back and forth. Hasn't felt well. Last time we saw the consultant was November. We were told about the Parkinson's nurse by a secretary, not by the consultant. We then had to ask the consultant if we could see the Parkinson's nurse.'

Sophie, wife of Ben, man living with Parkinson's

Some participants did not discover that specialist nurses operated in Essex for their specific conditions until much time had passed since their diagnosis conversation, and then only via joining local support groups. They felt that neurologists should be promoting the nurses and what they can do for people right from the beginning.

'To know that there's someone, when you ring, who you can talk to who's going to listen to you and understand what you're going through and what you're trying to say.'

Louise, woman living with MS

It was important for people to know that referrals would be made and followed up. Quite often, participants had to chase referrals, and this was detrimental to their health.

'I was backwards and forwards to the doctor, to the hospital, to wait for tests and eventually it was me that had to fight... It took me two years of fighting...'

Maria, woman living with MS

Many participants wanted to be referred to a neurologist who was a specific condition specialist, and felt that the earlier this was done, the better.

'If he doesn't know the answer you refer me onto somebody else, surely?'

Maria, woman living with MS

Referral to other services was seen by participants as essential if they were to maintain choice, control and independence for as long as possible after receiving their diagnosis. However, many participants spoke of referral waiting times and a lack of joined-up working.

'I was given special insoles just to keep my balance as best as possible four years ago. That is the last time that I saw orthotics. [The neurologist] was supposed to actually refer me to orthotics but that never occurred.'

Jenny, woman living with MS

However, the quality of this treatment varied from hospital to hospital, and consistency is an issue.

Case study

Sarah experienced a gradual worsening of her speech over a short period of time. She was later diagnosed with motor neurone disease. Sarah asked her consultant if it was MND and was told 'possibly'.

As the consultant at the hospital she was initially referred to was unsure, the woman and her husband, Oliver, requested a second referral. Oliver said, '[The hospital] haven't got the facilities...to carry out a comprehensive test. I mean all she could have done is just - what would it have mattered if she'd referred earlier?'

Sarah and Oliver found asking for a referral difficult and time consuming. 'The politics, you know, GP, "Can you refer me?" "Oh, you know, referring you outside of our area and you can't..." It's within our rights to go and see someone at any hospital we like. If we're getting a GP to do that is - it's difficult.'

She said, 'You get really frustrated, you know, what is going on with me? What is happening? Because it's not only the diagnosis, it's the support. You're just in a void. You haven't - you've got no advice, no support at all about MND. You can't make plans, because you don't know what you've got. You don't know what's the matter with you.'

Sarah decided to then use private medical insurance to access a specialist sooner. When she had her diagnosis conversation, it was a very positive experience.

'One of the things that [the neurologist] said when we left him after the private appointment was, "Right. I'm going to refer you to the clinic at Whitechapel and they will be your family now. So in other words, they will be your support from now on in."'

Sarah and Oliver found this approach very comforting. 'They will be your family now was his very [words], because that's the kind of thing you want in terms of support.'

The after care following the diagnosis conversation was also very positive for Sarah. Oliver said, 'Twenty-four hour email support...a specialist MND centre and family being allowed to be involved, which is one of the things that they've welcomed us taking our sons or whoever, family, along next time and they can ask all the questions that they want as well, which has been lovely.'

Waiting times for referrals varied, and several participants or their family members had to chase referrals. They expressed frustration at this, and found it overwhelming when trying to cope with symptoms at the same time.

'I asked the consultant if we could see her, and this was November. The appointment is now 18th April, so we still haven't seen the Parkinson's nurse.'

Sophie, wife of Ben, man living with Parkinson's

By providing patients with approximate time scales and outlining realistic expectations, neurologists may be able to provide patients with reassurance and reducing chasing. Every time services need to respond to an individual there are cost implications.

'I suppose I think I probably would've liked to have come out of that room with a firm appointment to see the nurse, or someone like that... because after I came out I did have to chase a couple of times actually to be fair. I think it would've been nice to come out with a date, "Okay, you've got an appointment in a month's time to see whoever."

Henry, man living with MS

Signposting people on to further support and information was expected by all the participants, but not necessarily received. Participants felt that neurologists could be great gateways to trusted resources and helpful contacts, but didn't always share this information during the diagnosis conversation.

'I think it's really being pointed in the right direction. You've come to a crossroads. There's a signpost there with nothing on it. That's what's happened, really.'

Matt, man living with Parkinson's

There are organisations out there who can provide information about financial support. Signposting to these could make accessing this information easier for patients.

Providing people with condition specific literature was seen as a good idea by many participants, and several mentioned that it would be beneficial to have specific literature around being newly diagnosed.

'Yes because a tiny thing like [a leaflet], there is hope.'

Ben, man living with Parkinson's

Many felt that hospitals could display a range of information about neurological conditions around the premises, so that patients could have choice and control over what they took away with them.

'Well, with the waiting room, it would be nice if there was something there for the neurology side of it, being Parkinson's, MS, anything like that that's involved, that you can actually pick up a leaflet.'

Sophie, wife of Ben, man living with Parkinson's

Many would like to have received a list of trusted websites to look at later on, and some participants said that they would like to be able to rely on the neurologist to provide this information during the diagnosis conversation.

'I think it would've been helpful just to say - with me, I'm computer-literate - "Go to the website Parkinson's UK", or, "Go to the site MS-UK. "Here's a leaflet which explains it a bit more.'"

Matt, man with Parkinson's

Information about condition specific charities was highly valued by participants at the 555 focus groups. Many people felt they would have contacted charities quickly following their diagnosis, if they had known about them.

'[Leaflets] would be helpful because to be fair not everybody knows their way around a charity system.'

Paul, man living with MND

Several participants mentioned charities that they wish they had heard about from the neurologist. Some patients were given details of charities that supported people with their specific condition, and this was seen to be a very positive thing by participants.

'I think for me, just being told about Parkinson's UK existed and the contact details...but just knowing that it's there...the Parkinson's UK website is amazing and they've got a really good support [network].'

Judy, woman living with Parkinson's

5. Making the most of future appointments

Many participants of the groups spoke openly about their concerns for the future, and the impact on their lives of living with a neurological condition.

‘We were led blind up an alleyway thinking, “What the hell are we doing here? We need help.”’

Ben, man living with Parkinson’s

All of the participants discussed the value of neurologists providing people with an ‘action plan’ or ‘care plan’ during the diagnosis conversation, and many felt it was an essential tool for them to take away with them.

‘In all honesty, I think I went in there a bit more prepared than what most people would be. But I was sort of unprepared for what I was likely to be asked. He said, “Parkinson’s.” “Fine, now what?” It’s like, “There’s a fishing rod. There’s a reel,” but they haven’t given you the bait.’

Matt, man living with Parkinson’s

Many participants felt uncertain of the future when they left their diagnosis conversation, and would have liked support immediately afterwards.

‘There’s the diagnosis. And this is what’s going to happen now.’

Oliver, husband of Sarah, woman living with MND

A plan outlining potential treatment, possible symptoms and what to do should they occur, was seen as reassuring and useful by participants.

‘It would be good to know what the care plan is... I think that’s the most important thing to know, and an emergency number, if you need more advice, really, of where to go to.’

Anna, wife of Matt, man living with Parkinson’s

Booking a follow-up appointment was a key concern of people in the groups, and something many felt should have been offered during the diagnosis conversation.

‘Knowing when you’ll be seen next? Really important.’

Grace, woman living with epilepsy

After their diagnosis conversation, some participants felt unclear of what their next steps would be and how to seek support in the future. Many felt that neurologists expected patients to self-direct their care once the diagnosis was delivered.

'I'm quite proactive with it. Some people that perhaps aren't in the same position, that are relying on [joined up services], they're going to really struggle.'

Roger, man who has survived stroke

Case study

Roger experienced a stroke at the age of forty. He partially lost his vision, 'like turning off a switch', but his vision soon returned. However, he went to Accident and Emergency to be on the safe side and then had a severe stroke while in the waiting room.

He said, '[The hospital's] got an acute stroke ward so they looked after me. A&E were probably the best people because when I got there...halfway through filling out the form, I said to my brother, "I can't move my arm," and he said, "You can't speak," so I'd had a massive stroke sat in A&E.'

Roger was aware he was having a stroke, and the nurse recognised it immediately too. The response was instant, and Roger received high quality care at the hospital following his diagnosis.

'I would say I had one-to-one care on that ward and they were excellent. A couple of days...I went into [the rehab ward]. They were excellent, absolutely brilliant. They were very, very good. I had my consultant and his understudy and they always came as a pair. You couldn't get one and not the other. They were excellent. They saw me, bearing in mind I wasn't in there long - I was only in there 18 days - I probably saw them 6 or 7 times.'

Upon leaving the hospital, rehabilitation was a key element of Roger's treatment plan. He did, however, sometimes feel that he was not able to get all the answers he needed. He said, 'I mean they can't answer the questions that I ask as well. I had, "Can I have a tattoo?"'

Providing answers to questions that are important to the patient for their quality of life is something neurologists could do. 'Although we're survivors, at the end of the day, we're some sort of customer almost.'

‘They need to be patient focused.’

Kim, woman living with MS

Knowing who to talk to and how to contact them in the future is essential for people newly diagnosed with a neurological condition. Participants felt that communication lines could be left open, and expanded, to make things easier for follow-up treatment.

‘I would love to be in a position where I could email my consultant’s PA and say to them, “Can I make an appointment?”’

Roger, man who has survived stroke

Many carers at the groups expressed their anxiety and stress over having to chase follow-up appointments and referrals.

‘Every appointment we’ve had I’ve had to chase.’

Sophie, wife of Ben, man living with Parkinson’s

A regular and constant service was highly valued by participants. Many expressed frustration at having to tell their story over and over.

‘In the first six months or whatever, you do feel there are lots of things they’re doing for you but after the initial period, you’re out on your own.’

Roger, man who has survived stroke

Participants spoke of the need for a long term approach for conditions which you live with for many years, and timeliness for those conditions that are life limiting.

Case study

Michael went to the hospital for surgery for carpal tunnel syndrome. During his assessment, the consultant stated it was not carpal tunnel syndrome and asked a specialist to join them.

There and then the specialist diagnosed Michael with motor neurone disease. He said, 'It was a shock, to say the least.'

Michael was alone at the hospital on the day of his diagnosis, and he travelled home afterwards. 'I had heard of motor neurone, but I didn't really know what it was...coming home on the train, I was trying to think, what is motor neurone?'

He would have preferred more explanations during the diagnosis conversation at that appointment. However, a follow up appointment was scheduled quickly after, and Michael returned to the hospital with his wife, Michelle. Michelle said, 'Since the diagnosis they've been brilliant.'

He said, 'In a week, or two weeks, [the neurologist] asked me to go, and he did sit down and tell us about it.' The man and his wife found this very helpful, and the man also said a charity representative was in the appointment, and signposted them to their local branch.

Participants cared about making the most of future appointments with neurologists. They valued neurologist's time, and wanted guidance on what they should bring to follow-up meetings.

"They always say, when you go to see a GP, you should make a list. It should be the case with this as well. That's something they could advise you on: "Next time you see me, just make a list of things that have happened."

Matt, man living with Parkinson's

Many felt that appointment waiting times could be reduced, and also that more use could be made of the time with the neurologist. People wanted to discuss medication, treatment options, possible breakthroughs in research, clinical trials and also any other support that may be newly available.

‘You have one appointment each year with [the neurologist] which is very much the same. You’ve been off all year and they just say, “How are you?”’

Denise, wife of William, man living with MND

Participants felt that neurologists could consider that a diagnosis will touch all areas of a person’s life. Offering long term support to patients would help to minimise impact on a wide range of services.

‘After care is massively important. It’s not just for the survivor if you like.’

Roger, man who has survived stroke

Many participants spoke about taking a ‘holistic’ approach to engaging with patients, and hoped neurologists could be mindful that each patient must leave their diagnosis conversation and tell friends, family members, children and their employers about their condition.

‘Because [your family have] got to go through it as well. And actually having that chance to have that one-to-one conversation rather than me passing it down second hand and probably wrong is far better.’

Oliver, husband of Sarah, woman living with MND

By treating patients how they want and need to be treated, neurologists can ensure that the patients of tomorrow feel more in control of their lives and empowered to make possible changes.

This new relationship, between neurologist and newly diagnosed patient, is a vital one. It may last a lifetime, and it is a relationship that people hold dear.

Listening to patients, and empathising on a human level, is the key to making the diagnosis conversation better for people in the future. Participants recognise this is difficult news to deliver, but by reading this report and taking on board the stories people have taken the time to share, these conversations should be easier for all.

‘You need to think about if you were being told something, how would you like somebody to tell you?’

Laura, woman living with MS

Other things to consider

During the 555 focus groups, many subjects came up, and participants were honest, open and candid. It was a chance to share ideas and highlight ongoing issues. Some of these issues did not fit within the themes we have identified. They are highlighted in this part of the report.

The importance of carers and loved ones

Many participants voiced their concerns about carers and loved ones being left out of the picture when considering the wider impact of living with a neurological condition.

'If they're your carer they see a different side to you that you probably haven't noticed...they see the things like when you fell over and tripped over the cat bowl, the cooker or something, or you've spilt something. I can't always remember that.'

Maria, woman living with MS

Several participants were accompanied by their spouse to the groups, and felt that the support of their loved ones made a big impact on their ability to cope with their diagnosis.

'They're an extension of you.'

Jenny, woman living with MS

Participants urged neurologists to consult with family members, especially anyone who is particularly involved in the care of the patient, such as a spouse. Often, participants felt they may forget things between appointments, and their family supported them to tell a true account of their symptoms.

'They're the ones that are with you 24/7.'

Maria, woman living with MS

Joined up services

Many participants spoke of a need for joined up working across health and social care as a whole following the diagnosis of a neurological condition. After a diagnosis, patients often come in to contact with several support services such as speech and language therapists, physiotherapists and Personal Assistants. A need for all of these services to speak to each other was clear.

Open lines of communication between GPs and neurologists was considered fundamental, especially with regards prescription medicines and referring back to the neurologist if needed.

'I was sent to discuss the test with my GP who read the result and said to me, "Yes, you've got a problem but I can't discuss it with you, you'll have to speak to your consultant."...Then another one, because I was put on sleeping tablets, said, "I'm so sorry to hear about your diagnosis" and I said, "I haven't had one yet." He said, "Well you'll get one when you see a consultant."'

Jane, woman living with MND

Specialist nurses

Many participants recognised that the specialist nurses in Essex via the NHS were stretched beyond capacity, and this impacted on the care they could provide to people.

'The problem with the Parkinson's nurse...there aren't many of them. They've got a particular area to cover.'

Matt, man living with Parkinson's

To many in the groups, nurses acted as conduits to other services, such as speech and language therapists or to contact local authorities for building adaptations. Many relied on their nurse to monitor medication.

'We saw [the Parkinson's nurse], she came and called at home, and saw the state he was in in the morning. He'd just got up and couldn't move, and didn't know much. She said, "You're under-medicated. You need more medication." Then we became aware that it needs to be more regular...It definitely needs to be regular. If you've forgotten it for a couple of hours, it does matter.'

Anna and Matt, wife and man living with Parkinson's

Supplying and supporting specialist nurses is a key consideration for the future.

'When I go and see someone like [my MS nurse], who's got about 700 people on her call list...she needs assistance... I just see so much wastage that I find a bit annoying actually when I just think someone like that needs help.'

Henry, man living with MS

Sharing best practice

Sharing best practice among hospitals was seen as a good idea by several participants. Some had experience of seeing professionals at hospitals outside of Essex, and where treatment was good they hoped it could be replicated locally.

Employment

Supporting people to communicate with their employers was highlighted by several participants at the groups. Advice on managing sick leave prior to diagnosis would be helpful for many people who have been living with symptoms for some time.

'I don't think my boss that I was working with understood epilepsy at all.'

Grace, woman living with epilepsy

Post diagnosis, it was recognised that employers may need help to understand how to support people living with a range of neurological conditions in the workplace, and quite often this meant the difference between the patient being able to work or not.

What should happen now

Conclusions

The purpose of the 555 Neurology Project was to capture the lived experience of patients being diagnosed with neurological conditions in Essex.

To make a real difference to people living with neurological conditions, we believe that we need to reach out particularly to neurologists, as it is they who deliver the diagnosis conversation and therefore hold a pivotal role in the journey of people with neurological conditions.

Unfortunately, some patients reported that their diagnosis conversation with a neurologist was a negative experience. We have heard that neurologists often talk about what patients 'can't do anymore', or do not provide answers to the questions that patients ask.

We want to change this by bringing Essex-based neurologists together with real neurology patients, to shine a light on the experiences they have had and what they feel would have been the best way that they could have been given their diagnosis.

Listening to patients, and empathising on a human level, is the key to making the diagnosis conversation better for people in the future. Participants recognise this is difficult news to deliver, but by reading this report and taking on board the stories people have taken the time to share, these conversations should be easier for all.

We recognise this qualitative snapshot of people's lived experience can only be the beginning of improving the way people in the county live with neurological conditions. There is further work to be done to enable people to speak about their experiences to ensure continuous improvement of neurology services, and to facilitate communication with neurology services.

We hope that this beginning will present a rich tapestry of voices that neurologists will hear. Some positive, some negative, but all worth listening to if we are to truly deliver what patients need in Essex.

Recommendations

All the participants in this 555 project recognised that diagnosing a neurological condition is not always easy. But by listening to the voices of this report, we hope that we can encourage changes that can make the experience better for people in the future.

Reflecting the five themes of this report, we offer the following recommendations. They cover a range of possibilities, whether from individual practitioners making small changes to everyday practice, to organisations such as the commissioners and providers of services making changes at a strategic level, to local charities, including Healthwatch Essex, making changes in how they provide information and work together in partnership.

1. Listening to patients, service users and carers

- Listening to patients and inviting feedback of people's lived experience is essential at every opportunity, to continue to improve services for people across Essex. This applies at a one-to-one level, between patients and practitioners, as well as at a strategic level in terms of how services are commissioned and provided.
- This report presents only a snapshot of people's lived experience of diagnosis conversations. We recommend that organisations initiate further meaningful listening activities to ensure lived experience informs neurological services going forward.

2. Better diagnosis conversations

- We recommend that neurologists and other practitioners reflect on their everyday experience of delivering diagnoses, and should aim to deliver diagnoses with appropriate time, and with appropriate openness, empathy, honesty and sincerity.
- Practitioners should also aim to provide patients with approximate time scales for therapies and next steps. By outlining realistic expectations of the condition, neurologists may be able to provide patients with reassurance and reduce the need for patients to 'chase' information and their next steps in terms of support and services. Every time services need to respond to an individual request, this will have resource implications.
- At a strategic level, we recommend that commissioners and providers of services consider how neurologists can be better supported in the process of delivering a diagnosis, such as by extending the length of appointments.

- If necessary, we recommend there be ongoing training and support for neurologists and other practitioners to support the aim of better diagnosis conversations. This could include training around empathy and active listening.

3. More holistic approach to diagnosis and prescribing

- We recommend that neurologists and other practitioners aim to take a more holistic approach to diagnoses, taking better account of the needs, medical histories and lived experiences of people (such as those with pre-existing conditions).

4. Better planning to care

- Recognising the role of carers and the need for people to self-manage their condition, we recommend that consideration be given to promoting better care planning, and expectation management, at diagnosis stage and in follow-up conversations with neurologists and other practitioners. By adopting a more person-centred approach to care planning, neurologists and other practitioners can ensure that the patients of tomorrow feel more in control of their lives and empowered.

5. Better information

- We recommend that provision of appropriate information (about the condition in question and support available, for example) is considered to be an integral part of any diagnosis conversation. We recommend that charities and other organisations (including NHS and social care providers and commissioners, and local Healthwatch organisations) work together to provide literature and resources to neurologists and other practitioners to ensure patients, service users and carers are kept up-to-date with relevant information or alternative sources of trusted information.

6. More joined up services and community support

- We recommend that commissioners and providers of services (including charities) consider how services can be better integrated to meet people's needs, in order to promote better outcomes for people and more efficient services and systems of support. This might include systems of referral and information sharing between GPs and acute care, for example, or a greater role for nurse specialists, who often act as the bridge between patients and services.

About Healthwatch Essex and the Essex Neurology Network

Healthwatch Essex

Healthwatch Essex is an independent voice for the people of Essex. We're here to understand the lived experiences of people who use health and social care services in the county and to make sure their voices are heard. We also provide an Information Service to help people access, understand, and navigate the health and social care system.

The Information Service can be contacted on 0300 500 1895.

www.healthwatchessex.org.uk

Essex Neurological Network

Essex Neurological Network aims to raise awareness and promote understanding of neurological conditions across Essex. It brings together voluntary organisations, the independent sector and statutory organisations for the purpose of working to secure the highest standards of service and improved care for people with or affected by neurological conditions.

MS-UK

MS-UK was established in 1993, and is a national charity dedicated to empowering people with multiple sclerosis to make the most of today, and live life to the full.

We put people affected by MS at the heart of our work. We provide high quality, professional services to support people living with multiple sclerosis, and we listen to people affected by MS.

www.ms-uk.org

Parkinson's UK

We're the Parkinson's charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson's. We provide expert information on every aspect of Parkinson's so that people affected by the condition can stay in control of their lives.

www.parkinsons.org.uk

Huntington's Disease Association

The HDA supports people with Huntington's disease, their friends and family and also the professionals who work with them. Anyone can self refer to the HDA by contacting Head Office or their local Specialist HD Adviser.

www.hda.org.uk

MS Society

The MS Society is the UK's leading MS charity. We've been providing information and support, funding research and fighting for change since 1953. We fund research, give grants, campaign for change, provide information and support, invest in MS specialists and lend a listening ear to those who need it.

www.mssociety.org.uk

Motor Neurone Disease Association

The Motor Neurone Disease Association is the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning. We are a membership organisation with over 9,000 members forming a powerful national and local network that provides information and support alongside fighting for improved services.

www.mndassociation.org

Headway Essex

The Headway Centre in Colchester provides rehabilitative care to survivors of brain injury. The centre is open five days a week. The Headway Community Support Service provides information, advice and support to people living with acquired brain injury and those who care for them.

www.headwayessex.org.uk

PSP Association

The PSP Association offers support and information to people living with PSP and CBD, while supporting research into treatments and ultimately a cure for these conditions. Our aim is that people affected by PSP and CBD do not feel they have to face the future alone. We offer support through our Helpline and Information Services, Local Groups, Specialist Care Advisers, a wide range of Resources and Publications and through the funding of Research.

www.pspassociation.org.uk

Stroke Association

Stroke Association is the leading charity in the UK changing the world for people affected by stroke. Undertaking research, offering support services and campaigning is the core activities of the Stroke Association.

www.stroke.org.uk

Find out more


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Information Service

We can answer your questions about health and social care services

Call
0300 500 1895

Monday to Friday 9am to 5pm
for the cost of a local call

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