NHS
Lancashire and
South Cumbria
Integrated Care Board

FUNCTIONAL NEUROLOGICAL DISORDER (FND) SERVICE MODEL

Listening to communities report

March 2025

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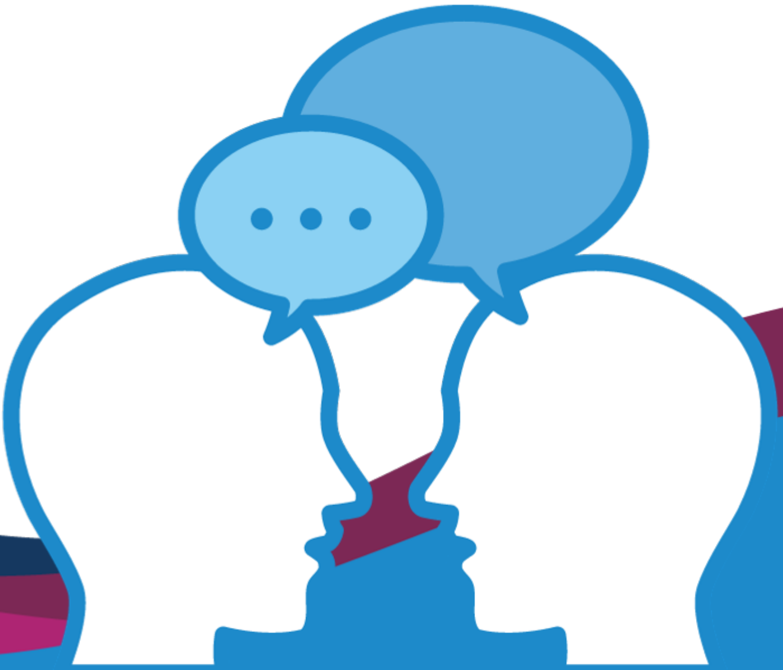


Contents

Acknowledgements

Thank you to all our healthcare professionals who shared the survey with their patients and to all the patients who took part.

Those who took part should be aware that, although comments received during the survey process have been summarised for the purposes of this report, all have been passed in full to patient experience and service leads so they are fully aware of the detail. We thank those that have highlighted their experiences.

Introduction

Since its creation in 2022 NHS Lancashire and South Cumbria ICB has been monitoring patient feedback on services and reviewing where improvements can be made.

As part of this a number of issues had been raised with the functional neurological disorders (FND) service which warranted further investigation and action to be taken.

A new service model has been developed that aims to overcome some of the issues raised.

This report outlines the method and findings of a period of engagement which took place in February 2025 to seek patient feedback on the new model prior to submission of a business case to progress implementation.

Executive summary

Key components of the model include employing FND specialist practitioners, implementing virtual Multi-Disciplined Team (MDT) meetings, and providing more education for Emergency department and GP colleagues.

The engagement process involved an online questionnaire, which received 26 responses over a period of one month.

The majority of respondents (88 per cent) supported the proposed model.

The feedback highlighted the need for better education and awareness among healthcare professionals, improved communication between different health services, and increased empathy for people with FND.

The FND specialist practitioners will play a crucial role in supporting patients, providing information, and coordinating care. Patients recognised the benefits this would bring.

Patients also said that the FND specialist practitioner also needs to be an ambassador for the condition itself. They need to work with healthcare staff at all levels to raise the awareness of FND in order for patients to feel their condition is being taken seriously. Based on the feedback received this part of the role needs to be a priority but there must be capacity for them to do this without making them unavailable for liaison with patients or it will potentially create more waiting.

The multidisciplinary team approach is welcomed, as long as it includes professionals from various specialisms relevant to individual patient needs.

It is suggested these recommendations from patients are taken into account when finalising the business case.

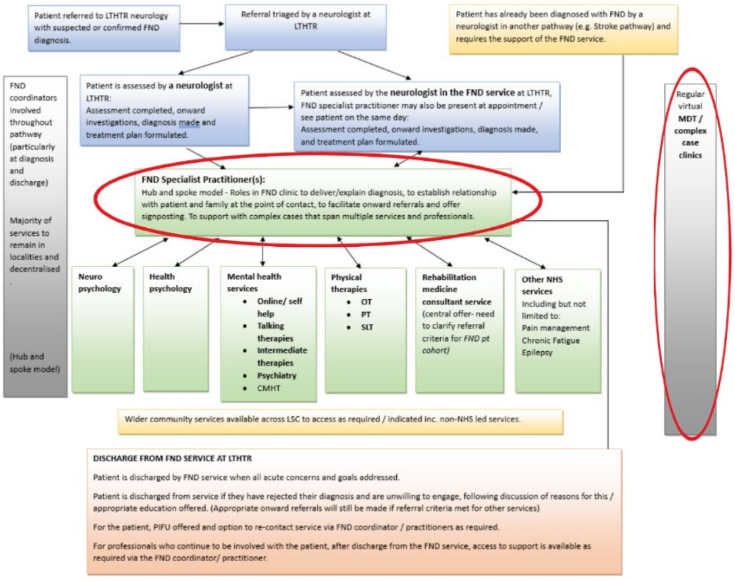
What have we been talking to people about and why?

The ICB has been coordinating a piece of work to review the service model for patients with Functional Neurological Disorders (FND). These patients sit under the neurology workstream and can have a complex presentation (which widely varies between patients of physical and mental health related conditions).

The review revolved around a number of insights gathered from complaints received from patients and MPs and various engagement activity such as the Your health Your future Your say roadshows in October 2024. This insight suggested a focus on patient experience, variable service levels, lack of 'joined up' services and waiting lists.

There has been a piece of work completed scoping the current offer across LSC (this varies at present). Currently (and recognised by the patients) there is only one neurologist, at Lancashire Teaching Hospitals NHS Foundation Trust, who runs an FND assessment clinic once per week. Most services carry significant waiting lists.

A new service model has been created which looks to overcome many of the issues with the service.



Patient referred to LTHTR neurology with suspected or confirmed FND diagnosis.

Referral triaged by a neurologist at LTHTR

Patient has already been diagnosed with FND by a neurologist in another pathway (e.g. Stroke pathway) and requires the support of the FND service.

FND coordinators involved throughout pathway (particularly at diagnosis and discharge)

Majority of services to remain in localities and decentralised

(Hub and spoke model)

Patient is assessed by **a neurologist** at LTHTR:
Assessment completed, onward investigations, diagnosis made and treatment plan formulated.

Patient assessed by the **neurologist in the FND service** at LTHTR, FND specialist practitioner may also be present at appointment / see patient on the same day:
Assessment completed, onward investigations, diagnosis made, and treatment plan formulated.

Regular virtual **MDT / complex case clinics**

FND Specialist Practitioner(s):
Hub and spoke model - Roles in FND clinic to deliver/explain diagnosis, to establish relationship with patient and family at the point of contact, to facilitate onward referrals and offer signposting. To support with complex cases that span multiple services and professionals.

Neuro psychology

Health psychology

Mental health services
- **Online/ self help**
- **Talking therapies**
- **Intermediate therapies**
- **Psychiatry**
- CMHT

Physical therapies
- **OT**
- **PT**
- **SLT**

Rehabilitation medicine consultant service
(central offer- need to clarify referral criteria for *FND pt cohort)*

Other NHS services
Including but not limited to:
Pain management
Chronic Fatigue
Epilepsy

Wider community services available across LSC to access as required / indicated inc. non-NHS led services.

DISCHARGE FROM FND SERVICE AT LTHTR

Patient is discharged by FND service when all acute concerns and goals addressed.

Patient is discharged from service if they have rejected their diagnosis and are unwilling to engage, following discussion of reasons for this / appropriate education offered. (Appropriate onward referrals will still be made if referral criteria met for other services)

For the patient, PIFU offered and option to re-contact service via FND coordinator / practitioners as required.

For professionals who continue to be involved with the patient, after discharge from the FND service, access to support is available as required via the FND coordinator/ practitioner.

The key addition is to employ FND specialist practitioners who will work potentially out of LTHTR in a hub and spoke model to support locality teams. They will also be a main point of contact for a patient throughout their active interventions for FND and coordinate referrals, answer queries and be a link for health professionals to 'join up' the pathway.

Other solutions built into the new model include virtual Multi-Disciplined Team (MDT) meetings, education programmes for Emergency department and GP colleagues and more networking for professionals across Lancashire and South Cumbria.

A business case has been prepared but must be supported by engagement to ensure the new model meets the needs of patients.

Who have we heard from and how?

Deciding who to talk to

Since the proposed new model is designed to make improvements to the current service it was decided to engage with patients who are currently using the service with a confirmed FND diagnosis and their families.

It was not easily possible to contact former patients since we would not have their prior permission to contact them for this purpose.

We reached existing patients via their existing links with health care professionals at clinics or appointments. The healthcare staff were contacted with a request to share details with patients.

The questionnaire was also promoted organically through social media.

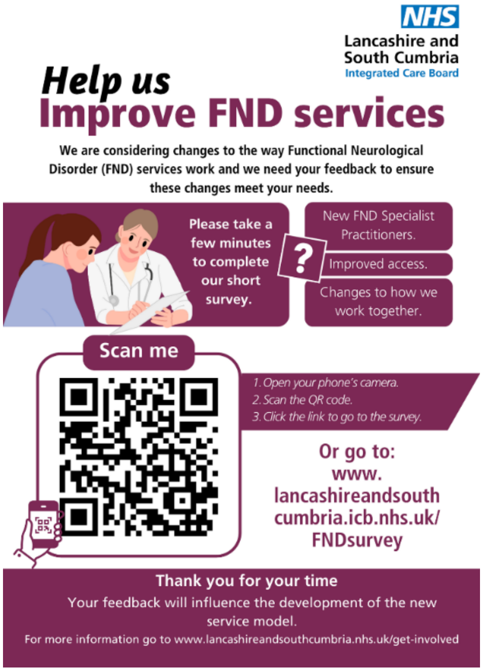
How did we speak to people?

Taking advice from specialists in the field it was decided that setting up focus groups with patients or approaching them in clinic waiting rooms would not be appropriate. We also had insight that suggested patients preferred communication online.

Questionnaire

An online survey was created which staff could go through with the patient during appointments or could be accessed by the patient.

A leaflet was also created to enable staff to pass the information to patients in a way that made it easy for them to access the questionnaire in their own time.



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Help us Improve FND services

We are considering changes to the way Functional Neurological Disorder (FND) services work and we need your feedback to ensure these changes meet your needs.

Please take a few minutes to complete our short survey.

New FND Specialist Practitioners.

Improved access.

Changes to how we work together.

Scan me

1. Open your phone's camera.
2. Scan the QR code.
3. Click the link to go to the survey.

Or go to: www.lancashireandsouthcumbria.icb.nhs.uk/FNDsurvey

Thank you for your time

Your feedback will influence the development of the new service model.

For more information go to www.lancashireandsouthcumbria.nhs.uk/get-involved

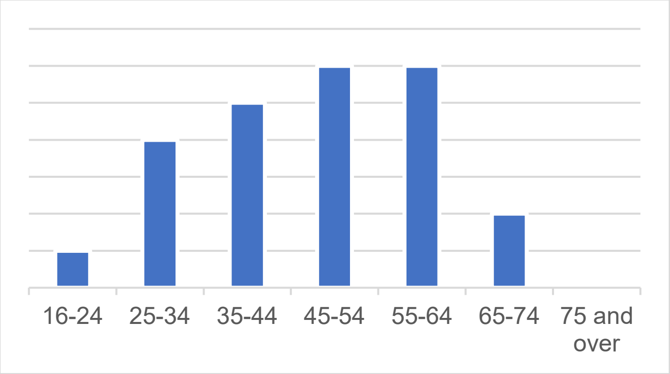
How many people got involved?

There were 26 responses to the survey which is a low number however we must also consider that there are relatively low numbers of patients with a confirmed FND diagnosis. The findings of this report also take into consideration the anecdotal evidence from healthcare professionals from patients they are in regular contact with.

Seventy-three per cent of questionnaire respondents said they were a patient currently accessing the FND service, 15 per cent said they were former patients and just over 12 per cent said they were a family member or carer of someone accessing the service.

Sixty-four per cent of the respondents were female and 32 per cent were male.

The ages of the respondents are broken down below.

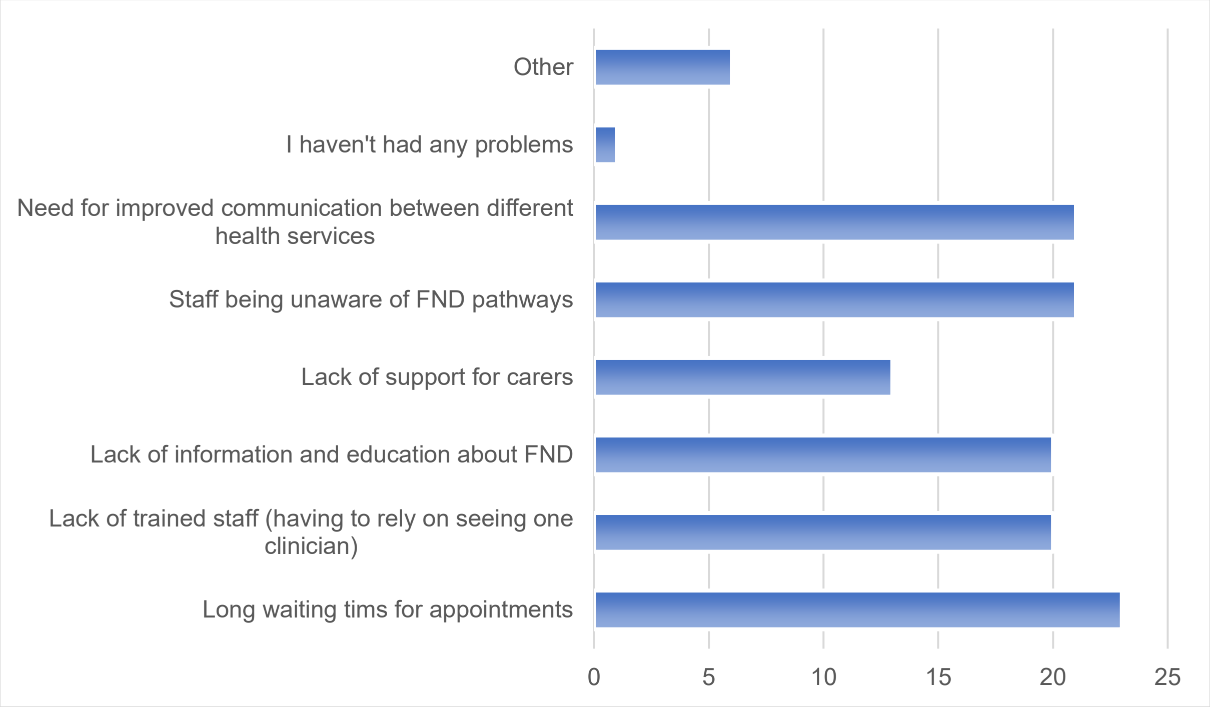


All of the respondents who chose to provide their ethnicity described themselves as ‘white British’.

What did we hear?

The following is a breakdown of the data collected through the survey.

Q1: Thinking about the current service, have you experienced any of the following issues which have been highlighted to us by other patients?



Twenty three of the 26 respondents had experienced long waiting times for appointments.

The comments from people who answered “other” also highlighted issues around:

- Staff in other parts of the health system not being trained on issues faced by people with FND.
- Referrals to services taking a long time.
- Lack of support following a diagnosis.
- Reliance on web-based information sharing.
- Lack of respect for people with an FND diagnosis or for the condition itself.

Q2: How would you prioritize the changes you want to see happen?

Based on what we had heard from previous engagement such as complaints etc participants were presented with four key changes the new model could provide. They were asked to rank these into an order of which they felt was most important.

This question served to reassure the programme leads that their analysis of the situation was accurate and to provide direction for areas of improvement that were a priority for patients.

The order in which they were ranked was:

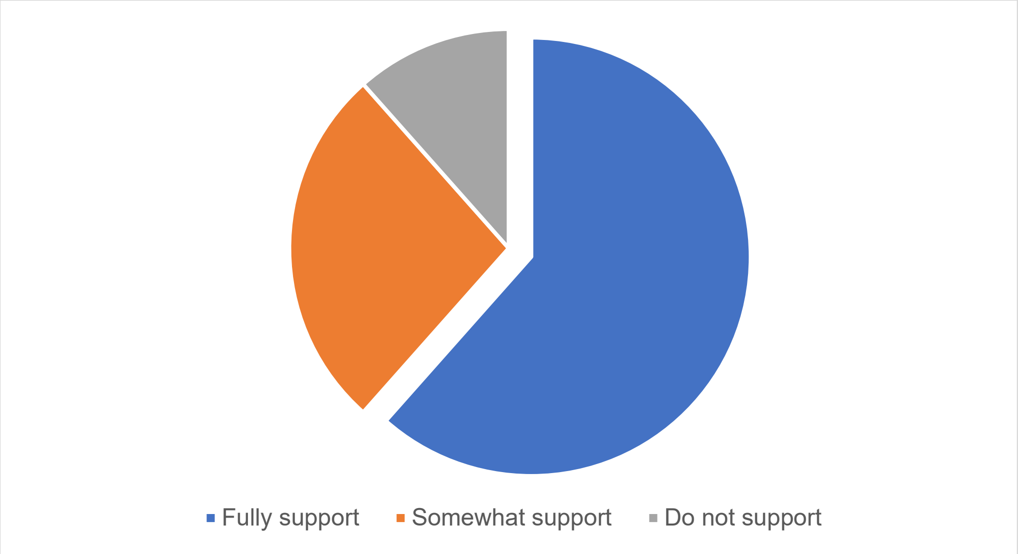
1. Shorter waiting times for appointments
2. More information and education on FND
3. Improved communication between different health services
4. Better support for carers.

People did offer other changes they wanted to see, and these included:

- More training and education for support staff
- More support following the FND diagnosis
- Increased empathy for people with FND
- A multi-disciplinary team approach

Q3: What do you think of the proposed model?

The majority of respondents said they support or somewhat support the proposed model with only 12 per cent saying they did not support it.



Those who did not support the proposed model were asked to give their reasons. These are summarised below.

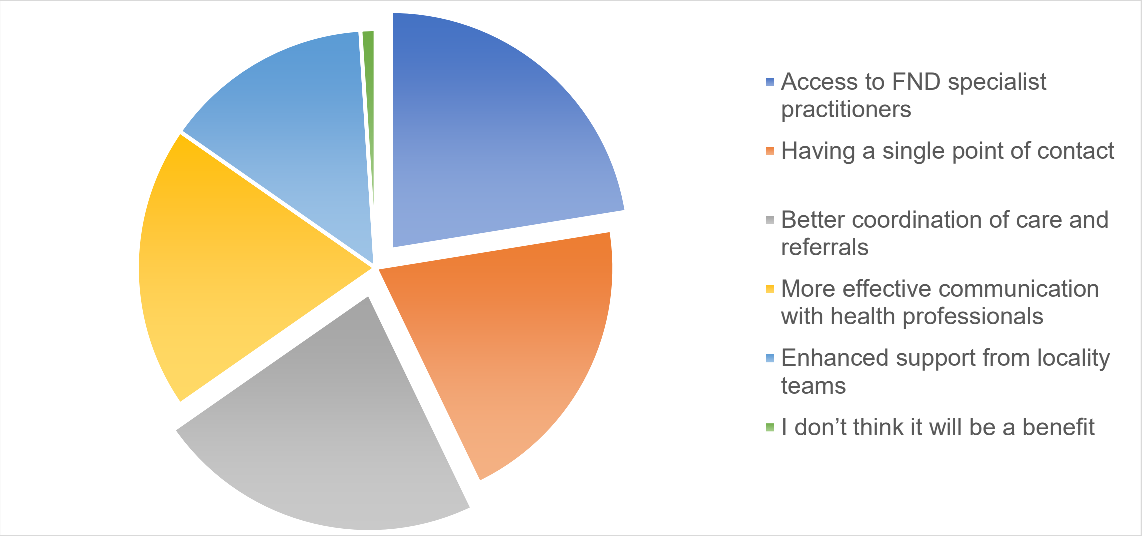
- It does not address the issue of FND being treated by many as a pseudo condition and therefore not being taken seriously.
- It does not say where the specialist practitioner will be based or whether their capacity will allow for all patients to go through them.
- It does not address the long waiting times for other services such as pain management for people with FND
- It does not account for nuances in patient need – "a model cannot apply to everyone." It needs to have pathways for people with complex needs or multiple conditions.

The primary concern was around the lack of awareness of the condition or the tendency for some professionals to dismiss a patient with FND as "all being in their head" and even being disrespectful to patients.

Suggestions were around ensuring there were enough staff to handle the need otherwise this would be another step in a process to see a consultant that would delay receiving support.

Many of the concerns are dealt with in the model but perhaps more emphasis on these elements is needed.

Q4: What benefits, if any, do you think the new service model will bring?



Access to the FND specialist practioners and better coordination came out top in this showing that participants recognised the potential improvements the model could make.

Two other benefits were offered by people, and they were:

- Effective referral to correct places
- Better care

Q5: Do you have any additional comments or suggestions?

Respondents were forthcoming in their responses to these questions with the majority being positive about the steps being taken to improve service. Some were more critical and highlighted some very poor experiences in the context of how those issues could be improved. Other comments were more constructive to give a direction for what more can be done to improve services. We have summarised the key themes as follows:

1. Quality of care and support:

- Many patients expressed satisfaction with the care they received from specific specialists and teams, highlighting positive experiences with regular specialists and rehab teams
- However, there were also concerns about the quality of care, with some patients feeling neglected or mistreated by NHS staff.

2. Waiting times and access to services:

- A significant number of comments mentioned long waiting times for diagnosis and appointments, with some patients waiting years to see a consultant.
- Patients also expressed frustration with the process of staying on waiting lists and the lack of timely follow-up appointments.

3. Need for better education and awareness:

- Several comments emphasized the need for better education and awareness among healthcare professionals.

4. Multidisciplinary and coordinated care:

- There were suggestions for a more multidisciplinary approach to care, with patients advocating for the involvement of various specialists to address the complex needs associated with FND.
- Some comments also highlighted the lack of coordination between different services, leading to ineffective care.

5. Use of technology and alternative methods:

- Patients suggested the use of video appointments and other technologies to make it easier for those with FND to access care, especially given the challenges of traveling to appointments.
- There were also calls for a more flexible and realistic approach to treatment models, taking into account the diverse needs of FND patients.

Continued…

What we have learned

What our patients have told us

Most patients who responded to the questionnaire had experienced one or more issues; primarily around waiting times for appointments and information available to the patient and to staff.

In general, most patients are supportive of the proposed model, especially if it allows for reduced waiting times and better coordination of services involved in a patient's care.

Most important to those we heard from was the education and awareness of healthcare professionals about FND. Many had poor experience because of a lack of awareness including examples of lack of empathy towards the patient and even being dismissive of their needs. Many patients felt that their care had suffered as a result of this and it should be a priority for the service to improve.

Conclusion and recommendations

There is a clear need and support for the new model although the role of specialist practitioner needs to be about more than being a central point of contact for the patient.

The FND specialist practitioner has a role to play in supporting patients and providing information and a point of liaison for them. They also need to be an ambassador for the condition itself. Working with healthcare staff at all levels to raise the awareness of FND in order for patients to feel their condition is being taken seriously.

They will need to have capacity to help provide training for staff.

The multidisciplinary team approach is welcomed as long as that team includes professionals in a range of specialisms that are relevant to the patient and caters for their individual needs.

It is recommended the business case takes these conclusions into consideration along with additional anecdotal evidence from healthcare professionals when making their decision to progress.