

Functional Neurological Disorder Strategy for Lincolnshire

Patient, Staff and Stakeholder Survey Report

Phase 2

April 2026

Author: Lauren Eason – LICB Engagement Team



Introduction

Between 23 January and 22 March 2026, the NHS Lincolnshire Integrated Care Board (ICB) carried out engagement to gather views from people living with Functional Neurological Disorder (FND), those who support them, and professionals. The feedback gathered will help inform the development of a new FND Strategy for Lincolnshire.

This work built on engagement undertaken in October 2025, which focused on understanding people's experiences of receiving an FND diagnosis and their experiences of accessing and engaging with services.

In total, **130 responses** were received (95 from members of the public and 35 from staff).

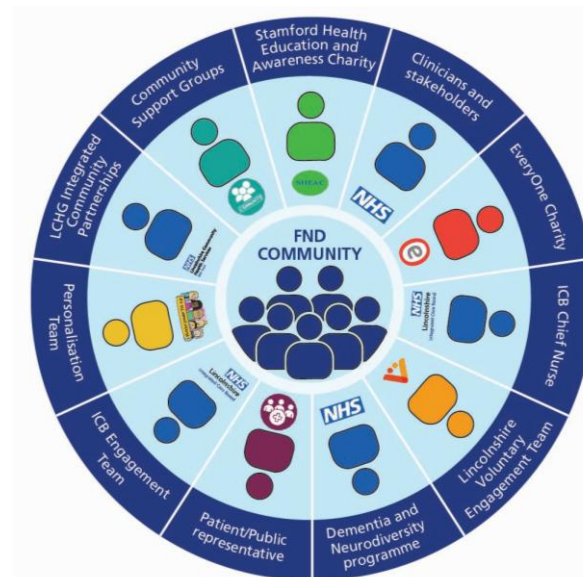
This report aims to:

1. Provide an overview of engagement activities to gather feedback
2. Present findings from the surveys, patient interviews for review and consideration.

The results of the survey will be shared with the NHS Lincolnshire Integrated Care Board and the Lincolnshire system partners to help to inform a review of the FND pathway and will be used as part of our plans to develop a FND Strategy for Lincolnshire.

Feedback received has been analysed across all population groups and equality categories and where there are differences these have been highlighted within the report.

130
responses to the
survey



Executive summary

Overall, feedback highlights **gaps in current FND provision in Lincolnshire**, with strong consensus across patients and staff that services are fragmented, difficult to access, and lack clear clinical pathways. Respondents consistently reported long waits for diagnosis and specialist input, limited local expertise, and poor coordination between services, often leaving individuals to navigate complex systems alone.

Key feedback includes:

- 1. Early and accurate diagnosis** – Both the public and workforce view this as critical. Key issues include limited professional understanding of FND, lack of GP confidence, stigma, and lengthy neurology waiting times. Better training, clearer referral routes, and timely access to specialist neurology were identified as essential.
- 2. Joined-up specialist support** – There is strong demand for a coordinated multidisciplinary model, including neurology, therapy services, psychology and rehabilitation, supported by a named care coordinator and shared records to improve continuity and communication.
- 3. Training and stigma reduction** – Respondents described persistent disbelief and misunderstanding of FND. Consistent, high-quality training across primary care, hospitals, mental health services and community settings is needed to improve confidence, empathy, and recognition of FND as a legitimate neurological condition.
- 4. Joined-up care with improved access to rehabilitation** – People reported little or no access to appropriate FND-specific rehabilitation locally. Both patients and staff support the development of a clear post-diagnosis rehabilitation pathway with timely, specialist input.
- 5. Community support close to home** – Particularly in a rural county, accessible local and community-based support is vital. Respondents highlighted the absence of community provision, workforce and funding constraints, and geographical barriers as key challenges.

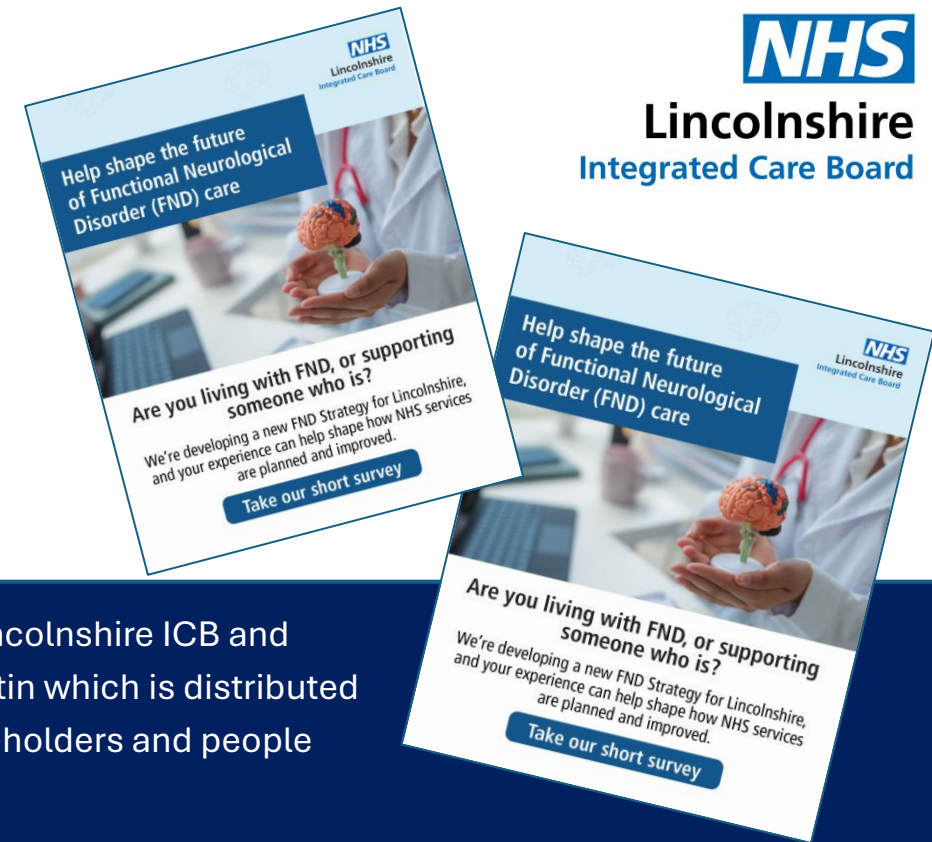
Across all themes, respondents emphasised the need for **investment, workforce development, clearer pathways, improved coordination, and culture change**. Early diagnosis and joined-up care were ranked as the highest priorities.

Promotion of engagement

Marketing materials

The NHS Lincolnshire ICB Marketing team created posters and social media assets to:

- Build awareness of the survey
- Signpost/link people to the survey
- Share with stakeholders to encourage participation
- Promote across a wide range of social media channels
- Encourage people to take part in our conversations



The survey was available in different formats on request as well as being available on the NHS Lincolnshire ICB and other partner websites. The NHS Lincolnshire ICB engagement Team produces a fortnightly bulletin which is distributed to a variety of community and voluntary groups, Patient Participation Groups, support groups, stakeholders and people who have subscribed via the NHS Lincolnshire ICB website.

The survey was regularly promoted through various channels including:

- Featuring in **4** NHS Lincolnshire ICB engagement bulletins and **2** Primary care bulletins.
- **4 posts** on the Nextdoor online forum - the total reach of the NHS Lincolnshire ICB Nextdoor account is **110,269 members** spanning across **471 'neighbourhoods'** enabling us to reach a variety of communities, villages and towns across Lincolnshire.
- Shared across providers' member databases and staff networks/newsletters.
- **7 Facebook posts, reaching 24,752 people, generating 181 reactions and 58 link clicks.**
- **346 people visited the webpage** - [Help shape the Lincolnshire's Functional Neurological Disorder \(FND\) strategy - Phase 2 - Lincolnshire ICB](#)

They also draft posts in the system Hootsuite to enable providers to duplicate and share across their channels and tagged in providers to some of the posts which were shared across provider organisations.

Promotion of engagement

The below groups receive the distribution via NHS comms cascade or the ICB engagement bulletin (11,000 contacts):

The engagement was shared in the below ways:

Via the FND Lincs Newsletter produced by our patient representative
With the FND Lincs support group/community

Audience	Distribution
Community stakeholders including volunteer groups, support groups etc. via the engagement bulletin	LPFT involvement database— 430 (service uses, carers, staff, voluntary sector reps & public supporters) Cancer groups Community, voluntary and support groups BAME communities LGBT Communities Carers Older people groups Young people groups Eastern European communities Disability groups (mental and physical) Patient Participation Groups (PPGs)

Audience	Distribution	
Health and Care Partners	NHS Providers Primary Care (Via PC bulletin) Lincolnshire Resilience Forum Community Connectors Neighbourhood leads	ASC Carers Service Healthwatch Everyone
District Councils inc. elected members and staff	City of Lincoln Council Boston Borough Council East Lindsey Council West Lindsey Council	North Kesteven Council South Kesteven Council South Holland Council
Local Employers	University of Lincoln	
Public sector providers	Lincolnshire Police and Crime Commissioners Lincolnshire Fire and Rescue	

About the respondents

Responses reflect a broad mix of lived experience, carers, clinicians and professionals from across Lincolnshire districts. Just under one half (47%) of respondents have an FND diagnosis and 18% (24) are a family member/carer of someone with FND.

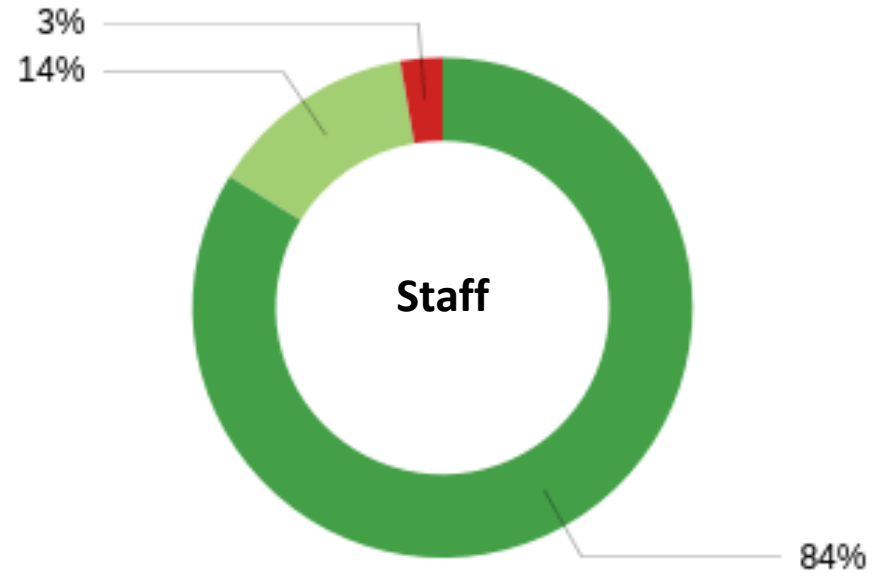
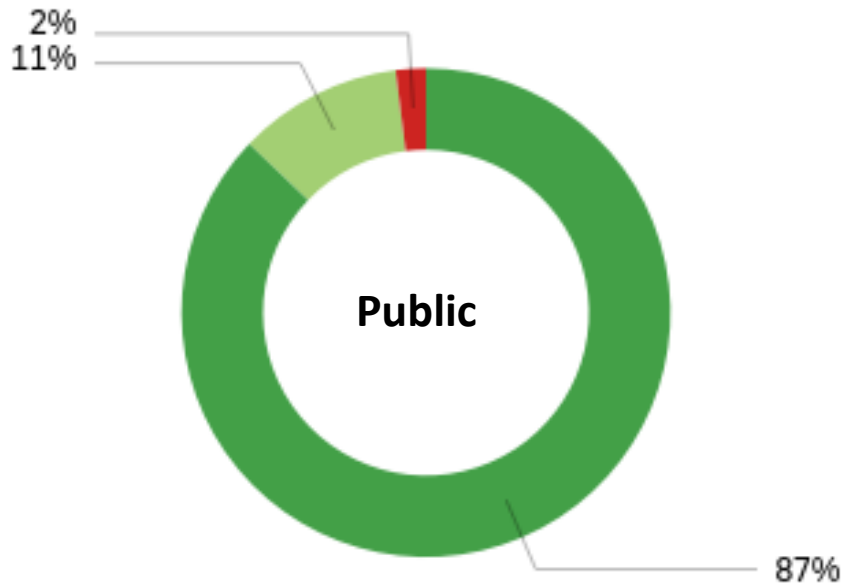


District	%	Count
South Kesteven	19%	25
North Kesteven	18%	23
East Lindsey	15%	20
South Holland	12%	16
Lincoln City	12%	16
West Lindsey	6%	8
Boston Borough	5%	6
<i>Unknown</i>	12%	16
Total		130

About you:	%	Count
A person with FND	47%	61
A family member/carer of someone with FND	18%	24
Member of staff working in secondary care	11%	14
Member of staff working in a service supporting people with FND	6%	8
Other	5%	6
GP/Community Care	5%	7
A person with symptoms of FND	4%	5
A family member/carer of someone waiting for an FND Diagnosis	4%	5
Total		130

Early and accurate diagnosis is viewed as critically important by both the public and the workforce.

How important is **early and accurate diagnosis** for you?



Very important Important Not very important Not important at all Don't know

(Base N = 95 response count)

(Base N = 35 response count)

Respondents say early and accurate FND diagnosis in Lincolnshire will improve most if **frontline staff (especially GPs) are trained to recognise FND, neurology waits reduce with access to local specialists, diagnosis is explained clearly with a ‘what next’ plan.**

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Improve professional knowledge, confidence and awareness of FND	<ul style="list-style-type: none"> • Respondents repeatedly call for training/education across NHS services so clinicians recognise FND earlier and understand how to support people.
Patients need to be listened to, believed, and treated with empathy	<ul style="list-style-type: none"> • A strong message is that people want clinicians to take symptoms seriously and stop implying it’s “in your head” or “putting it on.”
Quicker access to neurology and shorter waiting times	<ul style="list-style-type: none"> • Many responses focus on long waits and the need for speedy referral and earlier neurology input - sometimes describing waits of many months/years.
Access to local FND expertise in Lincolnshire	<ul style="list-style-type: none"> • Some respondents explicitly want Lincolnshire-based neurologists/specialists with FND expertise, so information is accurate and diagnosis is timely.
Clear, compassionate explanation at diagnosis	<ul style="list-style-type: none"> • People describe confusion and being left to figure it out alone. They want proper explanations and a clear care plan/signposting after diagnosis
Thorough investigation and avoiding diagnostic overshadowing	<ul style="list-style-type: none"> • Some respondents stress FND as a “diagnosis of exclusion” and want robust testing so other neurological conditions aren’t missed, and symptoms aren’t automatically attributed to existing diagnoses (e.g., ME/CFS, fibromyalgia).

Staff feedback emphasises the need for clear pathways, improved GP training and faster access to neurology.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Clear FND pathway	<ul style="list-style-type: none"> • Strong calls for a consistent diagnostic and referral pathway for FND in Lincolnshire • Respondents highlighted that FND is not treated with the same priority as other neurological conditions, leading to delays and inappropriate referrals.
Poor awareness and understanding of FND	<ul style="list-style-type: none"> • Widespread concerns about limited understanding of FND across primary care and wider health services. • FND is often misunderstood as “psychological” or a diagnosis of exclusion, leading to stigma and misdiagnosis.
Need for GP education and training	<ul style="list-style-type: none"> • Improved GP knowledge, assessment skills, and confidence in recognising FND symptoms. • Respondents stressed the importance of GPs listening, linking symptoms, and not dismissing patients.
Delays and limited access to neurology	<ul style="list-style-type: none"> • Long waiting times for neurology appointments (often 1–2 years) were frequently raised. • Early access to neurologists with FND expertise was seen as critical for timely diagnosis.
Access to specialist and multidisciplinary services	<ul style="list-style-type: none"> • Strong support for a dedicated FND service, including neurologists, physiotherapists, OTs, and psychologists with FND experience. • Calls for better connected physical and mental health services rather than default mental health referrals.
Better information and signposting	<ul style="list-style-type: none"> • Respondents highlighted the need for clear, accessible information on how to get a diagnosis, where referrals can be made, and what support is available after diagnosis.

Respondents believe early and accurate diagnosis/timely referral is most disrupted by **dismissal and stigma**, **low FND awareness/training**, and **system capacity issues**—particularly difficulty accessing GP appointments, **backlogged neurology waits**, and **fragmented, poorly coordinated pathways**.

Theme	Are there any barriers or gaps that could get in the way of this?
Not being believed / stigma / dismissal by professionals	<ul style="list-style-type: none"> A dominant barrier is people feeling dismissed, judged, or told symptoms are “all in your head”, including being treated like a “hypochondriac”. This undermines appropriate investigation and slows referrals.
Limited FND knowledge and training across the workforce	<ul style="list-style-type: none"> Respondents repeatedly point to a lack of understanding of FND, difficulty recognising early signs, and insufficient training—leading to misattribution, incorrect referrals, and delays in making a positive diagnosis.
Access barriers in primary care (difficulty getting GP appointments)	<ul style="list-style-type: none"> A practical, common gap is simply getting a GP appointment, with references to long waits, phone-only appointments, and concerns about access to seeing an actual GP (rather than other roles). This creates a bottleneck before referrals can even begin.
Long waits and backlogs in neurology / consultant access	<ul style="list-style-type: none"> Respondents highlight neurology services being backlogged and very long waits (e.g., “over a year”, “ten months”, “waiting lists”), which they feel is detrimental to early diagnosis and treatment.
Fragmented services and poor coordination (“sent round the houses”)	<ul style="list-style-type: none"> Many describe a disjointed/fragmented system, with services not talking to each other, departments not working together, and people “falling into a gap” unless they constantly self-advocate. Respondents explicitly mention lack of MDT working and poor communication between hospitals/NHS centres.
Lack of local specialist services + rural geography/travel burden	<ul style="list-style-type: none"> People describe limited local resources, needing to travel out of county, and rurality making access to specialist help harder. The lack of nearby services contributes to delays and missed opportunities for timely support.

Staff identify gaps in knowledge, unclear referral routes and system capacity as key barriers to early diagnosis.

Theme	Are there any barriers or gaps that could get in the way of this?
Poor awareness and understanding of FND	<ul style="list-style-type: none"> • Widespread lack of knowledge about FND across primary care and wider health services. • FND often misunderstood, not recognised, or still viewed as “not real” or purely mental health-related.
Inadequate GP knowledge and access issues	<ul style="list-style-type: none"> • Limited GP understanding of FND symptoms and presentations. • Difficulties accessing GP appointments and inconsistent recognition of signs leading to delays.
Lack of clear referral pathways	<ul style="list-style-type: none"> • Unclear or poorly communicated diagnostic and referral routes. • Confusion about who can diagnose FND and how to refer appropriately.
Poor coordination and continuity of care	<ul style="list-style-type: none"> • Weak MDT working across primary and secondary care. • Poor communication, missing information, and lack of continuity between services.
Long waits and limited neurology capacity	<ul style="list-style-type: none"> • Extended waiting times for neurology and reliance on diagnosis of exclusion. • Current neurology provision seen as insufficient to support timely diagnosis.
Stigma and previous mislabelling	<ul style="list-style-type: none"> • People previously labelled with somatoform, anxiety, or other diagnoses, which delays appropriate recognition of FND. • Experiences of not being treated with understanding or respect.

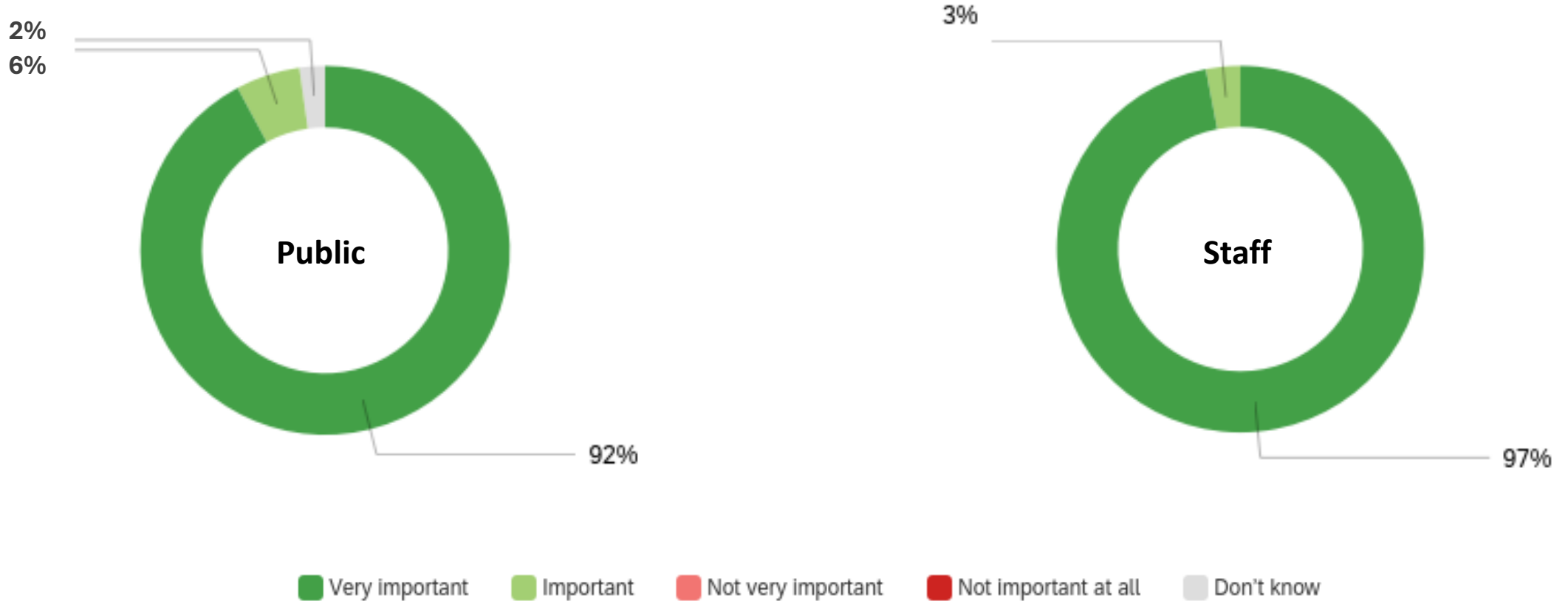
Consistent training, clearer pathways and better coordination are seen as essential to improving diagnosis.

Theme	Do you have any other suggestions to help make this work well?
Consistent, mandatory training (and refreshers) for staff	<ul style="list-style-type: none"> A dominant theme is training at all levels (GPs, practice triage staff, mental health staff, emergency staff, wider clinicians), with regular updates so people “know what they’re talking about” and patients feel less alone and more believed.
Local provision + community support (incl. children/young people)	<ul style="list-style-type: none"> People ask for more local groups (e.g., Gainsborough), community workshops, options like community hubs/drop-ins/self-referral, and a distinct pathway for children and adults, with recognition of family impact
Better referral/signposting systems (incl. booking systems)	<ul style="list-style-type: none"> Several comments highlight issues with referral routes and booking teams not finding the right service—suggesting all partner services must be visible/listed, with clearer signposting and assessment approaches comparable to other condition
Practical information + interim support while waiting	<ul style="list-style-type: none"> Suggestions include info packs at diagnosis, easy-read materials, a triage/support call, leaflets with clear tips (including OT-style safety advice), and interim symptom support while awaiting specialist appointments/tests.
A clear, joined-up pathway with MDT working (not fragmented signposting)	<ul style="list-style-type: none"> Many comments ask for a single, coherent FND pathway supported by a multi-disciplinary team (MDT)—with services working together rather than separately “doing their part then signposting.” This includes calls for joint MDTs and a more holistic model.
Better communication, coordination, and a single point of contact	<ul style="list-style-type: none"> People describe “chaos” from being passed around, repeating their story, and poor liaison between services. Suggested fixes include co-ordination, clearer communication, and a single point of contact/continuity.

Joined up specialist support

Joined-up specialist support is considered essential to people's experience and outcomes.

How important is **joined-up specialist support when you need it** for you?



(Base N = 89 response count)

(Base N = 33 response count)

How to improve joined up specialist support - PUBLIC



Lincolnshire
Integrated Care Board

Overall, respondents feel joined-up specialist support in Lincolnshire needs **stronger communication and MDT working**, underpinned by a **named lead/care coordinator** and **shared records**, so people are not left coordinating services themselves. Many say specialist FND support **does not currently exist locally** and want a **dedicated Lincolnshire FND clinic/team/hub** with neurology, psychology and therapy input, improved capacity to reduce waits, and consistent follow-up.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Better communication and shared working across services	<ul style="list-style-type: none"> Respondents want clear, coordinated communication between all professionals and services, with information passed on properly and quickly, so people aren't left "carrying messages" between teams.
A proper MDT approach (neurology + psychology + therapies + wider partners)	<ul style="list-style-type: none"> People highlighted the importance of regular multidisciplinary team (MDT) meetings, stronger links between neurology and psychology, and better involvement of education and social services to support children and families.
A single lead / care coordinator	<ul style="list-style-type: none"> A repeated ask is for one named person/team to oversee care, coordinate referrals, advocate, and reduce repetition and delays—so families don't have to manage everything themselves. Examples include calls for an "assigned care manager", "one lead clinician or team overseeing care"
Shared records / better IT	<ul style="list-style-type: none"> Several responses call for professionals to be "on the same systems" so records can be seen across providers (e.g., between Nottingham and Lincolnshire hospitals), using the NHS number to enable shared access
Consistency and continuity	<ul style="list-style-type: none"> Respondents want greater continuity such as seeing the same specialist, consistent contact, and more face-to-face options (with some frustration about repeated phone calls with different people and delays to get face-to-face appointments).
Clear information on "what's on offer"	<ul style="list-style-type: none"> Some respondents say they don't know what joined-up support means or what services exist and describe being passed between services ("referral circles") and told services can't support them—sometimes leading to going private. They want clarity on available support and smooth routes into the right services

Staff stress the importance of clear clinical ownership, MDT structures and effective cross-service communication.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Multidisciplinary team (MDT) working	<ul style="list-style-type: none"> • Clear support for a specialist MDT including neurology, therapy services psychology, and social support. • Importance of fully multidisciplinary meetings and shared responsibility for care.
Clear clinical pathway and ownership	<ul style="list-style-type: none"> • Need for defined clinical and treatment pathways post-diagnosis. • Calls for clear clinical ownership and consultant-to-consultant referrals to prevent people being passed between services.
Improved coordination and communication	<ul style="list-style-type: none"> • Poor communication across hospitals, agencies, and out-of-area services seen as a major barrier. • Desire for shared systems, better cross-agency communication, and consistent management within the same hospital or team.
Navigation, coordination, and continuity of care	<ul style="list-style-type: none"> • Strong support for a named coordinator (e.g. key worker, support worker, or peer role) to help people navigate services, reduce repetition, and manage cognitive and trauma-related impacts.
Awareness and access to specialist support	<ul style="list-style-type: none"> • Lack of clarity about what specialist support exists and how to access it. • Requests for simple, accessible lists of available services and resources.
Recognition and legitimacy of FND	<ul style="list-style-type: none"> • Continued need for professionals to recognise FND as a real condition and provide timely, appropriate specialist support.

Overall, respondents describe barriers to joined-up specialist support as **poor communication and silo working, limited or non-existent specialist provision in Lincolnshire, and long waits/delayed referrals**. These issues are compounded by **insufficient trained staff and high workloads, limited understanding and belief in FND, and fragmented IT/record systems** that prevent effective information sharing.

Theme	Are there any barriers or gaps that could get in the way of this?
Poor communication and silo working between services	<ul style="list-style-type: none"> The most consistent barrier is poor communication, teams “don’t talk to each other”, information is delayed (e.g., letters taking weeks), and services work in isolation so “the right hand does not know what the left hand is doing.” Respondents also mention communication problems between professionals and patients, and between health and care sectors.
Commissioning/funding constraints and gaps in what’s available	<ul style="list-style-type: none"> Respondents repeatedly reference funding/money as a barrier, including not currently commissioned services (e.g., speech/feeding support), priorities elsewhere, and calls for more government funding for better services
Equity and access variation (“postcode lottery”, county boundaries, accessibility needs)	<ul style="list-style-type: none"> Respondents mention a “postcode lottery” feeling, challenges accessing services across trust/county boundaries (including comments about Lincolnshire ICB working across boundaries), and “accessibility” as a barrier.
Professional culture and “who is responsible” issues	<ul style="list-style-type: none"> A few respondents note lack of respect/professional hierarchy, difficulty with specialists engaging with each other, and a “lack of responsibility” (particularly around mental health) where no one is clear who is accountable.
Fragmented systems and information sharing issues (records/IT/notes not accessible)	<ul style="list-style-type: none"> Barriers include outdated computer systems, different services using different systems, inaccurate GP records, lack of shared access to medical notes, and difficulty ensuring each specialist can read others’ reports and update files.
Continuity and consistency problems (different clinicians each time)	<ul style="list-style-type: none"> Some respondents describe lack of continuity—building confidence with one clinician and then seeing someone different next time—making support harder to coordinate and trust.

Staff highlight the absence of specialist services, capacity pressures and unclear accountability as key challenges.

Theme	Are there any barriers or gaps that could get in the way of this?
Lack of specialist FND services	<ul style="list-style-type: none"> • Consistent view that there are currently no dedicated FND services in Lincolnshire. • Absence of an MDT or coordinated service leaves people without joined-up support.
Funding and workforce capacity	<ul style="list-style-type: none"> • Services are described as overstretched, under-resourced, and lacking sufficient staff (nurses, therapists, psychologists, consultants). • Funding constraints prevent development of a bespoke, patient-led specialist service.
Poor awareness, training, and confidence	<ul style="list-style-type: none"> • Limited FND-specific knowledge and training across health and social care. • Lack of in-depth, accredited training leads to uncertainty, avoidance, and inconsistency in care.
Access barriers for patients	<ul style="list-style-type: none"> • Practical barriers such as travel, appointment access, long waiting lists, and digital connectivity. • More severely affected people struggle to attend appointments without flexible or home-based provision.
Navigation and signposting gaps	<ul style="list-style-type: none"> • Patients and professionals report not knowing where to go or how to access support. • Lack of local knowledge and clarity even where services may exist.
Fragmented communication and ownership	<ul style="list-style-type: none"> • Poor communication between neurology, psychiatry, and other services. • Unclear clinical ownership, with professionals unsure “whose responsibility” FND sits under

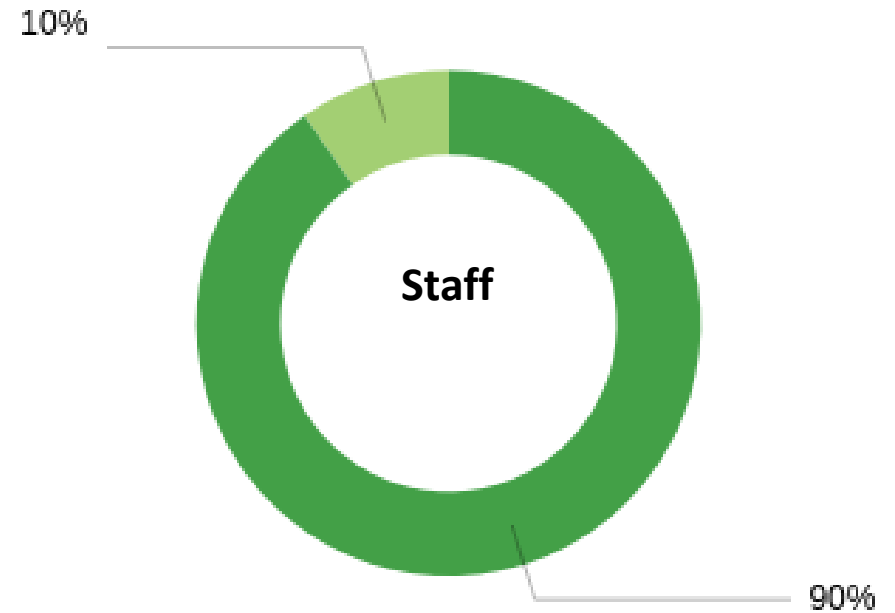
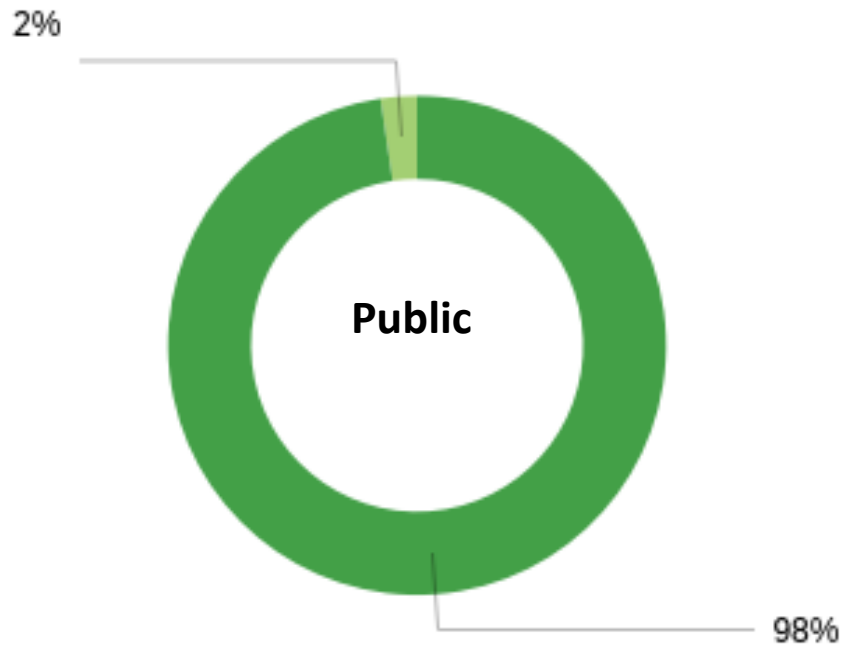
Training, coordination and personalised care are seen as vital to making joined-up specialist support work.

Theme	Do you have any other suggestions to help make this work well?
Training & education across the workforce (including CYP services)	<ul style="list-style-type: none"> Repeated calls for better education/training for professionals (including mental health staff), plus education as part of services for children and young people
Continuity of care	<ul style="list-style-type: none"> A consistent message is the need for care coordination and continuity (e.g., a nominated GP who knows the person, and a named coordinator to reduce repetition and missed connections).
Flexible, practical delivery to reduce burden (one-stop appointments, virtual options, travel impact)	<ul style="list-style-type: none"> Suggestions include coordinating multiple appointments on the same day, more virtual assessments, and more flexible admin/timeframes so people can explain non-attendance without losing energy battling systems
Individualised approach (FND isn't "one size fits all")	<ul style="list-style-type: none"> Respondents highlight varied FND presentations (e.g., different phenotypes) and want tailored pathways/care plans—plus separating support for any underlying mental health condition from FND itself (without assuming trauma/psych causes).
Better communication & information-sharing between services (single system/records)	<ul style="list-style-type: none"> A common issue is poor communication (e.g., neurology/psychology links) and the need for shared information across hospitals/services so patients aren't "joining the dots."
A clear, consistent pathway with MDT working	<ul style="list-style-type: none"> People want an explicit pathway into a multidisciplinary team, with regular MDT meetings and shared planning—less "refer on" and more joined-up case working.
Information & support for patients/families/carers	<ul style="list-style-type: none"> Requests include faster access to clear information, inclusion of parents/carers, and better family support/reassurance (some suggesting peer mentoring/volunteers with lived experience).

Building understanding and reducing stigma

Reducing stigma and improving understanding of FND matters deeply to both patients and professionals.

How important is building understanding and reducing stigma for you?



Very important Important Not very important Not important at all Don't know

(Base N = 85 response count)

(Base N = 31 response count)

People are asking for **better-informed and more compassionate professionals, clear information**, and a **proper, joined-up, long-term FND pathway** in Lincolnshire with **timely access, skilled staff, and personalised support**.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Training & education for professionals (all levels)	<ul style="list-style-type: none"> The strongest theme is the need for widespread, consistent FND education across primary care, hospitals, community services, ambulance/A&E, and wider health/social care—so patients don't have to explain FND repeatedly and staff don't give misinformation
Belief, empathy, and being taken seriously	<ul style="list-style-type: none"> Many responses focus on attitudes and validation—people want to be believed, listened to, treated with dignity, and not dismissed (e.g., because tests are “normal” or symptoms fluctuate).
Recognition of FND as neurological (not “all in the head”)	<ul style="list-style-type: none"> Respondents want clearer understanding that FND is a real, complex neurological condition, not simply anxiety/psychological, and they want care that avoids defaulting to “it's psychological” as the sole
Clear information and resources for patients, families, employers, schools	<ul style="list-style-type: none"> People describe being left to “do their own homework” and want easy-to-access information at diagnosis and beyond (including resources for relatives, carers, workplaces, and schools). Posters/literature in medical settings are suggested too
Awareness and inclusion across all of Lincolnshire	<ul style="list-style-type: none"> Some responses highlight the need to raise public/community awareness and ensure provision covers all localities (including areas feeling “met with a brick wall”)
Personalised care (one size doesn't fit all)	<ul style="list-style-type: none"> People emphasise that symptoms and needs vary widely, so pathways, training, and care plans should be flexible and individualised rather than uniform.

Staff emphasise training, shared resources and ongoing support to reduce stigma and improve understanding.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Consistent, high-quality training for professionals	<ul style="list-style-type: none"> • Strong emphasis on the need for improved, evidence-based training across health and care services, particularly for GPs, mental health staff, and consultants. • Calls for nationally recognised, specialist-led training and opportunities to further specialise.
Improved understanding and reduction of stigma	<ul style="list-style-type: none"> • Widespread concern about stigma, dismissive attitudes, and negative language used by professionals. • Respondents stressed that FND must be recognised as real, impactful, and not “just psychological.”
Clear information and accessible resources	<ul style="list-style-type: none"> • Need for accessible information on what FND is, how it can be managed, and how to access specialist support. • Desire for shared, multi-agency resources that professionals and patients can both use.
Access to ongoing support and support groups	<ul style="list-style-type: none"> • Calls for more accessible peer support and support groups to reduce isolation and share lived experience. • Emphasis on helping people live well with FND, not just focusing on diagnosis.

Barriers centre on **knowledge and attitude gaps (especially among professionals), system pressures (time/waits/communication), and low public awareness**, all compounded by the **complex and fluctuating nature of FND** and limited resources for training and specialist support.

Theme	Are there any barriers or gaps that could get in the way of this?
Limited professional understanding & inconsistent training	<ul style="list-style-type: none"> Many comments point to gaps in clinicians’ knowledge of FND and a strong call for more education/training across services (GPs, consultants, frontline staff).
Time pressures, access issues, and long waits	<ul style="list-style-type: none"> People describe not enough appointment time, difficulty accessing GPs, slow referrals, and delays in letters/referrals—making it harder to build understanding and continuity
Poor communication & lack of joined-up working	<ul style="list-style-type: none"> Respondents highlight weak communication between departments/services and a lack of holistic, coordinated care—undermining consistent messaging and support
Public awareness gaps (beyond those already affected)	<ul style="list-style-type: none"> There’s a clear view that the wider public and community groups don’t understand FND, and that awareness needs to reach beyond people already close to someone with FND
Workforce capacity & resource constraints	<ul style="list-style-type: none"> Barriers include funding for education, cost/time to train, staffing levels, and shortage of skilled/specialist staff (e.g., specialist physios).
Misinformation and “faking” narratives (especially online)	<ul style="list-style-type: none"> A smaller but notable theme is concern that people who “fake” FND on social media can harm credibility for genuine patients, worsening stigma

The primary barriers to improving understanding and reducing stigma around FND include poor awareness and belief in the condition, limited training and education, cultural resistance within services, fragmented systems, funding and capacity pressures, geographical inequality, and a lack of supportive infrastructure. Together, these factors reinforce stigma, reduce confidence among professionals, and limit consistent, person-centred support.

Theme	Are there any barriers or gaps that could get in the way of this?
Lack of awareness, understanding and belief in FND	<p>A dominant theme is poor understanding of FND across both professionals and the public. Respondents highlighted misconceptions, disbelief, and outdated views of the condition.</p> <ul style="list-style-type: none"> • FND is often wrongly seen as purely <i>psychogenic</i> or “not real” • Some professionals “do not believe it exists” • Limited understanding of the physiological changes involved
Insufficient training, education and skills	<p>Many responses point to limited access to high-quality training and education on FND.</p> <ul style="list-style-type: none"> • Lack of awareness, knowledge and training among staff • Difficulty accessing appropriate education programmes • Challenges sourcing suitable trainers • Inconsistent uptake of training, with some staff completing learning but not embedding it in practice
Fragmented systems and poor communication	<p>Several responses highlight system-level issues, especially around communication and integration.</p> <ul style="list-style-type: none"> • Services working in silos • Lack of shared systems
Funding, resources and capacity constraints	<p>Lack of funding appears repeatedly and cuts across multiple areas:</p> <ul style="list-style-type: none"> • Limited funding for training and education • Insufficient funding for research • Pressure on staff time and availability • Capacity issues affecting ability to engage, reflect, or implement learning

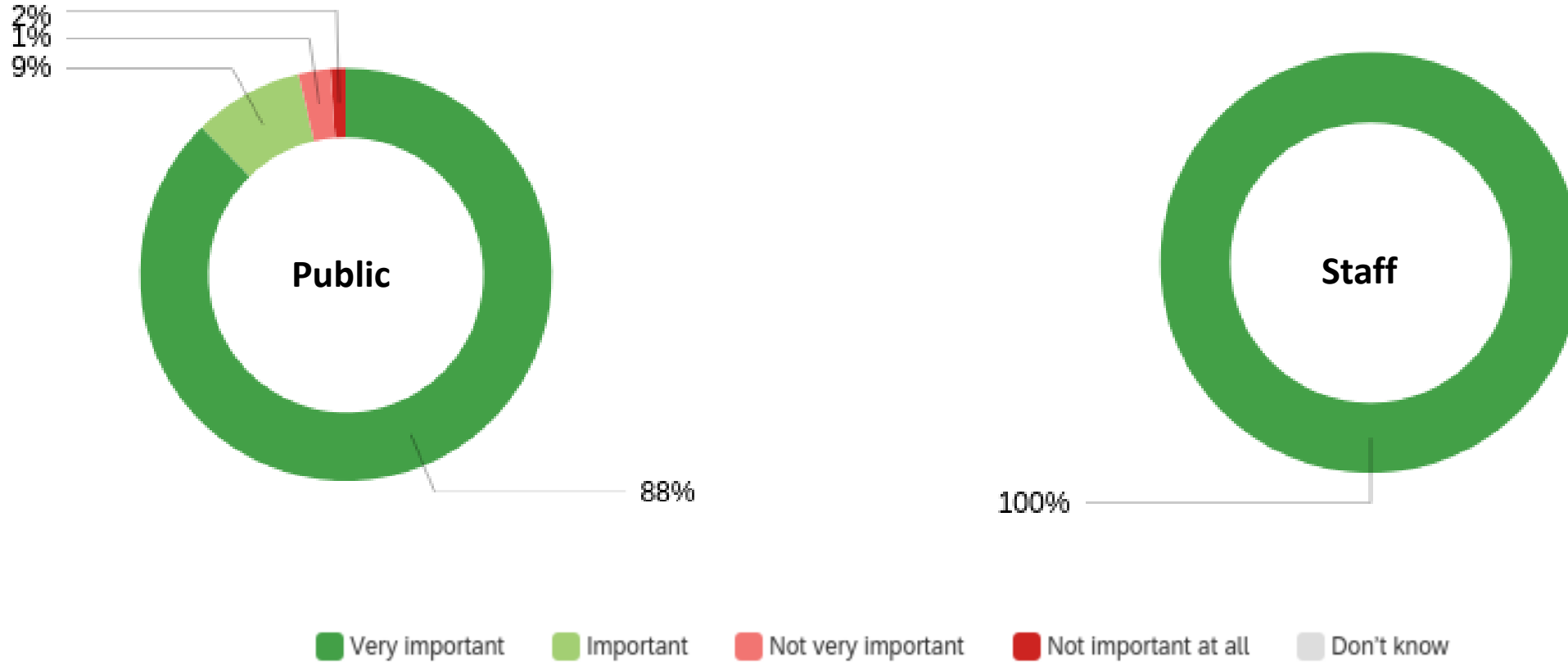
Awareness campaigns, lived experience involvement and investment are key to tackling stigma and misunderstanding.

Theme	Do you have any other suggestions to help make this work well?
Raising awareness for professionals the public	<ul style="list-style-type: none"> • Suggestions include awareness campaigns, social media and posters with links, local/national media coverage, and broader NHS England awareness—so FND is understood and taken seriously. • Training for schools/teaching staff so pupils with FND are supported similarly to other conditions.
Lived experience embedded meaningfully (peer support + co-learning)	<ul style="list-style-type: none"> • Many want people with FND and carers actively involved in shaping and delivering support—e.g., peer support workers, real-life stories, education sessions, and avoiding tokenistic structures • Create spaces where professionals, people with FND and carers learn together to challenge stigma and build mutual understanding
Training and workforce capability	<ul style="list-style-type: none"> • Training for schools/teaching staff so pupils with FND are supported similarly to other conditions. • Create specialist champions: professionals with an interest in FND who can pass down learning
Addressing stigma, behaviour and accountability	<ul style="list-style-type: none"> • Create specialist champions: professionals with an interest in FND who can pass down learning • Create a reporting route for stigmatisation and ensure concerns are properly managed.
Funding, capacity and infrastructure	<ul style="list-style-type: none"> • Invest in community sector support and more community services for FND. • Fund the Recovery College to provide an ongoing FND course for carers/newly diagnosed people (as suggested).

Joined-up care with better access to rehabilitation

Access to rehabilitation through joined-up care is a high priority for people with FND.

How important is **joined-up care with better access to rehabilitation** for you?



(Base N = 81 response count)

(Base N = 28 response count)

Overall, people want a **countywide joined-up FND service** with a **clear pathway, single point of access, timely specialist rehabilitation**, and **better-informed, consistent professional support**, backed by adequate **staffing and funding**.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
A clear pathway (and clear signposting)	<ul style="list-style-type: none"> • People repeatedly ask for a defined, step-by-step pathway that’s easy to understand, including what happens after diagnosis and where to go next.
Single point of access / care coordination	<ul style="list-style-type: none"> • A strong theme is needing one knowledgeable contact (or a coordinating role/team) to guide people through referrals, follow-up, and “who does what,” rather than being left to navigate alone.
Access to rehabilitation and specialist input	<ul style="list-style-type: none"> • Respondents emphasise the need for local rehabilitation (and specialist provision), including post-diagnostic MDT input (e.g., OT), rather than having “nothing available” or needing to travel out of county.
Staffing, appointments, and timely intervention	<ul style="list-style-type: none"> • Calls for more staff, available appointments, and timelier access/support are common - often linked to people reporting no support for long periods
Support outside routine clinics	<ul style="list-style-type: none"> • People ask for telephone advice/access points, clearer guidance on when to seek urgent help, and concerns about A&E defaulting everything to FND and changing the level of care
Funding and investment (including research)	<ul style="list-style-type: none"> • There are requests for funding, investment, and resources to make services real rather than “hypothetical,” including research investment

Staff identify MDT pathways, increased capacity and clinical leadership as essential to improving rehabilitation access.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Clear pathways and specialist provision	<ul style="list-style-type: none"> • Strong call for a defined FND pathway, including rehabilitation for adults and children, specialist FND expertise, and a dedicated or single-point-of-access service.
Joined-up, multidisciplinary working	<ul style="list-style-type: none"> • Need for MDT approaches, better collaboration between services, shared responsibility (“no wrong door”), and clearer understanding of who does what.
Training, knowledge and awareness	<ul style="list-style-type: none"> • More training and education for professionals to improve understanding of FND and confidence in delivering care
Improved access and capacity	<ul style="list-style-type: none"> • Local services, shorter waiting times, increased staffing, quicker support post-diagnosis, and reduced need to travel long distances
Continuity, coordination and leadership	<ul style="list-style-type: none"> • Clear care leads, ongoing follow-up, continuity of care, and practical support mechanisms (e.g. specialist advice line).

People face limited local rehabilitation, workforce shortages and access challenges linked to rural geography.

Theme	Are there any barriers or gaps that could get in the way of this?
Lack of local rehabilitation provision / services don't exist (or are very limited)	<ul style="list-style-type: none"> • Responses say there is little or no FND-specific rehabilitation in Lincolnshire, with calls for dedicated local rehab options and fewer out-of-area journeys.
Workforce and skills gap (need trained specialist staff)	<ul style="list-style-type: none"> • Repeated emphasis on a shortage of skilled, FND-aware professionals and the need for experienced staff “with the right attitudes” to provide effective rehab.
Access barriers due to rurality, distance, transport and time	<ul style="list-style-type: none"> • Practical barriers include travel distance, rural isolation, lack of public transport, time away from work/school, and the need for more local “hub” or mobile provision.
GPs as a key bottleneck (knowledge/awareness of what's available)	<ul style="list-style-type: none"> • Some feedback identifies primary care as a barrier, including GPs lacking awareness of available services and being central to delays or lack of signposting.
Quality of rehabilitation (generic approaches not effective)	<ul style="list-style-type: none"> • Some comments suggest current input can be too generic (e.g., repeating the same physio exercises), and that rehab needs to be more appropriate and hands-on
Support not sustained or not tailored to fluctuating needs	<ul style="list-style-type: none"> • People note rehab/support may be withdrawn when symptoms fluctuate or once someone reaches a “plateau,” despite ongoing needs (speech, mobility, mental health).

Staff report no clear rehabilitation pathway and insufficient specialist knowledge and capacity.

Theme	Are there any barriers or gaps that could get in the way of this?
No clear or dedicated rehabilitation pathway	<ul style="list-style-type: none">• Lack of a rehab pathway, particularly for children, and uncertainty about which service is responsible for rehabilitation.
Limited specialist knowledge and workforce capacity	<ul style="list-style-type: none">• Shortage of professionals with FND expertise, low awareness of available services, and time and staffing pressures.
Access and inequality barriers	<ul style="list-style-type: none">• Long waiting lists, transport and location challenges, rural isolation, and difficulties for people with limited means.
Lack of infrastructure, care planning and clarity	<ul style="list-style-type: none">• Absence of individual care plans, unclear access routes, and insufficient mental health and OT support linked to rehabilitation.

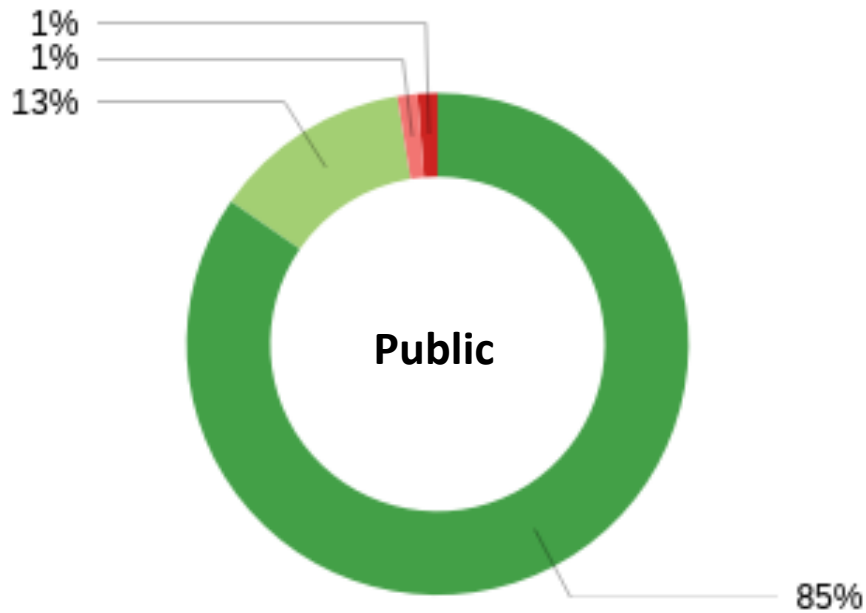
Respondents call for local MDT rehabilitation, clearer coordination and practical post-diagnosis support.

Theme	Do you have any other suggestions to help make this work well?
Build a local specialist MDT service + rehabilitation offer	<ul style="list-style-type: none"> • Fund and/or create FND-specific rehabilitation, including ideas like taking rehab into community venues or using a “rehab bus” • Improve access to specialists locally, rather than relying on out-of-county specialist centre waitlists.
Pathway clarity, single point of contact, and service coordination	<ul style="list-style-type: none"> • Add step-down support and a direct access point back into the service when needed. • Create a team/department to overlook and organise the overall structure
Diagnosis information and practical “day-to-day” guidance	<ul style="list-style-type: none"> • Include practical signposting: how to access physio, how to arrange OT adaptations, what to do if swallowing becomes difficult, and how to seek referrals (e.g., “salt team referral” is mentioned). • Enable patients to ask questions and get a quick return response
Lived experience involvement, carers, and listening	<ul style="list-style-type: none"> • Create a support network / register so people can be “counted (in a positive way).”
Digital access ideas	<ul style="list-style-type: none"> • Online platforms for self-referral and “automated triaging using AI” (suggested by one respondent).
Approach to need (avoid unhelpful categorisation)	<ul style="list-style-type: none"> • Don’t put FND into severity categories (comparison made to ME/CFS); instead accept the real daily impact and put a support plan in place to meet need.

Community support close to home

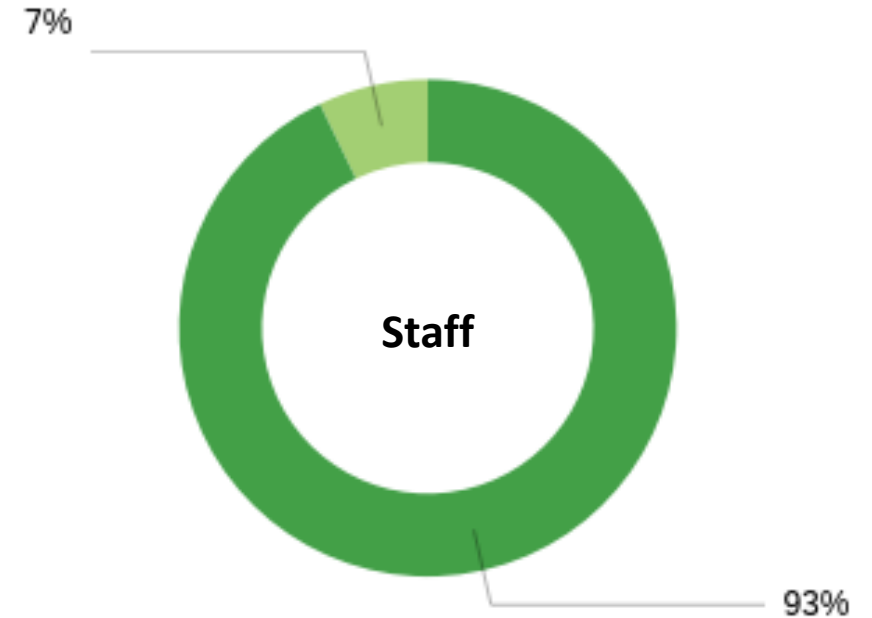
Community-based support close to home is highly valued and seen as essential in a rural county.

How important is **community support close to home** for you?



Very important Important Not very important Not important at all Don't know

(Base N = 78 response count)



(Base N = 31 response count)

Overall, the feedback calls for **real, visible community support in Lincolnshire**—with **local hubs, more trained staff, clearer signposting/referral routes**—plus options for **peer connection** and strong **support for children/schools**, delivered in an **accessible and flexible** way (including for people without digital access).

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
More community-based support	<ul style="list-style-type: none"> The strongest message is the need for more community services in Lincolnshire, with people describing little/no current support and wanting practical help available close to home
Local hubs and shorter travel distances	<ul style="list-style-type: none"> Respondents want local hubs/places to go (and not having to travel long distances or out of county) to access help, information, and one-to-one support.
Workforce capacity and training (more staff, better GP/community knowledge)	<ul style="list-style-type: none"> People call for more staff and better trained professionals—especially in GP practices and community roles (including social prescribers)—so patients can be supported and referred appropriately.
Peer support and connection (with choice, not one-size-fits-all)	<ul style="list-style-type: none"> Many want opportunities to share experiences through support groups, community champions, informal meetups (e.g., coffee mornings), but also note support groups won't suit everyone.
Support for children/young people and schools	<ul style="list-style-type: none"> A clear theme is the need for school-based understanding and support plans, more awareness among peers/families, and education from a young age to reduce isolation (especially where a child feels “the only one” with FND at school).
Practical support to stay independent and in work	<ul style="list-style-type: none"> People ask for specialist OT, help to remain independent, support to stay in employment, better links to adult social care, and more community/carer options (e.g., shared lives carers/outreach).
Financial and welfare impacts need addressing	<ul style="list-style-type: none"> Several comments describe the hardship when someone can't work (loss of sick pay/income) and the need for quick, accessible advice/support for families navigating this

Staff emphasise the need for countywide access through a dedicated, clearly commissioned FND service.

Theme	What one thing do you feel needs to happen or change for this to work well Lincolnshire?
Local, county-wide access to services	Strong need for services available across Lincolnshire, with community and satellite locations to reduce travel, especially for rural areas.
A dedicated specialist FND service and pathway	Repeated calls for a clearly commissioned FND service, with a defined pathway rather than fragmented or ad-hoc provision.
Multidisciplinary, coordinated support	Importance of an MDT approach, including key workers and close working with partner agencies to provide holistic care.
Better community support and signposting	Need for improved awareness, clearer signposting, local support groups, and stronger social prescribing and community networks
Early diagnosis followed by immediate local support	Emphasis on early, accurate diagnosis being matched with timely information and accessible community support.
Enablers: funding, transport and awareness	Adequate funding, transport support, and wider awareness are seen as essential to make community-based support work effectively.

Funding pressures, rurality and uneven provision limit access to community support across Lincolnshire.

Theme	Are there any barriers or gaps that could get in the way of this?
Lack of local community support / services don't currently exist	<ul style="list-style-type: none"> Many people say community support isn't available at all in their area (including "nothing at the moment" in parts of Lincolnshire), meaning support close to home is currently a gap.
Funding constraints (biggest/recurring barrier)	<ul style="list-style-type: none"> "Funding" is repeatedly cited as the main obstacle—particularly the ability to set up community hubs and sustain provision across towns and rural areas
Geography, rurality and transport/accessibility	<ul style="list-style-type: none"> The size and rural nature of Lincolnshire, poor transport links, and difficulty travelling (including mobility issues) are seen as major barriers to attending groups or accessing support.
Workforce capacity and skills (not enough trained staff)	<ul style="list-style-type: none"> Respondents highlight lack of skilled staff, challenges attracting staff to rural areas, and limited clinician capacity—leading to long waits and inconsistent support.
Poor communication/ coordination and unclear ownership	<ul style="list-style-type: none"> Feedback suggests no one is sure who is doing what, plus concerns about staff not engaging/communicating and weak links between professionals
Postcode lottery / uneven provision	<ul style="list-style-type: none"> A strong theme is concern about unequal access depending on where you live, with calls to avoid "postcode lottery" support and ensure border towns/rural communities are not excluded.

Staff identify transport, capacity and preparedness of community services as major barriers.

Theme	Are there any barriers or gaps that could get in the way of this?
Rurality and transport barriers	<ul style="list-style-type: none">Distance, poor transport options, and travel costs make it difficult for people, especially non-drivers or those with severe FND—to access community support
Limited local provision and inequity between areas	<ul style="list-style-type: none">A lack of locally available services, with some areas less well resourced than others, creates postcode-related inequalities.
Funding, capacity and investment gaps	<ul style="list-style-type: none">Insufficient funding, uncertainty about demand, and lack of investment limit the availability and sustainability of community support.
Community services not equipped for FND	<ul style="list-style-type: none">Community networks and social prescribing exist but are not adequately trained, supported, or resourced to meet the needs of people with FND.
Access and flexibility issues	<ul style="list-style-type: none">Time off work, difficulty leaving home, restrictive referral criteria, and limited virtual or alternative options hinder access to support.

Respondents want flexible, local, well-coordinated community support that reflects rural needs.

Theme	Do you have any other suggestions to help make this work well?
Rurality, travel and local access	<ul style="list-style-type: none"> Suggestions include more teams across the county, outreach clinics in market towns, and local check-ins/community staff.
Hybrid access + digital inclusion (avoid widening inequality)	<ul style="list-style-type: none"> Services should offer multiple formats (video, phone, paper/postal information, and home visits)
Awareness, education and training (public + professionals)	<ul style="list-style-type: none"> GP training, better-trained local nurses/doctors, and public awareness campaigns (e.g., posters, TV, hospital/GP messaging)
Employment, benefits and workplace understanding	<ul style="list-style-type: none"> People report being unable to work, fear discrimination, and ask for employer education, employment consultations, ergonomic support, and recognition that symptoms fluctuate (fatigue, brain fog, speech issues). Some also mention restrictive pension/medical retirement rules affecting volunteering and sense of value.
Peer/community support and voluntary/third sector models	<ul style="list-style-type: none"> Several people suggest support groups, regular newsletters, volunteers/buddy systems, and learning from successful charity models (e.g., condition-specific organisations).
Education settings: schools/colleges need support	<ul style="list-style-type: none"> Respondents want closer links with schools/colleges, training for staff, and better inclusion so young people can stay in education, including distance learning options where appropriate.
Practical access needs: transport, equipment, safe spaces and reasonable adjustments	<ul style="list-style-type: none"> Transport barriers are repeatedly referenced (public transport, taxis, adaptive transport). There are also practical suggestions like quiet waiting areas, walkers, and “patience” from staff given symptom fluctuation and fatigue.

Across all areas, feedback consistently highlights unclear pathways, fragmented care, limited FND knowledge and stigma, long waits, and a lack of specialist, locally accessible provision.

Theme	Feedback
Lack of clear, joined-up pathways	<ul style="list-style-type: none"> • No clear or consistent FND pathway (from diagnosis through to support and rehabilitation) • Confusion about “what happens next” and who is responsible • Being passed between services with no ownership • This appears repeatedly in feedback on diagnosis, specialist support, rehabilitation, and community services.
Fragmented care, poor coordination and communication	<ul style="list-style-type: none"> • Services working in silos • Poor information sharing between professionals and organisations • Patients and families having to “join the dots” themselves • Both public and staff repeatedly call for better MDT working, shared records, and single points of contact.
Insufficient professional knowledge, training and confidence	<ul style="list-style-type: none"> • Limited understanding of FND across primary care, hospitals, mental health and community services • Inconsistent or absent training • Lack of confidence recognising, diagnosing or supporting FND • This links directly to delays, misdiagnosis, inappropriate referrals, and inconsistent care.
Stigma, disbelief and lack of empathy	<ul style="list-style-type: none"> • People not being believed or feel dismissed • FND viewed as “not real” or “psychological” • Harmful language and attitudes impacting care and trust • Respondents describe stigma as affecting diagnosis, access to services, rehabilitation, community support, and quality of life.
Long waits, access barriers and system capacity pressures	<ul style="list-style-type: none"> • Long waits for neurology, diagnosis, therapy and rehabilitation • Difficulty accessing GP appointments • Workforce shortages and limited capacity

Early diagnosis and joined-up care emerge as the highest priorities across all responses.

Aim 1: Early and accurate diagnosis

Aim 2: Joined-up specialist support when you need it (Integrated Multidisciplinary Care)

Aim 3: Training and education (Building understanding and reducing stigma)

Aim 4: Joined-up care with better access to rehabilitation (integrated pathways)

Aim 5: Community support close to home (community model)

One most important thing respondents want to achieve

1. Get physical function back (mobility, walking)

2. Manage symptoms and reduce flare-ups (including pain)

3. Better quality of life / live a “more normal life”

4. Independence and living well at home

5. Early, accurate diagnosis and confidence it’s the right diagnosis

6. A clear, structured pathway with personalised long-term treatment

7. Joined-up, coordinated multidisciplinary care

8. Validation, being listened to, and stigma reduction

9. Information and practical support for patients & families (incl. work/benefits)

Ways respondents think we might achieve it

Investment, workforce development, clear pathways and culture change are seen as key enablers.

Increase funding and investment (stop cuts)

Reduce waiting times and provide timely intervention

Create a dedicated FND service in Lincolnshire

Train and upskill professionals (primary care, hospital, wider services)

Build a specialist MDT workforce (incl. Occupational Therapy/rehab expertise)

Raise awareness and tackle stigma (public and professional)

Implement a clear FND pathway (diagnosis → support → rehab)

Joined-up working, communication and one shared system

Improve referrals and access (GPs/social prescribers “on board”)

Patient-centred, respectful culture (listen, validate, individualise support)

The below comments and suggestions are displayed in order of mention. Those at the top were mentioned the most and those at the end, the least.

Themes and suggestions

Lack of FND services and clear pathways	Many people report that FND services in Lincolnshire are non-existent or inaccessible, with no clear post-diagnosis pathway, resulting in delays, rejection of referrals, or being left without support.
Poor awareness, belief and empathy among professionals	Strong feelings of not being believed, dismissed, or misunderstood by health professionals, linked to limited knowledge of FND, misinformation, and stigma.
Long waits and unmet need	Extended waiting times for diagnosis and support, lack of timely follow-up, and delays in communication (e.g. discharge letters) negatively impacting care and outcomes.
Fragmented, inconsistent care	People describe being passed between services, lack of continuity, exclusions due to complexity, and a need to self-advocate to access any support.
Insufficient rehabilitation, mental health, and holistic support	Limited access to appropriate rehab, FND-informed mental health care, therapy for seizures, and support that recognises the physical, psychological, and social impact of FND.
Impact on quality of life, wellbeing and inclusion	Feelings of isolation, being forgotten, loss of dignity, and concerns about education, employment, aging, and co-existing conditions, including poor understanding in schools.

Survey respondent demographics

Age	%	Count
16 and below	2%	2
17-20	0%	0
21-29	6%	6
30-39	12%	12
40-49	27%	27
50-59	26%	26
60-69	14%	14
70-79	8%	8
80-89	1%	1
90+	0%	0
Prefer not to say	0%	4
Answered		99

Ethnicity	Responses	
Bangladeshi	0%	0
Indian	1%	1
Pakistani	1%	1
Any Other Asian Background	0%	0
African	1%	1
Caribbean	0%	0
Any Other Black Background	0%	0
White and Asian	1%	1
White and Black African	1%	1
White and Black Caribbean	1%	1
Any Other Mixed Background	0%	0
White British	87%	85
White Irish	0%	0
Any Other White Background	5%	5
Chinese	0%	0
Gypsies/Travelers/Roma	0%	0
Any Other Ethnic Group	1%	1
Answered		98

Gender	%	Count
Male	17%	17
Female	79%	77
Intersex	0%	0
Non-binary	0%	0
Prefer not to say/ don't know	4%	4
Answered		98

Physical disability or mental illness expected to last more than 12 months	%	Count
Yes	74%	59
No	26%	21
Prefer not to say	1%	0
Answered		80

Survey respondent demographics

Health inequality information	%	Count
Have served in the UK's regular or reserved armed force	40%	4
Currently working in the Farming/ agricultural industry	0%	0
Have worked in the Farming/ agricultural industry	10%	1
Currently homeless	0%	0
Have experience of being homeless	50%	5
Currently serving in UK's armed forces	0%	0
Refugee, immigrant or asylum seeker	0%	0
Previous experience of being a refugee, immigrant or asylum seeker	0%	0
<i>Answered</i>		10

Employment status	%	Count
Employed full time	37%	31
Employed part time	9%	9
Homemaker	2%	2
Not employed and looking for work	2%	2
Not employed and not looking for work	13%	12
Retired	16%	15
Self employed	9%	9
Student	3%	3
Prefer not to say	3%	3
Other	9%	9
<i>Answered</i>		95