

Functional Neurological Disorder (FND) Survey

Patient and Public Report

November 2025



Introduction

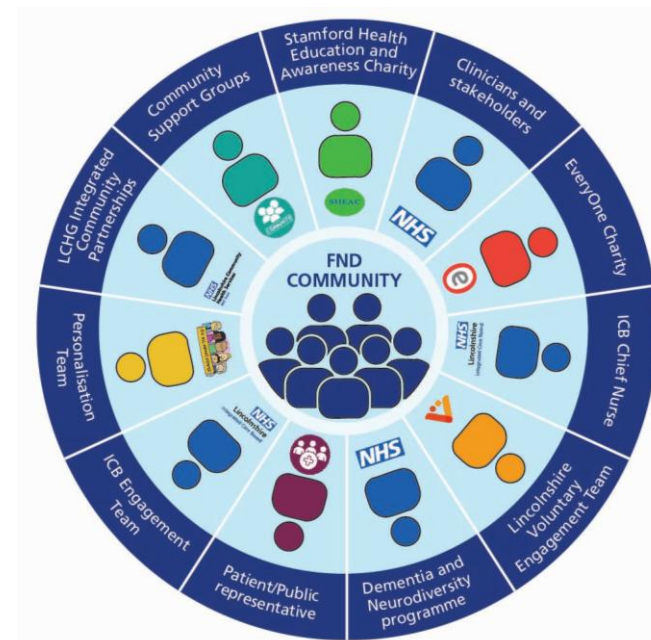
FND Lincs is an informal group of people with a lived experience of FND who live or use health and social care services in Lincolnshire. It was identified that many find it difficult to get the support, recognition or help needed following diagnosis or FND.

FND Lincs, NHS Lincolnshire ICB and system partners are working together to develop a FND strategy for Lincolnshire. As part of this we want to understand people's experience of how they were diagnosed with FND and the way they engaged with services.

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.

The survey was available to complete between **17 October – 30 November** and received **127 responses**.

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



127
responses to the survey

11%
completion rate
(Prevalence 1130 in Lincs)

Promotion of engagement

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 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:

- Featured in **3** fortnightly 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.
- Providers' member databases and staff networks.



Help shape better care for people living with Functional Neurological Disorder (FND)

Social media and website activity

NHS Lincolnshire ICB Communications team's used Facebook to push traffic towards the survey on the website. The team posted:

3 Facebook posts, shared **38** times, **reaching 17.077 people** and generating **521 engagements**

35 people visited the webpage - [Functional Neurological Disorder \(FND\) Survey - 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:

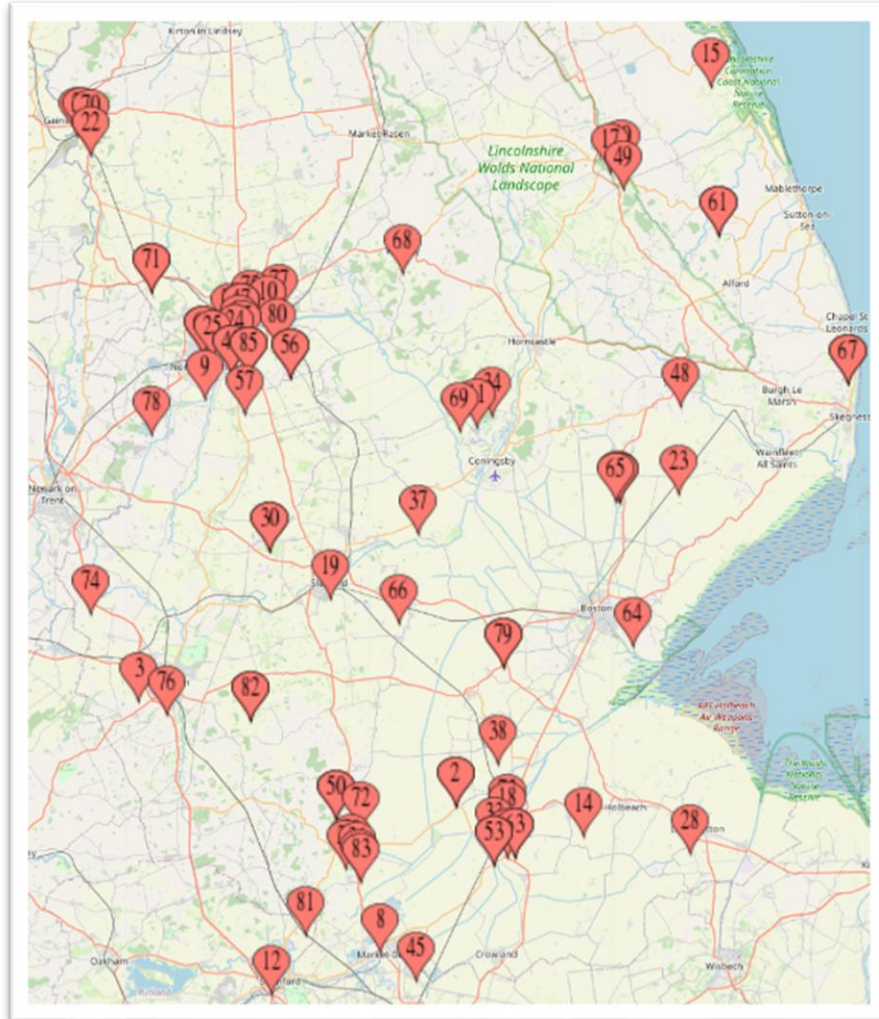
Via the FND Lincs Newsletter produced by our patient representative
 With the FND Lincs support group/community
 FND Lincs supported the 'Fit for the Future' event in Spalding to raise awareness of the survey and FND.

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)

Audience	Distribution
Health and Care Partners	NHS Providers Lincolnshire Resilience Forum Community Connectors Neighbourhood leads ASC Carers Service
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 respondent

90% (114) of 127 respondents identify as having Functional Neurological Disorder (FND). **90%** (102) of these 114 respondents have been formally diagnosed with FND. Below shows where the respondents are located within Lincolnshire.

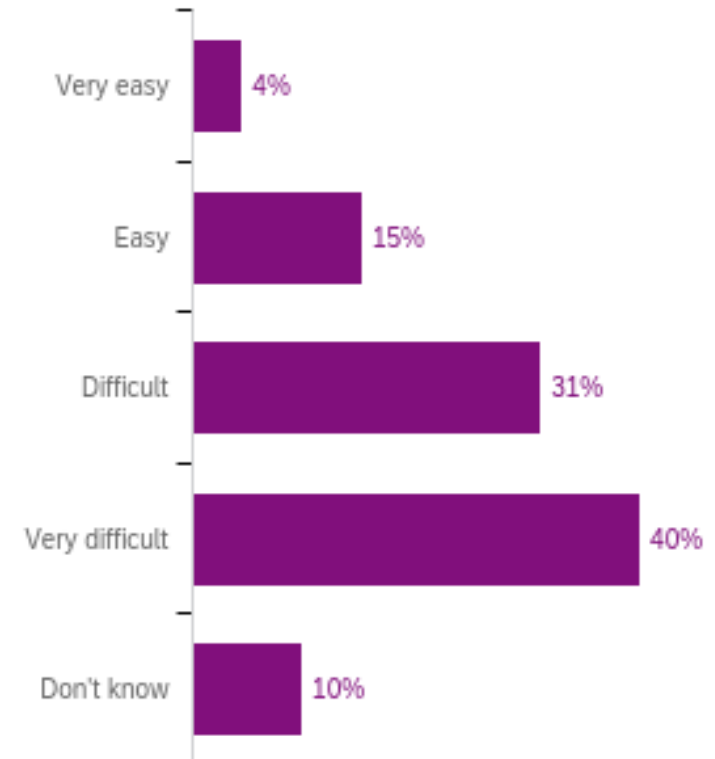


District	%	Count
East Lindsey	14%	18
South Kesteven	14%	17
North Kesteven	10%	13
Lincoln City	10%	13
South Holland	10%	13
West Lindsey	8%	7
Boston Borough	2%	3
<i>Unknown</i>	35%	44
Total		127

How long-ago respondents received their diagnosis	%	Count
0-6 months	8%	8
6-12 months	17%	17
1-2 years	18%	18
2-3 years	26%	26
4-5 years	6%	6
5+ years	26%	26
Total		101

Who diagnosed respondents	%	Count
NHS Consultant/ neurologist	73%	86
Other	13%	15
A GP	7%	8
Outside of NHS	5%	6
Self-diagnosis	3%	3
Total		118

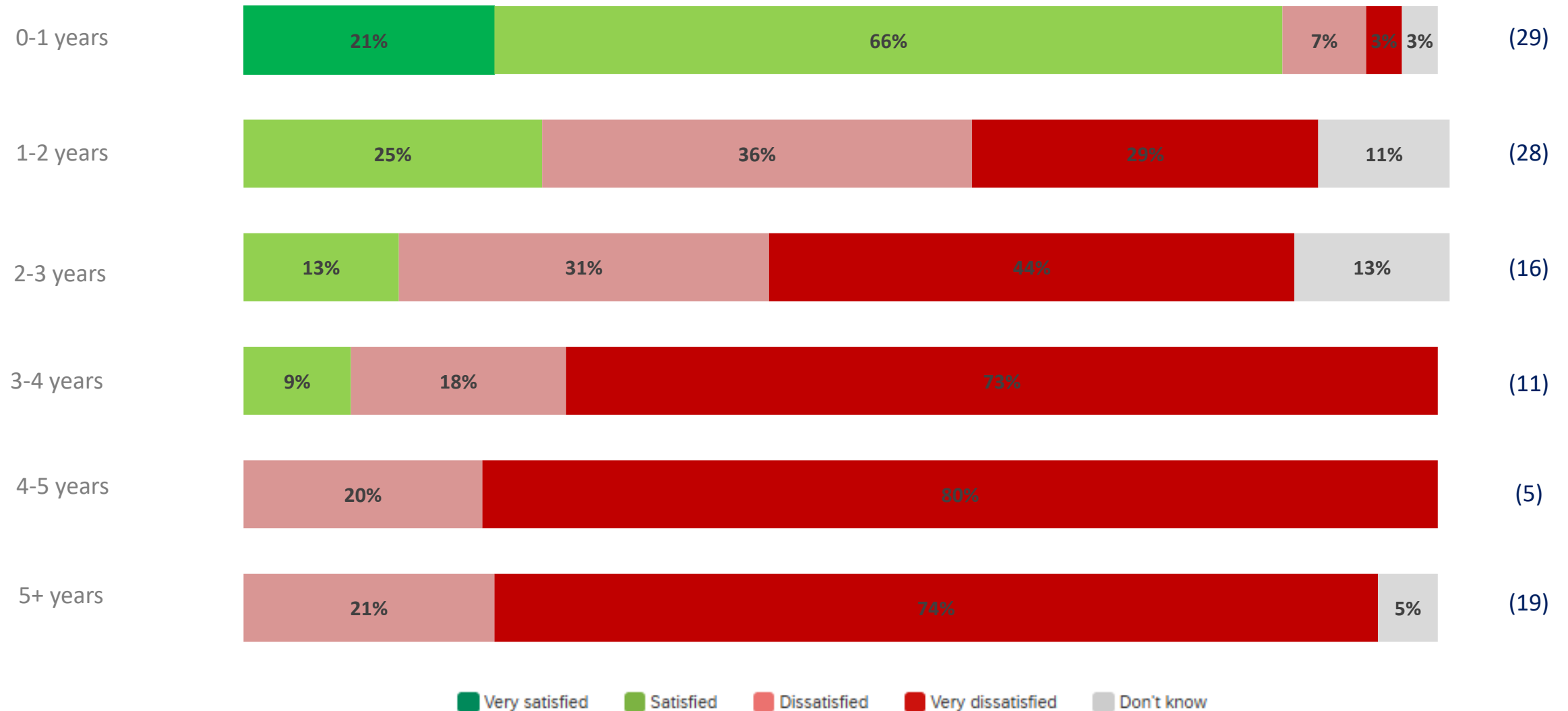
How easy respondents found it to get an FND diagnosis
(Base N = 113)



Most respondents **71% (80)** found it **difficult/very difficult** to get an FND diagnosis, compared to **19% (22)** who found it **very easy/easy**.

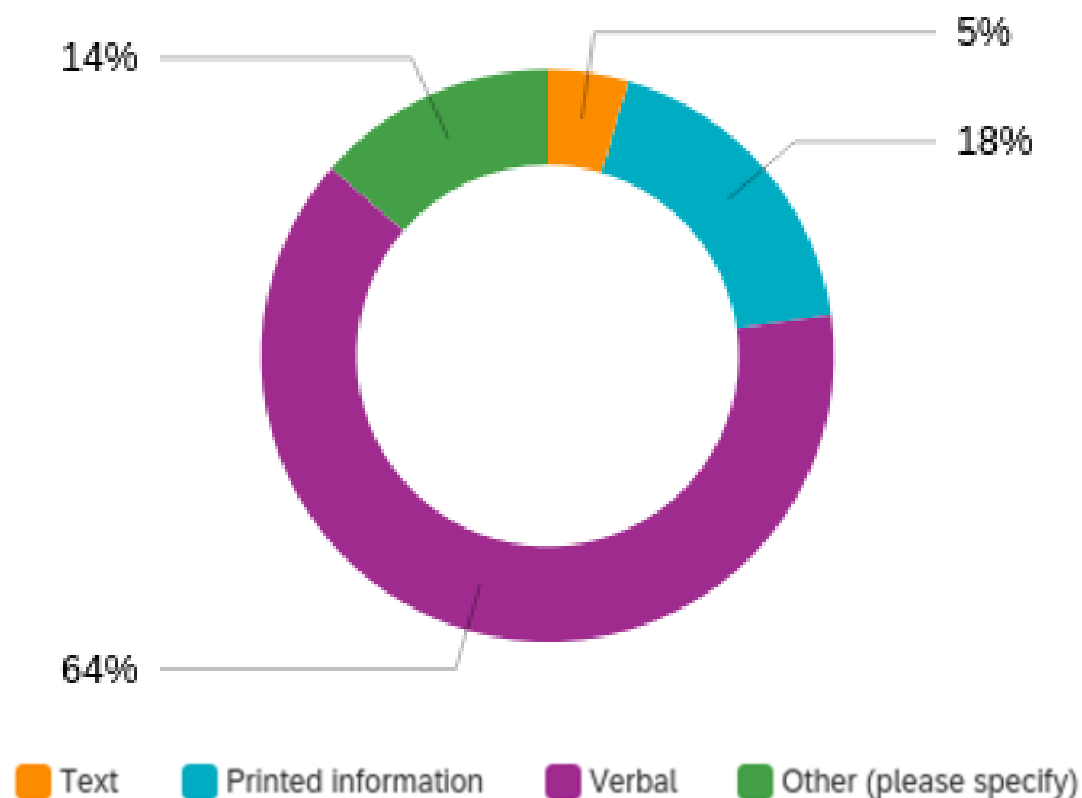
Speed of diagnosis

Just under **a third 31% (35)** of respondents were **satisfied** with the speed of diagnosis, whilst **62% (68)** were **dissatisfied**. The below chart shows the level of satisfaction vs the length of time respondents waited to get diagnosed from initial onset of symptoms.



Three quarters (**75%, 83**) of respondents did **not receive** information about FND and how to manage symptoms at the time of diagnosis. **20% (22)** **did** receive it and **5% (6)** were **unsure** if they were given any information.

Format in which respondents received information about FND and managing symptoms



(Base N = 22 response count)

Of the 22 respondents who did receive information, the majority (**64%, 14**) were given it **verbally**.

18% (4) received **printed information**, **5% (1)** via **text message**.

14% (3) were signposted to a website or took part in an FND trial in London.

Respondents aged 30-39 received initial information **more regularly** than all other ages.

The below table shows how satisfied respondents were with the **level of knowledge** held by the person who diagnosed them with FND and their **ability to answer medical questions**.

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Don't know	Total
A GP	0%	0%	60%	20%	20%	5
NHS Consultant/neurologist	9%	26%	34%	26%	6%	82
Outside of the NHS	0%	33%	50%	17%	0%	6
Self-diagnosis	0%	33%	0%	67%	0%	3
Other	0%	17%	17%	33%	25%	12

Respondents **aged 50-59** and those **without a disability** were more generally more satisfied with the **level of knowledge** held by the person who diagnosed them with FND and their **ability to answer medical questions**.

62% (67) of respondents feel that their medical symptoms were not managed efficiently. Similarly, high levels of respondents **83% (91)** feel that time/money was wasted by attending unnecessary outpatient appointments.

Do you feel that your medical symptoms were managed efficiently?

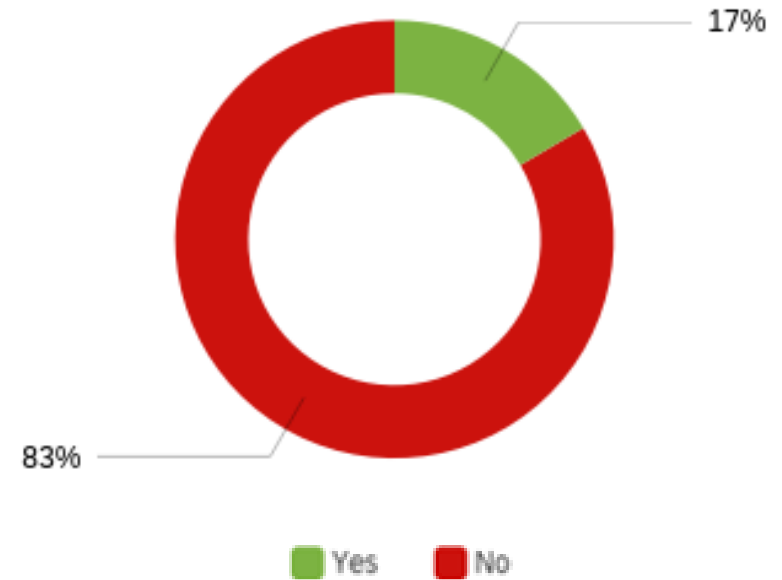


Yes No

(Base N = 109 response count)

(Base N = 108 response count)

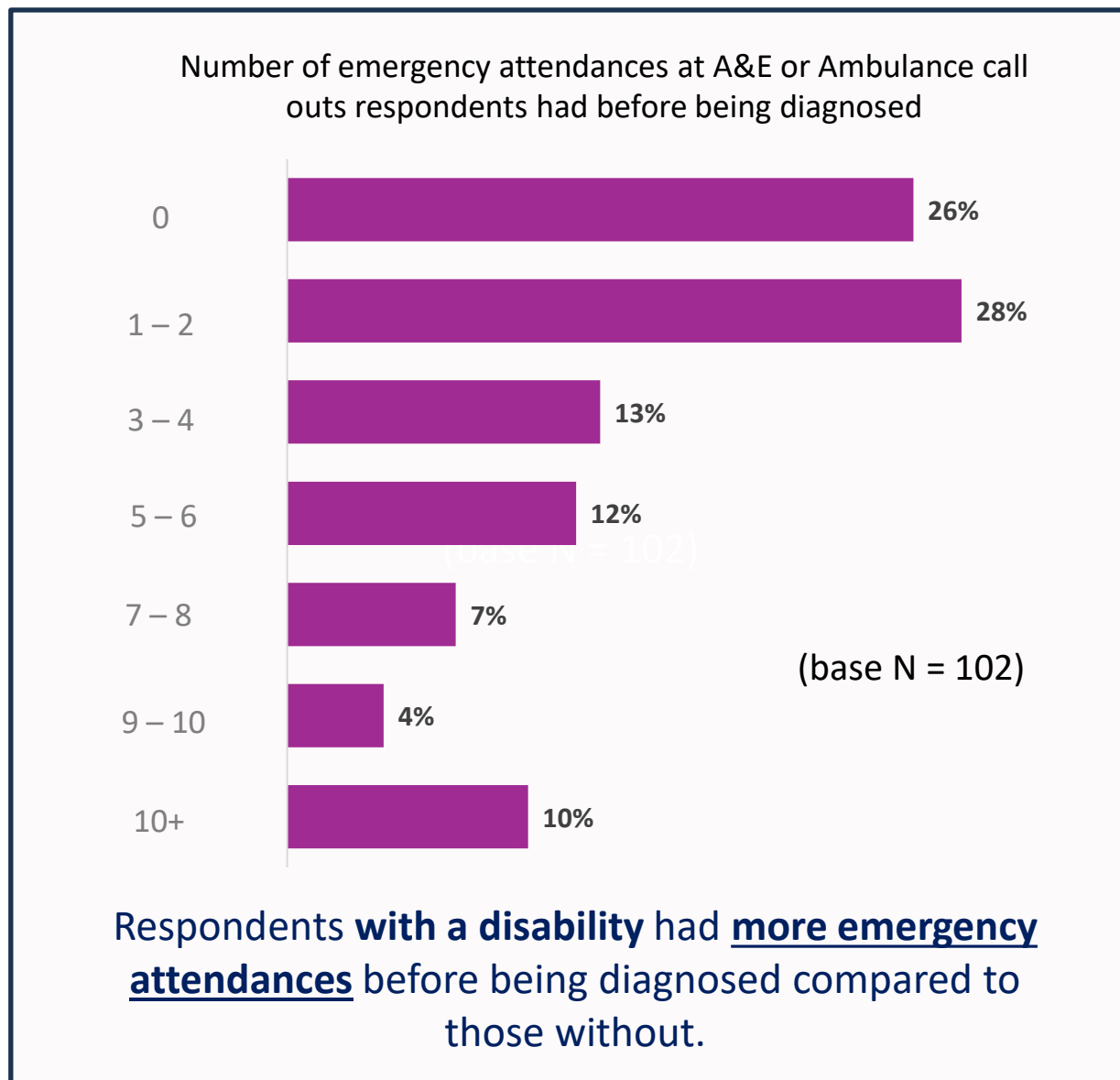
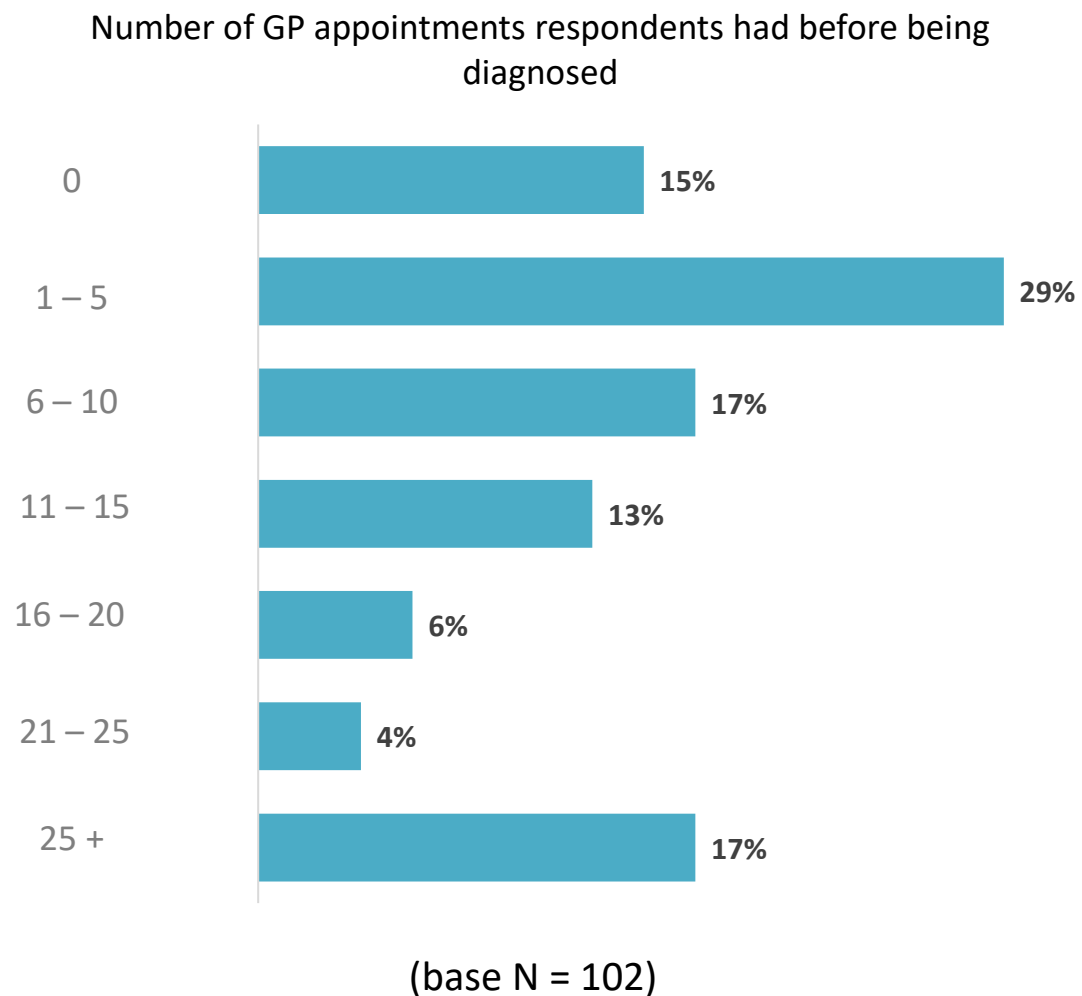
Do you feel that time/money was wasted by attending unnecessary outpatient appointments?



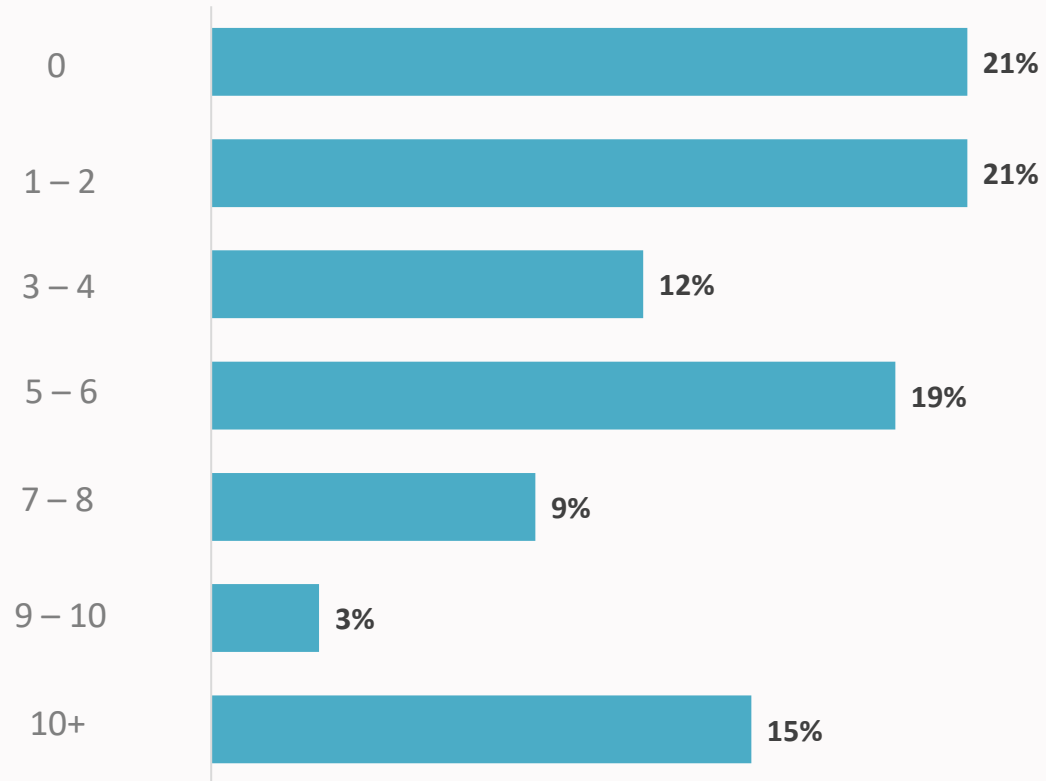
Yes No

Respondents **aged 40-59** and those **without a disability** felt that time/money was wasted more than those **aged 16-29** and **with a disability**.

Generally, the longer people had to wait to be diagnosed the more GP appointments and A&E attendances they had.

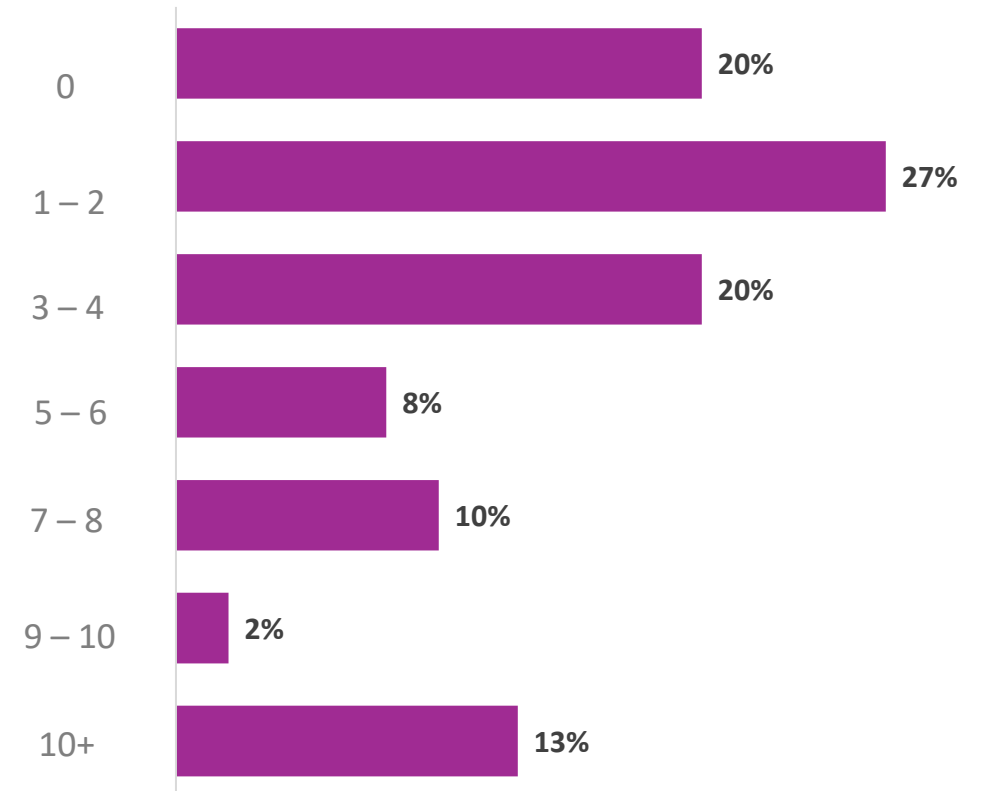


Number of outpatient appointments respondents had before being diagnosed



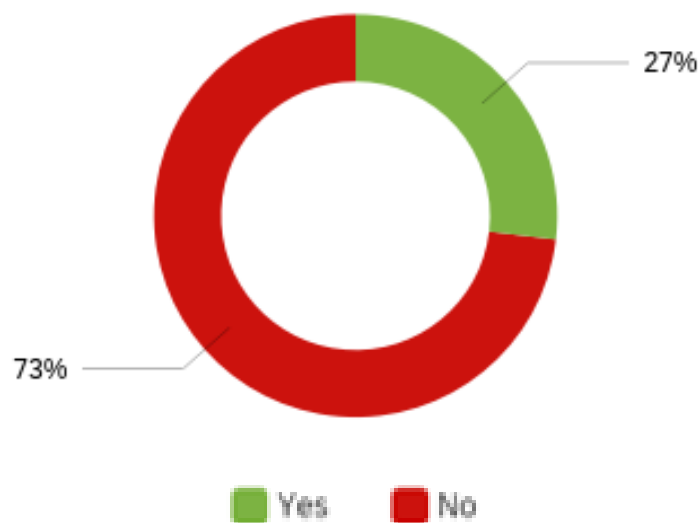
(base N = 102)

Number of other FND related medical appointments



(base N = 103)

Were other healthcare professionals helpful in enabling you to understand your symptoms?



(Base N = 93 response count)

Respondents aged **50-59** and those **without a disability** generally found other healthcare professionals **more helpful** in helping them understand their symptoms.

Reasons respondents felt others were helpful

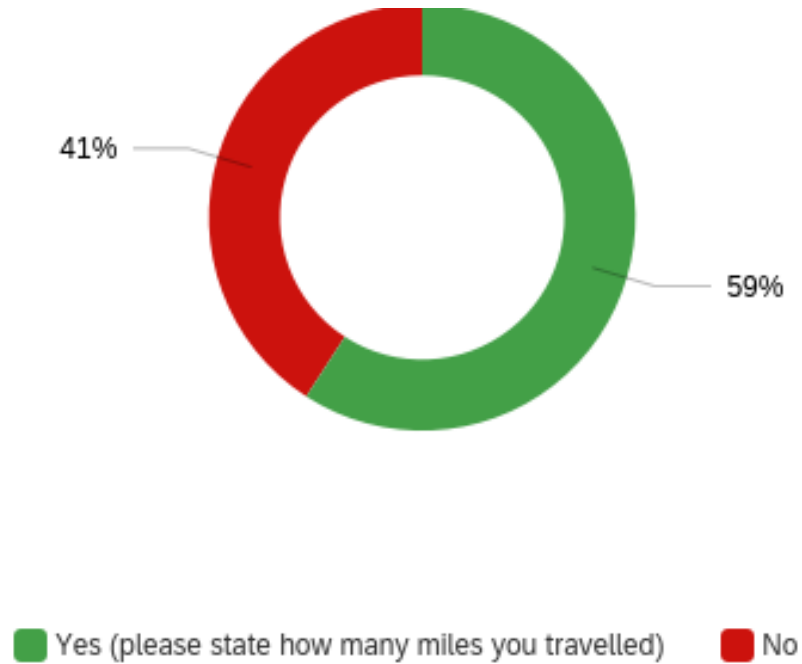
Knowledge and understanding	Respondents felt supported when professionals understood FND and could explain the condition and symptoms clearly. This reduced confusion and built trust
Emotional and practical support	Support was valued when professionals provided empathy, reassurance, and practical tools like CBT or pacing strategies to manage symptoms and mental health.
Signposting and patient advocacy	Respondents appreciated professionals who guided them to appropriate services, provided referrals, or involved them in specialist programs and trials.

Reasons respondents felt other were not helpful

Lack of knowledge and awareness	The most common issue was a fundamental lack of understanding of FND among healthcare professionals, leading to poor advice and inadequate care, GPs googling during appointments
Dismissive attitudes and stigma	Respondents felt invalidated and disbelieved, with some professionals implying FND was psychological or fabricated.
Lack of support and access to care	Many respondents were diagnosed and then abandoned, with no care plan or access to essential services.
Poor communication and information	Respondents were frustrated by minimal or unclear communication, leaving them to research and manage FND on their own.

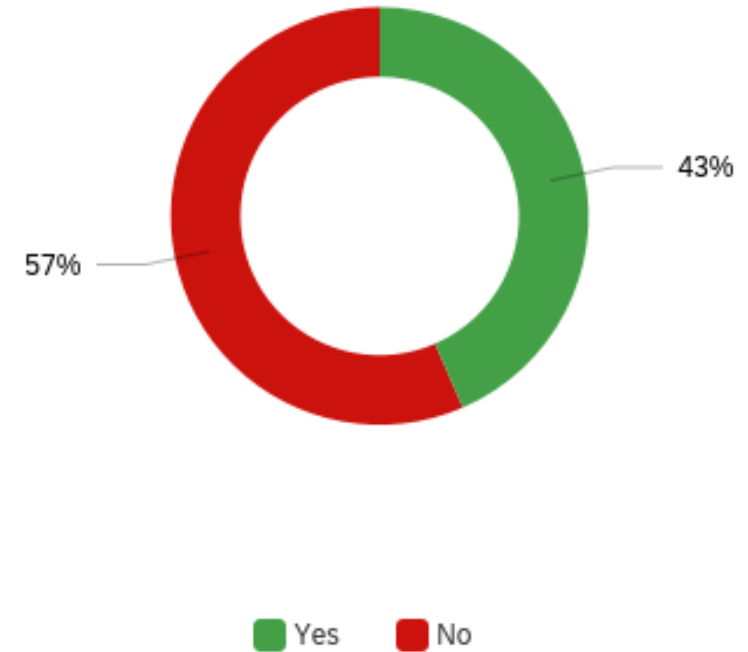
59% (55) of respondents have travelled outside of Lincolnshire for diagnosis or treatment. The average number of miles travelled is **89**. The highest number of miles travelled is **400**.

Number of patients who have travelled outside of Lincolnshire to see a consultant for diagnosis or treatment



(Base N = 93 response count)

Number of patients who have paid for diagnosis or treatment associated with FND



(Base N = 92 response count)

Reasons why respondents felt their experience of FND Care was **positive**

(The below themes are presented in order of most mentioned. Themes at the top have been mentioned the most and those at the end, the least)

Theme	Suggestions and feedback
Person-centred care and empathy	<ul style="list-style-type: none"> • Care that considered the patient’s individual needs and circumstances was highly valued. Respondents appreciated professionals who showed empathy, respected their experiences, and tailored treatment plans accordingly. This approach promoted trust and improved engagement with care. • <i>“I was granted full CHC funding for my care and this followed best practice in regard to a person-centred approach.”</i>
Support from social care and third-sector services	<ul style="list-style-type: none"> • Social workers and third-sector organisations played a crucial role in bridging gaps in NHS provision. They provided equipment, arranged private physiotherapy, and offered practical support that improved daily living and independence. • <i>“Lincolnshire adult social care have been fantastic at implementing care and equipment provision.”</i>
Family and community support	<ul style="list-style-type: none"> • Emotional and practical support from family, friends, and workplaces was highlighted as a key factor in coping with FND. This support helped patients feel less isolated and more empowered to manage their condition. • <i>“My previous GP, my family and my friends have been incredibly supportive.”</i> • <i>“Wife is extremely supportive.”</i>

Reasons why respondents felt their experience of FND Care was **positive** contd.

Theme	Suggestions and feedback
Supportive and understanding neurologists	<ul style="list-style-type: none"> • Respondents consistently highlighted the importance of neurologists who take time to listen, explain conditions clearly, and maintain ongoing communication. These professionals provided reassurance, clarity, and continuity of care, which helped patients feel respected and understood. Their ability to simplify medical jargon and offer written summaries was particularly valued by those with memory or cognitive challenges. • <i>“My neurologist is understanding and listens to symptoms/changes etc and helps me to understand them whilst also giving me the 'dummy' version of any medical terms”</i>
Effective physiotherapy and rehabilitation	<ul style="list-style-type: none"> • Physiotherapy and hydrotherapy were praised for improving mobility, reducing symptoms, and providing practical strategies for daily life. Respondents valued therapists who were knowledgeable about FND and tailored exercises to individual needs. Paediatric physiotherapy was described as life-changing, enabling children to regain independence. • <i>“The paediatric physio at Lincoln county hospital (Leanne) was truly amazing and provided life changing support, care and guidance.”</i>
Access to multidisciplinary or specialist programs	<ul style="list-style-type: none"> • Comprehensive programs involving neurologists, physiotherapists, psychologists, and other specialists were seen as transformative. These programs provided structured treatment plans, education, and coping strategies, often after long waits. Specialist centers like Great Ormond Street and St George’s were praised for their expertise and holistic approach. • <i>“Great Ormond Street Hospital were amazing... They helped get services set up in Spalding.”</i>
Helpful cognitive behavioural therapy (CBT) and mental health support	<ul style="list-style-type: none"> • CBT was frequently mentioned as beneficial for managing stress, fatigue, and symptom triggers. Respondents appreciated therapists who understood FND and provided practical coping strategies. Mental health support was seen as essential for improving quality of life and reducing symptom severity. • <i>“CBT has been especially helpful in managing my energy levels and coping with stress.”</i>

Reasons why respondents felt their experience of FND Care was **negative**

(The below themes are presented in order of most mentioned. Themes at the top have been mentioned the most and those at the end, the least)

Theme	Suggestions and feedback
Lack of knowledge and understanding by healthcare professional	<ul style="list-style-type: none"> • Many respondents reported that doctors, nurses, and other professionals did not understand FND, dismissed symptoms, or Googled the condition in front of patients. • <i>“A and E and any other professionals not knowing what it is, having to ask me and then expecting to give medical advice. Googling in front of me and then not knowing what to do.” “Doctors not knowing what FND is or calling it fake, left to seize and said to let me get bored.”</i>
Dismissal, gaslighting, and accusations of faking	<ul style="list-style-type: none"> • Patients felt disbelieved, accused of fabricating symptoms, or treated as if their condition was psychological only. • <i>“Told all in my head. Symptoms are not real. Told it was just mental health issues that triggered seizures.”</i> • <i>“Made to feel it was my fault and it was within my control. Felt medically gaslit and suffered CPTSD as a result.”</i>
No follow-up or aftercare post-diagnosis	<ul style="list-style-type: none"> • Patients were diagnosed and then left without ongoing support or treatment plans. • <i>“Following 2 collapses at home and a total of 9 weeks in hospital, I was given the diagnosis of FND. I have had no further follow ups.” “Absolutely non-existent. No one has asked, spoken or been interested in me having FND in any way shape or form.”</i>
Long waiting times and need for private care	<ul style="list-style-type: none"> • NHS waiting lists were extremely long, forcing patients to pay privately for essential care. • <i>“Had to pay private as the NHS waiting times were over one year and I was told that it wasn’t a priority.” “We have had to pay privately for psychotherapy due to long NHS waiting lists.”</i>

Reasons why respondents felt their experience of FND Care was **negative** contd.

Theme	Suggestions and feedback
<p>Lack of access to services (physio, speech therapy, pain management)</p>	<ul style="list-style-type: none"> • Patients were denied or unable to access therapies crucial for recovery. • <i>“I have been declined physio, speech therapy, pain management and every healthcare professional has not been able to help with any of my symptoms.” “Trying to get speech therapy but I have been told Lincolnshire has not been commissioned for this.”</i>
<p>Traumatic or unsafe hospital experiences</p>	<ul style="list-style-type: none"> • Patients described distressing incidents in hospitals, including restraint, neglect during seizures, and unsafe discharges. • <i>“I had to lodge a PALs complaint after being restrained in a crucifix position by six people on a hospital bed and being told repeatedly to stop and pack it in.”</i> • <i>“Being treated at A&E and being left while having seizures. Waiting for hours and being told there was nothing wrong with me.”</i>
<p>Emotional impact</p>	<ul style="list-style-type: none"> • Lack of support led to feelings of isolation, hopelessness, and worsening mental health. • <i>“It’s lonely and isolating. No support post diagnosis, no check in with neurologist.” “Made to feel valueless and suicidal.”</i>
<p>Systemic failures and poor care coordination</p>	<ul style="list-style-type: none"> • Patients fell through gaps between services, faced poor communication, and lack of integrated care. • <i>“There is no FND pathway in Lincolnshire. As soon as a service hears the word ‘functional’ they refuse treatment.” “The transfer between child services and adult services didn’t work at all instead all that happened was I fell through the cracks.”</i>

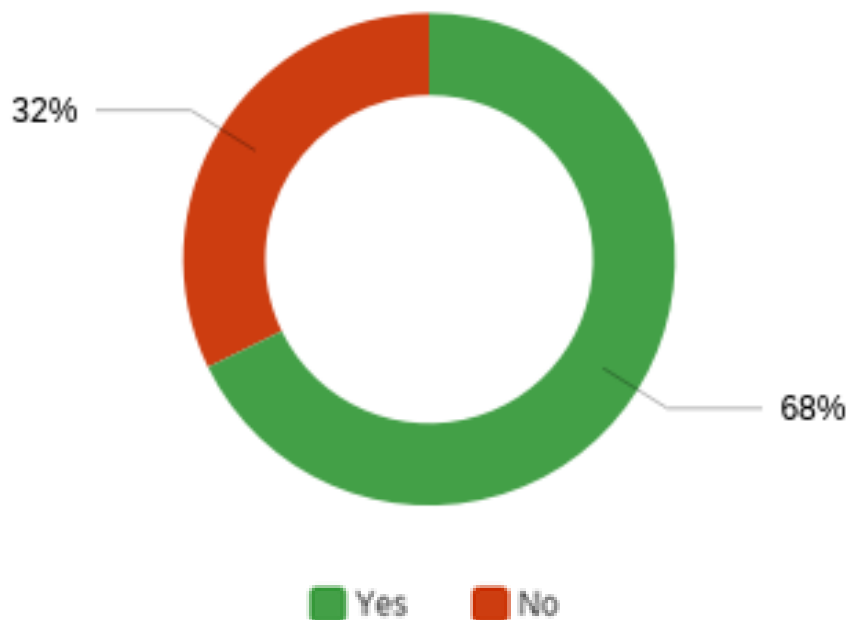
Respondents told us the one thing would they would change to **improve** services for FND in Lincolnshire

Theme	Feedback
Education and awareness for healthcare professionals	<ul style="list-style-type: none"> The most common suggestion was to educate NHS staff, GPs, consultants, and ambulance teams about FND. Respondents emphasized the need for training to reduce stigma, improve understanding, and ensure patients are treated with empathy and respect. <i>“Teach NHS staff, ambulance staff and all other staff that FND is real and the symptoms are real. So much stigma around FND it has to change.”</i>
Access to specialist services and multidisciplinary care	<ul style="list-style-type: none"> Respondents called for dedicated FND clinics, inpatient rehabilitation units, and multidisciplinary teams (neurology, physiotherapy, psychology). They stressed the importance of integrated care pathways and coordinated support. <i>“Have a dedicated multidisciplinary team that has experience and understands FND so everyone can be treated in a structured way.”</i>
Improved follow-up and ongoing support	<ul style="list-style-type: none"> Many respondents highlighted the lack of continuity after diagnosis. They want regular reviews, clear care plans, and named coordinators to ensure ongoing support. <i>“Follow-up care and support, post-diagnosis.”</i>
Faster access and reduced waiting times	<ul style="list-style-type: none"> Long delays for referrals and treatment were a major concern. Respondents requested quicker access to specialists, therapy, and mental health support. <i>“Having to wait a long time for a referral... it’s 1 year. I’m still waiting to be seen.”</i>

Respondents told us the one thing would they would change to **improve** current services for FND in Lincolnshire contd.

Theme	Feedback
More funding and resources	<ul style="list-style-type: none"> • Respondents stressed the need for increased funding to commission services, hire specialists, and provide integrated care systems. • <i>“More funding to have an integrated care system.”</i> • <i>“Fund rehab treatment for FND patients.”</i>
Better communication and listening to patients	<ul style="list-style-type: none"> • Patients want professionals to listen to their experiences, respect their input, and involve them in care decisions. • <i>“To listen to the patient at how FND affects them as a service user on a case-by-case basis and to truly listen and take note.”</i> • <i>“Listening to the patients... Consultant arrogance made me feel incredibly small.”</i>
Clear information and care pathways	<ul style="list-style-type: none"> • Respondents asked for clear explanations of FND, written information, and guidance on available services and treatment options • <i>“Have the information for the patients so they know what they’re dealing with.”</i> • <i>“Clear explanation of FND, help to manage symptoms, automatic referral to neurologist.”</i>

Does a family member or friend provide informal (unpaid) care to you?



The families of **disabled respondents** provided informal care **more** than those families of respondents without a disability.

(Base N = 90 response count)

Additional feedback provided:

Lack of support and abandonment after diagnosis

Respondents consistently reported being diagnosed and then left without treatment, follow-up, or guidance. Many described feeling “shown the door” with no help managing symptoms.

➤ *“Diagnosis 2017 and left alone. I’m now bedbound and life is ruined.”*

Heavy reliance on family and informal carer

Care often falls entirely on family members or partners, creating emotional, physical, and financial strain. Respondents described unpaid caregiving, selling homes, and sacrificing jobs to provide support.

➤ *“My husband gave up working to look after me, so it also affected his health and wellbeing.”*

Lack of knowledge and understanding among professionals

Respondents highlighted poor awareness of FND within the NHS, leading to dismissive attitudes, stigma, and mismanagement of symptoms.

➤ *“I wish there was more awareness and understanding both of what the condition is/isn’t but also how to help a sufferer.”*

Isolation and mental health impact

Respondents described feeling lonely, cut off from life, and mentally distressed due to lack of support and the burden of managing FND alone.

➤ *“We lost every penny of our savings and had to sell our home... This all affected my mental health very negatively.”*

Systemic failures and barriers

Respondents expressed frustration with systemic issues such as lack of treatment pathways, contradictory criteria for services, and poor coordination between departments.

➤ *“Criteria changes for physio meant I couldn’t access treatment because there was no psychological pathway.”*

Survey respondent demographics

Sexual orientation	%	Count
Heterosexual	74%	63
Gay	0%	0
Lesbian	6%	5
Bisexual	7%	6
Prefer to self-identify	4%	3
Prefer not to say	9%	8
<i>Answered</i>		85

Physical disability or mental illness expected to last more than 12 months	%	Count
Yes	77%	68
No	12%	9
Prefer not to say	1%	1
<i>Answered</i>		78

Caring responsibilities	%	Count
Yes	96%	44
No	0%	0
Prefer not to say	4%	2
<i>Answered</i>		44

Gender	%	Count
Male	22%	20
Female	75%	67
Intersex	0%	0
Non-binary	0%	0
Prefer not to say/ don't know	2%	2
<i>Answered</i>		89

Gender reassignment	%	Count
Yes	0%	0
No	100%	60
Prefer not to say	0%	0
<i>Answered</i>		60

Survey respondent demographics

Age	%	Count
Under 16	1%	1
16-20	3%	3
21-29	9%	8
30-39	15%	13
40-49	22%	20
50-59	25%	22
60-69	16%	14
70-79	9%	8
80-89	0%	0
90+	0%	0
Prefer not to say	0%	0
Answered		89

Ethnicity	Responses	
Bangladeshi	0%	0
Indian	0%	0
Pakistani	0%	0
Any Other Asian Background	0%	0
African	0%	0
Caribbean	0%	0
Any Other Black Background	0%	0
White and Asian	0%	0
White and Black African	1%	1
White and Black Caribbean	0%	0
Any Other Mixed Background	1%	2
White British	94%	82
White Irish	0%	0
Any Other White Background	2%	2
Chinese	0%	0
Gypsies/Travellers/Roma	0%	0
Any Other Ethnic Group	1%	1
Answered		87

Religion	%	Count
Christianity	41%	34
No Religion	28%	23
Atheist	18%	15
Buddhist	1%	1
Jewish	0%	0
Muslim	0%	0
Hindu	0%	0
Any other religion	6%	5
Prefer not to say	5%	4
Answered		82

Survey respondent demographics

Health inequality information	%	Count
Have served in the UK's regular or reserved armed force	56%	5
Currently working in the Farming/ agricultural industry	11%	1
Have worked in the Farming/ agricultural industry	22%	2
Currently homeless	0%	0
Have experience of being homeless	11%	1
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>		9

Employment status	%	Count
Employed full time	17%	15
Employed part time	14%	12
Homemaker	3%	3
Not employed and looking for work	0%	0
Not employed and not looking for work	18%	16
Retired	24%	21
Self employed	6%	5
Student	5%	4
Prefer not to say	6%	5
Other	7%	6
<i>Answered</i>		87