

CCG/Health Board Report 2022

In December 2021 and following discussions with the UK Medical Expert Committee which comprises of 21 Medical and Allied Health Professionals across the UK, we agreed to send a Freedom of Information request to each CCG and Health Board in England, Wales and Scotland.

This project aimed to explore issues reported by NHS clinicians and the FND community regarding accesses to treatment for people with FND. Anecdotal feedback was that some CCG's / Health Boards exclude people with FND from accessing physiotherapy, occupational therapy, speech and language therapy, and/or psychology. A common reason given is that they are not commissioned to treat this condition. Following discussion, FND Hope UK reached out to all CCG's in England and Health Boards in Wales and Scotland to determine the following questions

1. Does your commissioning agreement within your CCG include treatment for Functional Neurological Disorder?
2. Can you please confirm that the commissioning agreement within your CCG provides each of the following services and that people with FND are eligible to be referred and receive this treatment:
 - Neurological physiotherapy
 - Neurological occupational therapy
 - Speech and language therapy and
 - Psychological therapies
3. *Can you please provide a list of the services offered and contact details which include both Inpatient and Community/Outpatient Rehabilitation Services as advised in Q2?*
4. *If your commissioning agreement excludes the treatment of Functional Neurological Disorder, can you please provide details of which services in your CCG Areas accepts referrals for treatment for Functional Neurological Disorder?*
5. Do you have plans to improve access to treatment for people with FND? If so, can you provide details of what improvements are being implemented?
6. Would you or your colleagues be interested in accessing clinical support/education about FND involving specialist clinicians?

We contacted a total of 126 CCG's/Health Boards during December 2021 with FOI requests.

- 105 CCG's in England
- 7 Health Board in Wales
- 14 Health Boards in Scotland

Functional Neurological Disorder (FND) is one of the commonest reasons for people to see a neurologist. It is a condition that can cause a wide range of symptoms such as paralysis, seizures, tremors and loss of sensation. Historically it has been a marginalised illness, often falling down the gap between the artificial divide between neurology and psychiatry, with patients often told that symptoms are not real or imagined. However, FND remains a serious and often long-term condition, with levels of disability and impaired quality of life similar to that seen in people with MS or Parkinson's disease.

Set against this challenging background, there has been a remarkable increase in patient, clinician and academic activity and engagement in FND over the past 15 years. This has led to new insights into the pathophysiology of the condition, new evidence for successful treatment, development of an international health professionals' society and development of national and international patient charities. This work has continued to highlight the health inequalities faced by people with FND, especially in access to treatment.

We recently surveyed, through a Freedom of Information request, all of the Clinical Commissioning Groups and health boards in the UK as to their current provision of multidisciplinary rehabilitation for people with FND, as well as if they had active plans for developing or expanding services.

We found that:

- 50% of UK health boards / CCG's had no specific agreement to treat FND or did not treat FND, and almost 10% say that they do not accept referrals for treatment
- Between 14% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept physiotherapy referrals or provide physio for FND. Less than half (43%) said they had neurological physiotherapy services which would accept people with FND.
- Between 22% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept occupational therapy referrals or provide occupational health for FND and less than half (41%) said they had neurology based occupational therapy services which would accept people with FND.
- Between 17% (England), 14% (Scotland) and 43% (Wales) of services said that they did not accept speech and language therapy referrals or provide speech and language for FND and only 39% said they had neurology based speech and language therapy services which would accept people with FND.
- Between 16% (England), 29% (Scotland) and 43% (Wales) of services said that they did not accept psychology referrals or provide psychological therapy for FND, whilst 42% said they would accept people with FND.
- Only 35% said they had plans to improve their services for people with FND and only 35% said they were potentially interested in accessing further education or support to improve services.

This survey highlights the current patchy and inequitable provision of rehabilitative services for people with one of the commonest causes of neurological disability.

Breakdown of Question 1

Does your commissioning agreement within your CCG/ health service within your Health Board include treatment for Functional Neurological Disorder

Total CCGs / Health Board

No and referrals not accepted	11 (9%)
No, but some provision of treatment	52 (41%)
Yes	39 (31%)
Information not available from CCG/Health Board	24 (19%)

CCG Data for England

No and referrals not accepted	8 (8%)
No, but some provision of treatment	49 (47%)
Information not available from CCG/Health Board	24 (23%)
Yes	24 (23%)

Health Board Wales Data

No and referrals not accepted	3 (43%)
No, but some provision of treatment	2 (29%)
Information not available from CCG/Health Board	0
Yes	2 (29%)

Health Board Scotland Data

No and referrals not accepted	0
No, but some provision of treatment	1 (7%)
Information not available from CCG/Health Board	0
Yes	13 (93%)

Please note that 4 CCG's offered additional information for areas within their CCG, which has provided 11 additional responses (Total 116 minus 24 Information not available from CCG/Health Board equals 92 Responses for CCG's only) that have not been included in the above Data but will be included in the data breakdown below.

Breakdown of Question 2

Can you please confirm that the commissioning agreement within your CCG / health service in your health board provide each of the following services and that people with FND are eligible to be referred and receive this treatment: Physiotherapy, Occupational Therapy, Speech and Language Therapy and Psychological Therapies?

Breakdown of CCG's/Health Boards offering Physiotherapy

	England# 92	Scotland #14	Wales #7	Total
Physiotherapy offered Neuro services	36 (39%)	9 (64%)	4 (57%)	49 (43%)
Physiotherapy offered via general services	31 (34%)	2 (14%)		33 (29%)
No referrals or Physiotherapy offered	13 (14%)	3 (21%)	3 (43%)	19 (17%)
Physiotherapy but with (Individual Funding Request) required	2 (2%)			2 (2%)
Not specified	8 (9%)			8 (7%)
Depends on Clinic	1 (1%)			1 (1%)
Information not held	1 (1%)			1 (1%)

Physiotherapy via general services have been categorised as such based on information supplied by the CCG / Health Board

- Between 14% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept physiotherapy referrals or provide physiotherapy for FND. Less than half (43%) said they had neurological physiotherapy services which would accept people with FND.

IFR: Specialist Service –the request by an independent panel by expert clinicians and lay members.

Breakdown of CCG's/Health Boards offering Occupational Therapy

	England #92	Scotland #14	Wales #7	Total
Occupational Therapy offered	33 (36%)	10 (71%)	3 (43%)	46 (41%)
Occupational Therapy offered via general services	27 (29%)	1 (7%)	1 (14%)	29 (26%)
No referrals or Occupational Therapy offered	20 (22%)	3 (21%)	3 (43%)	26 (23%)
Occupational Therapy but with (Individual Funding Request) required	2 (2%)			2 (2%)
Not specified	8 (9%)			8 (7%)
Depends on Clinic	1 (1%)			1 (1%)
Information not held	1 (1%)			1 (1%)

Occupational Therapy via general services have been categorised as such based on information supplied by the CCG / Health Board

- Between 22% (England), 21% (Scotland) and 43% (Wales) of services said that they did not accept occupational therapy referrals or provide occupational health for FND and less than half (41%) said they had neurology based occupational therapy services which would accept people with FND.

IFR: Specialist Service –the request by an independent panel by expert clinicians and lay members.

Breakdown of CCG's/Health Boards offering Speech and Language Therapy

	England #92	Scotland #14	Wales #7	Total
Speech and Language Therapy offered	32 (35%)	9 (64%)	3 (43%)	44 (39%)
Speech and Language offered but via general services	33 (36%)	3 (21%)	1 (14%)	37 (33%)
No referrals or Speech and Language offered	16 (17%)	2 (14%)	3 (43%)	21 (19%)
Speech and Language but with (Individual Funding Request) required	2 (2%)			2 (2%)
Not specified	7 (8%)			7 (6%)
Depends on Clinic	1 (1%)			1 (1%)
Information not held	1 (1%)			1 (1%)

Speech and Language Therapy via general services have been categorised as such based on information supplied by the CCG / Health Board

- Between 17% (England), 14% (Scotland) and 43% (Wales) said that they did not accept speech and language referrals or provide speech and language for FND and only 39% said they had neurology based speech and language services which would accept people with FND

IFR: Specialist Service –the request by an independent panel by expert clinicians and lay members.

Breakdown of CCG's/Health Boards offering Psychological Therapies

	England#92	Scotland #14	Wales #7	Total
Psychological Therapies offered	34 (37%)	10 (71%)	3 (43%)	47 (42%)
Psychological Therapies offered via general services	31 (34%)		1 (14%)	32 (28%)
No referrals or Psychological Therapies offered	15 (16%)	4 (29%)	3 (43%)	22 (19%)
Psychological Therapies but with (Individual Funding Request) required	2 (2%)			2 (2%)
Not specified	8 (9%)			8 (7%)
Depends on Clinic	1 (1%)			1 (1%)
Information not held	1 (1%)			1 (1%)

- Psychological Therapies via general services have been categorised as such based on

information supplied by the CCG / Health Board. Between 16% (England), 29% (Scotland) and 43% (Wales) of services said that they did not accept psychology referrals or provide psychological therapy for FND, whilst 42% said they would accept people with FND.

- We found four (4) offered IAPT services as part of their criteria (This is based on the information supplied by the CCG), two (2) did not offer IAPT as per reason: Under the service specification for Improving Access to Psychological Therapies (IAPT), FND would be classed as exclusion and patients with FND would need to be seen by a specialist service which we don't have a commissioned service for and one (1) is currently reviewing business case to incorporate IAPT Services

Please see appendix A for additional breakdown of data

Breakdown of Question 5

Do you have plans to improve access to treatment for people with FND? If so, can you provide details of what improvement are being implemented?

Total CCG/Health Board from a total of 137 responses

Not Applicable response	15	11%
No	43	31%
Yes	48	35%
No Response or question left blank	31	23%

Of the 31 who did not provide a response or left the question blank:

- **8 did offer treatment including general services and did not have plans to improve services**
- **3 advised referrals were not accepted, and did not have plans to improve services**
- 20 advised information was not available from the CCG.

Of the 15 that answered not applicable:

- **11 did offer treatment, including general services and did not have plans to improve services**
- 4 advised information not available from the CCG.

Of the 43 who answered no?

- 40 offered treatment including general services
- **2 did not accept referrals and did not have plans to improve services**
- 1 advised information not available from the CCG

Breakdown of Question 6

Would you or your colleagues be interested in accessing clinical support / education about FND involving specialist clinicians?

Total CCG/Health Board

No Response or question left blank	43	34%
No	40	32%
Yes	41	33%
Maybe	2	2%

Of those who responded No to additional support and education on FND

- 35 of these were from CCG's
- 1 from the Wales Health Board
- 4 from the Scotland Health Board

Comments received

No and referrals not accepted

"The Planned and Specialist Team do not commission any services for FND patients. Despite "neurological" in the name, it is not considered a neurological condition, i.e. the patient's neurology is functioning properly. For this reason, the units we commission for specialist inpatient rehabilitation do not accept FND patients" CCG

"The CCG does not specifically include the treatment of FND in its current commissioning agreements" CCG

"No, therefore all other responses would be N/A" CCG

"Health Board (the UHB) does not provide treatment for FND. UHB Consultants diagnose FND in our neurology clinics – there are no consultants in the HB area that are specialising or leading on this currently". Wales Health Board

"The Health Board does not have a specific service for functional neurological disorder (FND)." Wales Health Board

"CCG have identified in year a commissioning gap in relation to treatment for patients diagnosed with FND. A Business Case has been developed which is currently being taken through our internal governance process with a view of working with our Community Neuro service to implement within the New Year. This will include a combination of physical therapy (with physiotherapy and occupational therapy input) and mental health support via Improving Access to Psychological Therapies – Long Term Conditions (IAPT-LTCs). It is envisioned that Consultants and GPs will be able to refer any X patient, with a diagnosis of FND into this service to receive both physical and mental health support" CCG

No, but some provision of treatment

“The CCG does not specifically commission an FND clinic in the community but the community provider provides support for patients diagnosed with FND”. CCG

“CCG does not commission a specific service for this disorder. Patients will be treated within the specialties listed”

“Individuals can access discipline specific interventions from clinicians who have an interest in the condition and who have some capacity to provide this care. Some persons with FND are seen within mental health services if they meet criteria for these services and the neuro physio department in HB also accepts referrals for FND”. Wales Health Board

“Health Board does not provide inclusive treatment for Functional Neurological Disorder” Scotland Health Board

Moving forward

The anecdotal reports of FND being excluded from treatment were supported by our data, with 50% of UK Health Boards/CCGs having no specific agreement to treat / not treat FND.

People with FND experience disabling neurological symptoms that often persist in the long term. There are promising, evidence-based treatments available on the NHS, but access is patchy and waiting times for treatment tend to be very long; which may potentially limit their effectiveness as longer symptom duration is associated with worse outcomes.

Improving access to treatment for FND should be a high priority for the NHS, on the grounds of the potential cost savings, but more importantly to limit distress and disability of large portion of the community.

Appendix A

CCG Data

From the 24 CCG's who responded YES - Does your commissioning agreement within your CCG/Health Board include treatment for Functional Neurological Disorder they offered the following treatments:

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
1	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes but not FND Specific	Yes
3	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
4	Yes	Yes	Yes	Yes
5	Yes Community Therapy	Yes Community Therapy	Yes Community Therapy	Yes Community Therapy
6	Yes	Yes	Yes	Yes but not FND Specific
7	Yes	Yes	Yes	Yes
8	Not Specified	Yes	Yes	Yes
9	Yes	Yes	Yes	Yes but not FND Specific
10	Yes	Yes	Yes	Yes
11	Yes	Yes	Yes	Yes
12	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
13	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes
14	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
15	Yes	Yes	Yes	Yes
16	Yes	Yes	Yes	Yes
17	Not Specified	Not Specified	Not Specified	Not Specified
18	Yes	No	No	No
19	Not Specified	Not Specified	Not Specified	Not Specified
20	Yes	No	No	No
21	Yes	Yes	Yes	Yes
22	Not Specified	Not Specified	Not Specified	Not Specified
23	Yes	Yes	Yes	Yes
24	Not Specified	Not Specified	Not Specified	Not Specified

From the 45 CCG's who did offer treatment but did not have a specific commissioning agreement to treat FND, they offered the following treatments

Please note that there are an additional 3 responses, this is due to a CCG breaking down the area to provide 3 additional responses. These have been noted with * next to them

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
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1	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
2	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
3*	Yes	Yes	No	Yes
4*	Yes	No	No	No
5*	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	No
6	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
7	Yes	Yes	Yes but not FND Specific	Yes
8	Yes but not FND Specific	Not Specified	Yes but not FND Specific	Not Specified
9	Yes	Yes	Yes	Yes
10	Yes	Yes	Yes	Yes
11	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
12	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
13	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
14	Yes	Yes	Yes	Yes
15	Yes	Yes	Yes	Yes
16	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
17	No	No	Yes but not FND Specific	No
18	No	No	No	Yes but not FND Specific
19	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
20	Yes	No	Yes	Yes but not FND Specific
21	Not Specified	Not Specified	Not Specified	Not Specified
22	No	No	No	Yes but not FND Specific
23	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
24	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
25	Yes IFR Request	Yes IFR Request	Yes IFR Request	Yes IFR Request
26	Yes	Yes	Yes	Yes
27	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
28	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
29	Yes but not FND Specific	No	Yes but not FND Specific	Yes
30	No	No	No	Yes
31	Yes but not FND Specific	Yes	Yes	Yes

32	Yes	Yes	Yes	Yes
33	Yes but not FND Specific	Yes	Yes	Yes
34	Yes IFR Request	Yes IFR Request	Yes IFR Request	Yes IFR Request
35	Yes	Yes	Yes	Yes
36	Yes	No	No	No
37	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
38	Depends of Clinic	Depends of Clinic	Depends of Clinic	Depends of Clinic
39	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
40	Yes	Yes	Yes	Yes
41	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
42	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
43	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
44	Not Specified	Not Specified	Not Specified	Not Specified
45	Yes	No	Yes	Yes
46	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific
47	Yes	Yes	Yes	Yes
48	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific	Yes but not FND Specific

Wales Health Board Data

From the 2 Wales Health Boards who reported YES, Does your commissioning agreement within your CCG/Health Board include treatment for Functional Neurological Disorder they offered the following treatments:

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
1	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	Yes

From the 5 Health Boards' who did offer treatment but did not have a specific commissioning agreement to treat FND patient, they offered the following treatments

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
1	Yes	Yes	Yes but not FND Specific	Yes but not FND Specific
2	No	No	No	No
3	No	No	No	No
4	No	No	No	No

5	Yes	Yes but not FND Specific	Yes	Yes
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Scotland Health Board Data

From the 13 Health Boards who reported YES, Does your commissioning agreement within your CCG/Health Board include treatment for Functional Neurological Disorder they offered the following treatments:

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
1	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	No
3	Yes	Yes	Yes	Yes
4	No	No	No	Yes
5	Yes	Yes	Yes	Yes
6	Yes	Yes	Yes	Yes
7	Yes	Yes	Yes	Yes but limited
8	Yes	Yes	Yes	Yes
9	No	No	No	Yes
10	Yes	Yes but not FND Specific	Yes but not FND Specific	No
11	Yes but not FND Specific	Yes	Yes	Yes
12	Yes	Yes	Yes	Yes
13	No	No	Yes but not FND Specific	No

As you can see from the table above, even though they have reported they are commissioned to treat FND, some Health Boards also reported treatments were not specific to FND or that some treatments were not available.

From the 1 Health Board who did offer treatment but did not have a specific commissioning agreement to treat FND patient, they offered the following treatments

CCG	Physiotherapy	Occupational Therapy	Speech and Language Therapy	Psychological therapies
1	Yes but not FND Specific	Yes	Yes but not FND Specific	No