

## Understanding the views of people affected by Functional Neurological Disorder (FND) on the optimised clinical pathway

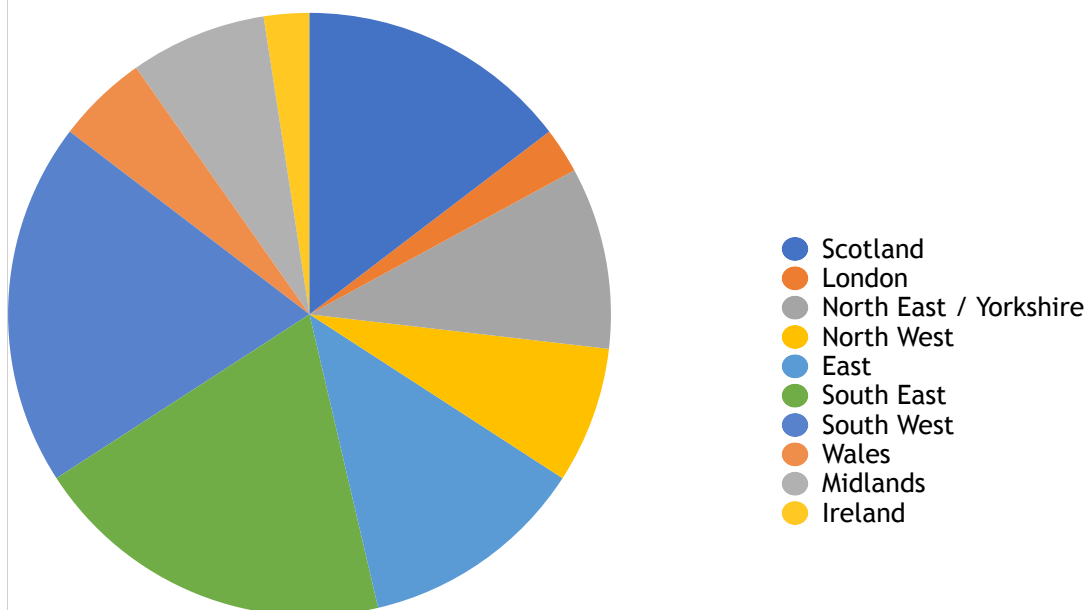
### Background

In March 2021, FND Hope UK facilitated a series of four focus groups with people affected by brain injury to review the draft optimum clinical pathway for functional neurological disorder. Dawn Golder, Executive Director of FND Hope UK, Professor Mark Edwards, and staff from the Neurological Alliance presented the pathway and facilitated the sessions.

### Who took part?

41 people with FND took part in four focus groups, including 6 people who identified as male and 35 who identified as female. The majority of attendees were from the South East or South West of England (16).

**Pie Chart to show the # of people attending in the different UK Areas**



### Key findings

The groups were asked to comment on different elements of the pathway, including diagnosis, ongoing treatment and support and access to research. Overall, the groups supported the pathway as presented. The group felt the following considerations and amendments could be made:

- **Diagnosis:** Members of the groups queried whether ophthalmology ought to be included, and felt that less common presentations of FND should be documented in the pathway
- **Education and training of ‘generalists’:** Every group provided examples of where they felt they had been let down by their GP or health and care professionals who did not specialise in FND. Many attendees felt that upskilling of primary care and emergency services was fundamental to implementing the pathway.
- **Criteria for diagnosing FND:** Participants felt that diagnosis of FND should not be ruled on the basis of a diagnosis of depression.
- **Relationship with clinicians:** Many participants highlighted the importance of a positive, trusted relationship with clinicians as being a central tenant of optimised care. Unfortunately, many participants also provided examples of where they felt they had not been listened to by their health and care professionals – care felt ‘done to’ rather than ‘done with’. Good care planning and coordination would help to address this.
- **Care coordination and consistency:** Nearly all attendees reported experiences of fragmented services, and/or different approaches being taken by healthcare professionals (for example, between two neurologists).
- **Self-management:** The importance of self- management, and the resources available to people with FND to support self-management, should be made more clear in the pathway.
- **Integration of health and social care:** Many participants felt that social care input could be enhanced in this pathway. Many were hopeful that NHS reforms, which in principle are working towards enhanced integration between health and social care, could bring about improved care for people with FND (although the jury is still out).
- **Support for those closest to you:** Participants raised the need for the pathways to consider the support required for friends and family, including informal carers. Some attendees reflected on the role of their child as a young carer, and felt that more support should be in place for them (including at school).
- **Presentation of the pathway:** All participants welcomed the pathway itself. Some felt that the presentation could be simplified to centre more clearly on the needs of the individual, and to allow people to appeal for the ‘right treatment’ when they feel there are gaps in their care.
- **First point of contact:** All of the attendees felt this to be invaluable. Some queried whether or not the role includes care navigation more broadly, and whether this could be explicit in the pathway.
- **Measures of good care:** Some participants felt adding measures of good care, for example ‘time to diagnosis’ or similar could support implementation.

- **Terminology:** Some participants felt that a glossary of terms could be useful.

### **Next steps**

The authors of the pathway have taken into account the feedback on the pathway and incorporated this in the final pathway document.

FND Hope UK and the Neurological Alliance will also work together to assess options to design up the pathway for use by people with neurological conditions.

The final pathway will be published on the NNAG website in 2021.