

# FND Expert-by-Experience collaboration to improve therapy research

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## Introduction

- Functional Neurological Disorders (FND) presenting with motor and sensory symptoms, causing serious disability and distress. <sup>1</sup>
- Experts-by-experience are people with experience of a particular event or disorder, who give expertise and advise on research to create solutions based on their insight. <sup>2</sup>
- In this study, experts-by-experience previously diagnosed with FND discussed how they engaged with and interacted with therapists, to identify areas of improvement in FND therapy and collaborate to improve fundamental research in FND.

## Aim

- To identify ways to make fundamental research into FND therapy relevant to real-life patient concerns.
- Use joint collaboration from experts-by-experience to form neurocomputational tasks assessing disengagement of therapy.
- Identify possible improvements in FND therapy.

## Method

- Recruited patients through 'FND Hope' - a global charity supporting those suffering with FND. <sup>3</sup>
- Discussed experiences and issues through four group discussions (Lived Experience Advisory Panel, LEAP).
- Identified common themes and recurring events experienced by FND patients, and the impact of these on engagement with therapy.
- Identified how to resolve issues and advised on future research to improve patient engagement with therapy.

| Initial concerns  | How this may lead to therapy disengagement   |
|---|--|
| Therapist seems dismissive of patient symptoms and experience   | Patient perceives that the therapist does not believe them and does not validate their experience or severity of their diagnosis |
| Therapist may take a reductionist approach and measure progress of symptoms using technical measures  | Emotional and mental wellbeing which is impacted by FND inadequately understood  |
| Comorbid conditions of FND patients often explained away as part of FND                               | Comorbid diagnoses missed and their treatment delayed  |
| Progress is too controlled – therapists set rigid timelines and targets for each session of treatment | FND patients experience various levels of progress, targets may be individually unattainable – not one size fits all             |
| Availability of appointments and therapy causing difficulty to attend                                 | Fear of discharge should patient not be able to attend all sessions, particularly when FND is affecting wellbeing                |

## Results

- Various areas for improvement identified, including:
- Introduce measures to build trust between patient and therapist.
  - Consider mental and emotional impact of FND, not limited to physical impairments.
  - Identify important research issues, as yet unaddressed. e.g. first impressions with a professional affected by previous experiences, which are often negative.
  - Create patient-centered timelines of progress, rather than service-centered protocols followed by many specialists.
  - Improve availability of treatment and appointment.
  - Need for joined-up treatments between different modes of therapy and medical professionals treating individual patient.

## Conclusion

- Important to involve experts-by-experience within research, particularly when assessing FND.
- Expert-by-experience opinion should be applied in many medical issues, not just FND as therapy disengagement is a common issue across many conditions.
- Collaborative involvement of both experts-by-experience, medical professionals and researchers will achieve most reliable understanding and progress.

## Take-home messages

1. Qualitative data indicates that patients often have similar and common experiences within therapies
2. Experts-by-Experience should be referred to and involved to improve research into therapies
3. Issues identified are difficult to research, must consider individual circumstances into research methods

## Participant comments

**'The prevalence of FND (the second most common reason to see a neurologist in the UK) has not resulted in the amount of research you would expect for something so common.'**

**'There needs to be more education, understanding and empathy around FND when it comes to healthcare professionals.'**

**'Many of us are just given a piece of paper with a website on it after our diagnosis with no option for treatment.'**

## References

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