

Use of focus groups to explore service users' experiences and inform future service development needs in an outpatient service

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Background

Functional electrical stimulation (FES) can be used to manage foot drop that is upper motor neurone in origin. Application of electrical pulses to the common peroneal nerve and tibialis anterior muscle through surface electrodes produces muscle contraction of the dorsiflexors and evertors to aid foot clearance during swing phase of gait. It is effective in improving walking speed, gait kinematics (walking mechanics), reducing trips and falls and quality of life; use is supported by national clinical guidelines.¹

The FES service at the National Hospital for Neurology and Neurosurgery (NHNN) was established in 2010 and is staffed by a team of physiotherapists and a consultant neurologist, and has administration support. We are a tertiary specialist rehabilitation service and accept referrals from throughout NHS England. The service supports people with foot drop as a result of a neurological condition and primarily treats unilateral or bilateral foot drop, but in some cases will also include stimulation of additional muscle groups to further aid gait. We assess and provide orthotics and physiotherapy expertise to optimise walking in a combination of both face-to-face and video clinics.

The NHS Long Term Plan and the UCLH Outpatient Transformation Strategy propose a vision of: 'getting the right care at the right time in the optimal setting, with patients as partners in their care'.^{2,3,4} However, interpreting what this may look like in practice has never been explored in the FES service. In the past we have sought service user feedback through questionnaires, but this method provides limited understanding of service user experience and priorities. Questionnaires rely heavily on clinicians' interpretation of the data and use the 'parent-child mode' of interaction, whereby the parent (clinician) ultimately decides what is best. Arguably, questionnaire methods do not work in partnership with patients.^{5,6} An alternative method, in order to draw upon attitudes, feelings, beliefs, experiences and reactions, is to use focus groups. Focus groups are particularly useful when there are power differences between the participants and decision-makers or professionals. They provide an opportunity for patients to feel valued as experts.^{7,8} As a team we felt focus groups were relatively simple and inexpensive to conduct and would offer us a better understanding of our service user experiences.

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Project aims

- To improve our understanding of patient experiences of our current model of care, particularly the shift to a 'hybrid model', combining both remote and face-to-face consultations.
- To establish aspects of the service valued by service users and areas we should prioritise for future service improvement work, in order to provide the 'right treatment, to the right person and at the right time'.

Method

A database of all NHNN FES users was accessed to complete purposeful sampling in an effort to capture a broad representation of our service users. Attempts were made to form a representative sample by including participants



with varying neurological diagnoses, different types of FES device (dual channel vs single channel), sex and length of time known to the service. A purposeful sample of 36 FES users was emailed an invitation to be part of a focus group. The advert and information were approved by the UCLH patient experience team. Written information was provided for consideration, and service users were asked to confirm in writing if they wished to participate. Those that responded were offered a selection of two focus group times and dates and indicated their preference. Collaboration with the UCLH patient experience team allowed us to offer a voucher as thanks for participation. The focus groups took place over Zoom and a reminder email was sent prior to the chosen focus group date.

Nominal group technique (NGT) was chosen for this project. NGT is described as a structured group activity designed to gather the views of all group members on a specific given topic.⁹ This technique is commonly used for evaluation and determining guideline purposes and is an effective way of combining both qualitative and quantitative elements.

As part of ensuring that the views of all group members were focused on discussion related to the project aims, pre-focus group information included a 'SurveyMonkey' link with four questions and a free text response box to complete prior to attendance. The questions included were developed by the clinical team and aimed to be open and thought-provoking in order to generate in-depth focus group discussion. The questions were:

- **Question 1:** What can we do to improve the FES service?
- **Question 2:** If you were designing the FES service what would you add or take away?
- **Question 3:** What is your experience of the FES service?
- **Question 4:** What is most valued in your FES appointments?

Participants were primed to consider certain aspects prior to completing their feedback including: Do we see you enough?; What do you think of the mixed model of video versus face-to-face appointments?; What do you find beneficial when seeing a therapist and what is a waste of time?; What do you find beneficial in addition to support with your device?; What is your overall experience compared to other services you access?; Do you find it easy to contact our service?

To introduce the focus group, the lead facilitator summarised the pre-focus group survey findings and allowed every participant equal time to contribute their thoughts. Once complete, the key response points were summarised back to the group. The session ran for one hour and a follow-up email was sent asking participants to vote on which points discussed were of most importance to them.

Results

Response rate to email invitations was 42% (n = 15). Unfortunately, seven attendees withdrew shortly before the groups were due to start due to personal circumstances. Two focus groups took place in September 2022; patient demographics are displayed in Table 1.

Table 1: Participant demographics

| Demographic | Result |
|---------------|--|
| Age | 38–71 (mean 58) |
| Sex | Male 4 Female 4 |
| Condition | Spinal cord injury 1 Multiple sclerosis 4 Stroke 3 |
| FES device | Single channel FES 6 Dual channel FES 2 |
| Length of use | 0.5–12 years (mean 6.25) |

Key themes

Due to time constraints, and significant discussion from participants, we were unable to fully address all four intended questions. Therefore, we adapted our approach to address Q1 (What can we do to improve?) and Q2 (What would you add or take away?).

Question 1 generated discussion regarding the use of outreach clinics outside NHNN so that treatment is more accessible throughout the country, and regarding supporting local teams to manage FES provision rather than provision at NHNN. The addition of more rehabilitation to optimise FES use and walking ability was suggested along with the use of FES groups to allow peer support and shared learning of 'tips and tricks'. Participants valued more appointments early in their FES journey to ensure they did not 'give up' or 'fail'. Challenges with conducting effective video appointments, including setting up a visible space, were highlighted and it was suggested more support should be available for this. Face-to-face appointments were perceived as more valuable and useful.

Discussion of Question 2 focused on raising the awareness of FES so that people who might benefit could access assessment and treatment at NHNN. Having improved continuity of care (meaning consistently seeing the same clinician and not using a 'cab rank model of treatment'), generated some debate and pros and cons were identified, although it was generally agreed that patients should at least be offered the option of seeing the same therapist. Again, there was a strong feeling that there was value in providing more gait rehabilitation or physiotherapy advice alongside FES support.

Post-focus group voting

Following the focus group participants were invited to vote on which discussion points raised were most important to them (Tables 2 and 3); response rate was 64% (n = 5).

Table 2: Question 1 patient priority votes

| Discussion point | Responses |
|---|-----------|
| Group rehabilitation sessions for device and walking support | 1 (20%) |
| Improving awareness of referral pathway so patients get to us quicker | 1 (20%) |
| Education on how to optimise video appointments | 1 (20%) |
| More early checks to ensure optimal comfort and settings; to help early users | 2 (40%) |
| Patient-initiated follow ups (PIFUs) for experienced users to help free up follow-up spaces | 0 (0%) |
| Understanding how to purchase a spare device | 0 (0%) |

Table 1: Participant demographics

| Demographic | Result |
|--|---------|
| More walking rehabilitation in sessions | 2 (40%) |
| Clinician outreach to more accessible locations | 2 (40%) |
| Better clinician continuity: the ability to see the same clinician at repeat appointment | 0 (0%) |
| More ways to show objective progress such as videos of walking | 0 (0%) |
| None of the above | 1 (20%) |

Discussion

Conducting focus groups and listening to patients' views in depth was a hugely valuable exercise for the clinical team. It highlighted areas for service development that had not previously been considered, such as considering the use of groups and peer support. The focus group method ensured that our service users are placed at the centre of our future service development plans.

The benefits of patient and public involvement (PPI) and co-design have been shown to be a valuable form of patient involvement. However, focus group methods do not fully satisfy engagement in co-design and service user leadership and this should be built upon in future work in the FES service and within therapy services at NHNN.⁵

This small sample focus group project was limited by sampling and participation bias. We acknowledge that many factors, such as ethnicity, were not applied to our method of purposeful sampling due to accessibility of relevant data. The use of email and Zoom would have excluded a number of people from participation and therefore this project was not representative of all service users. However, as novices in focus group facilitation, we found that applying NGT gave clear structure to maintain a discussion focused on key questions due to pre-focus group guidance and SurveyMonkey feedback. It also provided all participants with the opportunity to contribute. There were however some challenges in steering the discussions away from areas outside our sphere of influence and there are clearly many factors important to service users that were not addressed in the focus groups. For example, comments were made on specific device technology, product development and funding of spare FES machines, all of which are beyond our power to change.

In this instance the use of voting at the end of the focus group had a disappointing response rate and was of limited value. In future focus groups we would allow extra time for both the group itself and for live voting through the same digital platform used to host the focus group. This would prevent a time lag between discussion and votes and would negate the requirement for participants to remember to vote and minimise burden.

The information has shaped the team's next service improvement projects in a way that we did not anticipate. Future work in the FES service includes piloting FES group sessions and assessment of the efficacy of this. We also hope to explore ways in which we might provide satellite clinics or work jointly to upskill community services to provide treatment more locally. Having a tertiary national referral centre for specialist treatment situated in Central London presents a challenge for meeting the objective of 'right place'. In order to address this, collaboration with the new integrated care systems and development of innovative and flexible working models is required. Currently we are collaborating with other FES services to pool knowledge of national commissioning to ensure those that can receive treatment locally have knowledge to access it.

Conclusion

These focus groups have generated service user priorities for future service development projects. Focus groups are a valuable tool for involving service users in shaping design and setting priorities, and should be considered alongside more frequently used questionnaires.

References

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