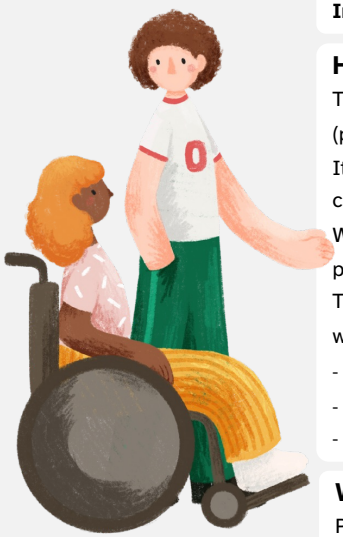
How can the experience of hospital outpatient departments for Neurofibromatosis (NF) patients with sensory challenges be improved? An Experience Based Co-Design project protocol.

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Go to bit.ly/3V1FjsC for references

Why this matters

In the UK, **nearly 17 million people have a disability**[1], including difficulties with hearing, seeing and sensory processing. These challenges can make healthcare environments much harder to navigate.

Research shows that the design and feel of hospitals can affect both patients and staff. But despite nearly **150 million NHS outpatient appointments** last year[2], a review of research looking at healthcare environments found little evidence about outpatient departments and even less on supporting people with sensory challenges[3].

Improving outpatient spaces can benefit everyone.

How we're doing it

This project aims to identify what makes it hard for people with sensory challenges (problems with seeing or hearing or experiencing things differently) to receive care. It will focus on people with nerve tumour conditions, because they often have sensory challenges.

We will use a modified version of Experience Based Co-Design (EBCD) to help patients, carers and staff work together and share their experiences and ideas. Together we will explore how outpatient environments can be improved for people with sensory challenges. This project will:

- **Understand** how people with sensory challenges experience outpatient departments.
- **Identify** what helps or makes it harder for them to receive good care.
- Support patients and staff to **work together** to create helpful solutions.

What people shared

Patient groups and charities have been asked about this project. They think it is useful, and their suggestions have helped improve this research. A project PPI group continues to guide the work to make sure it remains relevant and grounded in lived experience.

Thanks to **Miranda Seymour**, Royal Literary Fund Fellow, the GSTFT **Patient Experience Forum (PEF)** and the **Respiratory & Critical Care Patient Public Engagement Group** for early feedback, and to the **project PPI group** for ongoing support and guidance.

Rona Inniss, Doctoral Research Fellow, NIHR306421 is funded by the NIHR for this research project. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of Health and Social Care.

Stages of work

This project has four main stages:

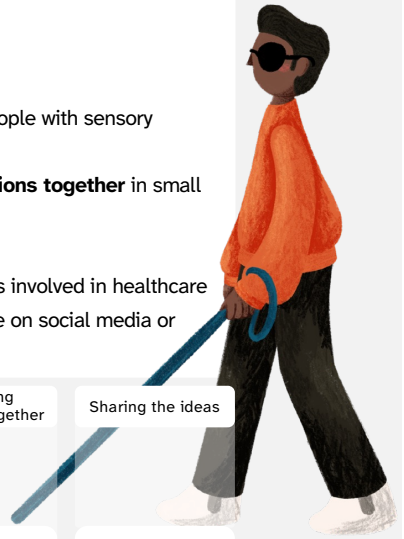
1. Collecting information by:
- 30 hours of observations in the waiting room.
- Walking and talking to 18 people with sensory challenges.
- Carrying out focus groups with staff.

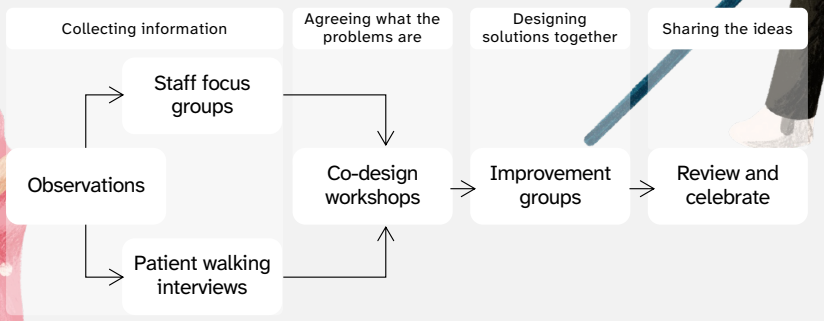
2. Agreeing what the problems are by helping staff and people with sensory challenges to talk together in groups.

3. Staff and people with sensory challenges **designing solutions together** in small groups.

4. Sharing the ideas and thanking everyone who helped.
- Reports will be shared with researchers, patients, and others involved in healthcare design. Findings will be shared in creative ways (this might be on social media or through community events).







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