Greater Manchester
Neurorehabilitation & Integrated
Stroke Delivery Network

Creating a Step Change in Patient and Carer Involvement to Improve Stroke and Neurorehabilitation Care in Greater Manchester

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Why did we need a step change?

Best practice patient and public involvement (PPI) means we should be sharing key decisions equally with people with lived experience (i.e. patients and carers) throughout our quality improvement. Effective PPI ensures our local stroke and neurorehabilitation services are more accessible and provide greater benefit.

When we initiated our step change in 2022, we primarily involved patients and carers via our two Patient and Carer Groups - one focusing on stroke care, and another on neurorehabilitation.

Within each group, opinions were sought of members, but their influence was often limited within improvement projects or input was at too late a stage to make a meaningful difference.

The groups were diverse in terms of geography, diagnosis, age and gender. However, the same members were being repeatedly approached for involvement which limited the range of lived experience being provided.

Best practice PPI demonstrates shared and equal power. Although some members appeared confident to share power, it was unclear how this translated in reality for many.

> “What I say doesn't matter”
>
> Patient and Carer Group member

The network understood the value of PPI but recognised there needed to be a step change in the way it worked with patient and carers when facilitating service improvement with stakeholders.

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What did we aim to do?

Abi Bisset
Patient and Carer
Involvement Co-ordinator,
2024 - 2025

The network collaborated with stakeholders to create a new role of Patient and Carer Involvement Co-ordinator within the team. The post was hosted by the Stroke Association and based within the network team but with access to charity's involvement expertise and resources.

After scoping current practice and understanding, the Co-ordinator identified three key objectives to help create a step change:

Empower members of a Joint Stroke and Neurorehabilitation Patient and Carer Group to have increased confidence to influence network decisions.

Equip the network to be better able to work to best practice PPI methods.

Create a sustainable PPI function which promotes the meaningful, efficient involvement of a diverse range of Lived Experience partners.

3 How the aims were achieved

Empower members of a Joint Stroke and Neurorehabilitation Patient and Carer Group to have increased confidence to influence network decisions.

In 2023, and following consultation, the two Patient and Carer Groups were merged to reduce repetition of topics and increase the frequency of the meetings.

The Group has then worked to:

- Provide feedback on network improvement projects
- Better understand the influence that PPI has brought on network activities
- Increase patient and carer understanding of best practice involvement, including the concept of shared power
- Co-design the infrastructure for PPI within the network

Network Patient and Carer Group meeting

Equip the network to be better able to work to best practice PPI methods.

This has been achieved by:

- Working with network Facilitators and wider teams to increase confidence and shape PPI in projects
- Developing a PPI toolkit and library of resources for the team and wider stakeholders
  - **https://gmnisdn.org.uk/patients-and-carers/involving-patients-and-carers-in-service-improvement/**
- Delivering two webinars and a workshop promoting the benefits of PPI and addressing some of the challenges
- Ongoing promotion of PPI via the network's social media channels and bulletin

Create a sustainable PPI function which promotes the meaningful, efficient involvement of a diverse range of Lived Experience partners.

The step change has resulted in:

- Embedding PPI into the common practices of all network team members, promoting sustainability
- Identification of under-represented patients and carers and lived experience to target for inclusion in network PPI
- Establishing robust recruitment pathways to ensure greater diversity of lived experience resulting in an additional 7 members (see below)

Changes in diversity of lived experience, as per the network's priorities

	Before Step Change	After Step Change
Greater Manchester boroughs represented	50%	70% ↑
Lived experience partners diagnosed in last 5 years	18%	26% ↑
Lived experience partners that are carers	16%	21% ↑
Lived experience partners that are an ethnic minority	25%	33% ↑

4 What has been achieved?

The collaborative approach of the new Co-ordinator role has improved understanding of partnership working and sharing power with those with lived experience. The collaboration has ensured best use of expertise and resources.

Patient and Carer Group members now better recognise the value of their input, have increased influence over network decisions, and are increasingly challenging the network's PPI practices.

> "Sometimes I wonder if it's worth my time coming, but then you hear about the difference it's making, and you know it is"

> "What about the carer voice?"

> "You need to consider an accessible version"

Members of the Patient and Carer Group

There has been a culture shift so that best practice PPI methods are better understood and considered by the network at the beginning and throughout service improvement projects.

The network team have increased their confidence with PPI, and are better equipped to ensure lived experience influences their work. Wider network stakeholders also have greater access to PPI training and resources.

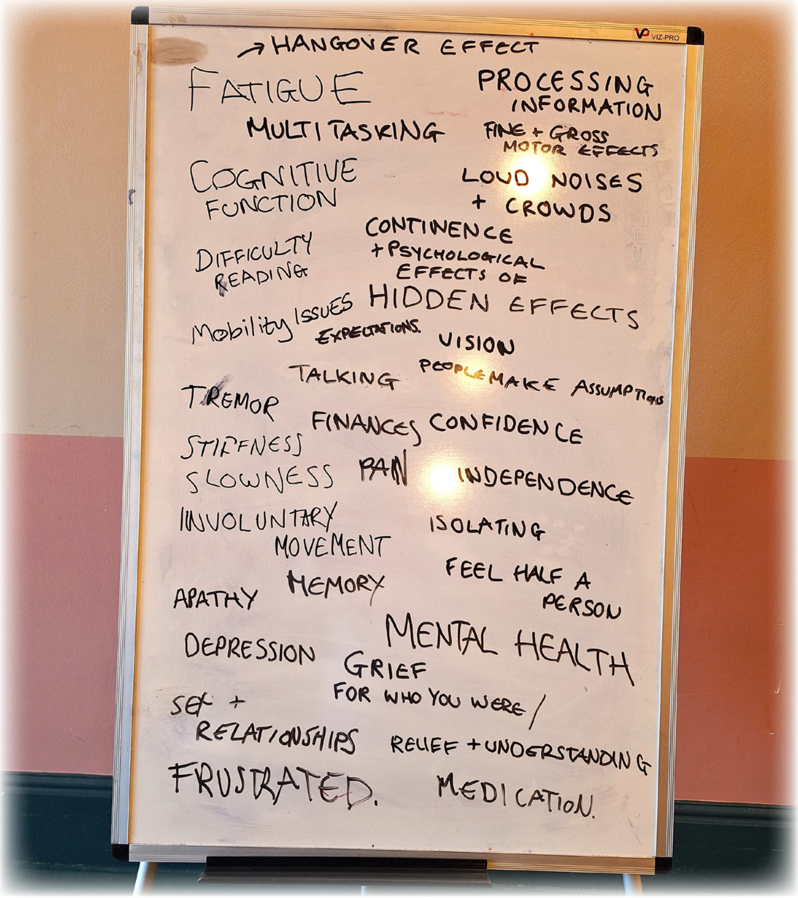
The team now actively consider opportunities for those with lived experience to bring a project ideas to the network and there is more flexibility to include within projects.

> **“We can’t plan too much, because the initial PPI focus group might change everything”**

Network staff member

PPI is not reliant on one member of the team, promoting sustainability.

There is increased diversity in the patients and carers who are involved. Recruitment pathways have been set up to help increase this further in the future.



Patients and carers share their experiences and ideas for service improvement projects.

5 Final reflection

The presence of a Patient and Carer Involvement Coordinator in the team has helped the network to work with people with lived experience in the right way and at the right time. This is a more effective way of driving changes which are important to patients and their family members.

The approach has ensured the step-change is sustainable without the Coordinator, including ongoing advice for continued empowerment and maintenance of recruitment pathways which promote diversity.

The collaboration with the Stroke Association has helped ensure the success of the role by making best use of expertise and resources. It allowed both the network and the charity to learn more about successful partnership working.

With improved PPI processes, the network can now better support quality improvement for stroke and neurorehabilitation services, and ensure they are designed and delivered in ways that meet the needs of those accessing them.

> “The thing that always stands out the most is when I hear one of the project leads say, “that's a really good insight, we hadn't thought of that”

Member of the Patient and Carer Group

> “The group's contribution really changed the direction of the work”

Network staff member

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