Neurological Insight Lab Series
Engagement & Co-Production Report

Understanding Lived Experience of Neurological Care in City & Hackney

Commissioned by: Homerton University Hospital NHS Foundation Trust

Delivered by: CoCreate Hackney

Engagement period: Six weeks

Total participants: 32 residents (24 patients, 8 carers)

1. Executive Summary

The **Neurological Insight Lab Series** was delivered over a six-week engagement period to understand the lived experiences of residents living with neurological conditions and carers in City and Hackney.

The Insight Labs aimed to explore experiences of diagnosis, ongoing care and support, coordination between services, and opportunities for improving neurological services and patient involvement in service development.

A total of **32 residents participated** in the engagement process, including **24 patients and 8 carers**, all living in City and Hackney. Participants represented a wide range of neurological conditions including stroke, acquired brain injury, Parkinson's disease, multiple sclerosis, epilepsy, brain tumours and ataxia.

Engagement was delivered through a series of **small, facilitated Insight Lab sessions**, alongside a **remote response option** for residents unable to attend in person. The sessions used participatory activities including care journey mapping, group discussions and co-production exercises to capture experiences and ideas for improvement.

Residents described neurological conditions as **life-changing events** that affected many aspects of their lives including employment, independence, relationships, and mental wellbeing. Many participants highlighted the emotional impact of sudden illness and the challenges of navigating complex health and support systems.

Participants reported that diagnosis could take a long time and was often characterised by confusion, misdiagnosis, or lack of clear communication. While some residents described positive experiences with individual clinicians, others reported feeling unheard or unsupported during the diagnostic process.

Across all sessions, residents consistently highlighted challenges of navigating services and accessing coordinated support. Participants described fragmented communication between services, difficulty accessing appointments, and limited signposting to community or voluntary sector support.

Peer connection and community support emerged as important protective factors. Many participants valued opportunities to connect with others living with similar conditions and expressed strong interest in ongoing community-based engagement.

Residents identified a number of priorities for improving neurological services locally. These included clearer communication from services, improved coordination between healthcare providers, better signposting to support, improved psychological support, and the introduction of **neuro navigators** to help patients navigate services.

Participants also expressed a strong willingness to remain involved in shaping services. Preferences for involvement focused on **in-person, community-based engagement** such as project groups, community discussions, and peer networks rather than digital-only feedback mechanisms.

Overall, the Insight Lab Series created a safe and supportive environment for residents to share their experiences and highlighted important opportunities to strengthen neurological services and community support for residents in City and Hackney.

Neurological Insight Lab Series

Engagement & Co-Production Findings

City & Hackney

NHS
Homerton Healthcare
NHS Foundation Trust

32 residents took part

- **24** patients
- **8** carers

Conditions Represented

- Stroke
- Brain Injury
- Multiple Sclerosis
- Parkinson's
- Epilepsy
- Brain Tumour
- Ataxia
- Cerebral Palsy
- Motor Neurone Disease

Communities *Represented*

- Black Caribbean
- White British
- Asian
- Turkish & Kurdish
- Black African
- Spanish
- Mixed Heritage
- Chinese

What Residents Told Us

"My mind says **YES** but my body says **NO.**"

"We have to be angry to be heard."

"Everything changes – loss of work, loss of identity."

"*Diagnosis* was a relief after the uncertainty."

How People Felt Arriving

- Running on empty
- Taking it slowly
- Foggy but here
- Quietly coping
- Heavy but present
- *Steady enough*
- More energy than expected
- Feeling sharp today

Key Challenges

- Navigating services
- Poor communication
- Lack of signposting
- Isolation

Priority Fixes

- Better communication
- Neuro Navigators
- *Psychological support*
- *Support to return to work*

What Helps

- Peer support groups
- Community organisations
- Supportive clinicians
- Family support & info

Ongoing Involvement

- Project groups
- Community discussions
- Regular forums

***32 residents** shared their experiences to help improve **neurological** services in City & Hackney.*

Thank you to everyone who contributed to the Insight Lab Series.

2. Background

Neurological conditions can have a significant and life-changing impact on individuals, families and communities. In addition to physical symptoms, many people living with neurological conditions experience changes to their independence, employment, relationships and mental wellbeing.

Understanding the lived experiences of people navigating neurological care is essential to improving how services are designed and delivered. Engagement with patients and carers helps ensure that services respond to the realities of living with neurological conditions rather than relying solely on clinical or organisational perspectives.

The **Neurological Insight Lab Series** was developed as an engagement and co-production approach to better understand the experiences of residents living with neurological conditions in City and Hackney. The series aimed to create a supportive environment where patients and carers could share their experiences of diagnosis, treatment, ongoing care and support.

The engagement also sought to explore how residents would like to be involved in shaping neurological services in the future, recognising that people with lived experience bring valuable insight into how services work in practice.

The Insight Labs were delivered in partnership with **Homerton University Hospital NHS Foundation Trust** and facilitated by **CoCreate Hackney**, an independent community engagement organisation with experience supporting resident-led service design and co-production.

Through a series of small group sessions and remote contributions, the Insight Lab Series captured experiences across the neurological care journey, from diagnosis through to living with long-term conditions and accessing ongoing support.

The findings from this engagement aim to support ongoing service improvement and strengthen opportunities for patients and carers to be involved in shaping neurological services across City and Hackney.

3. Methodology

The Neurological Insight Lab Series was delivered as a participatory engagement process designed to capture the lived experiences of residents living with neurological conditions and carers in City and Hackney.

The engagement took place over a **six-week period** and combined in-person Insight Lab sessions with a remote participation option to ensure residents could contribute in ways that suited their health needs and personal circumstances.

Insight Lab approach

Insight Labs are small, facilitated sessions designed to create a safe and supportive environment for residents to share their experiences. The format prioritises conversation, reflection and collaborative discussion rather than presentations or formal consultation methods.

The sessions used a range of participatory activities to explore residents' experiences across the neurological care journey. These activities included:

- arrival check-in exercises capturing how participants were feeling when they arrived
- **care journey mapping**, allowing participants to visually map their experiences from diagnosis through to living with a neurological condition
- discussions exploring care coordination and access to support
- co-production exercises identifying how residents would like to be involved in improving services
- priority-setting activities where participants identified key improvements they would like to see

These activities were designed to ensure that participants could contribute in different ways, including verbally, visually and through written responses.

Session delivery

A total of **three in-person Insight Lab sessions were delivered**, alongside a **remote response option** for residents who were unable to attend in person.

Each session included **4-10 participants** and was facilitated by **CoCreate Hackney**.

Sessions were supported by:

- a **CoCreate Hackney facilitator**
- a **Community Shaper volunteer**, who supported facilitation and note-taking
- an **NHS lead representative**, who attended each session to observe and support residents participating

The presence of NHS staff was positively received by residents and allowed participants to feel that their experiences were being heard directly by service leaders.

Participation and engagement

In total, **32 residents participated** in the Insight Lab Series, including both patients and carers with lived experience of neurological conditions.

The engagement included:

- three facilitated Insight Lab sessions
- remote written responses from residents unable to attend in person
- feedback forms completed by participants following sessions

The engagement process aimed to ensure that participation was accessible and supportive for people living with long-term health conditions. Participants were able to take part at their own pace and step out of activities if needed.

Challenges during delivery

As with many engagement activities involving residents living with long-term conditions, participation was affected by a number of external factors.

One planned session was cancelled due to **flooding**, reducing the number of in-person sessions delivered. Several residents who had initially expressed interest were also unable to attend sessions due to illness, hospital appointments or caring responsibilities.

The engagement period also coincided with **periods of heavy rainfall**, which may have affected attendance at in-person sessions.

Despite these challenges, the Insight Lab Series successfully engaged **32 residents**, generating rich insights into the lived experiences of neurological care in City and Hackney.

4. Participants

A total of 32 residents participated including 24 patients and 8 carers. All participants were residents of City and Hackney.

Participants represented a range of neurological conditions including stroke, acquired brain injury, Parkinson's disease, multiple sclerosis, epilepsy, brain tumours and ataxia.

Age range of participants:
20s - 3
30s - 5
40s - 9
50s - 6
60s - 6
70s - 2
80s –1

Ethnic backgrounds represented:
Black Caribbean - 12
White British - 9
Asian - 3
Turkish & Kurdish - 2
White Other - 2
Mixed (White / Black Caribbean) - 1
Spanish - 1
Black African - 1
Chinese – 1

The engagement included a **strong representation of Black Caribbean residents**, alongside participation from a range of other ethnic communities.

This diversity was particularly significant given that neurological engagement activities often struggle to reach residents from a broad range of communities.

5. Key Findings

The findings from the Neurological Insight Lab Series highlighted several consistent experiences across the care journey. While individual circumstances varied, residents described similar themes around diagnosis, navigating services, the emotional impact of neurological conditions, and the importance of community support.

Across all sessions, participants emphasised that neurological conditions often result in sudden and life-changing shifts in independence, identity, and daily life.

Diagnosis and the Journey to Answers

Participants described diagnosis as a complex and often lengthy process. Several residents reported experiencing uncertainty, delays, or misdiagnosis before receiving confirmation of their condition.

For some participants, receiving a diagnosis was a moment of relief after a long period of uncertainty.

"Diagnosis was a relief - the uncertainty was the rollercoaster. I knew what I was dealing with once I was diagnosed."
Insight Lab participant

However, others described frustration with the time taken to reach a clear diagnosis and the difficulty of navigating neurological assessments.

"Misdiagnosis is common - it takes too long to get a straight answer."
Insight Lab participant

Participants also recognised the complexity of neurological conditions themselves, noting that even clinicians can struggle to fully understand their impacts.

"Neuro is hard to understand - even for doctors."
Insight Lab participant

Residents highlighted the importance of clear communication at the point of diagnosis, particularly around what happens next and what support is available.

Living with Neurological Conditions

Participants described neurological conditions as having a profound impact on many aspects of life, including independence, employment, relationships, and personal identity.

Many residents spoke about the sudden nature of neurological illness and the challenge of adjusting to a new reality.

"My mind and body no longer work in sync - my mind says yes but my body says no."
Insight Lab participant

"Everything changes - loss of work, loss of identity - you're left on your own."
Insight Lab participant

Participants also described the emotional impact of changes to independence and daily life.

"Suddenly I was dependent on other people."
Insight Lab participant

For some residents, neurological conditions led to a sense of loss around future plans and identity.

"My future is not how I thought it would be anymore."
Insight Lab participant

Participants also highlighted the social impact of long-term illness, including changes to friendships and social networks.

"You lose friends - something I wasn't expecting and didn't understand."
Insight Lab participant

Emotional and Psychological Impact

The emotional and psychological impact of neurological conditions was a significant theme across all sessions.

Participants described feelings of anxiety, isolation, and uncertainty about the future.

“Living in constant fight or flight.”
Insight Lab participant

Some residents described feeling invisible within systems and society.

“I am invisible now.”
Insight Lab participant

Participants also highlighted how neurological conditions can affect confidence and willingness to speak up.

“I don’t want to say anything in case it’s my last breath sometimes.”
Insight Lab participant

Residents emphasised the importance of psychological support and community connection as part of ongoing care.

Care Coordination and Navigating Services

Many participants described difficulties navigating healthcare services and accessing coordinated support.

Residents reported that communication between services was often fragmented and that it could be difficult to know where to go for help when their condition changed.

Participants described the importance of relationships with individual clinicians, noting that experiences varied significantly depending on the professional involved.

“Service levels depend on the service and who you know. There is no consistency.”
Insight Lab participant

Some residents also described feeling that they needed to advocate strongly for themselves in order to access support.

“We have to be angry to be heard.”
Insight Lab participant

Participants also described negative experiences with primary care in some cases.

“I am angry at my GP… and his attitude to me.”
Insight Lab participant

However, there were also examples of positive experiences where clinicians took a supportive and empowering approach.

"I had an amazing GP who said 'you're not disabled - the world is not set up right.'"
Insight Lab participant

Participants emphasised the importance of clear communication from services and ensuring that patients and families fully understand information provided during consultations.

"Ask us if we understood. Let us bring our family to consultations."
Insight Lab participant

Community and Peer Support

Across all sessions, participants highlighted the value of connecting with others who have lived experience of neurological conditions.

Many residents described feeling isolated before finding peer support networks or community groups.

"No signposting. I feel very alone."
Insight Lab participant

Participants valued opportunities to share experiences with others who understood their situation. Peer support groups and community organisations were identified as important sources of emotional support and practical advice.

They also highlighted the importance of culturally sensitive support, noting that stigma around disability can make it harder to seek help in some communities.

"The cultural stigma around disability makes me feel cursed some days."
Insight Lab participant

"Culturally I felt alone - there was a reluctance to share or ask for support within my own community."
Insight Lab participant

6. Resident Priorities for Improvement

During the Insight Lab sessions, participants were asked to identify the most important improvements they would like to see in neurological services locally. Through a priority-setting exercise, residents highlighted a number of areas where they felt changes could significantly improve their experiences of care and support.

While individual suggestions varied, several key themes emerged consistently across sessions.

Communication and Being Heard

Participants repeatedly emphasised the importance of feeling listened to and respected by healthcare professionals. Many residents felt that communication from services could be clearer, more personalised and more responsive to the realities of living with neurological conditions.

Many highlighted the importance of ensuring that patients and carers are given time to understand information and ask questions during consultations.

They also emphasised the need for improved communication between healthcare providers, particularly between hospital teams, GPs and community services.

Participants suggested that services should:

- **ensure communication is clear and accessible**
- **check that patients and families understand information provided**
- **improve coordination and information sharing between services**

Participants also highlighted the importance of involving family members in discussions about care where appropriate.

Navigation and Access to Support

A strong theme across the sessions was the difficulty many residents experience navigating the health and support system following diagnosis.

Participants highlighted the need for clearer signposting to available services and more coordinated support pathways.

The groups all suggested the introduction of **"Neuro Navigators" (dedicated neurological care coordinators)** who could help patients and carers navigate services, access support and understand what help is available.

Participants also suggested that neurological services could benefit from a more joined-up approach, with clearer pathways linking hospital care, community services and voluntary sector support.

Several residents described the need for a **"one stop shop" approach** to neurological support, where people could access information, advice and referrals in one place.

Psychological and Emotional Support

Participants highlighted the emotional and psychological impact of neurological conditions and the need for stronger psychological support within neurological care pathways.

They described experiences of anxiety, loss of identity, isolation and uncertainty about the future – suggesting that psychological support should be more readily available following diagnosis and throughout the care journey.

Most also emphasised the value of peer support groups and community-based activities in helping people adjust to living with neurological conditions.

Supporting Independence and Return to Work

Several participants highlighted the impact that neurological conditions had on employment and financial stability.

Residents described how sudden illness or disability can disrupt careers and long-term plans.

Many suggestions that services should provide greater support for people who wish to return to work, including guidance on employment options and workplace adjustments.

Supporting independence and helping people rebuild confidence after diagnosis was identified as an important part of long-term neurological care.

Supporting Carers and Families

Carers highlighted the need for more structured support from the early stages of a neurological diagnosis.

All the carers suggested that they would benefit from clearer information about available support services, as well as opportunities to connect with other carers.

Lots of discussion that services could provide **family information sessions** to help relatives understand neurological conditions and learn how to support loved ones.

Participants also highlighted the importance of **carer respite and support services**.

Reducing Stigma and Increasing Understanding

Groups also highlighted the need for greater awareness and understanding of neurological conditions within healthcare services and the wider community.

Some described experiences of stigma or misunderstanding related to disability and neurological illness.

Participants suggested that training for healthcare professionals could help improve awareness and communication, including training based on the **Social Model of Disability –** emphasising that neurological conditions affect people in different ways and that services should adopt a more holistic approach to care.

7. Involvement and Co-Production

A key aim of the Neurological Insight Lab Series was to explore how residents would like to be involved in improving neurological services in the future.

Participants expressed strong interest in remaining involved in shaping services and contributing their lived experience to service improvement. Many residents described the sessions themselves as empowering and valued the opportunity to share their experiences in a supportive environment.

“Getting involved with this has really left me feeling empowered.”
Insight Lab participant

Participants emphasised that people living with neurological conditions bring valuable insight into how services work in practice and should be recognised as partners in service improvement.

Preferred ways to be involved

Through a co-production activity, participants were asked how they would prefer to be involved in future engagement or improvement work. They showed a clear preference for **in-person and community-based engagement** rather than purely digital engagement.

Preferred involvement methods included:

- **Project groups** - 18
- **Community groups** - 18
- **1:1 conversations** - 16
- **Regular forums** - 13
- **Story sharing or lived experience discussions** - 12
- **Surveys** - 11
- **Email feedback** - 9
- **Online sessions** - 8

The findings suggest that **residents value opportunities to contribute through conversation and collaborative discussion rather than solely through surveys or digital feedback mechanisms.**

Participants also highlighted the importance of building relationships and trust within engagement processes.

Conditions for meaningful involvement

Participants highlighted several factors that would make involvement easier and more meaningful for people living with neurological conditions.

These included:

- **accessible and community-based meeting spaces**
- **opportunities for informal discussion and peer connection**
- **clear feedback about how input will be used**

- **respectful communication from professionals**
- **flexibility to accommodate fluctuating health conditions**

Several also highlighted the importance of ensuring that engagement activities are inclusive and accessible for people experiencing fatigue, mobility challenges or cognitive difficulties.

Opportunities for ongoing engagement

Participants expressed interest in remaining connected to future engagement opportunities relating to neurological services. Some residents suggested that bringing participants together again following the Insight Lab Series would be valuable.

"Get all the groups that did this work together at the end for a social - share back with us and keep us involved."
Insight Lab participant

There is a clear opportunity to build on the relationships established through the Insight Lab Series by creating ongoing opportunities for patients and carers to contribute to neurological service improvement. This could include the development of a **patient and carer engagement group** focused on neurological services within City and Hackney.

8. Participant Experience of the Insight Labs

Participants were invited to provide feedback following the Insight Lab sessions. Overall, feedback was very positive and indicated that residents valued the opportunity to share their experiences in a supportive and respectful environment.

Many participants highlighted that the sessions provided a rare opportunity to speak openly about the realities of living with neurological conditions.

Residents particularly valued the small group format, which allowed for more in-depth discussion and ensured that participants felt able to contribute at their own pace.

Participants described the sessions as welcoming, supportive and empowering.

"I felt heard and my opinions were valued. Also helped me see gaps in services"
Insight Lab participant

Several residents also highlighted the importance of meeting others who understood the challenges of living with neurological conditions. For some, the sessions represented the first opportunity they had to share experiences with others in similar situations.

All welcomed the presence of NHS staff at the sessions, noting that it was positive to feel that their experiences were being heard directly by those involved in shaping services.

The Insight Lab format was designed to be accessible and flexible, recognising that people living with neurological conditions may experience fatigue, cognitive challenges, or fluctuating health. Participants were able to engage in different ways throughout the sessions, including through discussion, written responses, and visual activities.

Overall, feedback suggests that the Insight Lab approach created a **safe and supportive environment for residents to share their experiences and contribute ideas for improving neurological services.**

9. Conclusions and Opportunities

The Neurological Insight Lab Series provided valuable insight into the lived experiences of residents living with neurological conditions and carers in City and Hackney.

Participants described neurological conditions as having **a profound impact on many areas of life, including independence, employment, identity and emotional wellbeing.** Across all sessions, residents emphasised the challenges of navigating complex health and support systems while adapting to significant life changes.

The findings highlight several opportunities for strengthening neurological care and support locally.

There was an evident need for importance of clearer communication from services, improved coordination between healthcare providers and stronger signposting to available support.

Participants also highlighted they needed psychological support and a more holistic approach to neurological care that recognises the emotional and social impact of long-term conditions.

There is also a clear opportunity to improve navigation within the system. Participants strongly supported the idea of introducing **"Neuro Navigators" (dedicated neurological care coordinators)** to help patients and carers access services and understand available support.

Community connection and peer support emerged as important factors in helping people adjust to living with neurological conditions. Strengthening links between health services, community organisations and peer networks could help reduce isolation and improve wellbeing.

The Insight Lab Series also demonstrated that **residents are willing and motivated to contribute to improving neurological services**. Participants expressed strong interest in ongoing engagement and co-production opportunities.

Building on the relationships established through this engagement, there is an opportunity to develop a **patient and carer engagement group** focused on neurological services in City and Hackney. Such a group could support ongoing dialogue between residents, healthcare providers and community organisations.

Overall, the Neurological Insight Lab Series highlighted both the challenges residents experience when navigating neurological care and the opportunities for strengthening services through continued engagement and co-production.

Thank you to all residents and carers who shared their experiences through the Neurological Insight Lab Series. Your insights will help inform improvements to neurological services and strengthen opportunities for patient and carer involvement in shaping care.