Greater Manchester
Neurorehabilitation & Integrated
Stroke Delivery Network

PATIENT & CARER INVOLVEMENT TOOLKIT

For professionals involved in stroke & neurorehabilitation care

VERSION 1.0

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About the toolkit

This toolkit is aimed at professionals involved in the improvement of Greater Manchester stroke and neurorehabilitation services. This may include those working in the NHS, local authorities, independent providers of care, academia and the voluntary sector. The content is also likely to be applicable to those working outside of the region or in different disease settings.

It aims to:

- Provide a greater understanding of patient and carer involvement in developing, delivering and improving stroke and neurorehabilitation services
- Explain why it is important to hear a diverse range of voices and lived experiences
- Offer guidance and suggestions on how to make involvement a reality
- Signpost to useful resources
- Answer common questions and share practical tips

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1 What is patient and carer involvement?

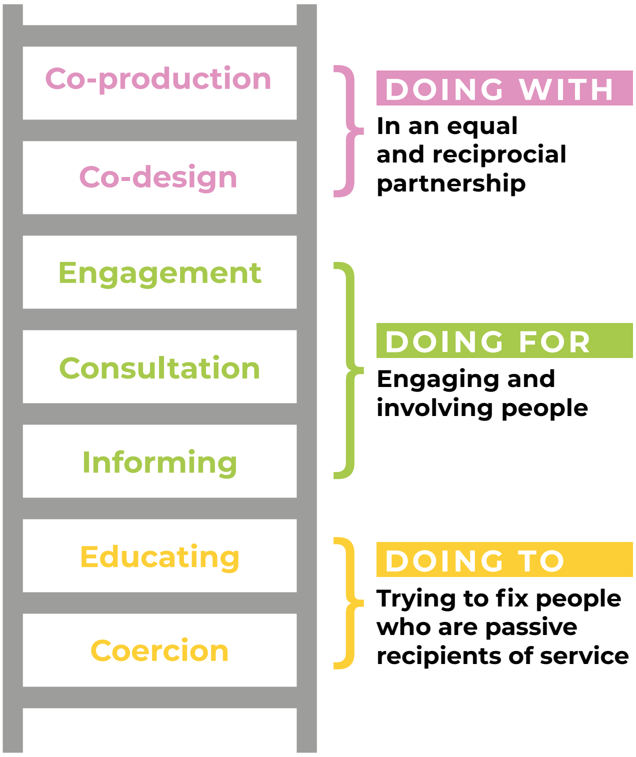
Patient and carer involvement ensures working in **equal partnership** with people who have lived experience of a condition. In this toolkit, we mean those with a neurological condition including stroke.

Lived experience describes those **affected** by a condition and is often termed "patient involvement" in healthcare settings. It also includes people within a patient's **support network**, such as family members or friends. They may have a caring or supportive role and so are often termed "carers".

Lived experience does not refer to **health professionals**, charity workers, paid carers, or members of the public.

Effective involvement means professionals must be prepared to give up some control. It involves **sharing power** with patients and carers when it comes to making decisions about services.

1.1. Levels of involvement



Co-production

Co-design

Engagement

Consultation

Informing

Educating

Coercion

DOING WITH
In an equal and reciprocial partnership

DOING FOR
Engaging and involving people

DOING TO
Trying to fix people who are passive recipients of service

We **are thinking about** making some changes to **some areas** of a programme- would you like to work **with us to design** them?

We are **planning to make some changes** to the programme. What would you like to see? **What do you think needs to change?**

We are **planning to make some changes** to the programme - **what do you think** about these suggested changes?

We **are going to make some changes** to the programme, this is what it is going to look like. Do you have any **feedback**?

Changes are made to a structured project / programme delivery, and the new version starts.

Source: Ladder of co-production (Think Local Act Personal)

There are different levels of working together, as shown in this **ladder**. You might not always be able to work at the top of the ladder but should always aim for as close as possible.

You can find out more in our presentation "Introduction to PPI" (see section 10). ➔

1.2. Examples of levels of involvement

Below are some real life examples of how we have used different types of participation within the network to help better describe each level:

DOING WITH

The network's **Patient and Carer Group** identified a training need around sex and relationships as part of a wider discussion about the impacts of their neurological conditions on their lives. The network team and other local stakeholders **listened** in detail, and gathered the views of patients and carers on what training on this sensitive topic should look like. Local clinicians used this input combined with their **knowledge and clinical expertise** to draft training content which was discussed again with patients and carers. Members of the group were invited to **attend the training**, answering questions and sharing their lived experience on the day.

> *"You can't overstate the value of their [patients and carers] insights"*

Reflection of a clinician developing the training

DOING FOR

The network team reviewed national clinical guidelines on **driving after a stroke** to update an existing model of best practice. A member of the team met with local **NHS stakeholders** and discussed in detail the **different aspects** of the guidelines. They used clinician's understanding of **patient and carer experiences** to guide their decisions as well as their own professional understanding of the guidelines. The changes were then presented to the network's Patient and Carer Group who made further comments and suggestions. The new driving pathway was **finalised, approved and published** by the network for teams to use locally with their patients.

DOING TO

The network manager provides regular updates on current service improvement projects at its **Patient and Carer Group**. The group are informed as to what is happening but are **not actively asked** to provide feedback or give input.

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2 Why involve patients and carers in our service improvement?

> *The insights of patients and carers really changed the direction of the project for the better*

Reflections of a project lead who worked with people with lived experience early in a service improvement project

Hearing the patient and carer voice is integral to working in a patient-centred way. Rather than asking why we should involve patients and carers, we should ask: why wouldn't we?

Why make decisions for patients and carers when we can make decisions **with** them? Why **assume** what patients and carers think when we can **ask** them?

Research into the value of working **co-productively** shows:

- **Efficiency**, in the long run - better decisions are made, enabled by diversity, reducing wasted energy and resources
- Working towards **social justice** - raises awareness of issues that have a huge impact on people with lived experience but weren't previously heard/understood by others, including researchers and professionals
- **Empowering** the people involved and building capacity for informed decision making - particularly impactful if people from more marginalised communities are involved and have opportunities for mutual learning
- Connecting us as humans, working towards **shared goals** - builds relationships between researchers, professionals and people with lived experience. Improves the trust between people and organisations

Involvement of those with lived experience can be used to improve our services by:

- Evaluating how they are working and especially from the **patient's perspective**
- Supporting **quality improvement** projects
- **Prioritising** planning of work and use of resources in future
- Helping to (co)produce patient/public facing information such as flyers/leaflets/online content etc
- Informing the development of **training** for both professionals and service users

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3 How to involve patients and carers?

To involve effectively, you first need to make sure you are open to **sharing decision making power** and releasing control. You will also need to make sure you have the time and resources to be able to do this properly. Read on for more detail about each step of the process.

3.1. Accessibility, inclusivity and diversity

It is important to draw from as **wide a range** of lived experience as possible. **Diversity** is key and this includes involving people with specific **"protected characteristics"** such as age, gender and ethnicity. Also consider how to include those affected by factors impacting their socio-economic status such as being a carer or homelessness. People who are more deprived may struggle to access healthcare services and you will need to **hear** their voices.

It is likely to be important to hear from patients at **different stages** of their healthcare journey as well as from **carers** of people affected with neurological conditions, as they will offer a different perspective.

Also consider how **inclusive and accessible** you are being in your approach as you may inadvertently exclude people who have different needs. For example, communication via email or videocalls may be a barrier for those with aphasia or older people who may be less confident using digital technology.

Be prepared to be flexible and adapt your methods to the person's needs, perhaps by using the phone or **meeting in person**. Emails can also be easily amended by using shorter sentences, larger fonts and pictures. Speakeasy are a local charity that have a range of resources that help support more inclusive communication.

You can find out more in our guide to being accessible (see section 10).

3.2. Quick Tips

- Involve patients and carers as early as possible, "do with" rather than "do to"
- To avoid tokenistic involvement; have a clear idea about what the patient and carer voice can bring
- Make sure you are truly open to sharing the power
- Value how additional lived experience, strengths and skills can improve your services and their outcomes
- Be open and honest about your decisions, expectations and limitations.
- Agree methods together where possible
- Regularly give and ask for feedback

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4 Planning for involvement

The **earlier** you involve patients and carers the better. But before their recruitment you should understand how much staff **time and resources** (especially money) you will realistically be able devote to the endeavour as it will require both. Communicate this honestly.

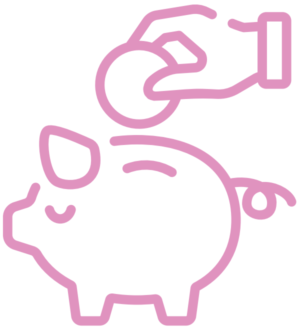
4.1. Time

Making your work processes accessible **takes time**, recruitment takes time, feedback takes time. But don't be put off. We involve patients and carers to produce better outcomes and save time overall by not having to duplicate effort or waste valuable resources.

As you plan, understand how much time you can give and design your activities within this. Set realistic expectations. Don't **over promise**.

4.2. Guidelines for paying patients and carers

Offering payment for involvement activities is becoming increasingly common and should be considered if you are expecting significant commitment and time from people. **NHS England** has produced some guidelines which are summarised below.



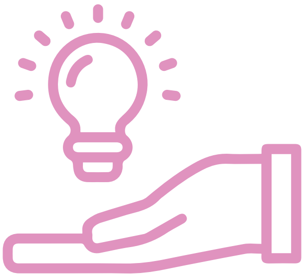
- If members of the public have worked in partnership with NHS teams, they should not be out of pocket. **Reasonable expenses** should be paid for most activities
- Be open and transparent about payments, including as part of the application process.
- **Reimburse** expenses as soon as possible. Many people will be reliant on the money they have spent. It should be no later than 2 weeks after the request is made.
- If an involvement activity is cancelled last minute and payments cannot be cancelled, expenses should still be paid
- For those **receiving benefits**, involvement activities can sometimes impact on their entitlement. It is the responsibility of the patient or carer to comply with the benefit or insurance conditions and seek advice if unsure. You should support informed decision-making during recruitment.
- Consider any measures you can take to promote inclusion e.g. Reimbursing expenses in cash where people may not have a bank account or using **petty cash** to reduce wait times for reimbursement
- You have a duty to keep **accurate record**s of payments

5 Recruiting people with lived experience

5.1. Promoting the opportunity

There are many ways you could **promote** the opportunity to participate. You could advertise **online**, through a flyer sent out by email, or by using social media. You could identify people via local neurologically based **charities** or non-specialist organisations supporting people from more marginalised groups or specific communities. You could also approach directly by having **conversations** with patients and carers your team come into contact with.

Before you begin, make sure you can answer these questions clearly:



- What is the aim of the work that needs involvement?
- Why do you want to involve patients and carers?
- Who, specifically, are you looking for?
- What support can you offer applicants?
- What are the benefits or impacts for the patient or carer?
- How can we ensure we are being inclusive and accessible to promote diversity?

If you choose to use a flyer or leaflet, try to design something which is **eye catching** and not too information heavy. It can help to include why you want patient and carer involvement, and what's in it for them. It should be clear that involvement won't provide access to additional care for their condition or affect any treatment they are currently receiving.

All patient or carer facing information, including recruitment information, should be **accessible and inclusive**. You also need to think about whether you are advertising in a way that will reach a wide and importantly diverse audience. Consider if you can **co-design** materials and develop promotional approaches with people who may be the target audience.

You can find an example of a recruitment flyer in our resources (see section 10).

5.2. Timing of involvement

You should consider **timing** of recruitment after someone's stroke or their neurological diagnosis. For many people it can take months before they are sufficiently over the shock to be able to offer a **balanced view** of their experience. There is also a danger they may view involvement as an opportunity to influence their care or get **emotions** off their chest.

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5.3. Incentives

Offering payment for involvement activities is a good way to reach people you might not normally hear from, for example groups of people who do not normally engage with health services.

Other **non-financial motivators** are:

- Opportunity to improve services and experiences for other people
- Chance to **learn more** about local services
- Being involved can **improve mental health**, give a sense of purpose as well as developing confidence and empowerment
- Opportunity to **meet** other people and get out of the house
- Work in new ways, learn **new skills**
- Free refreshments or lunch

Some employers will allow staff to use paid work time or be flexible with their hours for involvement activities. Encourage people to speak to their employer about their options.

5.4. Ensuring diversity of lived experience

As mentioned earlier, backgrounds and characteristics can dramatically change how a person experiences a service. Therefore, diversity of lived experience is crucial in ensuring that services are reflective of and **adaptable** to cultural and other differences in the way people live their lives. Always consider health inequalities when recruiting to make sure you don't **unintentionally or unconsciously** exclude people you really need to hear from.

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MAPPING LIVED EXPERIENCE

Diversity covers a lot of different aspects. Before you recruit, make sure you understand what your priorities are and why. **Mapping** is a technique you can use to help you think about what diversity of lived experience should look like for your project.

Begin by thinking about different groups of people and how your service or project might impact them differently. From here, you can pull together what your priorities are for diversity in recruitment. Reaching some communities can be difficult. Always aim for the best involvement you can.

Think about how you will approach these groups of people to tell them about your project. What are potential **barriers** for them finding out about or participating in your project?

USE WHAT YOU ALREADY HAVE

If you already have team members or links - perhaps a charity or another colleague - within the **communities** you want to hear from, ask them for help. People are often more open to new things if they are approached by someone they are familiar with.

ESTABLISH NEW RELATIONSHIPS

It's okay to acknowledge if you don't know something. Making **assumptions**, or pretending to know more than you do, can build **barriers**. Commit to being open and honest with each other to build a trusting relationship. Reach out to people, rather than expecting people to come to you.

BE OPEN TO WORKING IN NEW WAYS

For some communities, the way the NHS normally works might not be a **good fit** for them or they may not have positive experience of services in the past. Be open to adapting to other people's norms and working together in a way that works for the people you want to hear from. For example, holding face to face meetings in a hospital may be **triggering** for some. Think outside the box!

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5.5. The initial conversation

Once you have identified people who may be suitable, there may need to be an informal **"interview"** process to check that:

1) They meet the **criteria** for your involvement activity
2) They understand what is required of them, feel it is a **good fit** and are able to commit
3) They appear likely to be able to **contribute** objectively and positively
4) If they have any **needs** that need supporting to enable participation e.g. mobility or communication issues
5) You have sufficient **diversity** of lived experience represented

From your first interaction, set a **tone** of working in partnership. Take on board what they suggest, be mindful of making assumptions, be **open and honest** about what you are looking for and what you can offer. Consider how you conduct this process. People with neurological conditions may struggle with **phone or videocalls** or may not be available during the working day if they are employed.

5.6. Quick Tips

- Ask people for their preference for the first meeting
- A local coffee shop can offer a relaxed and non-clinical environment, although be aware of noise and privacy. However, other people might find a phone call or video call more accessible

QUICK TIPS!

You can find out more in our conversations guide (see section 10).

> *I was worried that service design would be over my head*

Patient reflecting on first hearing about an involvement opportunity

6 Induction of participants

Patients and carers tell us that they prefer an induction process that is **simple**. It could be blended within your informal "interview" conversation or combined with agreeing an approach to involvement. It could be done face to face or online, one to one or with multiple new recruits at the same time. Ask people what **works best** for them.

Whatever the format, before an involvement activity starts you should:

- **Introduce** what your team does
- Outline what the **opportunity** is, what the scope for change is and any previous work
- Share how you feel the involvement could **shape** the work – but beware this could change as it progresses!
- Set **expectations** – you may want to agree "ground rules" or develop an informal contract
- Talk about what they can expect from you – time, expenses, other incentives
- Confirm **accessibility** or other support needs
- Gain **consent** to store any personal details such as their contact information and for e.g. minutes that identify them that may be shared or photos you might take to promote the work

Keep the induction process **simple**. Provide just the necessary information and offer opportunities for further reading or conversations as follow up for those who want more.

More information about consent is included later (see section 8.3), ➔ and an example consent form (see section 10). ➔

7 Choosing an approach

Most involvement projects use more than one **approach**. It is important to select methods that suit the needs of the patients and carers you are working with. Where possible, select together.

The table offers some **examples** to help you decide what will work best for your project. Consider how you can remove potential barriers for the people you have recruited.

Summary of involvement approaches

Approach	Description	Benefits and When to Use
Engagement Event	An event based in the local community with 15-30 participants. An excellent way to generate broad discussions with a wide range of people.	Good for gathering broad range of insight or 'temperature checking' an idea.
Focus Group	Group of 6-12 people (8 is an ideal number as >10 can dampen voices) focusing on a specific issue or topic.	Can generate very detailed discussions. Can be held face to face or online.
Interview	A one-to-one meeting designed for a specific purpose or objective.	Some people are more comfortable sharing their opinions in a one-to-one setting than a group setting. It can be flexible to the accessibility needs of the person.
User / Reference Groups	User or Reference Groups are small ongoing advisory groups that meet over a period of time and can link into other decision making groups.	The ongoing meetings help build ownership and understanding for meaningful involvement. Meeting without being outnumbered by clinical staff can create a safe space for involvement.
Patient Representatives	Two or three service users are selected to be representatives of the larger population. They sit on decision-making groups alongside professionals.	Adds a service user perspective in all conversations. Encourages equal partnership working.
Online Network / Forum	A network of people who are willing to be engaged in an ad-hoc way, mainly via email although a dedicated and closed social media platform – such as Facebook or WhatsApp could be used. These people can also be invited along to focus groups or to review documents etc. as appropriate.	An efficient and cost-free way of keeping in regular contact with people and maintaining relationships with those who want to be engaged in an ongoing way. Can be useful for people who feel unable to commit to things in advance because of the changing nature of their condition or their employment for example.
Questionnaire	Gathering feedback via survey – either online or on paper. Questions can also be asked in person, online or over the phone.	Useful for accessing / collecting larger amounts of feedback. Data is often quick to gather and easier to analyse. Online surveys can be cost free. Allows flexibility for those who might struggle to commit to scheduled meetings or during working hours.

You can find a more detailed version of this table including what resources you will need for each approach in our resources (see section 10). ➔

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8 Working together

Sharing decisions can seem daunting; you might feel vulnerable or nervous. Remember that working together isn't about everyone knowing everything. Different people in the conversation can bring different perspectives and take on different roles.

> *During a project, power between individuals might fluctuate depending on the expertise required at any particular stage. But the aim is to ensure that power relations are more equitable than hitherto and that there will be joint ownership of key decisions on a project as people work toward a shared understanding.*

NIHR Guidance on co-producing a research project

8.1. Terms of reference

A terms of reference sets out **expectations** of how a group will work in a more formal way. It can help to create a safe space via a more formal contract within a group of people working together.

It should cover:

- Any **context/background** for the initiative
- The **aim and scope** of the project including what the meeting is not for i.e. not peer support or finding help with care
- The **time commitment** everyone feels is suitable – e.g. frequency of meetings
- How to **behave** in meetings – some organisations have formal codes of conduct that can be included
- **Confidentiality** – expectations on sharing private information

Doing this can help to avoid problems later. A terms of reference should be **written** together by the group and may need formal sign off in your governance structures.

You can find a template to create a terms of reference plus an example code of conduct in our resources (see section 10).

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8.2. Quick Tips

- Consider developing a terms of reference
- Be open and honest about any limitations or **risks** – manage expectations
- Share the evidence base for decisions. If a suggestion didn't change anything, explain why not. Be open to trying again or working in new ways
- Check in regularly with participants
- Recognise input and show appreciation throughout
- Use the ladder of participation to consider how you can ensure you share the power
- Think carefully about how accessible your communication is to someone who isn't used to working in a healthcare setting. An unfamiliar meeting venue, or a medical word to describe what a meeting is about, might be confusing

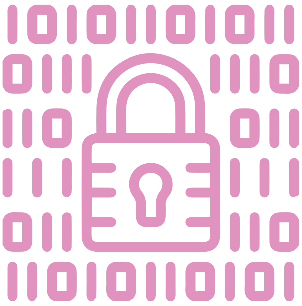
> *"The thing that always stands out the most is when I hear one of the project leads say, that's a really good insight, we hadn't thought of that"*

Patient reflecting on involvement activities

> *"You need to be aware of the changing nature of the neurological conditions when you're working together. I was working with a person living with MND on a project, but on the morning of the big workshop day he fell ill and couldn't come"*

Network facilitator

8.3. Ethics and data protection



Your involvement activities must **comply** with General Data Protection Regulation (GDPR) which is implemented in the UK under the Data Protection Act 2018. Consider what identifiable information is relevant for you **retain**, how you will ensure it is kept up to date and what will you do with it when you **no longer** need it. Consider how you will **store** data safely and who you will share it with. Check your organisations relevant policies or with your data controller if unsure.

Remember, a volunteer has the **right to withdraw** from an involvement opportunity at any time without giving a reason.

You can find examples of consent forms to collect data and also take photographs or videos in our resources (see section 10). ➔

9 Feedback

Patients and carers feel more **valued** and are more likely to get involved again or recommend to others when they get constructive feedback. Having feedback conversations throughout can make it easier to remember and faster to act on. Feedback is a **two-way** process: giving feedback and asking for feedback.

9.1. Giving feedback

Think about the experiences and comments shared and the **impact** they have had. Even if suggestions didn't change anything, you should give **feedback** about why not. Feedback can help a person to feel more **confident** in their involvement role, or help to improve how you work together.

> *Recognise, record and celebrate people's contributions and give feedback on the results of involvement; show people how they are valued*

NHS England

9.2. Asking for feedback

Ask for reflections to help you work better with patients and carers in the future. You could ask:

- How well do you feel you were listened to?
- How do you feel about being an equal member of the team?
- What did you learn?
- What could be improved?

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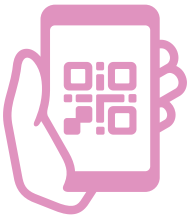
10 Key information

10.1. Network resources

All resources within the toolkit can be downloaded from the GMNISDN website in the Patient and Carer section or by using the QR code. These documents are aimed at professionals who will need to be registered and logged into the website to access.



https://gmnisdn.org.uk/patients-and-carers/involving-patients-and-carers-in-service-improvement/

10.2. Other references

- Co-Production Collective (2022): Interactive Summary: The Value of Co-Production Project Version 1.0
- UK Government: Data Protection Act 2018
- NHS England: B0869 Working-with-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments.pdf (england.nhs.uk)
- NIHR: Guidance on co-producing a research project
- NIHR: PPI resources for applicants to NIHR research programmes
- Think Local Act Personal: Ladder of co-production
- Speakeasy: aphasia charity

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