Involvement Guidance

This guidance will support you through the involvement process from idea, through recruitment, carrying out your project and providing feedback to those who took part. Many of the ideas and suggestions in this document have come from people affected by stroke and represent the support, accessibility and feedback they have asked for.

This guidance contains examples of documents we use at the Stroke Association as part of our involvement projects.

Contents

Before you begin your project

Although we encourage involvement in all pieces of work, we don't want involvement for involvement's sake as this would not be meaningful.

The guidance provided here all links to our eight '**Principles for Meaningful Involvement**'.

Principles for Meaningful Involvement:

- **Inclusivity and diversity:** we will ensure that involvement activities are accessible to all and we will actively encourage participation from those whose voices may not be often heard. We will encourage and respect different beliefs & opinions.
- **Commitment:** we will be willing to share power and control with the people who get involved and we will commit to act and make changes to our decisions, policies and products as a result of the involvement activity.
- **Early involvement:** we will challenge ourselves to involve people as early as possible in the process.
- **Clarity:** we will give potential participants clear information about the requirements of the role, including time, travel and activities so they can make informed choices about when and how to offer their time. We will ask people how they want to be involved.
- **Transparency:** we will share clear aims of the involvement activity with all participants, be honest about any resource limitations and other constraints, and if information has to be kept confidential we will explain why.
- **Support:** we will provide the right training and support for people who get involved with us.
- **Resource:** we will ensure the right resource is available (time/money) to conduct the involvement activity and ensure the participants are fully supported.
- **Feedback:** we will give feedback on the results of the involvement and acknowledge people's contributions. We will listen to and act upon people's views of how best to involve people.

Involvement Project Outline

This document is to help you when planning your project. It supports you by:

1. **Reinforcing your reasons** for involving people.
2. Helping to **identify areas** of the project where involvement is possible.
3. Outlining **what decisions can be influenced**.
4. **Planning how you will give feedback** to those who you involve.
5. Aiding you to think about how you will **measure the satisfaction** of the people involved, this helps us **evaluate the impact** of the involvement work.

It helps you to think carefully to make sure involvement is meaningful and demonstrates a commitment to involvement throughout your project.

It supports you to understand the limitations of your project and so are able to offer transparency and support. And it encourages you to think about the ways you will provide feedback and the overall impact the involvement has had for the people affected by stroke you have involved.

Example Involvement Project Outline:

Designing the Involvement Network

Why have you opted to involve people in this project?

1. To support with the design of the involvement network.
2. To ensure the network is suitable for the people it is there to serve, including offering the right support, right communication and right opportunities.
3. To ensure the network name is relatable to those it is trying to attract

What method/methods on involvement do you plan to use?

Focus groups and interviews

How many people are you planning to involve?

Approximately 20 (2-3 via interview, 16-24 via focus group)

How will you share feedback with those involved? Remember, feedback can occur at different points of the project.

1. Feedback provided immediately after the project using a You Said, We Did table.
2. Links to website when it is ready to see input in action (approx. 1 month later)

How will you measure how satisfied those people involved were with their experience of being involvement in the project?

Via survey with option for open-text email if preferred.

Our research has found that individuals want a personal approach to accessibility and support to be involved in projects. The involvement team will support you with how to do this during and post-recruitment.

Part of Project	Involvement taking place	What can be influenced?	How will you feedback on this work?
Researching existing practices (interviews)	Interviews with members of Stroke Voices in Research to find out their experience of involvement and identify good/bad practices.	The communication methods and frequency from the network, the types of projects that would be available and the support offered.	Through a "You Said, We Did" table via email.
Understanding views and experience of volunteers (Focus group)	Focus group with active Stroke Association volunteers to understand their opinions on involvement and the support volunteers might need to be involved.	Support offered through the network, types of projects available and communication with our current volunteers. The name of the network (within brand guidelines)	Through a "You Said, We Did" table via email. Links to website pages as soon as launched.
Focus groups with people affected by stroke (non-volunteers)	Six focus groups with up to 6 people affected by stroke (carers and stroke survivors) including a diverse geographical area, diverse range of stroke dates and impacts.	The communication methods and frequency from the network, the types of projects that would be available and the support offered. The name of the network (within brand guidelines)	Through a "You Said, We Did" table via email.
Feedback on website during focus groups	User-feedback on screen grabs of website as not yet able to user-test.	Title of the page, pictures used, wording used.	Links to website pages as soon as launched.

Advertising roles: Role Profiles

To advertise your project and the role/roles available you will need to create either a **Role Profile** or a **Short Role Profile**.

This will help to attract the right people affected by stroke to your project.

Role Profile (Example on page 8)

Suitable for roles that require a high level of input or ongoing involvement e.g.

- Joining a Patient Voices group.
- Joining an ISDN.
- Co-creation/co-design project roles.
- Co-writing health information.

A **full Role Profile** is a 2-page document giving **details** of the role including:

- The project introduction and aims of the role.
- The specifications of people affected by stroke you are looking for.
- Practical requirements of the role e.g. time commitment, tasks.
- Support which can be offered.
- Contact details and information to include.

Short Role Profile (Example on page 10)

Suitable for roles that require a lower level of input or one off involvement e.g.

- Answering a survey
- Attending a focus group/interview
- Proof reading documents
- User-testing

A **Short Role Profile** is a paragraph giving **key details** of the role including:

- What – activity, date, time, how often
- Where - Location
- Who – requirements to apply
- How many roles are available
- Contact details

Accessibility in advertising roles:

- Offer **multiple contact methods**, ideally an email and phone number and welcome contact via text and WhatsApp.

- Offer **multiple ways** for someone to **contribute** your project. For example:
    - Offering a Zoom call if telephone isn't suitable.
    - Contribution via chat bar only in a focus group.
    - Providing ideas via email only (no speaking required).

  Try to make these adjustments clear in the advert.

- You could include a **pre-written expression of interest** to copy and paste:

Copy this email address into the 'to' field:

Nancy.smith@stroke.org.uk

Copy and Paste this template into your email:

Dear Ms Smith,

I am interested in applying for your project to work on the Digital Health Assistant. I believe I meet the criteria you are looking for.

The best way to contact me is:
Me: **[Insert phone / email]**
Caregiver: **[Insert phone / email]**

I hope to hear from you soon.

Many thanks,
[Insert name]

Example Role Profile: Task and Finish Group Member

Project introduction

The Stroke Association's local teams are divided into 10 geographical areas called localities.
We are making an **advisory group** in each area of **10-12 people affected by stroke.**

The advisory group will **work with** the Stroke Association to **plan services, design projects** and **make decisions**.

The members are **experts** of **stroke** as well as **experts** of their **local area**.

Aims of the Task and Finish Group:

- To **provide support** to the 10 areas to set up their group
- To **develop guidance** and **resources** for areas to set up their groups
- **Decide** the **role** of the **advisory group** members and what **decisions** they are involved in
- **Identify** what **training** is needed for advisory group members

Role Summary

We are looking for **3 people** affected by stroke to join our Task and Finish group to **help design this project**.

We are looking for people who:

- Have **lived experience of stroke (**stroke survivor, carer, family member**)**
- Have **access to a computer, laptop or tablet** for meetings

Requirements:

- **1 hour** online meeting **weekly**
- **1 hour preparation** between meetings (reading, reviewing)
- Available **January 2022 - July 2022**
- We use **Teams** to hold our meetings and can **provide support** using Teams.

How we can support you

- We will meet with you to **discuss how best to support you**
- We will schedule **breaks in meetings** as requested
- We will discuss the **most accessible way** for you **to feedback your ideas** e.g. written, verbal
- We can offer **practice using technology**

Interested in applying?

Please contact: **Rachel Smith**
Email -rachel.smith123@stroke.org.uk
Phone or **Whatsapp** or **Text - 077765085513**

Closing date: **Monday 6 December 2021**
Thank you for your interest, we would love to hear from you.

Example Short Role Profile

Focus group participant – Gathering ideas for a stroke information video on fatigue with the health information team.

- Attend **three** focus **groups** – **February 1st, 8th** and **15th** at **10am-11am**
- Location – **Zoom**
- Must be a **stroke survivor, carer** or **family member**
- Must have **experience** with **post-stroke fatigue**
- Able to **use Zoom** (**support/practice** can be **offered**)
- Option to **contribute** via **chat bar** only.

5 roles available

Contact: Nancy Smith:
Email - nancy.smith@stroke.org.uk

Phone or **Whatsapp** or **Text – 0776508513**

Closes - January 18th 2021

How to select people for your project

We asked people affected by stroke how they would like us to choose people for a role if it was over-subscribed.

These were the criteria they suggested:

1. **Skills** should be main factor – make the skills you are looking for clear.
2. **Diversity** incl. ethnicity, age, geographically etc.
3. **Diversity of stroke** incl. experiences, impacts, type, time since etc.

Sometimes it may also be appropriate to find other ways to involve interested people in your project e.g. through a focus group or survey.

Please also remind people that there will be other opportunities in the future and ensure they know how they can hear about these.

During your project

Support and accessibility during a project

We asked people affected by stroke what support they would need when getting involved. Below are popular suggestions.

It's vital to discussing accessibility needs on an individual basis and work with people to ask what is best for them to provide the right support.

Clear dates/times/ requirements	Ideally included in the role profile, clear dates and times and the additional commitments to the project e.g. 1 hour of prep before each meeting.
Timetable	On successful application a timetable to outline all dates so these can be planned for.
Single point of contact (SPOC)	The role of the point of contact: • Discuss stroke/accessibility needs for individuals • Discuss communication needs • Put reasonable adjustments in place • Help rest of team to carry our adjustments • Send reminders about meetings/interviews/focus groups as required • Provide admin e.g. agendas and minutes • Provide dedicated opportunities for questions and suggestions part way through the project.
Project induction	Keep it short and project-specific. An opportunity to meet colleagues on project.
Reminders	Preferred way to receive these e.g. email/text, frequency and time before to be decided with SPOC.
Administrative support	Agendas for meetings in advance Minutes/notes from meetings Offer for recordings from meetings as needed
Technological help	Zoom is the preferred online platform.* Offering practice with technology. Supporting with issues throughout as needed.

The Stroke Association also have aphasia-friendly **Zoom Guidance** which we can signpost involved persons to.

After your Project

Providing feedback after involvement activity

Feedback is a vital part of involvement work. People have given their time, provided expert knowledge and often shared personal experiences and it is extremely important that they understand the outcomes of the project.

It is also one of the key principles that makes involvement meaningful.

There are a number of ways you can provide feedback and the method you choose should correlate with the involvement work undertaken.

Think about:

- How much time was given to the project by people involved?
- Was there work to be completed between before/after meetings?
- Have they received any feedback throughout the project?

On page 15 there is a guide to the different methods of giving feedback.

Reminders!

- Feedback happens at the end but should be planned for at the beginning.

- If you have involved multiple people in different ways or at different times you might need to conduct multiple forms of feedback.

- In all feedback, please remember to use plain English and aim to meet preferences for those with communication difficulties or accessibility needs.

- Feedback is two-way. You should ask the people you have involved for their opinions on the process and the project.

When to feedback

Feeding back regularly throughout the project can help people to understand the projects' progress and continue to feel connected to the work.

Initial feedback – immediately after the activity

- Thank people for their time, expertise and remind them why their input and insight is vital for your work.
- Give a reminder of the aims of the project and how their contribution will be used.
- Explain your next steps and give timeframes for the project.
- Give a timeframe for when you will next be in touch with an update.

Interim feedback – part way through the project (if needed)

- Sometimes projects can last for many months and so it is important to keep in touch to update people who have been involved in the project of its progress.
- Send an update on the work so far and describe the next steps that will be taken.
- Try and include an update on how the involvement work is being incorporated.
- Remind people you will be in touch at the end of the project and give a time frame.

Final feedback – when the project is complete

- At the end of the project a more detailed level of feedback should be provided, focus on the outcomes and the impact that involving people affected by stroke has made.
- If there were some key ideas that were not able to be implemented explain why.
- Provide the people involved with a copy of the results if possible or a link to any created materials e.g. webpages etc.
- Ask participants for their opinions on the involvement process (see page 15).

How to feedback:

1. Email, Flyer or 'You said, we did board'

Best for – providing mass feedback

Pros – simple to create, feedback on multiple points, can be emailed or posted, shows clearly where their ideas have been incorporated and that we are listening.

Cons – not personalised, no opportunity for discussion

Suitable for – surveys, focus groups/workshops, one-off involvement work

NOTE! If conducting a survey provide the results in full as part of the feedback.

2. Group meeting

Best for – providing group feedback

Pros –opportunity for discussion, can share additional information and answer questions

Cons – some people may not feel confident to provide feedback in the group

Suitable for – focus groups/workshops, group projects

3. Telephone call/Video call

Best for – a rich two-way discussion

Pros –offers opportunities to both provide personalised feedback and receive in-depth feedback. Adaptable for communication difficulties.

Cons – time consuming

Suitable for – long-term projects, high levels of involvement

You Said, We Did Example

You said...	We did...
You wanted a timetable and clarity on what you would need to do (dates, times, activity).	We have created a Role Profile template to be used to advertise projects that gives the keys details of what, where, when and who.
You wanted a single point of contact who you could discuss accessibility needs with and ask any questions to throughout the project.	We love this idea. We will work with projects teams to help them understand the role of the point of contact and help you to be supported.
You wanted appropriate reminders throughout the project of meeting dates and times.	This will be part of the role of your single point of contact, let them know when and how you would like to be reminded.
You wanted administrative support e.g. meeting agendas, minutes and recordings.	These will be made available from your project team and emailed to you accordingly.
You said you wanted involvement opportunities to land in your inbox.	We will email opportunities, with the option to call for further details if needed. In the future, we hope to have an involvement bulletin sent via email on a regular basis.

What we haven't implemented yet and why:

- You requested a weekly or fortnightly **bulletin** of opportunities – right now, we **don't have enough opportunities** to do this but hopefully will soon.

- You wanted the involvement network to offer forms of **peer support** – currently we want to focus on getting members of the network opportunities to join projects they are interested in. We understand how important this is and **we will** work to **build** this into **the network** as it grows.

Measuring the satisfaction of the people you involved

It is vital that you also collect opinions and ideas from people who have been involved. This way you can see if they felt they had the right support, were involved at the right time and what they benefited from in the project.

This helps to provide a consistent experience and give people the opportunity to have their voices, opinions and ideas heard.

Options of ways to gather feedback from those you have involved:

- Feedback questionnaire
- Open-text email
- Email template
- Telephone call
- Group debrief

As with recruitment, try to offer multiple methods to meet accessibility needs.