

Empowering stroke patients to have their say in a person-centred NHS in Scotland

Juliet MacKellaig, Nicola Cotter, Louise Peardon and Dave Bertin

In 2001, the Scottish Government proposed a move toward patients, carers and the public becoming more involved in the NHS. This culture shift was originally explored in the document *Patient Focus and Public Involvement* (Scottish Executive, 2001), within which NHS Scotland recognised that it was no longer good enough to simply do things *to* people; a modern health-care service must do things *with* the people it serves. In 2010, NHS Scotland declared in its Healthcare Quality Strategy the need for people to be at the heart of the NHS (Scottish Government, 2010: 5):

‘It will mean that our NHS will listen to peoples’ views, gather information about their perceptions and personal experience of care and use that information to further improve care.’

Chest Heart & Stroke Scotland (CHSS) (2010) is building on this philosophy with ‘Stroke Voices’. This is an inclusive communication and public involvement training and support programme applicable to the majority of patients with experience of stroke, including those with cognitive and communication difficulties. The programme supports these patients’ voices in the development of Scottish NHS stroke services.

Public engagement through Stroke Managed Clinical Networks

Stroke managed clinical networks (MCNs) were developed across Scotland to ensure the coordination and integration of stroke care between organisations and departments in primary and secondary care and the wider stroke community (Scottish Office Health Department, 1998; Scottish Executive Health Department, 2002). The members of stroke MCNs are multidisciplinary specialists in stroke and make decisions related to service redesign and service provision alongside patients and carers.

In 2012, the Scottish Government reiterated its commitment to MCNs and stated that each must have a clear strategy for involving those for whom services are provided (Feeley and Burns, 2012). At CHSS, a suggested framework has been developed (*Table 1* and *Figure 1*). This pathway and model of public involvement for a mutual organisation (CHSS, 2010) was based on the 2007 vision of a ‘mutual NHS’ from the

ABSTRACT

‘Stroke Voices’ is a fully inclusive communication and public involvement training and support programme from Chest Heart & Stroke Scotland. It is applicable to the majority of patients with experience of stroke, including those with cognitive and communication difficulties, and supports their voices in the development of Scottish NHS stroke services. Stroke Voices is a workshop presented over 3 days, with each session being around 3 hours in duration. It teaches participants how to present their ‘case for change’ for stroke service improvement across Scotland. This article describes the course content, training delivery methods and resource development. It also includes a suggested pathway and model for public involvement that NHS bodies such as Managed Clinical Networks can use to become person-centred organisations. Stroke Voices suggests that it is possible, through training and quality support, to support people who have had a stroke to present their views for stroke service development. Stroke Voices is now offered for free across the 14 Scottish NHS boards.

Key Words Public involvement, Voices Scotland, Chest Heart & Stroke Scotland, stroke, inclusive communication training, accessible resources, co-production

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then deputy first minister and cabinet secretary for health and wellbeing, Nicola Sturgeon:

‘This realisation presented new opportunities to develop a “mutual” NHS in Scotland in which each one of us sees ourselves as partners in the service, with rights and responsibilities.’ (Scottish Government, 2007: 3)

The Voices Scotland model for this vision of mutuality was recommended to the MCNs in 2012 by Sir Harry Burns, chief medical officer, and Derek Feeley, former director general of NHS Scotland.

Mutual MCNs: a pathway and model

The mutual model for MCNs was developed from Voices Scotland’s experience of working with

Step 1: information days	Inform patients and carers about the work of the network and how they can get involved
Step 2: mail, email, social media and virtual network	Collect the contact details of those interested in getting involved
Step 3: discussion groups	Invite patients to discuss specific subjects face-to-face, via video conferencing or online
Step 4: patient and carer subgroup	Encourage those from discussion groups and open days to form or join a patient and carer subgroup, offering user involvement training where possible. This can also include video conferencing
Step 5: open days	Encourage partnership working by involving patients and carers regularly and asking for feedback and suggestions

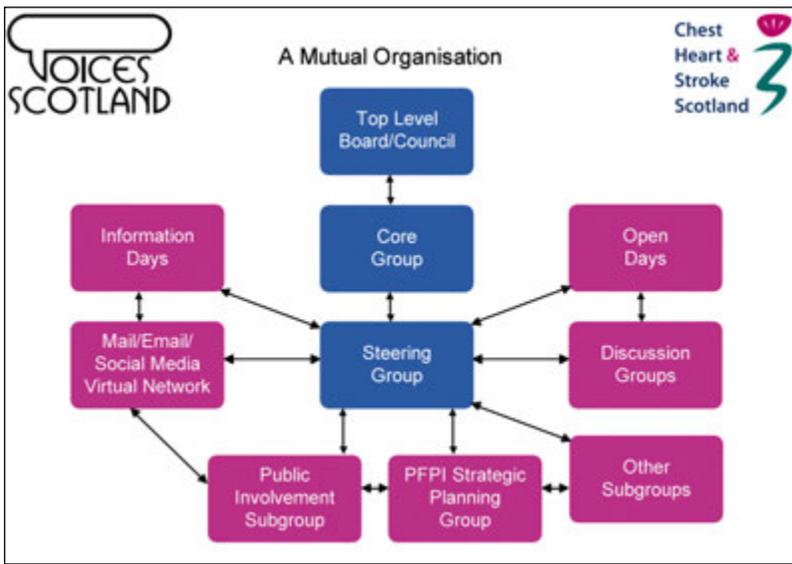


Figure 1. A suggested model to enable effective public involvement, e.g. in a Managed Clinical Network. Originally developed in association with NHS Greater Glasgow & Clyde

respiratory, cardiac and stroke MCNs across Scotland. Where there has been no public involvement in an MCN, or merely tokenistic involvement, Voices Scotland has encouraged the MCN management to start the process of effective engagement by setting up a framework following the pathway in Table 1. Step 1 is to hold an information day for stakeholders and the local community. At this event, the public should be informed of the work of the MCN, and the contact details of people who want to become more involved should be collected. The next step is to set up a wider public involvement network alongside specific topic discussion groups and both a strategic patient focus and public involvement group and a public involvement subgroup to the MCN (Figure 1). These all report to the MCN steering group. This gives the MCN a number of different groups and virtual groups to consult with on its work and who can voice public concerns. It also gives the public the chance to become

involved face-to-face in various groups or to give feedback via post, email and telephone.

Introduction to public involvement training at Voices Scotland

CHSS provides public involvement training and support to NHS Scotland through its Voices Scotland programme. The training is offered to any members of the public who are already involved in—or want to become involved in—the mutual organisation model represented in Figure 1. Where there is no public involvement subgroup, those members of the public who come on Voices Scotland training are encouraged to form one. Voices Scotland was recognised as the gold standard in patient and carer involvement in NHS Scotland’s Chief Executive Letter in 2012 (Feeley and Burns, 2012).

A co-production approach to service improvement

Voices Scotland is based on a co-production approach to improving services—an approach used since the training’s inception at CHSS in 2006. This concept was first introduced into mainstream Scottish Government literature in the Christie Commission Report (Scottish Government, 2011a: 23), which stated that co-production is necessary:

‘... to ensure that public services are built around people and communities, their needs, aspirations, capacities and skills, and work to build up their autonomy and resilience ...’

Needham and Carr (2009), in their Social Care Institute for Excellence research briefing on co-production, emphasised that models of co-production have the potential to create new relationships between people who use services and staff. These models reposition service users as experts and ask what assets they can contribute to collaborative relationships that will transform provision. They take a ‘whole-life focus’ that incorporates broader quality-of-life issues, rather than just clinical or service issues. Voices Scotland aims to facilitate this approach in health and social care by providing an interface between the public and services, in particular through the MCNs across Scotland. The MCN managers normally invite Voices Scotland to help advise on their patient involvement strategy and support the MCN with the training of its public representatives. The Voices Scotland team often goes on to support a public involvement group attached to the MCN (Table 1 and Figure 1).

Stroke Voices

Engaging with people who have been affected by stroke can present additional challenges, in particular because they may have complex communication and cognitive problems. There had been no attempt to engage with this client group in the Scottish NHS until the Scottish Government funded CHSS to

expand the successful Voices Scotland public involvement training programme for respiratory and cardiac patients and carers ('Chest Voices and Hearty Voices Scotland') into an accessible format for people living with a stroke, branded as 'Stroke Voices' (Scottish Government, 2009).

In this article, the terms 'accessible format', 'accessibility' and 'inclusive' are based on the Principles of Inclusive Communication (Scottish Government, 2011b: 4):

'For service providers, it means making sure that you recognise that people understand and express themselves in different ways. For people who use services, it means getting information and expressing themselves in ways that meet their needs.'

In the context of Stroke Voices, information is always presented in more than one format. Words, both written and spoken, are always backed up by summary symbols or pictures of the concept. Participants are also given the support and tools, if required, to enable their voices to be heard via alternatives to speech and writing. These are known by speech and language therapists as low-tech (e.g. drawing pads, written key messages, symbol cards) and unaided (gesture, vocalisation, facial expression) augmented communication aids.

An extensive review of the literature, including the grey literature, has revealed that this approach is unique in public involvement training. However, work carried out by Communication Forum Scotland (2009a; 2009b) between 2007 and 2011 focused on removing barriers to active citizenship for people with communication support needs, with one of the project's aims being to provide inclusive communication training. This expertise was built on for Stroke Voices through Communication Forum Scotland's representation on the project steering group.

Course content

The Stroke Voices course aims to give the participants knowledge and skills relating to:

- The structure of health and social care in Scotland
- Different levels of involvement
- Which health and social care service bodies are looking for public involvement
- How stroke affects people differently
- How to communicate with people who have communication difficulties (aphasia)
- Effective communication with professionals
- Becoming a public representative for health and social care services
- Accessing national and local health and social care resources and using these to obtain credibility and influence change.

The training was developed through participants' feedback from the pilots and with the oversight of a

steering group that included members of the public living with stroke, and stroke professionals. The steering group decided that the course should run for 3 hours on three non-consecutive days, offering frequent breaks to suit the participants.

As recommended by the Scottish Government (2011b), the course attempts to match the trainer's communication methods and tools to the participant's needs. Those with more severe disability are assisted by someone who has been trained in supported communication techniques. The Voices Scotland trainers are also trained in the effects of stroke and supported communication techniques, enabling them to oversee the supporters and the participants. All of this support creates an environment that gives participants the confidence to express their views on how to improve health and social care stroke services in Scotland.

Inclusive training delivery methods and resource development

The course is also designed to enable all adult learners to maximise their ability to learn, by aligning the sessions with key learning styles originally proposed by Neil Fleming in New Zealand in 1987 (Fleming and Mills, 1992) and now known as VARK:

- Visual
- Auditory
- Reading/writing
- Kinaesthetic/tactile.

The participants who have attended Stroke Voices are living with aphasia, sight, mobility, memory, cognitive and perceptual problems or no disability at all, following their stroke. Underpinning the training methods with these adult learning approaches (Russell, 2006) also enables those living with the effects of a stroke to maximise their understanding of the material presented to them.

Visual

For the visual learner, much of the material presented is in a variety of interesting visual formats, such as PowerPoint presentations, pictures, visual aids, symbol cards and video clips with subtitles. This will also help aphasic participants and those with memory problems and concentration difficulties. These participants are relying on the use of other, undamaged, neurological pathways to maximise their communication.

Auditory

For the auditory learner, the learning points are emphasised and rephrased and audio clips are used. This also helps to support the slower cognitive processes of some people who have had a stroke.

Reading and writing

People who have a strong preference for learning by reading and writing are encouraged to use the participants' manual if they wish to follow the workshop. The manual aligns with the PowerPoint presentation



Figure 2. Widget symbol cards and Talking Mat



Figure 3. Body Boards

and presents colour-coded information simply and clearly, with a lot of white space on each page. Those who can write are encouraged to write their responses to different sessions when required. Those who cannot do this are supported to respond in alternative ways through symbol card choices or by working with their supporter to write or draw their view.

Kinaesthetic/tactile

Kinaesthetic learners remember best when they are physically involved in whatever is being learned. The course has many hands-on physical activities that involve the participants in understanding the learning outcomes. For example, at the start of the course, participants are invited to stand up and go to a table covered with symbol cards of various emotions and choose one that represents their experience of care in the NHS. Each participant then presents their card to

the group as they introduce themselves. This approach has been adapted from work by Dewar et al (2009) on 'emotional touchpoints' that allow participants to express their story in a controlled manner and feel their related emotion has been acknowledged.

In an attempt to enable those without aphasia to understand what it feels like to have aphasia, participants are invited to make a Play-Doh model and then others have to guess what it is without the modeller being able to speak, responding only through gesture.

There are frequent breaks to allow movement and/or rest. This approach suits those with aphasia, memory and cognitive problems, all of whom are easily tired (Warlow et al, 2008).

Other resources

Other resources used to promote the different learning styles and provide an aphasia-friendly format include:

- Talking Mats (www.talkingmats.com), a communication toolkit that uses picture communication symbols. Stroke Voices uses these in an adapted format to suit the needs of the training. A simple mat provides a surface in front of the participant that functions as a clear 'work area' for exercises in which the participant is asked to choose from picture symbols around the course topic (Figure 2)
- Body Boards and their props (Headon Ltd, no longer operational), which have been used to illustrate two sessions. They provide a visual aid of a human body to represent a health professional and a public representative. This enables the results of the session on how participants feel about health professionals and how health professionals feel about the public to be portrayed visually to enhance understanding (Figure 3)
- PowerPoint presentations to emphasise key points, with graphic illustrations to accompany each theme
- Graphic facilitation to illustrate the issues raised
- 'Stop' and 'slow down' cards for the participants.

Participants have stated that, as the course went on, the props, visuals and aids became imperative for their understanding and active participation.

Many of the communication aid resources were developed using the 'Communicate in Print 2' software and its Widgeit and Boardmaker symbols (www.widgeit.com/products/inprint/index.htm). Those people living with the effects of a stroke on the project steering group reviewed a number of symbol systems. Stroke Voices predominantly adopted the Widgeit symbols, as the more adult look of the Widgeit symbol system used in adult education was preferred by the steering group.

Guidance on engaging with the public in an inclusive manner

When MCN managers responded to a questionnaire at the beginning of the project, it became apparent

that they had either left people with aphasia out of their public involvement, or struggled with how to engage with this group effectively. They asked that the project include information on how to support this specific group. Therefore, to assist these professionals to provide the appropriate support for those who have completed Stroke Voices, CHSS developed public involvement guidance in association with Communication Forum Scotland. The guidance offers managers the tools and information they need to provide communication support. It was developed from the experience gained from the Stroke Voices pilot courses on how best to engage with this group. It also built on CHSS's 10 years of experience of working with this client group through its Community Stroke Services, which have around 1000 service users at any one time in 100 services across Scotland. The guidance also provides general best practice for a strategic approach to public involvement for MCNs and the framework, based on 8 years of Voices Scotland experience working across Scotland (*Table 1* and *Figure 1*).

Topics included in the guidance are:

- Models of engaging the public in health and social care services
- Five principles of engagement, summarising best practice (*Box 1*)
- Checklists for communication support needs
- Venue checklists for those with communication support needs
- Equipment aid suggestions, including magnifiers, easy-grip pencil holders and coloured paper for distinguishing between handouts
- Information on how to run a meeting in a way that takes a stroke user representative's needs into account
- Guidelines on writing documentation that is accessible to people with aphasia
- Suggestions for how to choose a picture symbol set software package
- Best practice principles in communication techniques for those with communication support needs
- Guidance for those who support the public at meetings
- How to adapt a topic for different levels of severity of aphasia
- Overview of possible effects of stroke, in particular, its hidden effects.

Evaluation

Feedback from participants

An extensive four-part evaluation of the methodology of the Stroke Voices course was undertaken. The participants provided the following feedback on the key points of communication inclusion:

- 95% said that they understood the content
- 100% found the activities helpful
- 95% found the information clear
- 95% found the visual aids helpful.

Participants commented that the language of the

Box 1. Stroke Voices principles of engagement

1. Understand how the stroke has affected the individual representative. Remember that its effects may be hidden.
2. Ask the representative what is required for them to be effectively involved.
3. Match the representative's needs with inclusive communication resources and support. If this does not succeed at first, keep trying!
4. Support the representative throughout their involvement, not just at meetings.
5. Effective engagement takes time—be prepared to take this time!

course was very understandable, the slides were useful, the mats and symbol cards were helpful as sometimes words were difficult to find, the graphic illustrations were very useful, the training session was thoroughly enjoyable and aphasia-friendly, the course was easy to understand, the explanations were thorough and the atmosphere conducive to learning, and the course increased feelings of self-confidence.

Feedback from NHS managers

Stroke Voices has now been delivered in conjunction with Stroke MCN managers in NHS Ayrshire and Arran, Dumfries and Galloway, Fife, Lanarkshire, Greater Glasgow and Clyde and Highland and Tayside. Stroke MCN managers are asked how the participants have subsequently participated in their public involvement consultation groups after their training. Responses have included that public confidence had greatly increased and that the public:

'... seemed to actively listen, feed back accurate information and make a positive contribution to conversation ...'

'... were thinking more proactively, looking at how things could be changed in a positive way, trying to problem-solve and come up with ideas and suggestions for service improvements ...'

All course participants are put on the mailing lists for future consultations by the stroke MCNs in all areas. Some 70% have gone on to become more involved in local stroke MCNs, patient involvement subgroups and forums, community health partnerships and local GP surgery forums. The Stroke Voices participants were encouraged to join a patient and carer reference group for the hosting stroke MCN (*Figure 1*).

All of the issues relating to the participants' experiences of stroke services are fed back to the stroke MCNs. They are also kept in a database by Stroke Voices that has been shared with the Scottish Government's Better Together patient experience programme. The types of issues most commonly encountered are clinical care issues, largely related to rehabilitation services, followed fairly closely by information issues. However, much of the feedback to the

MCN managers is positive, with patients expressing their gratitude to staff.

An example of successful change in stroke services

One of the Stroke Voices participants is now a co-chair of a public involvement MCN subgroup. An example of work carried forward by her group was encouraging the facilitation of aphasia-accessible menus in a local hospital. This was in response to hearing of someone with aphasia who was unable to choose their own food for the duration of their stay in the stroke unit and wards. This specific issue was brought up through the public involvement group and fed through to the stroke MCN. The two groups then worked together to introduce the new menu card system into the hospital. The group meets regularly and conveys the public's concerns to the MCN, which also consults the group on its current work plan.

Lessons learnt from Stroke Voices

Pre-course assessment

Course participants are given a self-assessment form with their booking form to say how their stroke has affected them. This enables the training team to provide the right support equipment, ensure an appropriate number of communication supporters are available and know where to seat the participants on the training (it would be unwise to have two people with the same difficulties beside each other).

Relevant health professionals are also approached about the prospective participants, and the trainers share this information with supporters prior to the courses. The booking form also discloses whether someone has very little residual disability, meaning that they need not come onto the fully stroke-adapted course unless they want to.

It became evident during the pilot stages that it would be beneficial to meet participants face-to-face to get a feel for how they would cope in the training environment. Therefore, taster sessions to be taken before the delivery of a Stroke Voices course have become mandatory and are used as a recruitment method for the training. They also allow the trainer to collect the issues of those people whose disability would limit their ability to participate effectively despite the supportive environment of the training.

Support for participants

It also became apparent that the key to the success of Stroke Voices is the quality of support provided for participants on the training days. Those providing support should have knowledge of specialist techniques for assisting those with communication support needs. These are based around Connect's (2014) 'Ten top tips for talking to people with aphasia'; these include such things as the supporter writing down key words, drawing diagrams and recapping to check that both

parties understand. Identifying good ongoing support for people with aphasia is critical for their ability to become effectively involved with their local stroke services.

Further adaptations of the Stroke Voices training and engagement model

Neurological Voices

It has become evident that the techniques used for Stroke Voices are transferable to people with other communication support needs and cognitive problems. The model has now been adapted for stroke carers and reworked for people with various other neurological conditions through the Neurological Alliance and Neurological Voices Project.

Public participation in stroke research

Boote et al (2013) stated that it is good practice for the public to be involved in developing health research. In line with this, the Stroke Voices methodology has been used to inform a feasibility trial run by TeleScot. TeleScot, based at the University of Edinburgh Medical School, is a programme of academic research investigating telemetrics-supported self-monitoring of long-term health conditions. Stroke Voices training was offered to a group of stroke patients and their carers to enable researchers to set up a patient panel to inform their research design. TeleScot has fed back to CHSS that:

'The design and the running of the stroke feasibility trial have been transformed by the stroke study patient panel ... The panel has helped us find the right way to communicate with people who have had a stroke, from collaborating on written communications, to helping us find ways of ensuring that those written communications can be understood and responded to. The panel has also given feedback on the intervention that we are testing, helped us think about the best way of measuring blood pressure in this group, and how blood pressure measurements can be communicated. The panel has also provided considerable input into the development of the study's qualitative strand: reviewing interview schedules, advising on communication issues and commenting on data analysis.' (P Fairbrother, personal communication)

Fairbrother et al (2013) have now published their experience of working with the involvement panel. Three Stroke Voices participants who worked with TeleScot have also fed back positive accounts of their involvement in shaping the research design:

'Being a member of the patient panel was very interesting and I felt good being able to offer something back after my stroke. Because we were living with a stroke, we were often able to pinpoint areas of concern for the research design quite quickly that the researchers did not see.'

'It was good to be able to clarify the researchers' thinking ... it was a good collaborative effort ... it changed from being "them and us"; it became just "us" working on the research; their skills and our experience.'

Conclusion

As stated in the Healthcare Quality Strategy for NHS Scotland (Scottish Government, 2010), NHS services must be entirely person-centred. This is only possible if the views of the public are listened to. This is extremely challenging in the case of people living with complex disability after a stroke, and the temptation is for the NHS not to engage with this group. Stroke Voices allows the stroke services of Scotland not only to train people in public involvement after their stroke, but also to gather the views of this client group and feed them back to the relevant parts of NHS Scotland. For those whose disability would limit their capacity to move on to further engagement possibilities, the Stroke Voices tasters allow their voice to be carried forward on their behalf by the Voices Scotland team to the relevant Stroke MCNs and other bodies to improve the local health and social care stroke services. Stroke Voices has demonstrated that it is possible to support people who have had a stroke to have their say through inclusive communication training and quality support. **BJNN**

Further information

For further information, visit www.chss.org.uk or email voicesscotland@chss.org.uk.

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Declaration of interests

The authors have no conflicts of interest to declare.

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KEY POINTS

- Stroke Voices from Chest Heart & Stroke Scotland is an inclusive communication and public involvement training and support resource for those with aphasia and cognitive problems after stroke.
- Stroke Voices has empowered people who have had a stroke, through training and quality support, to present their views for service development to the Scottish NHS stroke services and other providers.
- The inclusive communication training resources have been adapted for other organisations and researchers to engage with patients with neurological conditions.
- Stroke Voices is available free to NHS stroke services across Scotland, and expertise on the resource development is available to other organisations.
- The article includes a pathway and model for public involvement for health and social care organisations to use the public's views to become more person-centred.

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