

Background

Patient Focus Public Involvement

Patient, carer and public involvement has been actively promoted by the Scottish Government since the initial comments in *Patient Focus Public Involvement (PFPI)* in 2001. "It is no longer good enough to simply do things to people; a modern healthcare service must do things with the people it serves." In 2007, *'Better Health, Better Care'* stated that the NHS was to... "move to a more mutual NHS where partners have a real involvement, representation and a voice that is heard." For those who living with the long term effects of stroke, engaging with the NHS can be considerably difficult due to accessibility, communication and cognitive problems.

Aim

The aim of the Stroke Voices Project at CHSS was to develop a robust and sustainable patient involvement training package, applicable to all patients with experience of stroke, to empower their voices in the development of stroke services.

Methodology

The Long Term Conditions Unit at the Scottish Government funded CHSS to expand the highly successful Voices Scotland patient and carer involvement training programme into an accessible format for stroke patients. CHSS employed a project manager with a background in stroke to manage the unique two year project. A steering group was set up which included health professionals with an interest in stroke and training, and patients living with stroke. Initially the project manager researched into existing models of public engagement in Scotland. This led to a consultation day, to engage with professionals with the backgrounds in stroke, training, speech and language therapy, public involvement, learning disability, care of the elderly, Stroke Managed Clinical Network (MCN) management and patients who were living with stroke. This day informed the development of the sessions that would ultimately make up the Stroke Voices three day programme.

Stroke MCN Engagement

The project then engaged with three Stroke MCNs in NHS Lanarkshire, Greater Glasgow & Clyde and Highland. Taster sessions were held in two out of the three NHS Boards to recruit participants for the courses through the Volunteer Stroke Service (VSS) groups at CHSS. Many of the members in the VSS were left with communication problems after their stroke. These taster sessions also gathered the views of those not attending the training. The Stroke MCNs also put forward new and existing people from their user involvement programmes. The pilots were subsequently held in the three NHS Boards and the training and resources were then thoroughly evaluated.



Fig 1. NHS Highland pilot

Results

The workshops

The final format of the Stroke Voices training programme runs over three days and is presented in an accessible format for stroke patients to empower them to have their views heard to improve NHS stroke services in Scotland (see Fig 1). It is presented over three hours on three non-consecutive days, offering frequent breaks to suit the participants. The issues gathered at the training sessions were fed back to the Stroke MCNs who work with public involvement groups to then take them forward (Fig 2).

The evaluation

The pilot courses trained 20 Patients, 3 Carers and 8 Health Professionals/supporters over the three NHS Boards. Participants presented with sight problems, dysphasia, mobility problems and memory problems. 80% of the participants rated the days excellent. All areas showed an increase in confidence before and after training; NHS Lanarkshire showing a 52% increase.

Delivery

An aphasia accessible approach was taken to the training which also helped participants understand and retain information. This complemented the different visual, auditory and kinaesthetic adult styles of learning of the participants.

Resources

Accessible resources were developed for the training using the software "Communicate in Print 2" Widgeit and Boardmaker symbol systems (See Fig 4).

"Easy to understand, explanations were thorough and atmosphere conducive to learning"

"Thoroughly enjoyed this session"

"Confidence builder"

"Very interesting way of explaining things"

"As the course progressed, I found the props essential"

"I understand now that I can make a difference."

Stroke Voices pilots' evaluation 2009/10



Fig 4. Widgeit symbol cards for one of the Stroke Voices sessions

Support for participants

It became evident 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 problems. Identifying good ongoing support for these people will be critical for the success of their ability to go on to become effectively involved with their local stroke services (see Fig 5).

Issues database and PFPI resources

Issues were gathered throughout the training from stroke patients and carers and have been recorded in a database. Stroke Voices has also developed guidance for managers to help them support those patients who have accessibility, communication and cognitive problems and are working closely with the MCNs. This includes a Patient Involvement Toolbox of PFPI resources.



Fig 2. Graphically illustrated issues behind participants on the wall in NHS Highland

Stroke Voices Pilots Evaluation

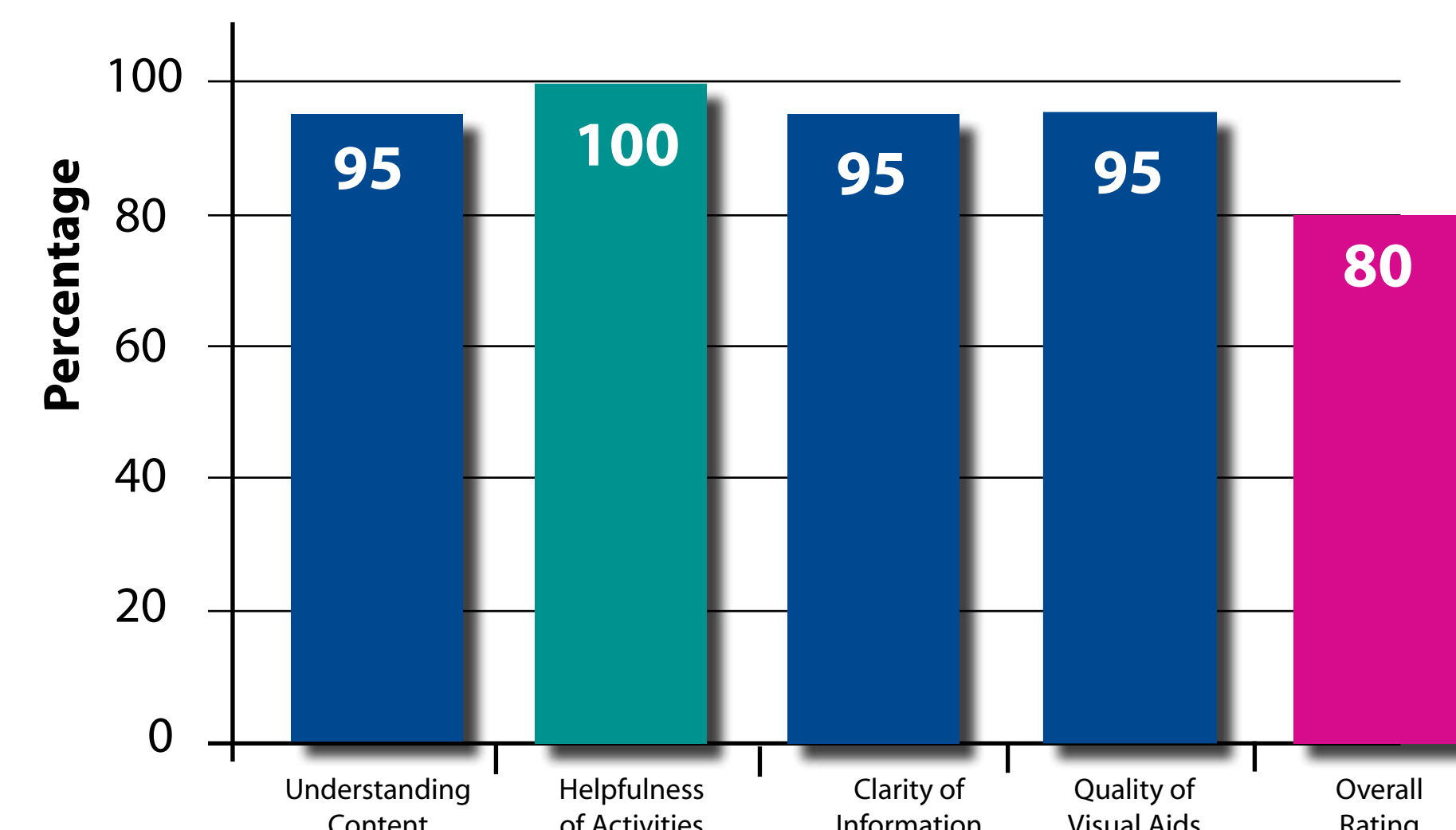


Fig 3. Overall result of three pilots where participants scored "good" or "excellent".



Fig 5. A participant makes his "Case for Change" with support.

Conclusions

The Stroke Voices Project has demonstrated that it is possible to empower people who have had a stroke through accessible training and good quality support. Stroke patients' issues regardless of the disability of the patients, can be fed back through Stroke Voices to improve the local NHS stroke services. It has become evident that the techniques used for Stroke Voices will be transferable to those with other accessibility, communication and cognitive problems other than stroke. Stroke Voices will now be offered across the 14 Scottish NHS Boards.

Further information is available on the CHSS website at www.chss.org.uk or email voicesscotland@chss.org.uk

References

Patient Focus, Public Involvement 2001 (Scottish Executive)
Better Health, Better Care: Action Plan 2007 (Scottish Government)

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