



Evaluation of Chest Heart and Stroke Scotland's Voices Programme

Briefing

April 2014



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Background

Chest Heart & Stroke Scotland is committed to ensuring that:

- the patient and carer voice is heard across health and social care service redesign and delivery, and
- self management is key to ensuring person-centred care is provided for people living with long term conditions.

Voices Scotland addresses both these issues. It is a programme of workshops and support for patients and carers, together with advice and facilitation for NHS managers and clinicians, aimed at helping patients to become effectively involved in health service improvement. Voices Scotland is core funded by Chest Heart & Stroke Scotland, and has also been supported by Scottish Government funding.

Voices Scotland has been running since 2005 and is delivered by a dedicated team at Chest Heart & Stroke Scotland. The original aim of the programme was to equip patients with influencing skills ('Voices' training) but over the past three years it has developed to include training for service users to become 'Champions of Self Management in Care' ('COSMIC' training). The ultimate aim of COSMIC training is to develop a network of individuals within each NHS Board area who will champion self management locally.

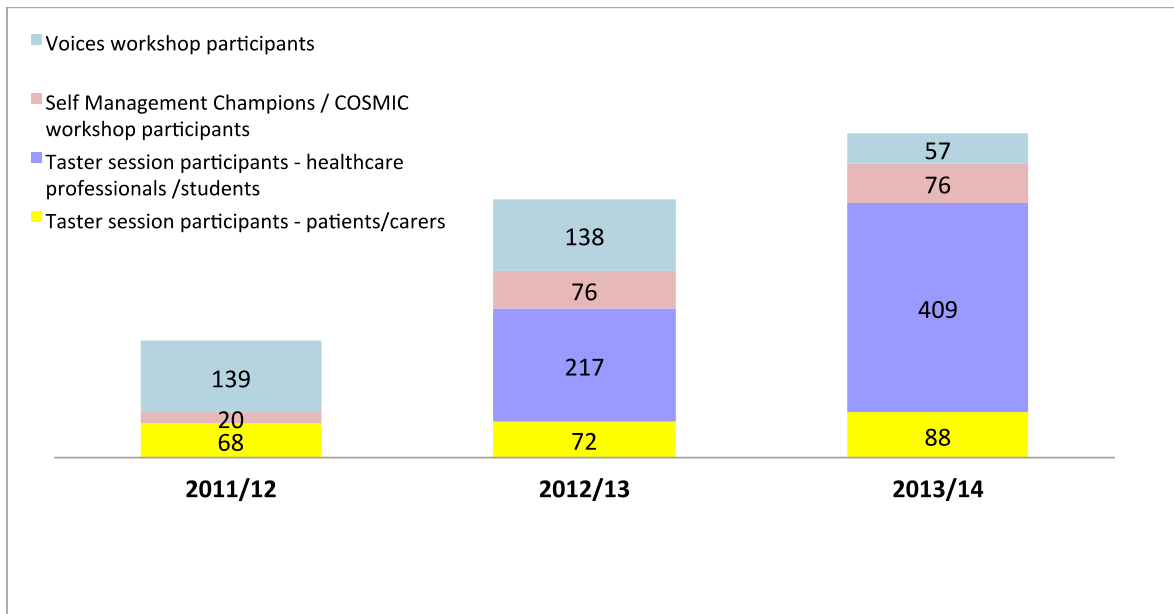
In 2013, the Scottish Health Council and Chest Heart & Stroke Scotland commissioned an independent evaluation of the Voices Scotland programme. The evaluation was carried out by independent consultants Mynors Suppiah between November 2013 and February 2014. They reviewed programme data, surveyed programme participants and healthcare managers involved in the programme over the past three years, and held in-depth focus groups and telephone interviews to understand the issues more fully.

This briefing summarises the results of the evaluation. The full evaluation report is available on the Scottish Health Council website at www.scottishhealthcouncil.org

The reach of the programme

Since April 2011, the Voices Scotland programme has trained 506 workshop participants and delivered 'taster' sessions to a further 854 patients, healthcare professionals and healthcare professional students. In addition, some 45 organisations have expressed interest in the COSMIC programme by downloading programme materials from the COSMIC Resources website (www.cosmicresources.com). A number of patient organisations and others are working, with the support of the Chest Heart & Stroke Scotland team, to adapt the programme for their own audiences and extend its reach.

Figure 1 Participants in Voices Scotland training over the past three years

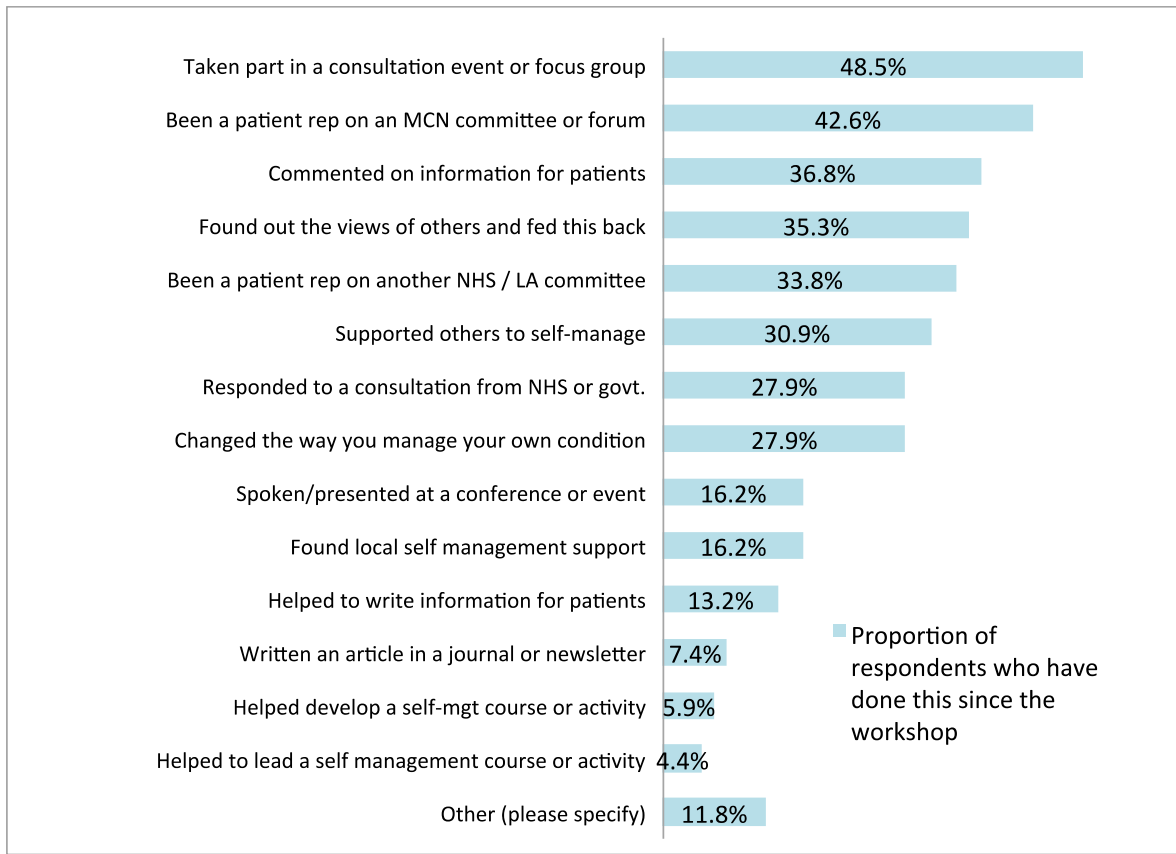


The impact of the programme on participants' ability to become engaged and involved service users

Of the programme participants who responded to the evaluation survey:

- 90% reported that they spend at least some time on involvement activities since attending a Voices Scotland or COSMIC workshop. 32% said that they spent five days or more per month on such activities.
- 68% rated the Voices Scotland workshop as 'very important' in enabling them to do the things they were most proud of having achieved in the workshop, with a further 25% saying it was 'somewhat important'.
- Of those who said that they had not been able to achieve as much as they would have liked since attending the workshop, the most common reasons cited were their own health and lack of time.
- Although participants reported that healthcare service organisations were largely receptive to their contributions, and gave many examples of successes in patient and public involvement activity, a minority reported frustrating experiences where they felt that they had not been listened to.
- Participants reported having undertaken a wide range of influencing and self-management activities, as shown in the following chart.

Figure 2 Proportion of participants undertaking the involvement activities since the workshop



The following quotes were provided by participants who attended workshops.

“Trainers have attended meetings and passed on tips based on their experience which has helped others who were not at workshop. We benefit greatly from their knowledge and experience.”

“I have attended two Chest Heart & Stroke Scotland meetings and discussions are always lively and interesting. Thank you for the chance to participate in these.”

“A very nice lady (the Chest Heart and Stroke Scotland trainer) helped our Respiratory Managed Clinical Network patient subcommittee to get going. One of the things we have worked on is putting together a case to make funding for pulmonary rehab permanent. This is vital as it helps patients to improve their own health and stay out of hospital.”

“The Dice Game and the Case for Change template were very instrumental in bringing home the difficult choices NHS staff have to make to make best use of scarce resources and the difference effective self management can contribute to making the most of these resources by reducing hospital admissions.”

Participants’ examples of their proudest achievements since they attended a workshop included:

“Becoming a member of the Managed Clinical Network Patient & Carer Sub Group.”

“Fighting for pulmonary rehab funding all the time. It's good for patients to be involved in choices which affect them a great deal.”

“Championing the cause at the Scottish Parliament.”

“Being trusted by the local Health Board to project their need for the public to be involved by representing them at local agricultural shows and with local voluntary organisations.”

“Improving my own knowledge, helping NHS by managing my condition to help reduce costs, being able to use experiences to help others.”

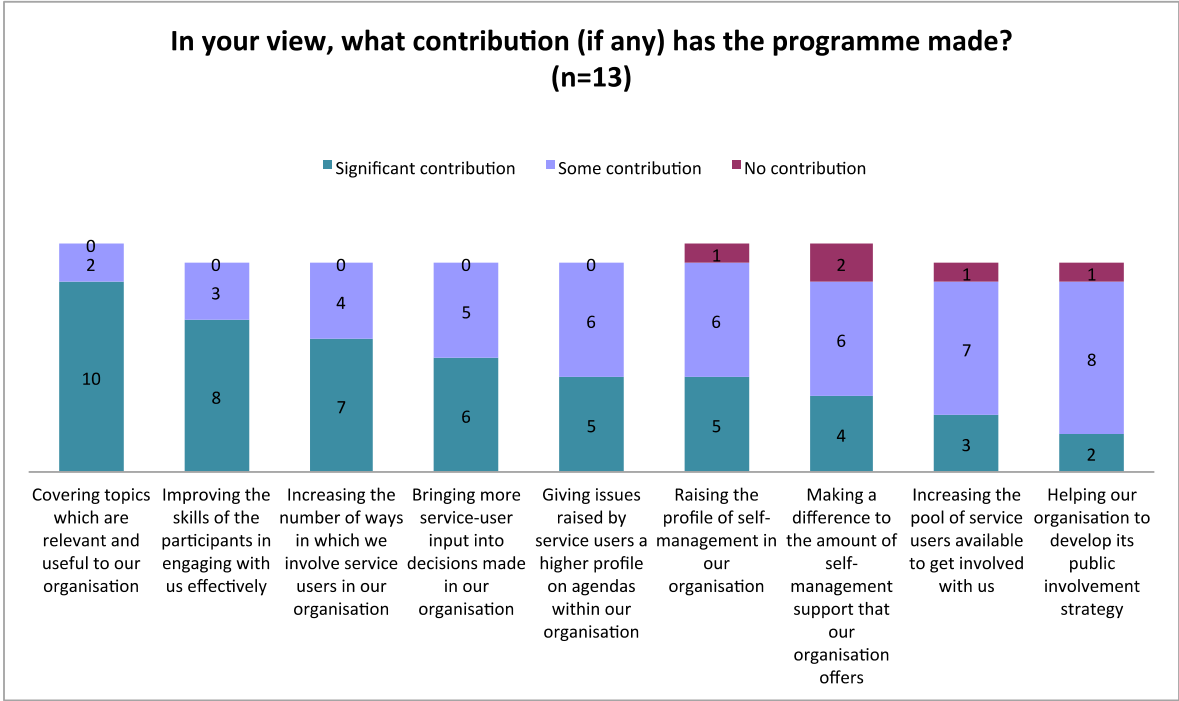
“My main role is as a community support volunteer. I've had experience of setting up exercise groups for people after a heart attack, and now I go around these groups, explaining my experience and promoting the importance of regular exercise. In addition to the benefits of exercise, these groups are really important and useful for sharing experiences, impact of different drugs etc.”

“In some situations you're in, it can be hard not to become angry... what I really learnt through the training was to be assertive and not aggressive.”

The impact of the programme on NHS organisations in Scotland

Healthcare service managers who responded to the evaluation survey reported the following impacts on their organisations:

Figure 3 Views of healthcare managers commissioning the programme locally about what it has achieved



The most significant barrier reported by healthcare managers to involving service users more in their organisations was lack of dedicated staff time to support service users in being involved. Staff attitudes and culture were reported as a ‘slight barrier’ in more than half of the organisations represented.

The following quotes were provided by healthcare managers.

“[After the workshop], patients are able to put in context their contribution to meetings and to be appropriate in the content of conversation and the impact that it has on others. It has also helped people to appreciate the complexities of the organisation and how they can positively influence the improvement agenda.”

(Managed Clinical Network Manager)

“Participants benefit directly in that they are more prepared on an individual level to come along to forums. They have a background understanding of what difference they could make and what contribution they could offer – and in particular about whether they are speaking as an individual or as a representative of a collective.”

(Managed Clinical Network Manager)

“The Chest Heart & Stroke Scotland approach has helped people to focus on the agenda of self management and make a positive impact – not just to use their voice as user reps to complain or gripe about things like parking.”

Factors identified as key to the programme’s success

The evaluation found that the notable success of the programme in achieving its aims can be attributed to a number of factors including the following.

- The relevance of the programme materials and the appropriateness of the messages, developed and refined over many years.
- Chest Heart & Stroke Scotland’s respected and neutral position and wider role as a patient organisation and in Scottish healthcare policy.
- Close and ongoing working relationships between the trainers and NHS organisations working with involved service users, especially Managed Clinical Networks. This enables participants to be deployed effectively after the training.
- Ongoing support from the trainers for both participants and healthcare service staff after the training. This enables problems to be resolved as they arise, and keeps participants motivated, despite occasional setbacks.
- The flexibility and adaptability of the programme for different situations and to suit service users with particular needs, coupled with the expertise and experience of the facilitators.
- The inclusivity of the programme to all comers, enabling a diverse range of service users to be involved and to use the programme in different ways.

Conclusions

The evaluation found that the Voices Scotland programme has made a significant and distinctive contribution over a sustained period of time. However, there is still much to do in terms of extending the reach of training to people with conditions relating to chest, heart and stroke, reaching every NHS Board area and replenishing the supply of trained service users.

The evaluation found that the programme goes far beyond simply providing a set of effective training materials, but crucially combines these with an approach to facilitation and support which has been developed over years by the dedicated Chest Heart & Stroke Scotland team. Replicating this is not straightforward, and any organisation seeking to do this will need to pay attention to the features of the programme that make it work.

Placing self management front and centre within the programme is an innovative development which differentiates it from other public involvement training, and gives participants an immediate agenda to work with which is directly relevant to them. Voices Scotland is ultimately about enabling healthcare professionals and managers to value the lived experience of patients and move towards co-production. This fits squarely with the national policy of 'co-creating health' with patients, extending from the level of shared decision making between individual healthcare professionals and patients through to service users being involved in setting national health policy. Thus the programme is highly relevant to the NHS agenda in Scotland.

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