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Chest Heart & Stroke Scotland

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Evaluation of Chest Heart & Stroke Scotland

Voices Scotland Programme

April 2014

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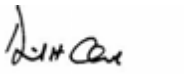
Introduction

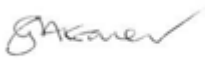
This evaluation was jointly commissioned by the Scottish Health Council and Chest Heart & Stroke Scotland. Voices Scotland is a core funded project within Chest Heart & Stroke Scotland, and has also been supported by Scottish Government funding.

“Through Voices Scotland, people are empowered to use their own experiences of care to work alongside health & social care professionals, to improve existing services and develop new approaches. The programme also plays a vital role in supporting the professionals involved to engage effectively with their public. I am delighted that this independent evaluation has demonstrated such positive outcomes. The very wide range of involvement opportunities which participants go on to take up is testament to the growing understanding that a mutual and partnership approach is both vital, and effective, in developing new and improved services.”



David Clark, Chief Executive, Chest Heart & Stroke Scotland

“Living with a long term health problem can provide many daunting challenges for people and providing meaningful services that meet the needs of people is also a challenge for healthcare professionals and managers. Both need strong collaborative partnerships with each other and require people who are enabled to be in the driving seat of their care. The Voices Scotland programme is not just an exemplar of how to support partnership working but also provides valuable insights into the challenges that this involves.”



Dr Graham Kramer, National Clinical Lead for Self Management and Health Literacy, the Scottish Government

“This positive independent evaluation puts Chest Heart & Stroke Scotland at the forefront of supporting activated patients and empowered service users who are able to contribute with confidence to shaping and improving local health and social care services. We look forward to working with Chest Heart & Stroke Scotland to pilot this approach in the new integrated health and social care bodies and to developing high quality models of public and service user involvement. The pilots will involve Scottish Health Council staff and NHS practitioners delivering an adapted version of the Voices Scotland programme with ongoing mentoring and support from the Chest Heart & Stroke Scotland team.”

Richard Norris, Director, Scottish Health Council

Executive Summary

This report follows an independent evaluation of the Voices Scotland programme, which is delivered by a dedicated team at Chest Heart & Stroke Scotland. The evaluation was jointly commissioned by the Scottish Health Council and Chest Heart & Stroke Scotland and carried out by Mynors Suppiah Ltd between November 2013 and February 2014.

Voices Scotland 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 healthcare service improvement. The programme has been running since 2005. Over the past three years, the programme has evolved to incorporate training for service users to become 'Champions of Self Management in Care' (COSMIC) training), with a view to developing a network of individuals within each NHS Board area who will champion self management locally.

Since 2012, COSMIC training resources have been made available to other patient and healthcare organisations who might wish to adapt and use it with the service users they work with.

This evaluation involved a review of existing data and reports about the programme, surveys of programme participants and healthcare managers involved in the programme, together with focus groups and telephone interviews.

Key evaluation findings were as follows:

- Since April 2011, the programme has trained 506 workshop participants and delivered 'taster' sessions and other short workshops to a further 854 patients and healthcare professionals (including healthcare professional students).

- Of the 68 programme participants who responded to the evaluation survey:

    - 90% reported that they spent 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.

    - Over 40% had gone on to be a patient representative on a Managed Clinical Network committee or forum. 37% had commented on information for patients, 49% had taken part in a consultation event or focus group. Numerous other examples of engagement activities were given.

- 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.

- Of the 13 healthcare service managers who responded to the evaluation survey:

    - 73% said that the programme had made a significant contribution to improving participants’ skills in engaging effectively with their organisation.

    - 55% said that the programme had made a significant contribution to increasing the number of ways in which they involve service users in their organisation.

    - 91% said that the programme had made ‘some’ or ‘a significant’ contribution to the development of their organisation’s public involvement strategy, reflecting the strategic role of the Chest Heart & Stroke Scotland trainers in engaging with organisations beyond the workshops.

    - 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 becoming involved. Staff attitudes and culture were reported as a ‘slight barrier’ in more than half of the organisations represented.

- The wider impact of the programme on other organisations who might seek to roll it out has been relatively limited to date, but there are encouraging signs. Forty-five organisations have downloaded resources from the COSMIC resources website. The significant investment of time and expertise needed to implement the programme through other organisations means that it will take time to encourage them to do this.

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.

The evaluation also revealed a number of factors, below, which have the potential to limit the impact of the programme and which need to be addressed on an ongoing basis by Chest Heart & Stroke Scotland (and any other organisations considering implementing it).

- Working with healthcare service staff with limited time and who may turn over quickly is challenging. An ongoing investment in building relationships with local NHS organisations is required.

- Working with participants with serious health conditions means that, for some, their contribution is limited by health issues. There is, therefore, an ongoing need for succession planning for key service users, and ongoing training to bring on new users as needed.

- Although the Voices Scotland team has developed enduring relationships with many involved service users trained in the workshops, there is scope to find ways to keep in regular contact with a greater proportion of those who have attended.

- Covering self management and influencing all in one session is ambitious, and it is acknowledged that not all parts of the NHS are ready for 'Champions of Self Management in Care'. Standalone 'Voices' training remains relevant and needed, alongside COSMIC training. The evaluation found that the flexible modular approach to selecting the training elements required for each particular situation works well, but this could be made more explicit.

- Time and resource needs to be put into a proper branding and marketing plan for the programme going forward. This should link the different elements of the programme in a way that is simple to understand for participants and healthcare managers engaging with it.

In summary, the evaluation found that the Voices Scotland programme has achieved notable impact. There is still much to do in terms of extending the reach of training to people with conditions other than those relating to chest, heart and

stroke, reaching every NHS Board area and replenishing the supply of trained service users, but the Voices Scotland team has made a significant and distinctive contribution over a sustained period of time.

The evaluation also 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.

1. Introduction

Voices Scotland is a programme of workshops and support for involved patients and carers, together with advice and facilitation for NHS managers and clinicians, delivered by a dedicated team at Chest Heart & Stroke Scotland. The programme equips patients and carers to participate in Managed Clinical Networks and other health and social care planning and redesign groups from a local to a national level and, more recently, to champion supported self management for people living with long term conditions.

This is the report of an independent evaluation of the Voices Scotland programme. The evaluation was jointly commissioned by the Scottish Health Council and Chest Heart & Stroke Scotland and carried out by Mynors Suppiah, an independent consultancy appointed through a competitive tendering process. The evaluation research was carried out between November 2013 and February 2014.

Note on terminology: As described in section 2 below, the programme and workshops have been known under a number of names, including 'Voices Scotland', 'Having your say', 'Self Management Champions' and 'Champions of Self Management in Care' (COSMIC). **For ease of reference, we refer to the programme throughout this report simply as 'Voices'**, but we draw out, where relevant, the differences in the approaches taken as the programme has evolved. Throughout the evaluation, we referred to the programme with participants by whatever name(s) they had known it as.

The rest of this report is structured as follows. **Section 2** describes the objectives of the programme and its evolution over the past eight years. It then describes in some detail how the programme is delivered today. **Section 3** explains our approach to the evaluation and the evaluation methodology and tools. **Section 4** describes the results of the evaluation in terms of the outputs of the programme for the past three years, the impact of the programme on programme participants and their ability to bring about change, the impact on managers and professionals in the health service who have been involved with the programme, and the impact on other organisations who might adopt and use the programme with their constituents. **Section 5** interprets these findings and provides an analysis of the features of Voices Scotland which make the programme work, as well as recommendations to address some of the challenges the programme faces. Finally, **Section 6** sums up with some brief concluding remarks.

2. Objectives, evolution and delivery of the programme

a. Development of the programme – from Voices Scotland to Champions of Self Management in Care (COSMIC)

In the past decade, a priority of health policy across the whole of the UK has been to shift the culture of healthcare services from one in which patients were viewed as passive recipients of care, to one where patients are active partners in their own care, supported to get involved in the decisions which shape healthcare services and told how their views have been taken into account. Within Scotland, **Better Health Better Care**[1] (2007) and the **Participation Standard**[2] (2010), which followed from it, set the aspiration for a "mutual NHS" where health services meet the needs and preferences of individuals. The **NHS Scotland Quality Strategy**[3] (2010) builds on these foundations and commits to "putting people at the heart of our NHS… Our NHS will listen to people's views, gather information about their perceptions and personal experience of care and use that information to further improve care".

Chest Heart & Stroke Scotland is fully committed to ensuring the patient/carer voice is heard across health and social care service redesign and delivery, and that self management is key to ensuring person-centred care is provided for people living with long term conditions. Voices Scotland, which addresses both these issues, is a core funded project within Chest Heart & Stroke Scotland, although it has also been supported by Scottish Government funding.

The Voices programme was first implemented in 2005 by Chest Heart & Stroke Scotland as 'Hearty Voices', delivered in partnership with the British Heart Foundation who had developed and used it south of the border. The programme's aim was to equip patients with the knowledge, skills and confidence to work with the NHS to improve services. Supported by Scottish Government funding, Chest Heart & Stroke Scotland extended the programme in 2009 by developing 'Chest Voices' and 'Stroke Voices', the latter being an innovative adaptation of the programme that enabled people affected by stroke, including those with aphasia

[1] NHS Scotland, Better Health Better Care: a discussion document http://www.scotland.gov.uk/Resource/Doc/194854/0052337.pdf

[2] Scottish Health Council, A participation standard for the NHS in Scotland http://www.scottishhealthcouncil.org/patient__public_participation/participation_standard/participation_standard.aspx

[3] Scottish Government, NHS Scotland Quality Strategy – putting people at the heart of our NHS (2010) http://www.scotland.gov.uk/Publications/2010/05/10102307/0

(loss of speech), to take part. In this same year, the Voices Scotland umbrella brand was created. The stated objectives of the programme were as follows[4]:

> The Voices Scotland project supports the Scottish Government's vision of a mutual NHS by ensuring that chest, heart and stroke patients' and carers' views are represented, and their voices heard, and that they have the opportunity to be involved in a meaningful way in the work of NHS Scotland. 'Voices Scotland' aims:
>
> - to provide people affected with chest, heart or stroke conditions, and their carers, with the skills and confidence to work alongside the NHS to develop person-centred services
> - to empower patients and carers through access to information, training and support
> - to develop a supportive network of chest, heart and stroke patients and carers, and
> - to encourage partnership working between the NHS and the voluntary sector.

2011 saw the development of Self Management Champions training as an element of the Voices programme. This reflected the Scottish Government strategy of promoting supported self management in order to improve patient outcomes for

[4] Scottish Government, Better Heart Disease and Stroke Care Action Plan (2009), http://www.scotland.gov.uk/Resource/Doc/277650/0083350.pdf

people with long term conditions[5]. The vision of the project, built on the work of the Long Term Conditions Collaborative, was to galvanise the people of Scotland to become advocates of self management; encouraging their local NHS Boards and Managed Clinical Networks to ensure self management was at the heart of service planning and redesign. The programme was to be implemented not only by Chest Heart & Stroke Scotland but also by other voluntary and patient organisations. Chest Heart & Stroke Scotland developed a programme of networking and 'showcase' events to promote the programme, together with a 'train the trainer' approach to helping other organisations to deliver it. The Scottish Government Long Term Conditions Unit funded this work. The objectives were[6]:

- to empower patients/carers through training to become champions for self management, supporting local initiatives and promoting strategies among healthcare professionals, patients and carers
- to work with existing organisations and initiatives to ensure an integrated and generic approach to the training
- to disseminate the training session, resources and evaluation through the Long Term Conditions Alliance Scotland for use by other voluntary organisations, and
- to integrate the key concepts of self management into the existing Voices Scotland training.

The Self Management Champions workshop was piloted and evaluated in the first quarter of 2011, and was incorporated within Voices Scotland in the summer of 2011 under the name 'COSMIC' (Champions of Self Management in Care). COSMIC is offered over two days: day one is about self management, and day two is the 'Having your say' training day about influencing the NHS, which is also offered as 'Voices' training. The COSMIC workshop gives programme participants a very tangible agenda item around which to focus their influencing skills by promoting self management support and initiatives in planning and service development at national and local level. It also encourages participants to get involved in promoting self-management approaches within their own communities and support groups.

The vision for COSMIC is to develop a network of individuals within each NHS Board area who champion self management within their own community. This network will have a practical remit to support others who have been affected by the same condition to encourage them to self manage. This is currently being piloted with stroke patients in Lanarkshire and Tayside, and there is an active patient and carer group in Fife who have been influencing self management within their respiratory Managed Clinical Network since attending the COSMIC training.

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[5] Scottish Government and Health and Social Care Alliance Scotland, "Gaun Yersel" The Self Management Strategy for Long Term Conditions, http://www.alliance-scotland.org.uk/resources/library/search/Gaun+Yersel/

[6] Unpublished document: Chest Heart & Stroke Scotland update to the Scottish Government on the development of Self Management Champions, 2011.

In the summer of 2012, the full set of materials for COSMIC training, together with a comprehensive, practical manual on how to combine and deliver the different elements, were made available on the COSMIC Resources website[7], accessible directly and also via the Health and Social Care Alliance Scotland ('the ALLIANCE') website. Showcase events, together with informal support for other organisations interested in adapting and implementing COSMIC, have been ongoing.

This programme history can be summarised at a glance as follows:

Figure 1 Overview of Voices Scotland development

2005	Hearty Voices introduced in Scotland by Chest Heart & Stroke Scotland, in partnership with British Heart Foundation
2009	Chest Voices and Stroke Voices piloted and introduced, supported by Scottish Government funding
2009	Voices Scotland brand established as the umbrella for the programme
2011	Pilot of Self Management Champions course, funded by the Scottish Government (February) Voices Scotland incorporated Self Management Champions under the name COSMIC (Champions of Self Management in Care) and piloted (December)
2012	COSMIC 'Train the trainer masterclass' pilot (February) Full COSMIC resources available on the ALLIANCE website (summer)
2013	Chest Heart & Stroke Scotland continues to offer the full suite of Voices Scotland sessions either as COSMIC training or Hearty Voices, Chest Voices or Stroke Voices This evaluation of the Voices programme (including COSMIC) commissioned (November)

[7] http://www.cosmicresources.org.uk/

b. Delivery of the programme

i. The Chest Heart & Stroke Scotland team

Voices Scotland is delivered by a team of three Chest Heart & Stroke Scotland staff, who describe themselves as follows:

Nicola Cotter (Voices Scotland Lead) has a training background. She has been leading the programme for Chest Heart & Stroke Scotland for the past eight years and has been integral in its development, as well as being responsible for over 70 Heart & Chest Peer Support Groups across Scotland. She is passionate about ensuring all patients and carers are supported to enable them to constructively feed into the NHS at the appropriate levels, and she is keen to pass on the lessons learned from the Voices Scotland programme to other Long Term Conditions Organisations.

Dave Bertin (Voices Scotland Trainer) is an experienced nurse who has spent most of his career in the mental health field as a Cognitive Behavioural Therapist, lecturer and manager. As a manager, he led a major redesign project which was praised for the way in which the public was involved. During that time he developed the belief that the patient must be seen as the centre of services and that the litmus test of service design is how comprehensively the service meets the needs of the end users – the patient and their family and carers. He now promotes this way of working though teaching about self management and public involvement – both of which place the person at the centre of care.

Juliet MacKellaig (Voices Scotland Co-ordinator) had a nursing background before joining the Chest Heart & Stroke Scotland Advice Line and joined the Voices programme in 2009 to support the piloting of Stroke Voices. Her role is to administrate the programme, develop new materials, recruit participants to the workshops and provide ongoing evaluation support.

The two Voices trainers usually deliver workshops individually, and each takes responsibility for particular NHS Boards and areas, but occasionally run larger events together.

ii. Participant recruitment

Chest Heart & Stroke Scotland has developed a number of materials including leaflets and postcards aimed at publicising the programme to ‘host’ NHS organisations who might want to invite Chest Heart & Stroke Scotland to run it locally. They also recruit participants directly via a number of channels, including:

- Chest Heart & Stroke Scotland affiliated patient support groups and Breathe Easy groups, and
- community stroke services run by Chest Heart & Stroke Scotland, which provide a social and therapeutic forum for people who are recovering from stroke, especially those with speech and language difficulties.

The programme now has sufficient profile that most workshops are put on in direct response to an approach from an NHS organisation. In other instances (though less frequently), the Chest Heart & Stroke Scotland team will initiate a workshop if they become aware that there is a local patient group who are particularly keen to do more, or are struggling to find a forum to raise their local issues. Before delivering a workshop, the facilitators meet the key NHS staff involved in the Managed Clinical Network or Public Partnership Forum, discussing the practicalities of training, how the content can be tailored to the local situation, the tone of the training and the 'mutual model' philosophy which underpins it.

A key principle employed by the team is to ensure that participants trained up in workshops have 'somewhere to go' afterwards in terms of an opportunity to use their new skills through being involved in a local network or group. Both programme participants and NHS staff who have invited the Voices team in to run workshops are encouraged to keep in touch with the facilitators afterwards and seek them out for further information and advice, and many do (as discussed in section 4.2 below).

iii. Workshop contents

An outline of the core two-day workshop contents and learning objectives, as currently delivered, is given in Appendix A and described in detail in the COSMIC trainer manual[8]. The materials are often adapted to meet local requirements and may be delivered in alternative formats (for example over a larger number of shorter sessions for people for whom whole days are too taxing). The core workshop comprises two days:

Day 1: Understanding self management

Aim: To develop a strategic understanding of self management, what it constitutes, including the various models of self management and the breadth of support that is available to help someone self manage.

It is not a prerequisite of attending the workshop that participants should have taken part in a self-management course in relation to their own condition, and many participants use the opportunity of day one of the workshop to reflect on how they manage their own health and wellbeing, before thinking about how this might be used to influence others.

Day 2: Champions of Self Management ('Having your say')

Aim: To empower the Champion of self management with the knowledge, skills and tools to enable them to influence local services in a logical and evidence-based manner.

[8] Available at http://www.cosmicresources.org.uk/day-1-understanding-self-management/

Based on the original Voices training, day two is about influencing healthcare services. An important element of day two is a degree of agenda setting and identifying priorities for the group to take forward after the workshop. Participants work through the 'Case for Change' template which helps them to organise the arguments for a change or improvement in services using a real example of a local issue.

The following case study illustrates how the Voices training day has been adapted for use within one NHS Board.

Case study: Flexible delivery of elements of COSMIC at NHS Greater Glasgow and Clyde

NHS Greater Glasgow and Clyde has developed a patient and carer forum[9] which now includes over 200 patients and carers with a variety of long term conditions, facilitated by the NHS Greater Glasgow and Clyde Long Term Conditions Health Improvement Team. The forum provides representatives for six Managed Clinical Network patient subgroups – Cardiac, Stroke, Diabetes, Rheumatology, Respiratory and Pain Management. Other members of the forum get involved in a range of other projects, respond to consultations and share their stories in a variety of ways.

NHS Greater Glasgow and Clyde offers Voices training, delivered jointly with Chest Heart & Stroke Scotland, to all the Managed Clinical Network representatives.

Marion O'Neill, Long Term Conditions Lead, said: "The benefit of Chest Heart & Stroke Scotland being an external organisation is that they are independent and have a real patient voice. It's not the NHS telling these people what's expected of them".

iv. Ongoing support for participants and healthcare service managers

An important element of the Chest Heart & Stroke Scotland team's work is providing informal support and coaching to NHS managers before and after training workshops. The trainers often return to where they have delivered training to attend forum meetings and provide a degree of facilitation, especially where public involvement teams encounter difficulties. The team reports that one of the challenges to patient involvement is when a key member of NHS staff leaves or moves post, or if an engaged patient in a leading role needs to step aside (for example due to ill health). It can then take a while to find others who are committed to patient engagement and to support them in taking forward the involvement agenda locally. Providing support for this kind of continuity is a significant part of the trainer role.

[9] http://www.nhsggc.org.uk/content/default.asp?page=s1421_2

v. Other sessions delivered by the Voices team

In addition to the workshops, the Voices team has delivered a range of other sessions in support of the programme's aims. For example:

- 'Taster' sessions for patients, e.g. at the Active Ageing Conference held in 2012.

- 'Taster' sessions and lectures for healthcare professionals and healthcare professional students, including lectures about self management and the mutual model of care to 150 nursing students at Napier and Queen Margaret Universities in Edinburgh during 2012/13.

- 'Showcase' events, run eight times in the past year, which combine elements of the workshops in a 'taster' format with presentations from organisations who have implemented the programme locally talking about how it impacted on them.

- Sessions to gather ideas and feedback from patients and carers, including focus groups held with 53 people and results fed back as part of the Audit Scotland review of Cardiology care held in 2011/12.

- Presentations at National Advisory Committees and all party parliamentary groups.

A summary of participants in workshops and other sessions is given in section 4.1 below.

3. Evaluation approach

a. Developing the evaluation framework

Our approach to evaluating the Voices Scotland programme began with the development of an evaluation framework to define:

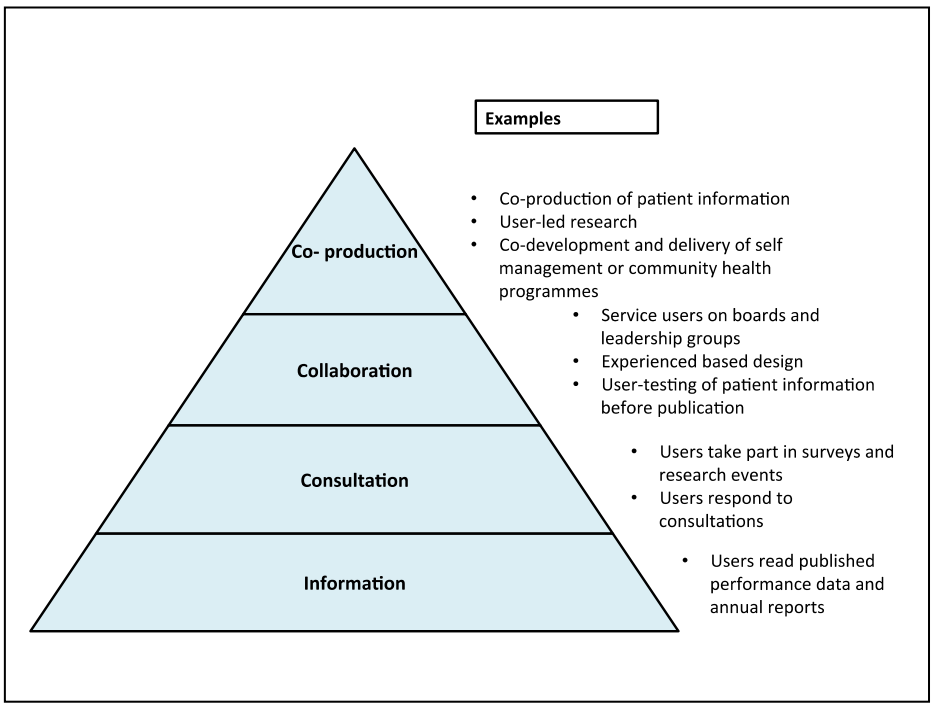
- **Audiences:** the different groups which the programme works with to achieve impact.
- **Activities:** what the Voices Scotland team does, for example delivering training workshops to service users, and providing informal support to Managed Clinical Network managers to enable them to involve patient representatives effectively.
- **Outputs:** the raw numbers describing the activities delivered, for example number of attendees at training workshops.
- **Intermediate outcomes:** the short-term goals of activities, such as workshop participants having greater knowledge of how healthcare systems work or an intention to get involved in championing self management.
- **Endpoint outcomes:** the longer-term results of the programme, such as patients participating meaningfully in decisions about healthcare services and making a tangible difference to services provided.
- **Indicators:** these signal whether outcomes have been achieved. An example would be numbers of workshop participants who have gone on to be actively and meaningfully involved in improving healthcare services.

The process of populating the evaluation framework was informed by a review of the stated objectives of the Voices Scotland programme. In addition, we reviewed workshop evaluation forms completed over the past two years, and carried out formative discussions with the Voices team and an early Voices participant and involved service user.

We noted that the range of involvement activities carried out by participants as a result of the programme is potentially very wide, as shown in figure 2[10]. It was important to capture the full spectrum of involvement in our evaluation tools.

[10] Mynors Suppiah model, based partly on Arnstein, Sherry R. A Ladder of Citizen Participation JAIP, Vol. 35, No. 4, pp. 216-224 (July 1969)

Figure 2 Levels of patient and public involvement in healthcare



Having agreed our evaluation framework, we then designed evaluation tools to collect data against the elements of it.

b. Evaluation tools and methodology

Data for the evaluation was collected in the following ways:

i. Interviews with Chest Heart & Stroke Scotland team and document review

We carried out formative interviews with members of the Chest Heart & Stroke Scotland team delivering the programme, and reviewed documentation including workshop evaluation forms, data on numbers of programme participants, internal reports on the project and Google analytics data on the use of the COSMIC Resources website.

ii. Survey of Voices/COSMIC participants

We developed a survey which was sent to 136 participants at Voices and COSMIC workshops between April 2011 and November 2013. These were all the participants where Chest Heart & Stroke Scotland either held contact details or could contact them via other organisations who had hosted the workshops, and represent approximately 40% of people who attended a workshop over this period. Seventy people were invited to participate via an email containing a link to the online version of the survey, and the remaining 66 participants (where no email address was held) were invited to take part by letter and sent a paper survey.

Invitations were sent out in the week of 9th December 2013. An initial deadline of Christmas was given, but this was subsequently extended into the second week of January 2014. Those surveys which were returned by post were entered into the online tool. In total, 68 surveys were completed, resulting in a response rate of 49%.

iii. Focus groups and telephone interviews with participants

Two focus groups, each of two hours' duration, were held on 4th and 5th February 2014, in Dundee and Edinburgh respectively. These were supplemented with eight 20-30 minute telephone interviews with participants who were unable to attend either of the groups. Participants for the focus groups and telephone interviews were self-selected through the survey, which asked respondents whether they would be willing to take part in one or both of the focus groups. The two focus group locations were chosen out of a possible nine given in the survey, based on where most participants could attend. Focus group participants were given a £30 gift voucher in thanks for their time, and travel expenses were paid. Of the initial respondents to the survey, 33 indicated that they would be willing to take part in a focus group, and 19 (with some overlap) in a telephone interview. Everyone who put themselves forward was given the opportunity to take part in either a group or interview, and those who did not either dropped out because of illness or changed their mind due to personal circumstances.

The purpose of the focus groups and telephone interviews was to explore in greater depth whether and how the Voices programme had supported participants to achieve change. The topic guides were based on the evaluation framework and with input from the project steering group.

iv. Survey of managers/commissioners of the programme

A short online survey was sent to 25 NHS managers and others who had commissioned or hosted the Voices workshops. Thirteen responded, giving a response rate of 52%. The survey explored the impact of the programme on participants with whom the respondents had worked, as well as its wider contribution to improving patient participation locally.

v. Telephone interviews with managers/commissioners of the programme and other stakeholders

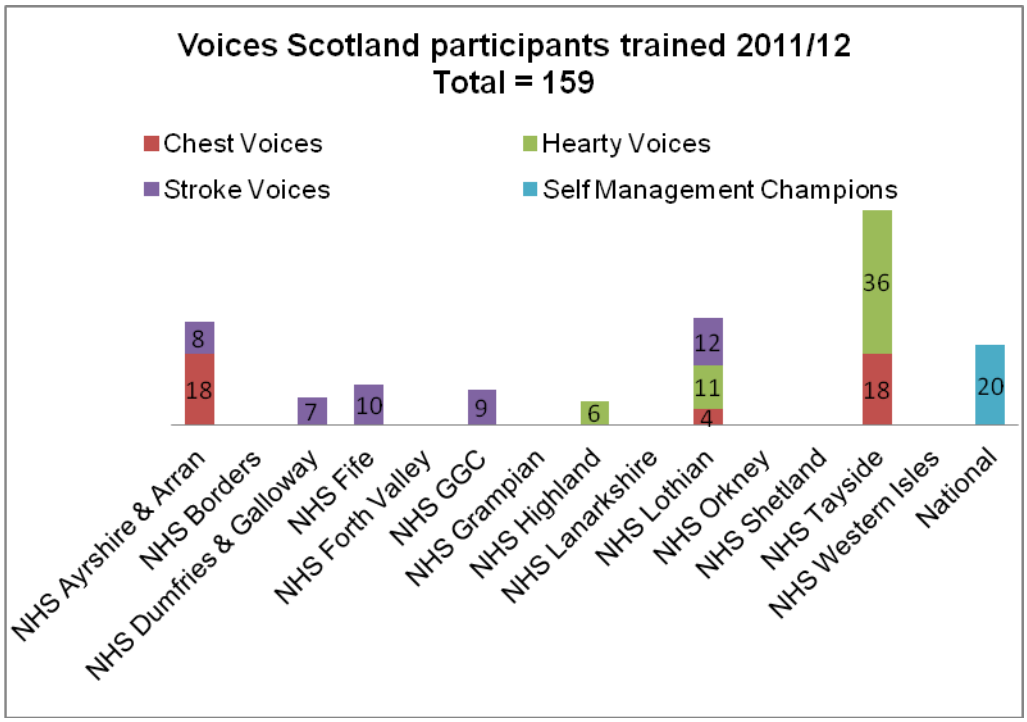
We carried out eight telephone interviews with NHS managers and commissioners of the service, including Managed Clinical Network managers, together with three telephone interviews with other people who had been involved in the programme – from the Scottish Health Council, the ALLIANCE and the Lothian Centre for Inclusive Living (who have adapted and used the programme).

4. Evaluation findings

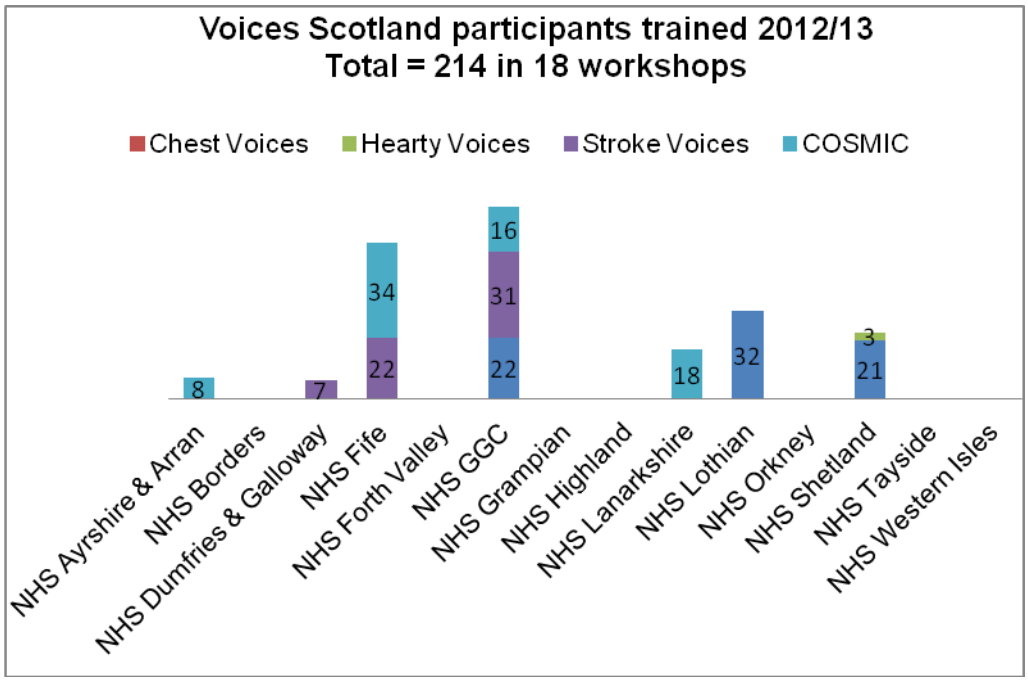
a. Programme outputs – events held and participants trained

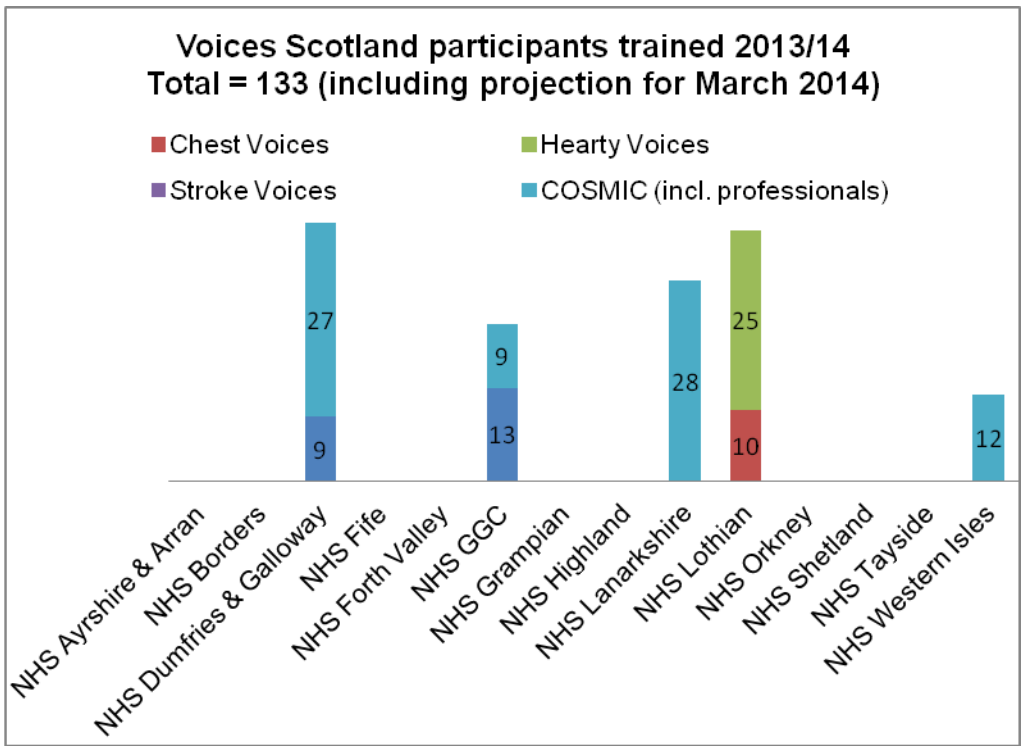
The three charts in figure 3, below, show the number of participants on Voices Scotland workshops over the past three years, by NHS Board. These include both workshops hosted by Chest Heart & Stroke Scotland and by other NHS organisations who invited the participants locally. The total number of participants trained in the past three years[11] is 506.

Figure 3 Participants in Voices workshops over the past three years



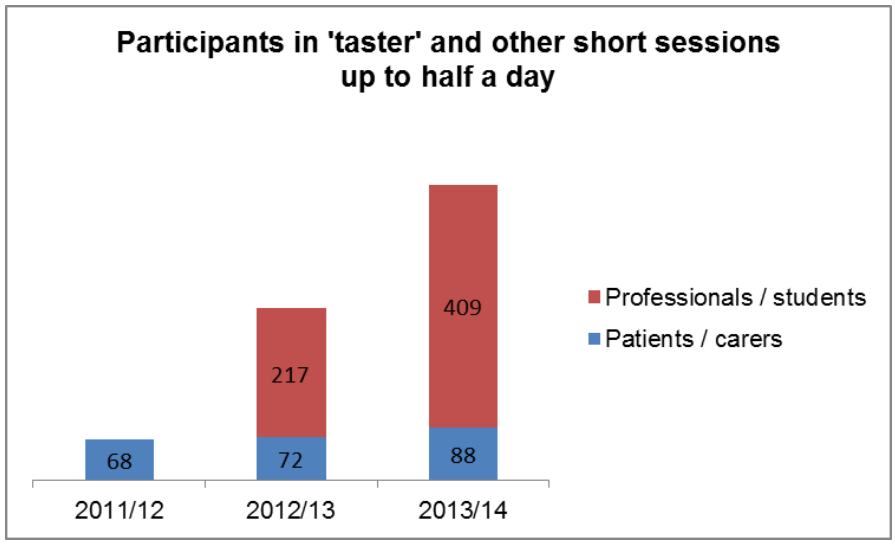
[11] Including a projection for March 2014





In addition, a total of 854 patients and healthcare professionals (including students) have taken part in 'taster' and other short sessions, introducing them to the ideas contained within the programme, as shown in figure 4.

Figure 4 Participants in taster sessions 2011/12 - 2013/14



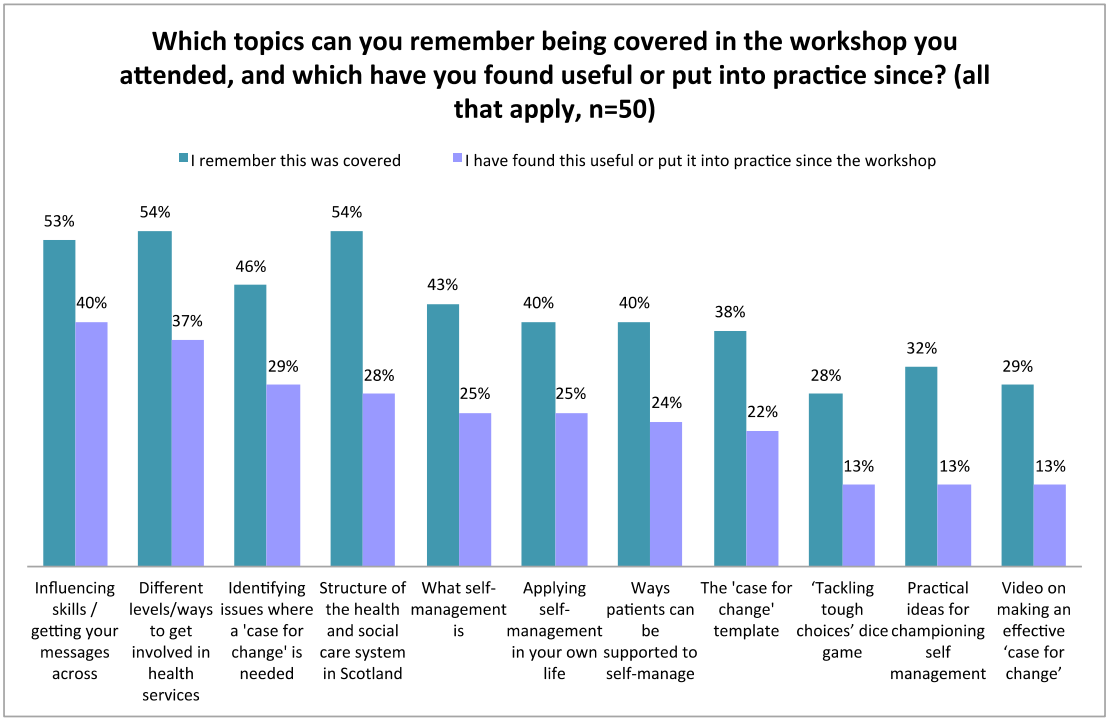
b. Impact of the programme on participants, and their ability to effect change

Sixty-eight programme participants responded to the survey, and a description of their demographics, when they attended the workshop, and any roles they played at the time is given in Appendix B. Not all respondents answered all the questions in the survey, and in the following charts the number of respondents to each question is given as 'n' in each case. Quotes from the survey are supplemented with quotes from the focus groups and telephone interviews.

Many respondents were unclear about which version of the workshop they had attended – unsurprising given the range of different names that the workshops have been known under and the fact that they attended up to three years ago. However, the responses indicate that most of the respondents went through Voices training rather than the newer COSMIC training, incorporating the self-management element. 62% of respondents said they were already involved in some kind of public representative role before taking part in the programme, but 38% were not. 12.5% were not involved in healthcare services in any way, even a support group.

The survey asked participants to think back to the contents that they recalled having been delivered at the workshop they attended, and which elements they had found useful since, and the results are shown in Figure 5.

Figure 5 Topics from the workshop recalled and used participants



Comments on the most useful elements of the workshop included several references to the 'case for change' approach and influencing skills session, together with the contents on the structure of the NHS in Scotland:

> "Cogent, logical structured argument of case."
>
> "Evidence gathering to present a case for change."
>
> "The Dice game and 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."
>
> "Importance of focusing on achievable issues and reducing verbiage."
>
> "The video, the info on the structure of the NHS and the change template."

Some respondents stated that the workshop had helped them to understand the role of self management.

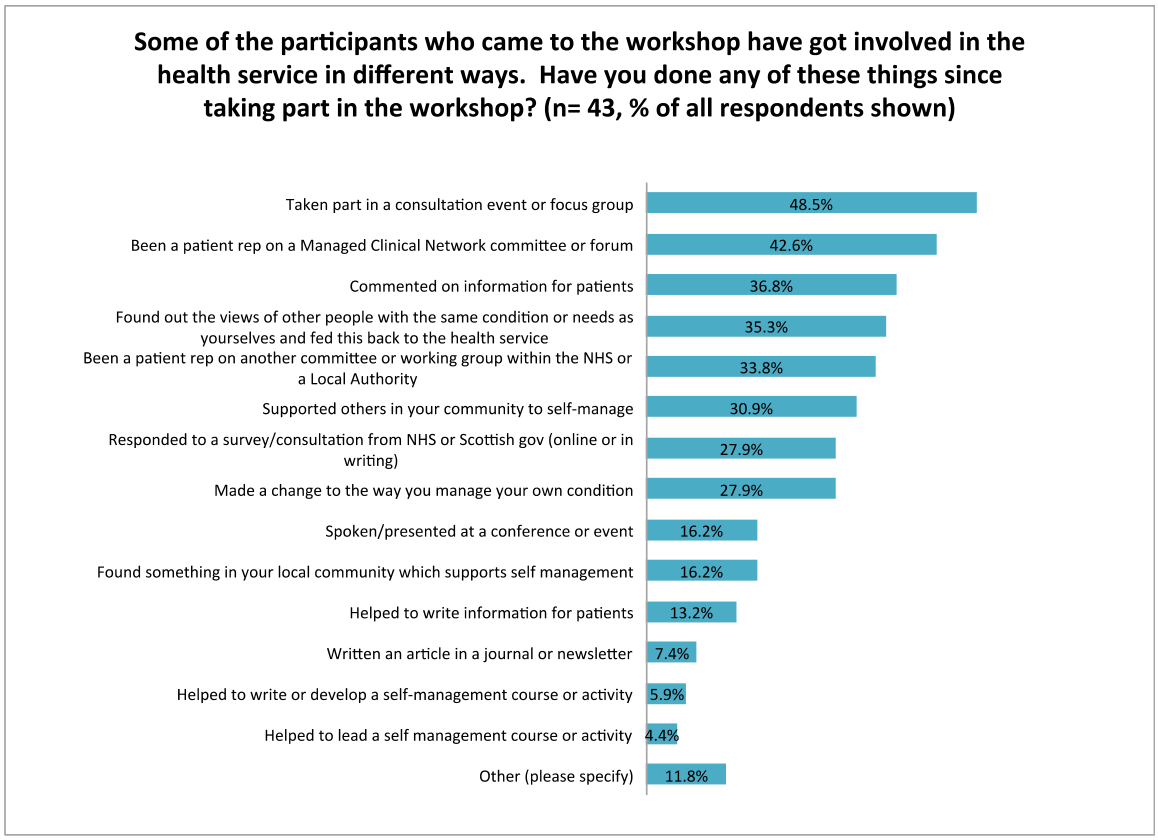
> "One has to take responsibility, in co-operation with NHS doctors/nurses etc, for one's own health."
>
> "The effectiveness of self-management and how to promote that message to others."
>
> "Gaun Yourself - learning about self management and understanding it doesn't mean doing it all yourself."

Others mentioned the inclusive and supportive atmosphere generated in the training itself as having been the most useful element.

> "Being able to exchange ideas and express views in a non-challenging atmosphere."
>
> "Trainers allowed everyone to get involved in their own time. I think that is very important as stroke survivor."
>
> "[The Voices Scotland trainer], he's definitely the expert at running and organising it. He was very encouraging, getting you thinking. I give the time that I have [to patient involvement] because I got so much from the training at a time when I was very low." (Telephone interview participant)
>
> "There was a lot on learning to listen, and respect others views, and if not respect, take it on board anyway – finding a middle ground."
>
> "It was also good to see the wide variety of ages, personal circumstances, how diverse the population was that was affected, and how different their priorities were."

Over a third of participants reported that they had gone on actively to use the influencing skills and techniques to get their message across. This is reflected in the range of different activities that participants have been involved in since attending the workshop. Figure 6, which shows the activities carried out by participants as a percentage of the full sample of 68 respondents, speaks for itself. Of note, over 40% of workshop participants have gone on to be patient representatives on a Managed Clinical Network forum or committee.

Figure 6 Activities carried out by participants since the workshop



'Other' activities cited by respondents included the following.

> "I supported an NHS initiative to supply pulmonary rehabilitation classes and maintenance classes in my community. We raised funds to pay for hire of venue."

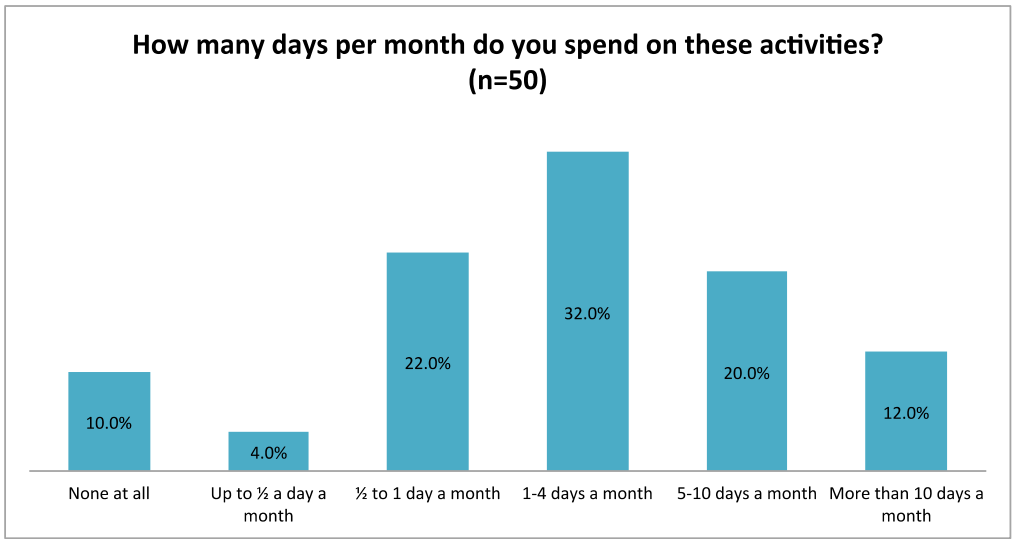
> "I prepared a Case for Change relating to clinic times convenient for patients."

> "I met with senior hospital staff at top level to discuss the poor care of a deceased family member."

> "I chair a respiratory patients' group and am part of a Buddies group."

Figure 7 shows the amount of time spent by participants on these activities. For some, being involved service users is akin to a part time (voluntary) job. 90% of respondents said that they spent some of their time on these activities.

Figure 7 Time spent by participants on involvement activities

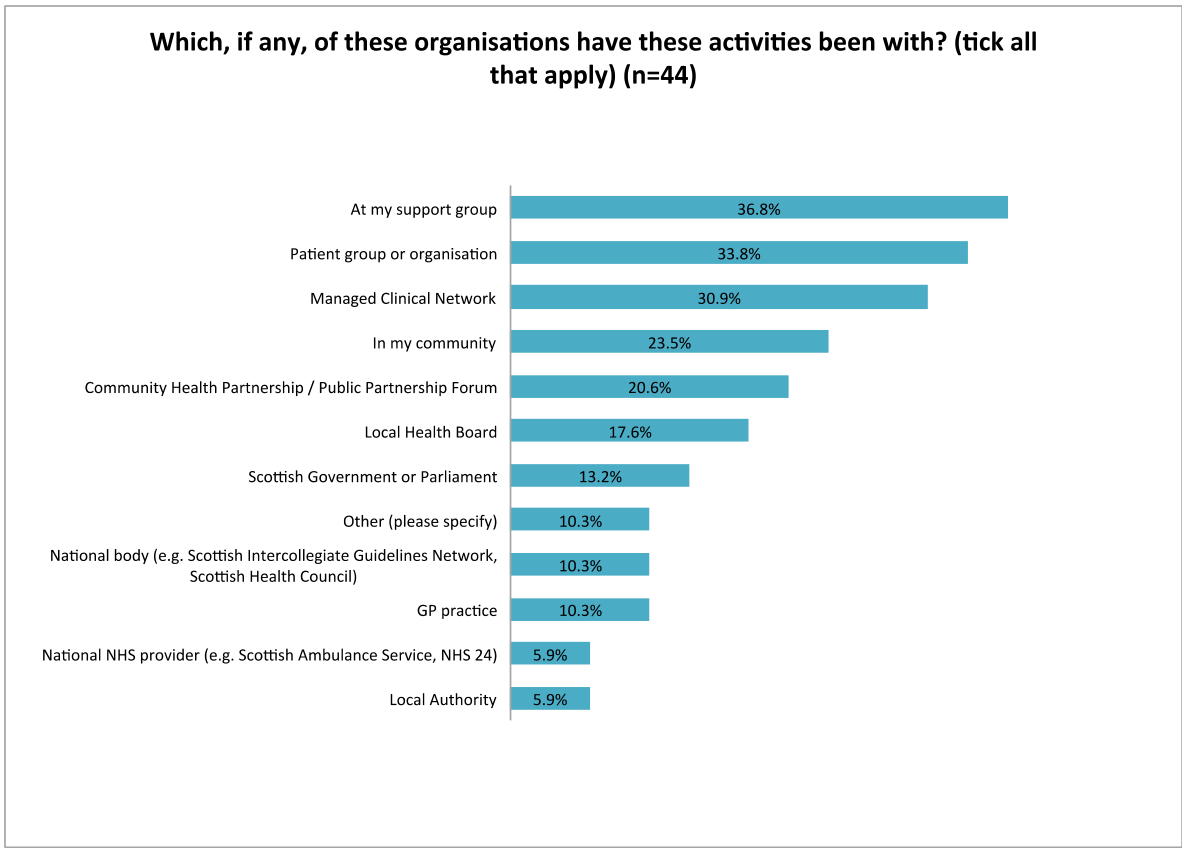


As figure 8 shows, the most common arenas for programme participants to be involved are patient support groups and patient organisations, but nearly a third of respondents who answered the question have been involved with a Managed Clinical Network. 14% said that they had been involved at national level with the Scottish Government or Parliament, and two focus group participants' experience illustrated how the power of a patient story could have a direct effect on policy:

> "I gave a presentation to the cross party group when it was looking at heart failure and NHS 24. I made a couple of suggestions that have been taken on board… one of these was that notes were available to out-of-hours doctors, based on my (late) husband's experience of out-of-hours care. Nicola Sturgeon was at the meeting. She said she would do something about it, and she did."

> "We spoke in front of MSPs to show that B's situation has been improved by the input of a clinical psychologist. We were there to show that people with long term conditions who receive psychological support are less likely to get depression. We really felt listened to. There were so many questions for B from the clinicians and the MSPs and we later received three letters from clinicians thanking us for sharing our story."

Figure 8 Organisations where programme participants have been involved



We asked participants to say what they felt most proud of having achieved since attending the workshop. Thirty-three respondents gave examples. Of these around half related to having **made a difference to the NHS**, for example:

> "Continuing with the process of making the case for more pulmonary rehab."

> "Becoming a member of the Managed Clinical Network Patient & Carer Sub Group."

> "Keeping the flag flying re relevant issues."

> "Fighting my corner where this is needed."

> "Becoming a member of several patient groups with contact/influence on decision makers."

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

> "My involvement as a lay facilitator with service users AND clinicians. My NHS Scotland SECC activity. My continuing activity with Co-Creating Health."

> "Facing up to management to help possibly bring about change."

"Championing the cause at the Scottish Parliament."

"As a group, putting a case forward for ongoing funding for pulmonary rehab."

"Chairing the Fife Managed Clinical Network Patient and Carers subgroup."

"Assisted in redesigning pathway of Cardiac Rehab."

"Being involved and helping focus of SIGN Guidelines and Clinical Standards re Cardiac Illness."

"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."

A smaller number of examples were about **helping other patients in a similar position:**

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

"Trying to help others to look and help themselves."

"Being involved in helping to prepare ways to help other people who are in hospital at present. Also giving advice in preparing questions to help patients just after having a stroke."

"Spreading the word to other patients re self management etc."

"Try to provide information sheets via Libraries and Exhibition Stands."

"Becoming co-ordinator for Different Strokes Ayrshire."

And a focus group member cited a similar example:

"My main role is as a community support volunteer. I've had experience of setting up exercise groups for people in Phase 4 recovery after a heart attack[12], 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 difference drugs etc."

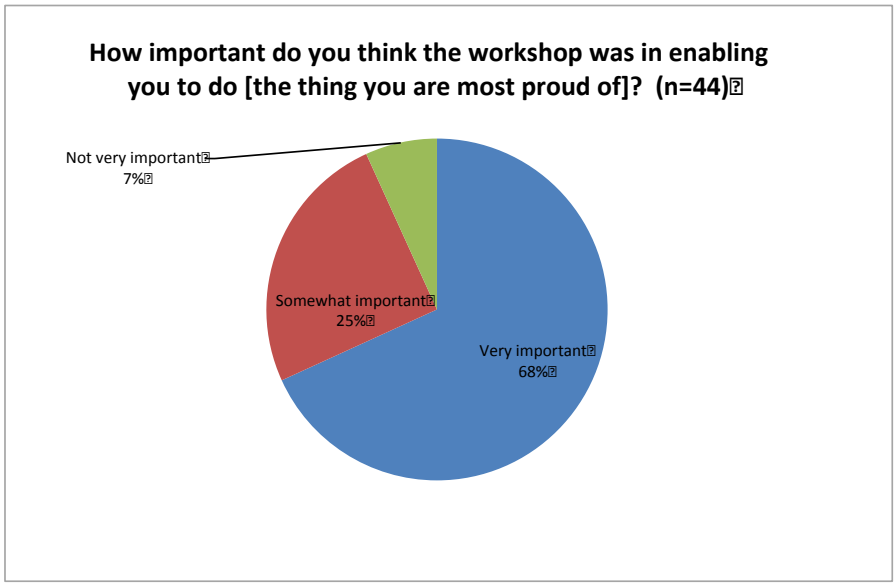
[12] Phase IV recovery after a heart attack recommends regular exercise 6-8 weeks after a heart attack http://www.chss.org.uk/pdf/publications/heart/H7_Heart_attack_a_guide_to_your_recovery.pdf, p9

A set of examples provided by respondents were about how **they had improved their own skills and knowledge or become more adept at managing their own condition.** In some instances, the programme and the participation which followed from it had clearly made a difference to their self-esteem and zest for life:

> "Being more confident at meetings and putting my points across."
>
> "I am now mostly attending a Local Authority gym twice a week for a programme set out for me by a specialist instructor. This exercise, I find, is beneficial to my breathing problems. I look forward to going to the gym each week. You've got to look forward to it in order to get the most out of it."
>
> "Accepting my condition (COPD) and trying to keep as healthy and active as possible."
>
> "Starting working again."
>
> "Self management of breathing problem."
>
> "Becoming a stroke survivor, not a stroke victim."
>
> "Keeping in control of health conditions which now affect me by reading up on them and asking questions of clinicians as the occasion arises."
>
> "It made a big difference to me. Before this I was just sitting, watching the TV." (Focus group participant)
>
> "What I really learnt through the training was to be assertive and not aggressive. In some situations you're in, it can be hard not to become angry." (Focus group participant)

The survey also asked how significant the workshop had been in helping participants to achieve what they were most proud of having achieved – in other words, could their contributions be attributed to the programme? As figure 9 shows, 68% said that they thought it had been 'very important', with only 7% saying 'not important'.

Figure 9 Perceived importance of the Voices workshop to participants' effectiveness



The survey asked about barriers to participants doing as much as they would wish since the workshop. As figure 10 shows, around a third of respondents felt that they hadn't achieved as much as they would have liked. The reasons they gave for this are shown in figure 11. Perhaps unsurprisingly, given the health conditions of many participants, personal health was given as the biggest barrier to success. A focus group participant expanded on this problem:

> "People who are struggling with health problems are already busy, and also they worry about what will happen if they get ill – they don't want to commit to something and then let people down."

Most of those who cited 'Other' barriers talked about specifics about their health, and five gave comments along the lines of 'there's just a lot to be done'. One stated that a lack of access to a computer and the internet had been a barrier.

Figure 10 Respondents' views on how much they had achieved since the workshop

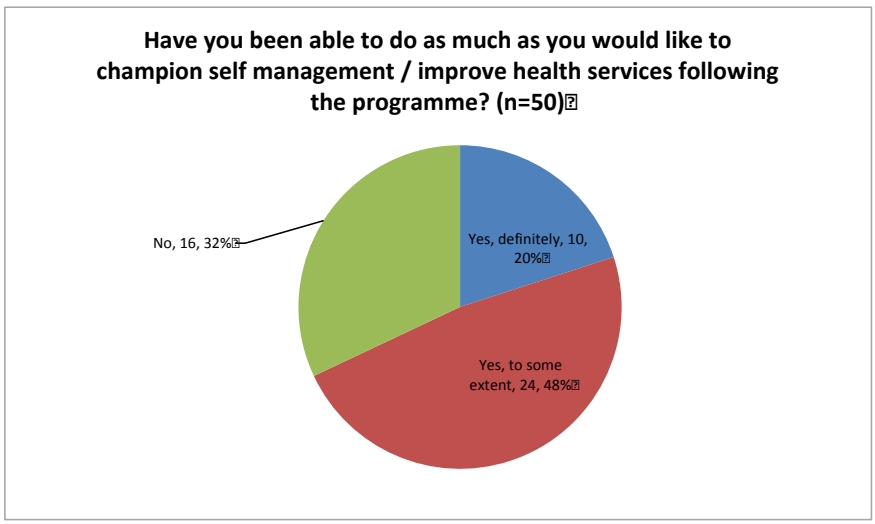
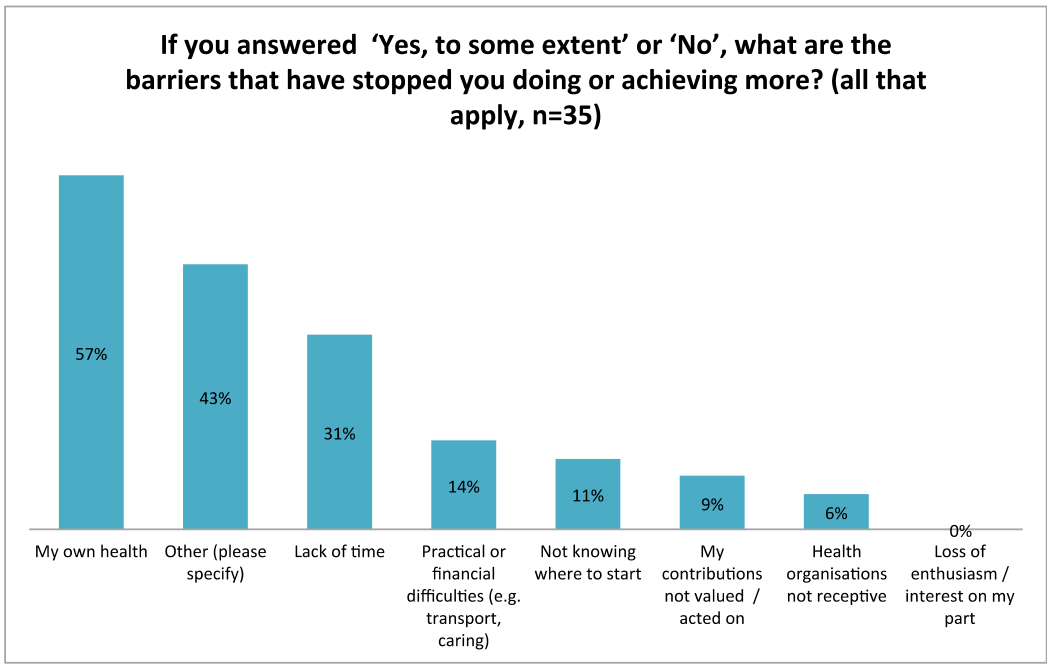


Figure 11 Reasons for participants not achieving as much as they would have liked



Encouragingly, as figure 10 shows, relatively few respondents stated that healthcare organisations being unreceptive to their involvement had been a barrier to them achieving what they would have liked. However, in the focus groups, we heard a number of stories about user involvement efforts being thwarted due to NHS culture and funding constraints, leading to considerable frustration:

> "We don't get listened to as much as the government thinks we do."

> "We raised the issue (of the reorganisation of oxygen distribution) at the Managed Clinical Network and how it has caused difficulties for people needing to access additional oxygen supplies at short notice. I heard back from another service user representative that the issue had been raised at the Community Health Partnership, but nothing has come back to us about whether this issue is being progressed."

> "In some groups patients make a difference, and in others a little, and in others none at all. Sometimes it's like you're just not there – they are speaking across your head, using NHS acronyms. At one group I asked them to stop using acronyms and they actually gave me a book with all the different acronyms and abbreviations in it – as if I'd have time to look at it in the meeting. I was a member of a 'Short life group on [omitted to preserve anonymity]' – I really felt I was just ticking a box there. The SIGN Guidelines group is really different – I'm listened to and patients are going to have a big say."

> "My experience is very mixed. Everyone always says 'thanks for attending'. I'm on the national advisory committee. I get sent a copy of the Chair's agenda that has some narration on how to contribute. However they decided to have a subgroup on…. It's what I have experience and interest in but I've just not been invited. At this level, clinicians, consultants, surgeons

all have their corner to flight. They are not interested in patient representatives influencing the process."

Given the setbacks and disappointments sometimes experienced by patients and carers as they try to influence services, ongoing support from the Chest Heart & Stroke Scotland trainers is potentially important. We asked about this in the survey. 21 out of 68 respondents said that they had had some form of ongoing support and, of these, 14 (66%) saw it as very important and 5 (24%) as somewhat important. Comments and examples about the ongoing support from trainers included the following:

"He (Dave Bertin) has kept in touch with the group. We know if we hit a problem /issue/barrier we can simply phone and get advice or an 'uplift'!"

"[They are] at meetings to give advice if required."

"[They help by] chairing meetings, providing minutes, guidance at meetings."

"Trainers have attended meetings and passed on tips based on their experience which have helped others who were not at workshop. They have been very receptive to suggestions made by patients/carers and made efforts to incorporate these in leaflets, websites etc. 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 from time to time."

"A very nice lady helped our Fife 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."

"Helping me understand what I can do and learning me how do things." (sic)

"David and Nicola have been very important in providing advice and opportunities to help me promulgate my belief that self management provides the best paradigm for coping with the demographic pressures that long term conditions will exert on a finite health budget."

"Very helpful and supportive in inviting attendance at national forums."

"Just understanding."

"They explain things in a way you can understand."

"They can advise us on different things."

"Attend, advising and supporting our subgroup."

"Support and feedback. Adding enthusiasm and encouragement."

"Updating skills and knowledge."

"Provision of examples of 'Cases for Change'."

One focus group participant provided an example of where Chest Heart & Stroke Scotland was able to intervene directly in a local situation:

> "It's good when Chest Heart & Stroke Scotland gets directly involved. For example, in [our local town] there was a cardiac group that was getting nowhere and Chest Heart & Stroke Scotland came in and interceded between the local group, the NHS and the Local Authority. Direct intervention is sometimes the answer."

Finally, we asked for comments from the focus group participants on any improvements or developments that they would like to see to the Voices Scotland programme. There were few suggestions, but those that there were included the following.

- Ensuring sufficient attendees at the workshops. One participant said only four people were in the training she attended – it wasn't enough to share and promote learning as two of these participants were quite ill and didn't attend the full days.

- Offering refresher training, and updates for new patient representatives joining groups.

- More varied attendance at training. For example, bringing user representatives and NHS staff together, involving managers as well as clinicians. Having said this, other participants saw benefits to training participants on their own prior to engaging with NHS staff.

- Ensuring that participants understand clearly what they are attending. For two focus group participants who had attended COSMIC, they had clearly misunderstood what the training would be about, and thought it was a part of their treatment or rehabilitation programme.

The following case study illustrates how the training has resulted in greater public participation in NHS Shetland, and how Chest Heart & Stroke Scotland were able to collaborate with the local officer of the Scottish Health Council to facilitate this.

Case study: Voices training at the Shetland Public Partnership Forum

Members of NHS Shetland's Public Partnership Forum first came into contact with Voices in April 2013 when the Voices Scotland team from Chest Heart & Stroke Scotland was invited to Shetland to run a day-long session on influencing the NHS. Few people managed to attend, however Chest Heart & Stroke Scotland took up an offer to rerun the training at the Public Partnership Forum's next meeting. It took the whole agenda but was worthwhile.

"A lot more people were there so course ran more like it was intended to. It felt that we were learning something" *(*Public Partnership Forum Member*).*

On both occasions the training covered the structure of healthcare services and the roles of public bodies, getting your voice heard and making change happen.

At this time, the Public Partnership Forum did not have a lay Chair; something that members were keen to change. As Camille Brizell, the Scottish Health Council's Local Officer in Shetland, explains:

*"*It was a result of the Voices training that Harold stepped forward to be the Lay Chair and as a result of [the Voices Scotland trainer]'s suggestion to develop a list of priority areas for work that they identified the Health Centre issue and set up a Public Partnership Forum subgroup to work on it."

The lack of timely access to GP and nurse appointments at Lerwick Health Centre had been an issue of public concern. In order to establish evidence of patients' experience, the Public Partnership Forum subgroup carried out a patient survey in August and September 2013.

There was a real collaborative effort to help the group. The questionnaire was developed by members of the Public Partnership Forum subgroup, and reviewed by a researcher based in the Scottish Health Council's national office. The survey was made available online by the Health Improvement team. Paper copies of the questionnaire were distributed across the town's shops and libraries. All this work resulted in an amazing response. Over 900 patients (10% of those using the health centre) took the time to explain their experience and views.

In addition to the patient survey, Public Partnership Forum members separately interviewed GPs, nurses and administrative staff working at the Health Centre. The decision to do this was influenced by the emphasis placed on understanding the wider picture and all sides of the argument at the Voices workshop.

The Public Partnership Forum has been using the 'Case for Change' template, introduced in the Voices workshop, to collate evidence into an argument for change, and presented this to NHS Shetland in December 2013. A response to this was received in February 2014, and although it is early days in an ongoing process, there are signs that this patient and public-led initiative has the potential to make a real difference to service provision on the island.

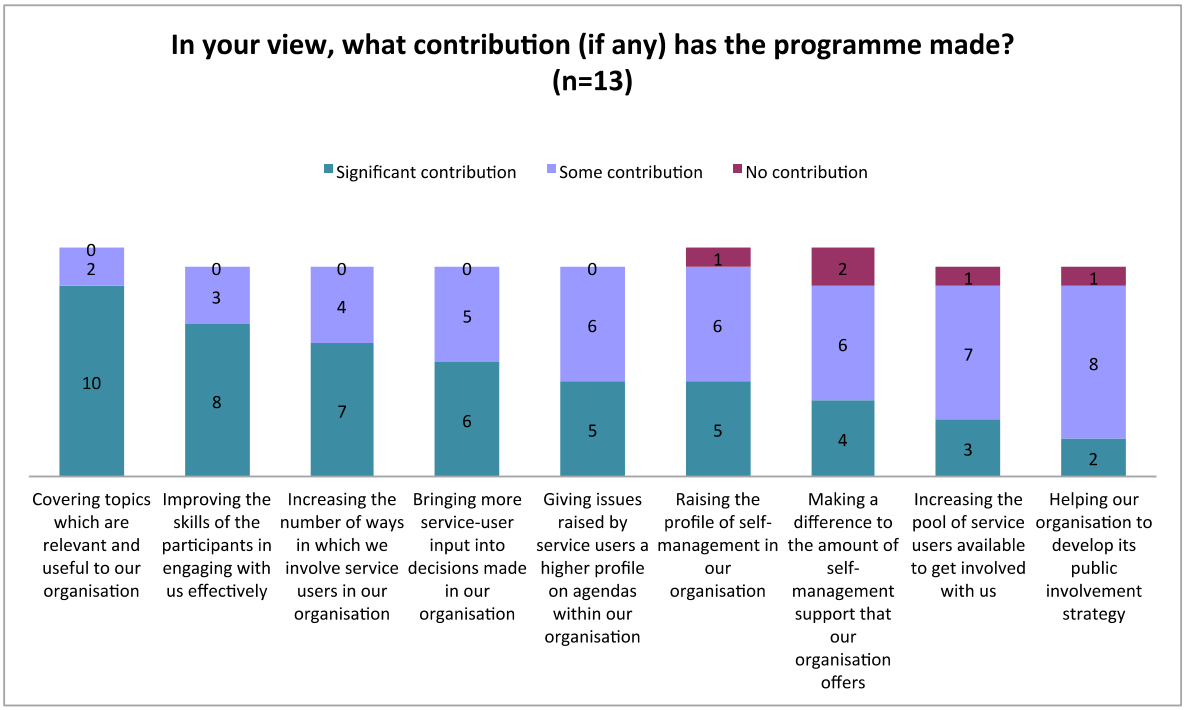
c. Impact of the programme on commissioning organisations (e.g. Managed Clinical Networks)

Thirteen managers who had been involved in commissioning the programme from Chest Heart & Stroke Scotland locally, or who had worked with participants on the programme, responded to the online survey (a response rate of 52%). An overview of the organisations they represented is given in Appendix B of this report. Of the thirteen, seven were Managed Clinical Network managers, four worked in other local NHS roles, and two in national NHS roles. Nine of the 13 respondents had

direct experience of the workshops, having attended all or part of a workshop themselves. Telephone interviews were carried out with eight managers so that they could expand on the comments they had made.

We asked managers to comment on the contribution the programme had made to their organisations, and figure 11 shows the results. 73% (8 out of 11) of those who answered said the programme had made a significant contribution to improving participants' skills in engaging effectively with the organisation, and 55% (7 out of 11) said it had made a significant contribution to increasing the number of ways in which they involve service users in their organisation. 91% (10 out of 11) said that the programme had made some or a significant contribution to the development of their organisation's public involvement strategy, reflecting the strategic role of the Chest Heart & Stroke Scotland trainers in engaging with organisations beyond the workshops.

Figure 12 NHS Managers' views of the contributions made by the programme



Examples given by managers of these contributions included the **impact on participants' skills**, making it easier for the organisations to engage them effectively:

> "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."

> "The 'Making Your Case for Change' template is really useful and ideal to promote in a practical setting."

"Following training, patient reps more confident and motivated about participating in meetings, projects, etc."

"I have seen increased confidence in service users in terms of becoming more involved and expressing their thoughts within the Managed Clinical Network."

"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."

"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 representatives to complain or gripe about things like parking."

The following case study sums up the views of one Managed Clinical Network manager.

Case study: The view of one Managed Clinical Network manager on the impact of Voices locally

"The impact of the Voices programme was that it got people talking, enabled people to understand the background of getting involved and the expectations of them. They came up with ideas for improving respiratory services and thought about a case for change. They formed a patient group as a result of the programme on an ongoing basis as a subgroup of the Managed Clinical Network. The group continues – they meet every six weeks. They have had some turnover but there are still 8-10 of the original group. Dave has continued to have an input. I organise the meetings and get them a venue but I'm not always there all of the time and they have organised their own chair and vice chair. Availability of pulmonary rehabilitation has been a big agenda item for them which they have found frustrating: unfortunately there is no overnight solution. But thanks to patient input there is an acknowledgement from managers and physiotherapists that there is a shortfall, and this is an achievement in itself.

In a recent development, the group has taken on a project to create patient information packs, rolled out to public libraries. It's been a real success and they have a great sense of achievement. Two members of the subgroup also sit on the Managed Clinical Network steering group so they are a point of liaison.

[The Voices Scotland trainer] is always there when there are any issues, so that's a strong relationship and I would always call them. Patients feel really supported by Chest Heart & Stroke Scotland – it's positive all round."

Managers also gave some examples of impact on the **wider patient engagement strategy and infrastructure** of their organisation:

> "Following Chest Voices workshop a respiratory patient group was established as a subgroup of the Managed Clinical Network."

> "Support from Chest Heart & Stroke Scotland has helped bring more involvement from service users in terms of engagement with ourselves."

One manager cited the fact that Voices is delivered by an organisation with a wider role and particular insight into the Scottish context.

> *"*I think Chest Heart & Stroke Scotland do an amazing job as an organisation. They are incredibly easy to link into and probably the best people that I work with. With 'Scotland' at the end of their name, it makes a huge difference – they intimately understand how policy works, how the networks work. Nicola and Dave are so fantastic, so supportive, so steady – it's really great working with them*."*

Relatively few managers talked about the impact of the programme on the self-management agenda, reflecting the fact that COSMIC is still a new iteration of the programme. However, some talked about how they were using it locally in support of a self-management strategy for particular conditions and seeking to develop a local COSMIC network. An example is in NHS Tayside, where COSMIC is being implemented with people who have experienced stroke. The Stroke Coordinator told us:

> "We are currently running COSMIC over a number of sessions for stroke patients. Around 16 patients are going through it. The impetus came from the patients themselves - after an eight week post-stroke exercise programme, they set up their own self management/exercise group and affiliated it to Chest Heart & Stroke Scotland. The plan now is to train up these patients and use this so that they can decide how to progress self-management training for stroke in Tayside. The feedback from patients is that they have really enjoyed the sessions so far and are keen to take things forward. The healthcare professionals involved – stroke liaison nurses, social workers and nurses from the ward - have had two training sessions alongside. What I've been impressed by is the fact that they worked with us and the programme can be adapted. What would work here for us in Tayside might not work elsewhere. They were willing to sit down and talk with us about talk with us to decide what the next steps would be. We also sat down after the first session and thought about how it could be improved – for example by introducing talking mats for people with communication problems."

The survey asked about managers' views on the level of patient engagement in their organisation, and what some of the remaining barriers are. Only two said that they were currently satisfied with the amount that their organisation was doing to involve service users (figure 13), and figure 14 shows the barriers that they thought were most significant.

Figure 13 Managers' satisfaction with current service user involvement

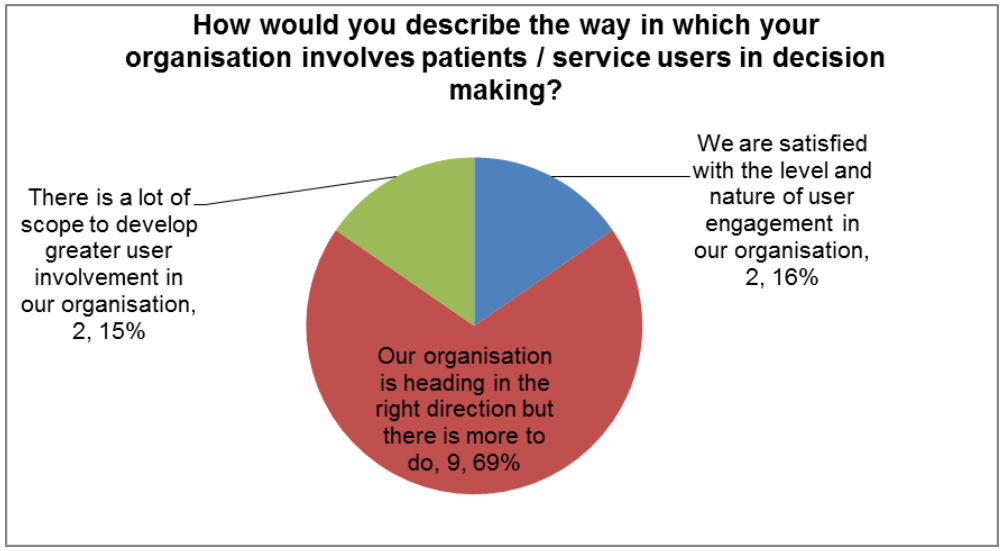
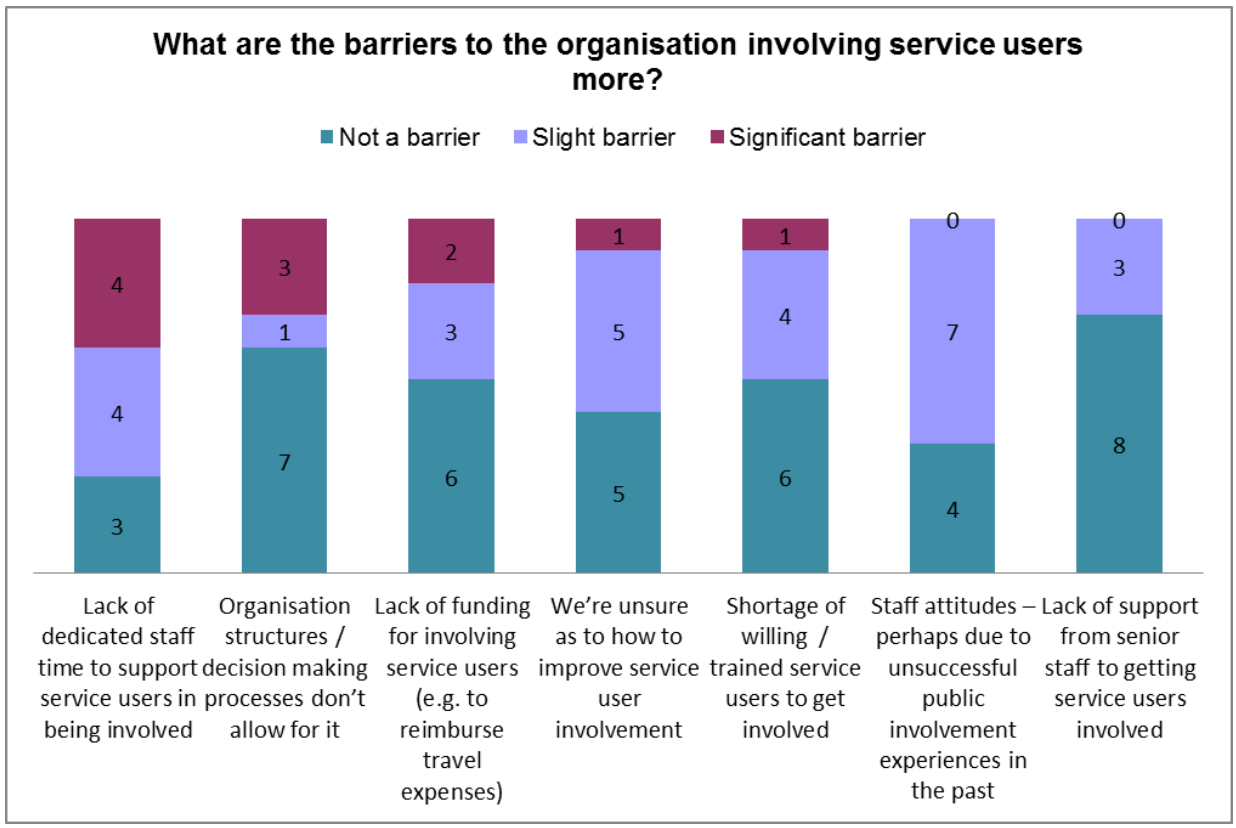


Figure 14 Barriers to involving service users more



This report is not the place to examine the wider issues around patient engagement in Scotland, but these data show some of the issues which the Voices programme approach is seeking to address.

The adaptability of the programme materials is illustrated by the following case study which describes how the workshop was adapted for use in training patients to participate in a scientific research study.

Case study: Delivering an adapted version of Voices in a research study at Edinburgh University

A team at Edinburgh University who were running a pilot trial of home blood pressure monitoring for patients who had experienced stroke approached Chest Heart & Stroke Scotland to find some patient volunteers to get involved in shaping the pilot trial processes. The Voices trainers offered to adapt and run a Stroke Voices training programme for these participants so that they could contribute more effectively.

The training took place over three days. Twelve people who had had strokes came along (invited by Chest Heart & Stroke Scotland) to the training, which was hosted by Edinburgh University. At the end, the participants were asked whether they would be willing to become members on a Patient Public Involvement group for the research project and six volunteered, of whom four were selected.

Lucy McCloughan – eHealth Research Manager, University of Edinburgh, said, **"**The people who came along all found the programme very engaging and exciting. Far more wanted to carry on working with us than we anticipated – our only challenge was to get a manageable number with a mix of experiences of stroke."

The study they were involved with finished a few months ago and is now awaiting publication. Informal contact with the participants has been maintained for future projects.

Commenting on the involvement of the patients, Lucy McCloughan said: "They came on board after funding for the study had been secured and hence the design was pretty well finalised, which was a shame, but they were still able to give a lot of advice about the acceptability of the intervention, and that helped shape the research team's decision about which blood pressure monitor to choose. They also commented on project documentation such as the letter to potential participants and the protocol for patient follow up. The patients really helped us to understand how best to approach and present information to people who had had stroke. Most people in the research team understood the basic concepts, but had not worked with people at that level."

"At the end of the study, the research team held a day with the Patient Public Involvement group to create a lay summary of the work. They helped to pinpoint the parts of the results which would be of most interest to people with stroke and, according to the researchers, radically changed the way that they presented the information."

Richard Brand, one of the patients who took part, said:

> "[The training programme] prepared me well - I thought that I could participate quite well. We had participated in all the 'information getting'; from using the kit, commenting on the letters and leaflets, the sample etc. We were not so much involved in the analysis side – the internet side of things, although I did get to see it, and play with it. The involvement in the trial was useful."

The impact of the programme was to make the research team much more confident in how they were working with patients. Lucy McCloughlan added: "Chest

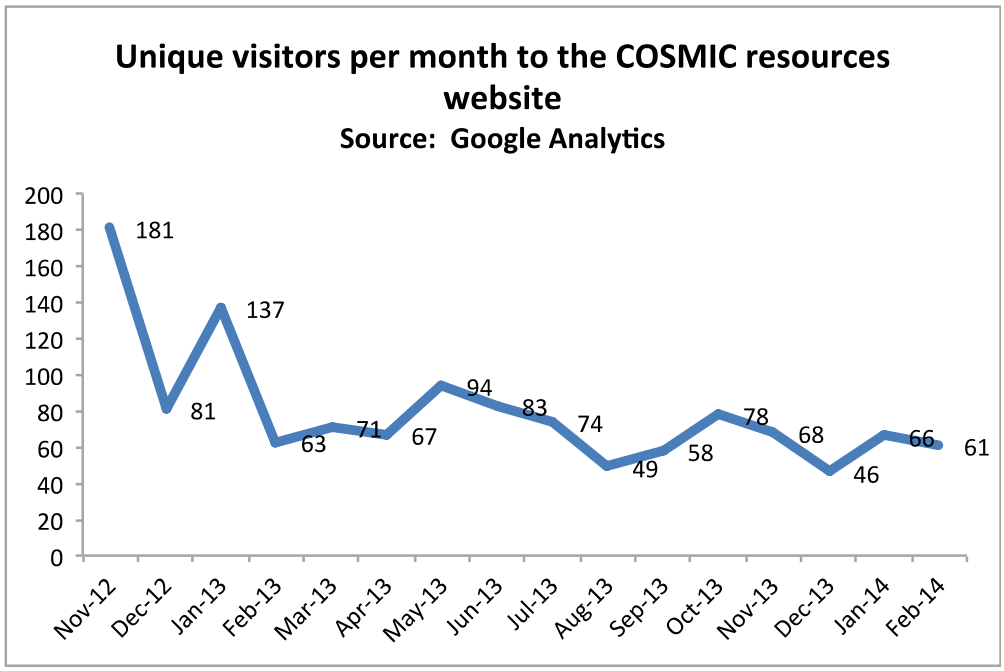
Heart & Stroke Scotland held our hand, but more than that they enabled us to communicate with people who might have difficulties. They opened our eyes to what the problems might be and how to overcome them. They also found willing individuals which would have been very difficult for us to do. So on a practical level that was really helpful. They were all fabulous, the people we worked with, and we would certainly repeat the experience if we could."

d. Impact of the programme on other organisations who may roll it out

As described in section 2.1 above, Chest Heart & Stroke Scotland has been funded by NHSScotland to make the COSMIC workshop materials available to other patient organisations and groups who might be able to implement it within their own constituencies. In the past year, Chest Heart & Stroke Scotland has specifically tried to engage with other patient organisations through Showcase Events, one-to-one meetings and networking through the ALLIANCE, to demonstrate what COSMIC has to offer and encourage them to consider using it. The Voices trainers offer practical coaching in adapting the tools and will also co-deliver the programme with the other organisation the first time around, to lend confidence. Beside the COSMIC workshop materials, a comprehensive trainer manual, published on the COSMIC Resources website and free to download, describes every aspect of how to deliver the workshops – from invitation letters and presentation slides to room layout and equipment needed.

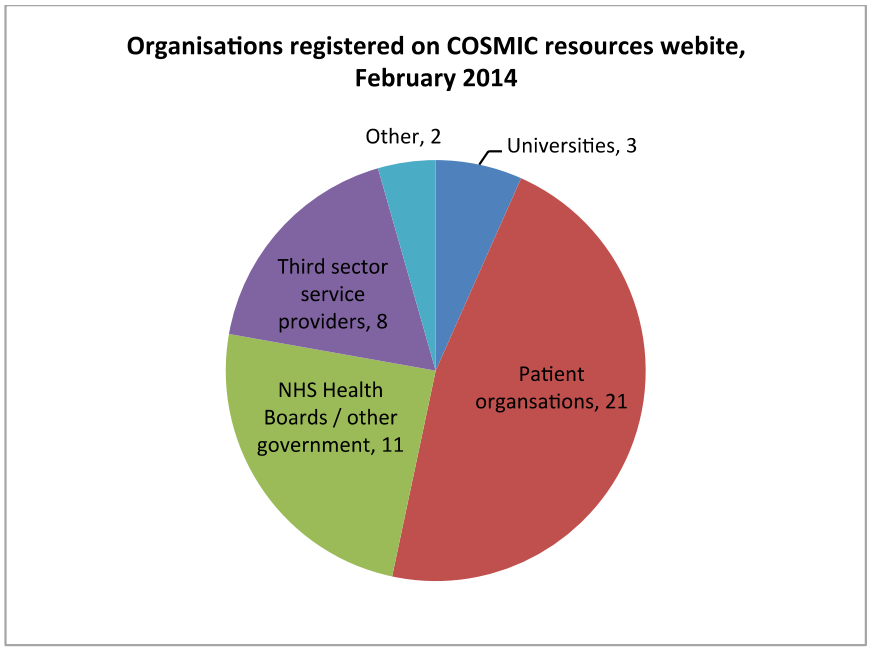
One indicator of the interest in COSMIC is visitors to the COSMIC Resources website. This has averaged 80 visitors per month since November 2012 (soon after launch, when data began to be recorded), as shown in figure 15.

Figure 15 Visitors to www.cosmicresources.org.uk since November 2012



Chest Heart & Stroke Scotland has a database of 45 organisations who have registered (free of charge) on the site in order to be able to download resources. A breakdown of organisation type is shown in figure 16. Between them, these organisations downloaded a total of 1423 documents between November 2012 and March 2014.

Figure 16 Organisations registered to download resources from COSMIC Resources website



Our findings on the impact of this work are somewhat limited because, although there has been active interest from a number of organisations considering taking COSMIC forward, including Macmillan Cancer Support and Arthritis Care, the work is still at a relatively early stage. However, promoting uptake of COSMIC is not a quick endeavour. As Kevin Geddes Director of Development and Improvement at the ALLIANCE, commented, “Organisations are very focused on what they are doing – sometimes they don’t have time to lift their head up and look outside. They also need funding to take good ideas forward – but often funders are looking for something new and innovative, not just a reapplication of an existing approach. Having said that, the ALLIANCE Self Management Fund has a focus on learning and sharing from other things – we have never had an application from another organisation to take forward COSMIC and we would welcome such ideas and applications.”

An example of the benefits which organisations can reap if they learn from COSMIC and make use of the resources is the experience of the Lothian Centre for Inclusive Living.

Case study: COSMIC as the basis for Champion training at the Lothian Centre for Inclusive Living

The Lothian Centre for Inclusive Living is user-led organisation which supports disabled people, people with long term conditions and older people, to live independently in their communities.

The Lothian Centre for Inclusive Living has recruited and trained a group of disabled people, people with long term conditions and carers to promote understanding of Independent Living and self-directed support, and to raise its profile and those of disabled people's organisations.

The nine Champions, all of whom are involved in the Lothian Centre for Inclusive Living and its services in different ways, work in a variety of settings – both at one-off events and as part of longer-term working groups or committees. They are volunteers, and have expenses for travel and any personal assistant wages reimbursed.

Having seen COSMIC presented at a conference, Debbie Bayne of the Lothian Centre for Inclusive Living adapted the COSMIC materials to create a six-session training programme for the Champions, implemented between April and June 2013.

Debbie Bayne explained: "The Champions programme is critically important to us – we have nine Champions and only 21 members of staff, so their role is key and it was vital to invest in training and supporting them well. In adapting the COSMIC model, we expanded the idea of people doing work between sessions – there were take-home tasks for each session, for example one was to research the social model of disability and the independent living movement. Another was to look at newspaper articles about disability and comment on the images portrayed of disabled people."

Champions are appointed to work indefinitely and meet with their 'buddy' (a member of the Lothian Centre for Inclusive Living staff) before and after events to prepare and debrief, and also all get together as a group every eight weeks. Champions have gone on to play a wide variety of roles on behalf of the organisation, including giving evidence to MSPs, user-testing new websites, taking part in consultations and advising other organisations on disability issues.

The Champions programme has added an extra dimension to the Lothian Centre for Inclusive Living profile, visibility and credibility with the four local authorities it works with – local authority staff are now regularly asking to have a Champion come to speak to them, or take part in 'road-testing' new procedures.

Debbie commented: "We had to adapt the COSMIC programme significantly, but the structure and backbone were there, which saved a huge amount of time. The twin aims of training people about a topic and then giving people the skills to do their work they are going to do was vital to us. The strength of the team at Chest Heart & Stroke Scotland (Nicola, Dave and Juliet) is their openness to sharing and developing ongoing collaborative relationships."

It is very clear that the COSMIC workshop tools and materials cannot simply be ‘taken off the shelf’ and implemented – they do not stand on their own but work only alongside expert, experienced facilitation of the kind provided by the Chest Heart & Stroke Scotland team. Any organisation wanting to implement COSMIC will need to invest significant time and energy in understanding the programme, adapting it for their own purposes, recruiting and supporting participants and working with other stakeholders to ensure that those participants have a clear role and purpose afterwards. Chest Heart & Stroke Scotland has made the resources and time available to help other organisations to implement it, but they need a compelling motivation to do so – which will to some extent depend on the priorities of their own organisations.

5. Discussion and recommendations

Having examined the evidence about the impact of the Voices Scotland programme to date, this section draws together what this says about the factors which make the programme work and things which Chest Heart & Stroke Scotland may wish to think about in improving it further. These conclusions will also be useful for other organisations seeking to develop and implement the programme further.

a. Factors in the success of the programme

The data in section 4 demonstrate considerable success for the Voices Scotland programme in training, supporting and retaining involved service users. A number of features of the programme stand out as having been important to its success:

The relevance of the programme materials and the appropriateness of the messages

Our evaluation found that the programme contents are highly relevant to the needs of the participants in the roles that they may be going to fulfill. The combination of knowledge building and, importantly, soft-skill development through practical exercises is very effective at equipping participants with what they need. This relevance is borne out of the fact that the programme has been delivered, and continuously refined, for many years, and the fact that the trainers have direct ongoing links to patient participation groups and so are able to see what is needed.

Chest Heart & Stroke Scotland's respected and neutral position and wider role

We heard from many respondents about the respect that Chest Heart & Stroke Scotland is held in, and the fact that they combine deep knowledge of chest, heart and stroke-related health conditions with an understanding of NHS policy in Scotland (not necessarily held by senior staff in UK-wide patient organisations). Respondents also talked about the importance of their neutral, facilitative role, which enables them to bring people together. There are clear synergies between the objectives of Voices and COSMIC and other Chest Heart & Stroke Scotland wider activities (such as provision of patient information and self-management support) which adds further benefits.

Close working relationships between the trainers and receptive organisations

Key to the programme's success is the strength of the relationships forged by the Chest Heart & Stroke Scotland team with 'host' NHS organisations, especially Managed Clinical Networks. This has several benefits. Firstly, programme participants are not trained 'in a vacuum' but have somewhere to play a real role after the training. People can put their skills into practice straight away. Secondly,

the training itself can contain an element of real issue gathering and feed directly into the agenda for the patient forum. Finally, ongoing relationships make it more likely that the Chest Heart & Stroke Scotland trainers will be brought back in to resolve problems or provide additional training.

Ongoing support from the trainers for both participants and health service staff

Related to the point above, the ongoing support provided by the trainers to those involved in the programme has often been instrumental in overcoming difficulties which may arise after the workshops are over and keeping them motivated. Furthermore, we heard on several occasions that the willingness of the Chest Heart & Stroke Scotland staff to 'go the extra mile' in the way in which they delivered the programme created a sense of allegiance from participants which was a motivator to them doing something with it afterwards.

The flexibility of the programme

As some of the case studies demonstrate, the modular nature of the workshop programme means that it has been possible to tailor it for numerous different situations depending on local circumstances and even extending into other sectors (for example university research and independent living for disabled people) whilst keeping the core contents and underlying philosophy intact. The ability to do this does, however, require training and facilitation expertise.

The inclusivity of the programme

An open question at the start of the evaluation was whether the programme did enough to select the 'right' participants – those with the motivation to gain the most from it. However, based on the discussions with programme participants, it is clear that the diversity of experience, motivation and interests of programme participants is a positive strength of the programme. People have come to the programme through many different channels, some almost by chance ("because a friend had extra room in their car and lunch was on offer" was one example we heard), but this does not seem to have been a barrier to a large proportion of participants going on to use the workshop contents in their own lives or for the benefit of others – often in ways that they would never have anticipated or predicted before they came along. The fact that the programme is open to all comers probably makes it more risky and challenging to facilitate, but the experience of the Chest Heart & Stroke Scotland facilitators means that this can be accommodated. Our conclusion is therefore that, although it is important to give participants a clear idea of what to expect by coming along to a workshop, doing more to 'pre-select' participants beforehand could be counter-productive.

The inclusion of self management in the programme

Placing self management front and centre in the recent (COSMIC) iteration of the programme has to be seen as a strength. It is a highly innovative development which differentiates the programme from other public involvement training, and gives participants an immediate agenda to 'get their teeth into' which is directly

relevant to them. COSMIC 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.

b. Challenges and recommendations for the programme

We also heard about a number of factors which have the potential to limit the impact of the programme and which are worth Chest Heart & Stroke Scotland (and any other organisations considering implementing the programme) considering.

Working with staff with limited time and who may turn over quickly

We heard from NHS managers and the Chest Heart & Stroke Scotland trainers themselves that one of the biggest obstacles to sustaining the impact of the Voices programme was the limited time and sometimes rapid turnover of staff in key NHS roles. Structures can also change quickly, sometimes with a catastrophic effect on local patient and public involvement initiatives. Some NHS staff are dedicated to patient and public involvement, but in other NHS Boards this responsibility is an 'add on' to other roles, which can result in it taking a lower priority. Facilitating patient and public involvement locally is a time consuming and ongoing task which needs dedicated input: putting patients into unmoderated forums where there is no clear channel for listening to their views or deploying them is a recipe for frustration and disengagement. This is not an issue which is easy for the Voices team to address, but it is essential that the team continues to focus on ensuring that the right local environment and organisational commitment is in place before running the programme. This includes senior management commitment beyond just the individual Managed Clinical Network manager, for example, who commissions the training.

Working with participants with serious health conditions

Inevitably, some participants with serious and sometimes life-threatening conditions will find it hard to stay the course, and the time over which they are able to contribute may be limited. The evaluation revealed some of the ways in which the programme had been adapted to accommodate people with particular needs (for example by offering more, shorter sessions or communication aids for people with aphasia). However, it is inevitable that there will be a degree of turnover amongst involved service users, making it very important that the programme considers succession planning for leading user representatives and offers training for new participants coming on board, beyond the initial training that was perhaps offered when a forum was being established.

Keeping in touch with participants after the programme

As this report has shown, the Voices Scotland team has developed enduring relationships with many workshop participants who have gone on to play active

roles in the healthcare system. In addition, we know that the team keeps in touch with a wider network of participants through occasional newsletters and events. However, we also found that the team had contact details for only around 40% of those who had taken part in workshops in the past three years, due to the fact that many of these are organised by other organisations, and participants must 'opt in' to giving their contact details to Chest Heart & Stroke Scotland. We would suggest that the team considers how to increase the number of workshop participants who give their consent to receiving ongoing communication about the programme, and plans a range of communications to keep in touch with participants. This would also enable further evaluation of the programme at a later date, potentially including a repeat of the impact survey developed for this evaluation.

Complexity of covering self management and influencing all in one session

The COSMIC workshop is very ambitious in its objectives for a two-day training workshop. For someone with no previous experience of self-management training or of influencing the NHS, it involves a journey through understanding the concept as it relates to themselves, seeing the benefits of spreading the approach across the wider community, understanding the practical ways that this could be achieved and then learning about the interpersonal skills and case-building techniques needed to make it happen. The evidence of the evaluation suggests that many participants have successfully navigated this journey – not necessarily in two days, but over a longer period of time. Some have taken on board some elements of the programme but not others.

However, not all NHS organisations may be ready for the full COSMIC programme at this point. Some have a long way to go to develop their self-management strategies, and may find it hard to respond to the people who have been trained up. One senior clinical manager we spoke to described it as being almost "ahead of its time". Voices (influencing) training still has a valid and important place, and is still sometimes offered on a stand-alone basis, as illustrated by the Shetland case study in this report.

Communicating and branding the programme

Linked to the challenge above is the potential confusion caused by the different names used for the programme. The name 'COSMIC' is appealing and some people (wrongly) understood it to be a 'replacement' for Voices, which it is not. There is a need for clarity about how the programme is described and packaged. The programme is, in effect, a series of tools and facilitator support which can be combined in different ways to fit with what is needed locally. An explicit, flexible 'pick and mix' menu approach to selecting the elements required for a particular situation may work well. Retaining one clear brand for the overall approach (which could be 'Voices Scotland'), which doesn't imply that self management is always part of the offer, is sensible.

Time and resource needs to be put into a proper branding and marketing plan going forward.

6. Conclusion

This evaluation report has defined the objectives of the Voices Scotland programme, explained its development and history, and measured its impact both on service user participants and healthcare service organisations. It has demonstrated that the programme has had considerable success in achieving its aims and has identified a number of features of the programme which have contributed to its success.

Although Voices Scotland has achieved a great deal, there is still much more to be done to train involved service users in Scotland. There remain NHS Board areas that the programme has not yet reached, and there is a need to refresh the pool of involved service users over time. There is also a need to reach people with conditions other than those related to chest, heart and stroke. Taking forward supported self management as a real option for everyone with a long term condition is an even bigger ambition. Extending the COSMIC programme to many more patients with many more conditions could be an important part of making this happen. But, as this evaluation shows, any organisation seeking to do this will need to pay attention to all the elements of the programme, which goes far beyond a set of workshop materials and involves long term relationship building and expert facilitation, if they are to succeed.

Appendix A – Outline of the workshop as delivered in 2014

Day 1: Understanding self management

Aim: To develop a strategic understanding of self management, what it constitutes, including the various models of self management and the breadth of support that is available to help someone self manage

Session	Learning Objectives
Welcome and introductions	To introduce the trainers and participants to the trainers and each other. To feel heard and valued.
Expectations of the course	To get all to sign up to the Group Agreement. To clarify the nature and content of the day.
What is self management?	To be aware of your and others' definition of self management and be aware of the definition used in Scotland (Long Term Conditions Alliance Scotland) but that there is no definitive definition of self management. To gain an understanding of the 'jargon' associated with self management and when it is appropriate to use the terms. To understand that 'you' (the participant) are the expert on self management and to appreciate the value of your own experiences To understand the tasks that are required to self manage.
Self-management initiatives	To expand the understanding of the range of what self management constitutes and understands the pros and cons of different initiatives. To be able to recognise the best fit for a self-management initiative for an intended audience.

Session	Learning Objectives
Models of self management	To understand two different models of self management. To understand what constitutes a collaborative relationship to enable self management.
Gaun Yersel?	To understand the various roles that can support someone to self manage; both within the NHS and associated organisations. To understand also how people can be encouraged to maximise their own family and community support to self manage.
Tackling Tough Choices Part 1 (a brief understanding of health economics)	To provide a basic understanding of health economics and its competing priorities and demonstrate the “tough choices” managers make. The game also highlights that self management work does have an initial cost implication and introduced the concept that cost-benefit analysis for self management initiatives have to be assessed over the longer term
Take Home Task	To be able to recognise what is provided in their local area for self management of their conditions. To be aware of any gaps in provision.

Day 2: Champions of Self Management (Having your say)

Aim: To empower the Champion of Self Management with the knowledge, skills and tools to enable them to influence local services in a logical and evidence based manner.

Session	**Learning Objectives**
Welcome and recap	
Tackling Tough Choices Part 2 (a brief understanding of health economics)	To provide a basic understanding of health economics and its competing priorities and demonstrate the "tough choices" managers make.
The role of the Champion of self management	To understand the role and remit of the Champion of self management and all the skills and knowledge required for this role. Also covers course out line for the day.
The structure of health and social care	To understand the structure of the NHS and associated bodies and which organisations welcome involvement.
Working effectively together with professionals Levels of Involvement	To understand the benefits and barriers of public involvement. To recognise how to work effectively with professionals by being aware of how personal experiences can influence this process. To understand there are various levels of commitment and that it is important to work out your own personal level to be able to fit the work into your life realistically.
Preparation for making a case for change • Identifying issues to consider	To be able to identify a public involvement issue to take forward for the afternoon session. To be able to identify self-management issues.

Communicating with professionals	To be able to communicate and influence effectively with professionals.
What's out there? Local self-management support	To be able to recognise what is provided in their local area for self management of their conditions. To be aware of any gaps in provision.
Making a case for self management	To understand how to, and how not to, present an issue to professionals.
What's next?	To understand how they can get involved locally. To understand firsthand the work of Champion of self management.

Appendix B – Overview of survey respondents

Respondents to the patient survey

The 68 respondents to the survey were 52% male and 48% female, and described themselves as follows.

Figure 17 Year in which survey respondents attended a workshop

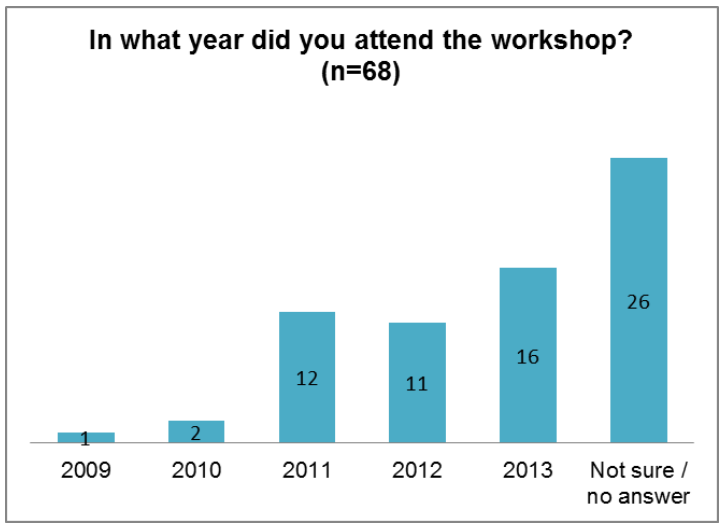


Figure 18 Version of the workshop attended by respondents

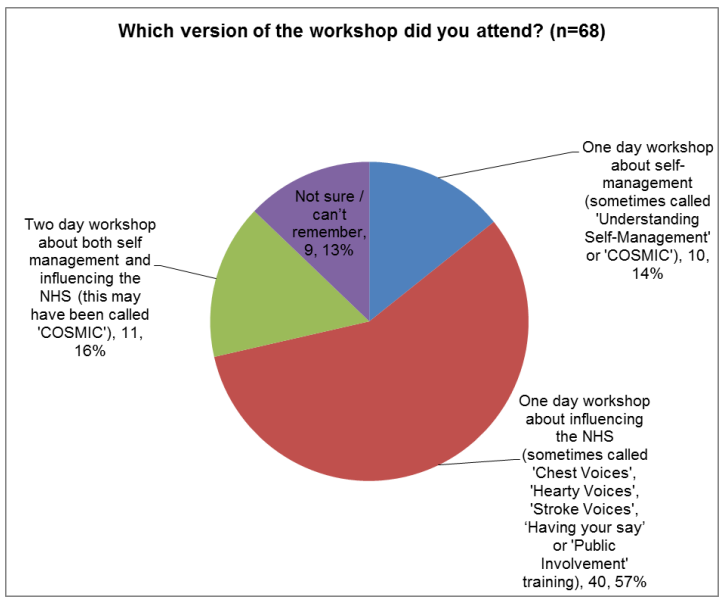


Figure 19 Role of respondents when they attended the workshop

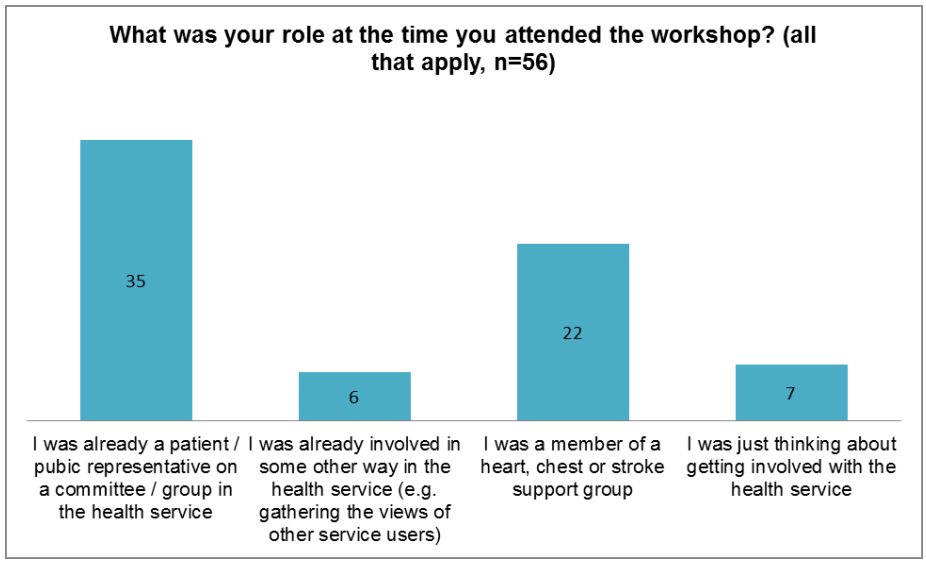


Figure 20 Respondent age

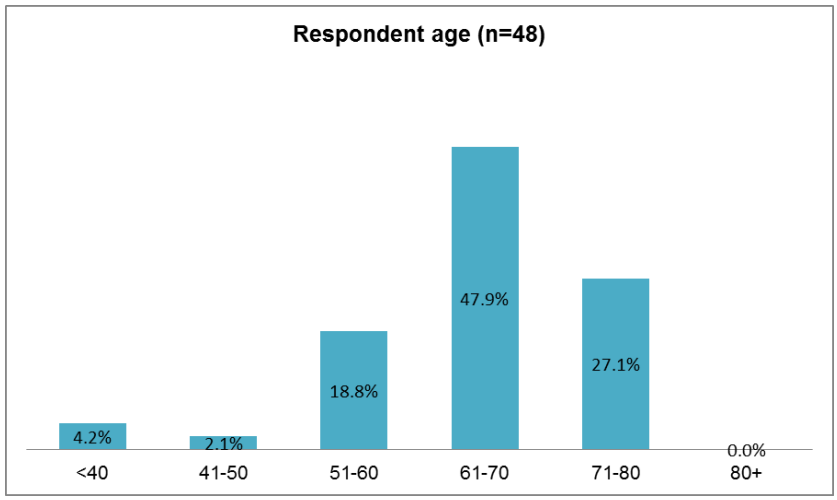
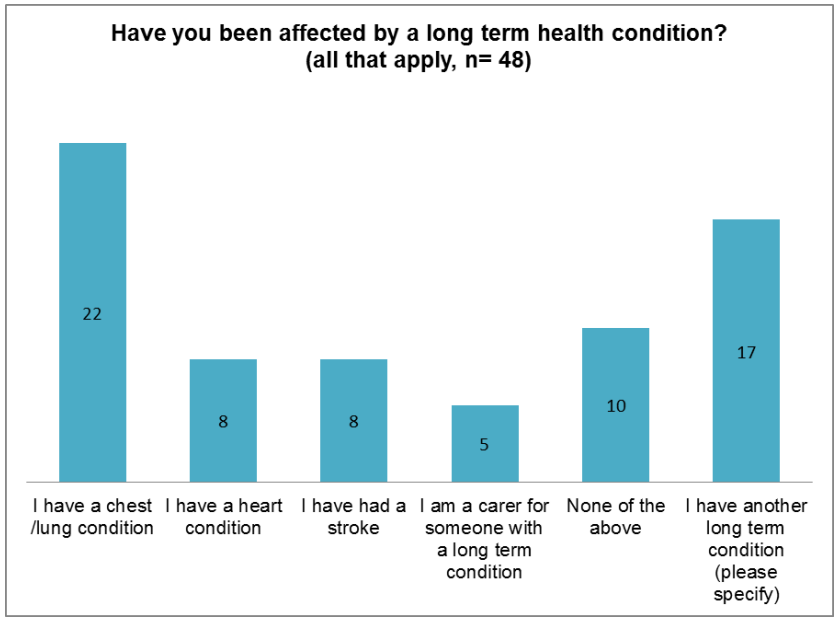


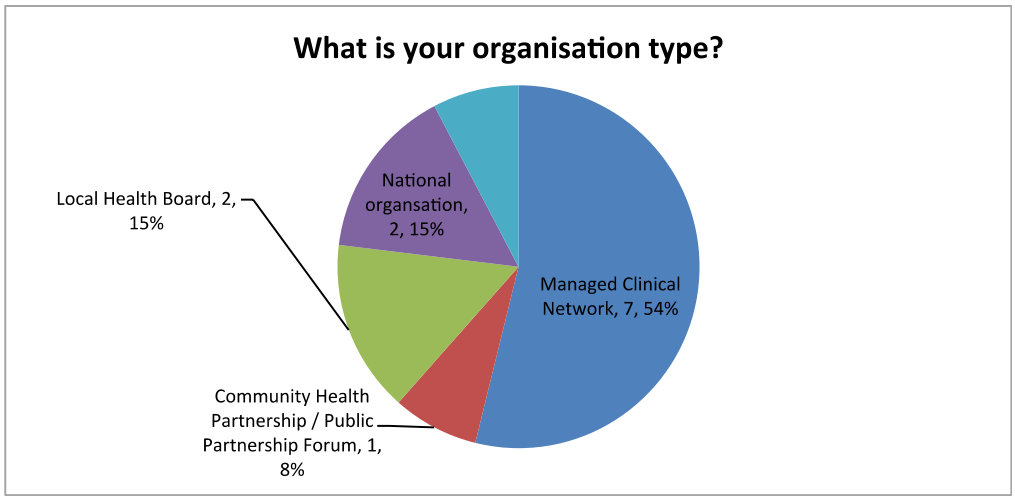
Figure 21 Long term conditions experienced by respondents



Respondents to the Healthcare Manager survey

The 13 respondents to the healthcare manager survey represented the following organisation types:

Figure 22 Organisation types represented by respondents to the healthcare manager survey



The respondents worked in NHS Boards including the following (three people chose to participate anonymously):

- NHS Ayrshire & Arran
- NHS Fife
- NHS Greater Glasgow and Clyde
- NHS Lanarkshire, and
- NHS Tayside.

Appendix C – The Evaluation Team and Project Steering Group

Evaluation Team

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Project Steering Group

The project was overseen by a steering group comprising the following people who provided useful input and sign off of the evaluation tools during the project:

Name	Role
Nicola Cotter	Voices Scotland Lead and Trainer at Chest Heart & Stroke Scotland
Dave Bertin	Voices Scotland Trainer
Paul Towning	'Champion' who has been on the programme
Rosemary Hill	Participation Network Manager, Scottish Health Council
Gary McGrow	Social Researcher, Scottish Health Council
Pauline Boyce	Head of Operations, Scottish Health Council

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