Neurological Voices

Empowering people affected by neurological conditions to contribute to the development and improvement of neurological services

Project Report
2011—2014
Neurological Voices 3rd Year Report

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1 **Project Background**

The Neurological Voices project commenced in March 2011, in the main funded by the Scottish Government Health Department, with additional funding provided by Hugh Fraser Foundation. The aim of the project was:

‘To provide robust and sustainable patient and carer involvement training to empower those in Scotland affected by neurological conditions to contribute to the development and improvement of neurological services.’

The project was set up during Healthcare Improvement Scotland’s (HIS) two-year Implementation and Improvement Support Programme (March, 2010-12)\(^1\) that required all health boards to:
- Identify a local Neurology Improvement Lead and establish a local multidisciplinary Improvement Group, Network or Managed Clinical Network
- Evaluate their services using the Clinical Standards for Neurological Health Services (2009)
- Develop Three Year Plans with local priorities for improvement.

Patient and carer involvement has been a key strand of NHS Scotland healthcare strategy, from the publication of the founding ‘Our National Health: a plan for action, a plan for change’ (1996)\(^2\) to the present day, as evidenced by ‘The Patient Rights Act’ (2011)\(^3\); ‘The Charter of Patients’ Rights and Responsibilities’ (2012)\(^4\); the Healthcare Quality Strategy for NHS Scotland (2010)\(^5\); and, most recently, the ‘Person Centred Health and Care Collaborative’ (2013)\(^6\), using the Three Step Improvement Framework, to focus on local improvements in patient and staff experience.

When the HIS Implementation and Improvement Support Programme commenced for neurology in 2010, however, patient and carer involvement in neurological services was minimal or absent in most NHS boards.

The Neurological Voices project set out to recruit and train people affected by a range of neurological conditions to form diverse, yet cohesive groups in local health boards, equipped with skills and confidence to participate with NHS professionals in local improvement activity.

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1. [http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services.aspx](http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services.aspx)
4. [http://www.scotland.gov.uk/Publications/2012/04/6273](http://www.scotland.gov.uk/Publications/2012/04/6273)
5. [http://www.scotland.gov.uk/Publications/2010/05/10102307/8](http://www.scotland.gov.uk/Publications/2010/05/10102307/8)
1.1 Neurological Voices Training

Neurological Voices is based on the ‘Voices Scotland’ programme led by Chest, Heart & Stroke Scotland (CHSS)\(^7\) that has successfully engaged people with heart disease, respiratory disease and stroke in improving their treatment and health care. The CHSS ‘Voices’ model was recently described as the ‘gold standard’ for user involvement in health in Scotland (Chief Medical Officer CEL 29; 2012) \(^8\).

Neurological Voices training adapted the CHSS ‘Voices’ package, developing content, resources and a timetable that took into account the range of conditions, issues and support needs likely to be present in a group of patients with mixed neurological conditions and participant carers. This was a departure from CHSS practice which, until recently, involved working with single condition specific groups.

Neurological conditions included in the programme to date are arachnoiditis, ataxia, brain tumour, chronic fatigue syndrome/ME, dystonia, epilepsy, headache, Huntington’s disease, medically unexplained/functional neurological symptoms, motor neurone disease, multiple sclerosis, myasthenia gravis, neuropathies, Parkinson’s disease and transverse myelitis.

Neurological conditions may impact on areas such as cognitive function, attention, concentration, memory and all aspects of oral and written language processing — all of which affect personal confidence and capacity to participate. Physical considerations, such as fatigue, tremor and weakness, seizures, continence issues and medication schedules, also need to be taken into account. The Neurological Voices programme was carefully structured to give participants the knowledge and skills they needed, in accessible form, at a suitable pace, with regular breaks and in a fulfilling and enjoyable way.

Factors to consider in delivering training to people affected by neurological conditions

- Cognitive, psychological and physical impact of condition
- Additional complex health needs
- Diagnosis may have been protracted or may remain unclear
- Range of high and low incidence neurological conditions
- Conditions are often progressive though rate of progression varies
- Variable attendance and turnover of participants due to health status
- Patient participants may require support person to attend
- Ongoing support will be required to sustain local group.

\(^7\) [http://www.chss.org.uk/voices_scotland/](http://www.chss.org.uk/voices_scotland/)

Neurological Voices training commenced in Autumn 2011. See Neurological Voices Year 1 Report for full description of ‘Taster’ and training content.

Neurological Voices ‘Taster sessions’ and ‘Full Training’ have now been delivered in eight health board areas: Ayrshire & Arran, Dumfries & Galloway, Forth Valley, Grampian, Greater Glasgow & Clyde, Lothian, Tayside and Western Isles. (See Table 1, page 6, for details.)

‘Follow up’ training was delivered in seven of the above areas, excluding the Western Isles.

‘Induction’ training of additional patients and carers was carried out in three health board areas with already established groups: Dumfries & Galloway; Forth Valley; Tayside.

The Neurological Voices programme (Tasters, full training, induction), as delivered by the training team, has consistently received extremely positive ratings of 85-100% satisfaction. However, at this point, it is the progress, achievements and ongoing viability of the groups since training that is of interest.

Patient participant feedback

“Training is best I have ever experienced, including my 39 years in local government”

NHS Tayside

Talking Mat – Impact of my condition (Epilepsy and Parkinson’s disease)

9 http://www.scottishneurological.org.uk/content/res/Neurological_Voices_Year_1_Report.pdf
### 1.2 Table 1. Local NHS Board Neurological Voices Tasters, Training, Follow-up, Induction

<table>
<thead>
<tr>
<th>NHS Board (A-Z)</th>
<th>Date Tasters/ Training commenced</th>
<th>No. of Tasters</th>
<th>No. Taster Participants</th>
<th>No. of Training Participants</th>
<th>No. of NV post-training</th>
<th>Follow-Up Date/ Participants</th>
<th>Induction Dates/ Participants</th>
<th>Participation @ March 2014</th>
<th>Local Meetings held</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire and Arran</td>
<td>Sept ’11</td>
<td>4</td>
<td>13</td>
<td>9</td>
<td>9</td>
<td>Mar ’12/ 8</td>
<td>n/a</td>
<td>Local group 4</td>
<td>Imp Group 1-2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>National 2</td>
<td></td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>March ‘12</td>
<td>3</td>
<td>24</td>
<td>8</td>
<td>8</td>
<td>Oct ’12/ 6</td>
<td>Dec ’12 5</td>
<td>Local group n/a</td>
<td>Imp Group 0</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>Oct ‘11</td>
<td>3</td>
<td>21</td>
<td>8</td>
<td>8</td>
<td>Mar ’12/ 6</td>
<td>Sept ’13 5</td>
<td>Local group n/a</td>
<td>Imp Group 1-2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>National 3</td>
<td></td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>May ‘12</td>
<td>1</td>
<td>14</td>
<td>10</td>
<td>9</td>
<td>Feb ’13/ 9</td>
<td>n/a</td>
<td>Local group 6</td>
<td>Imp Group 1-2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>National 2</td>
<td></td>
</tr>
<tr>
<td>Grampian</td>
<td>Oct ‘11</td>
<td>2</td>
<td>28</td>
<td>10</td>
<td>1</td>
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<td>n/a</td>
<td>Local group n/a</td>
<td>Imp Group 1</td>
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<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>National 1</td>
<td></td>
</tr>
<tr>
<td>Lothian</td>
<td>Sept ‘12</td>
<td>2</td>
<td>12</td>
<td>10</td>
<td>8</td>
<td>Jan ’13/ 7</td>
<td>n/a</td>
<td>Local group 5</td>
<td>Imp Group 1</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>National 2</td>
<td></td>
</tr>
<tr>
<td>Tayside</td>
<td>Oct ‘11</td>
<td>3</td>
<td>13</td>
<td>9</td>
<td>8</td>
<td>Mar ’12/ 8</td>
<td>5</td>
<td>Local group n/a</td>
<td>Imp Group n/a</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>National 2</td>
<td></td>
</tr>
<tr>
<td>Western Isles</td>
<td>March ’13</td>
<td>0</td>
<td>0</td>
<td>22</td>
<td>16</td>
<td>n/a</td>
<td>n/a</td>
<td>Local group 8-12</td>
<td>MCN 1-2</td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td>18</td>
<td>125</td>
<td>86</td>
<td>67</td>
<td>44</td>
<td>15</td>
<td>56</td>
<td></td>
</tr>
</tbody>
</table>
2 Progress and Achievements

2.1 Local Involvement

Neurological Voices’ local groups in Ayrshire & Arran, Dumfries & Galloway, Greater Glasgow & Clyde (GGC), Lothian, Tayside and Western Isles have functioned effectively since initial training, yielding valuable outcomes according to the NHS professionals, patients and carers involved. Neurological Voices meetings generally last 2 hours and take place every 6-12 weeks, according to health board timescales, i.e. regularity of Improvement Group or MCN meetings. As well as contributing to the general meetings and the topics under discussion, Neurological Voices have contributed to areas such as reviewing local strategic plans from a patient and carer perspective, reviewing patient information including websites and hard copy, developing specific local information, providing feedback on building/facility design (and redesign), contributing to survey design and commenting on care pathways. (A more detailed Table of activities by NHS board area is provided in Appendix 1, page 20.)

As one of the NHS Boards states “All aspects of the improvement group work and discussions are shared with the Neurological Voices Group and their perspectives have been hugely valuable…”

NHS Dumfries & Galloway and NHS Grampian local groups are not currently meeting. However, interest continues amongst past participants in Dumfries & Galloway, and in Grampian, one Neurological Voice continues to attend the Neurology Services Review Group and is linked with other Neurological Voices nationally.

NHS Forth Valley and NHS Tayside are currently reviewing their modus operandi and considering the way forwards in 2014.

2.2 National involvement

More recently, during 2013-14, the project has fostered Neurological Voices participation at a national level (since the establishment of the National Neurology Advisory Group).

(i) National Neurology Advisory Group

Neurological Voices representatives are now established on the National Neurology Advisory Group (NNAG), Operational Management Group (OMG), associated work streams and task groups. There is a spread of representation in terms of conditions and health board areas. (See Table 2, page 10, for details.) Indeed, some national representatives come from areas where the local group is not currently active: national activity has offered an
alternative opportunity for getting involved in improving services and keeping the patients perspectives on services on the agenda.

Neurological Voices on the NNAG and OMG have commented that the agendas and business of these groups is complex and challenging. Nonetheless, there is a strong sense of commitment to participating at a national level and to linking national and local levels, as channels for gathering and cascading information.

To date, the NNAG Co-ordinator has offered pre-meeting briefings and post-meeting debriefs to the four Neurological Voices who first became active at a national level on the NNAG and OMG. As national Neurological Voices engagement steps up (e.g. via work stream and task group involvement), it is anticipated this role will be taken over by the Neurological Voices Training and Support Co-ordinator who will also help implement a wider communication strategy of gathering and cascading of information to Neurological Voices local groups and individuals across Scotland.

(ii) National Neurology Advisory Group/Neurological Voices Learning Event

In November 2013, a NNAG one day learning event for Neurological Voices was attended by representatives from seven out of the eight health boards where training has taken place. This event explained the NNAG framework and outlined opportunities for national involvement. Participants also shared their experiences of local engagement, although this was not the formal focus of the event. This was the first time Neurological Voices from different health boards had the chance to meet and it proved to be a positive and constructive day.

Nineteen patients and carers with a wide range of conditions applied to attend. In the event, 13 people were present on the day, due to the complex and fluctuating health conditions represented. Only Dumfries & Galloway was not represented, as local group participants felt unable to travel to Stirling for a day.

Participants stressed the need for strong local Neurological Voices groups connected to national activity with support from their local NHS and the Neurological Alliance of Scotland. Evaluation of the day identified the need for further opportunities for Neurological Voices from different areas to meet face to face to build on the gains of this inaugural meeting. The full report from the day is available on the National Neurology Advisory Group website.\(^\text{10}\)

(iii) National Neurology Advisory Group Annual Conference

Nine Neurological Voices attended the first NNAG Annual Conference on 20\textsuperscript{th} March 2014. Neurological Voices involvement at the event was as follows:

- Neurological Voice on the NNAG delivered a plenary patient perspective on her first year of meetings, supported by Neurological Voices Training and Support Co-ordinator. (See Case Study p 23.)
- 2 Neurological Voices participated from the stage in the plenary Q&A and discussion
- Neurological Voice collaborated with NHS professionals to deliver two workshops on the impact of Neurological Voices involvement
- Neurological Voices delegates asked questions/ participated in discussions throughout the event.
### (iv) Table 2: National Neurological Voices Activity

<table>
<thead>
<tr>
<th>NNAG groups</th>
<th>No. of NV</th>
<th>NHS Board</th>
<th>Condition(s)/Carer</th>
<th>Meeting schedule per annum</th>
<th>Hours per meeting (not inc. travel)</th>
<th>Hours briefing/de-briefing</th>
</tr>
</thead>
<tbody>
<tr>
<td>NNAG</td>
<td>2</td>
<td>Greater Glasgow &amp; Clyde Forth Valley</td>
<td>MS / Epilepsy</td>
<td>3</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>OMG</td>
<td>2</td>
<td>Lothian Tayside</td>
<td>Carer (PD) / MS</td>
<td>4</td>
<td>2</td>
<td>16</td>
</tr>
<tr>
<td>Person centred Patient</td>
<td>1</td>
<td>Western Isles Tayside</td>
<td>Carer (MS)</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Satisfaction Survey</td>
<td>1</td>
<td>Western Isles Tayside</td>
<td></td>
<td>4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Care Pathways</td>
<td>1</td>
<td>Tayside/Forth Valley</td>
<td></td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Condition Specific H&amp;SC Data</td>
<td>1</td>
<td>Forth Valley Tayside</td>
<td></td>
<td>6</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>and Audit</td>
<td>?</td>
<td>?</td>
<td></td>
<td>Tbc</td>
<td>2</td>
<td>Tbc</td>
</tr>
<tr>
<td>Workforce Planning</td>
<td>1</td>
<td>Greater Glasgow &amp; Clyde Ayrshire &amp;</td>
<td>Carer (MS)</td>
<td>3</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Improvement Review</td>
<td>1</td>
<td>Arran</td>
<td></td>
<td>4</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>National NV Event</td>
<td>13</td>
<td>Ayrshire &amp; Arran Forth Valley</td>
<td>Arachnoiditis Ataxia</td>
<td>1</td>
<td>6</td>
<td>n/a</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Greater Glasgow &amp; Clyde Grampian</td>
<td>Epilepsy ME/CFS Multiple</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lothian Tayside</td>
<td>Sclerosis Neuropathy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Western Isles</td>
<td>Parkinson’s Disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National NNAG Conference</td>
<td>9</td>
<td>Ayrshire &amp; Arran Forth Valley</td>
<td>ME/CFS Multiple sclerosis</td>
<td>1</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>GGC</td>
<td>Epilepsy Carer Parkinson’s</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Lothian Tayside</td>
<td>Disease Carer Multiple Sclerosis</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
2.3 Neurological Alliance of Scotland Involvement

Neurological Voices have participated in Neurological Alliance of Scotland (NAoS) events and activities in a range of ways:

- 3 NHS Lothian Neurological Voices delivered a presentation on the programme at a N AoS Members’ Open Meeting, October 2012
- Brain Awareness Weeks – Parliamentary Events
  - 1 Neurological Voices representative delivered a keynote presentation on the importance and value of patient involvement and the Neurological Voices programme (March 2012)
  - 6 Neurological Voices spoke to MSPs and other guests on the impact of their neurological condition as part of an exhibition/marketplace event, ‘We are the Missing Millions’ (March 2013)
  - 6 Neurological Voices participated in an art workshop to create images representing their journey with their condition since diagnosis. The ‘artists’ accompanied their work at an exhibition in the Scottish Parliament, attended by MSPs, NHS and voluntary sector professionals and other N AoS stakeholders (March 2014).
- Approximately 5 Neurological Voices participate at the N AoS AGMs.
3 Learning and Challenges

The learning and challenges identified throughout delivery of the first three years of the project have highlighted ongoing support as crucial to the success and sustainability of the programme. An additional evaluation exercise was carried out in March 2014 by the NNAG Operational Management Group Chair, Susan Walker, in which all health boards were asked to provide information on the current status of Neurological Voices in their local area and their experience of the programme. This evaluation exercise concluded that the key to success appears to lie in local ownership and the support provided by the NHS health board. As one NHS board stated, “Engagement is a two way process in which Boards and services need to prioritise engaging with the programme.”

The Neurological Voices training programme equips participants with the skills and confidence to become key stakeholders, with local NHS professionals and voluntary sector representatives, in improving neurological health care services. However, the success and effectiveness of local Neurological Voices groups beyond initial training is directly correlated to the consistency of local NHS investment and support during and after training and the nature of the NHS input. Administration is also an important consideration from the outset.

**Neurological patients and their carers are enthusiastic and capable of engaging with NHS professionals to improve neurological services, however, they require support to fulfil their potential for effective patient involvement.**

3.1 Consistency of NHS Input

Unfortunately, when the HIS programme came to an end in March 2012, many of the Improvement Leads or other identified contacts for Neurological Voices moved on to other posts, often with adverse consequences for the groups.

The impact of consistency of NHS input is clearly reflected in the effectiveness of local Neurological Voices groups: Local groups in NHS Ayrshire & Arran, NHS Greater Glasgow & Clyde and NHS Lothian continue to meet with the original contact, established during initial training. NHS Western Isles met with consistent NHS support, now affected by maternity leave; however, the group is continuing to meet regularly with alternative NHS input. Local groups in NHS Dumfries & Galloway, NHS Forth Valley, NHS Grampian and NHS Tayside have all been affected by the loss of the original contact and changing priorities, though NHS Tayside met productively with the original Improvement Lead for the first year. Similarly NHS Dumfries & Galloway met regularly and successfully with an alternative NHS contact for approximately six months.

Movement of NHS staff posts continues to be a challenge for the ongoing support of local Neurological Voices groups and can be destabilising for members. It is evident that
consistent NHS support of groups is important if ongoing engagement of Neurological Voices is to be effective.

3.2 Nature of NHS Input

The nature of NHS input in local groups has varied across health boards. NHS input has come from a range of professionals with management and clinical backgrounds, e.g. Service Managers and Planners, Allied Health Professionals and Specialist Nurses. In some boards two NHS professionals regularly attend meetings. For example, in NHS Greater Glasgow & Clyde, the group meets with the General Manager for Regional Services and the Lead Nurse for Neurosciences and in NHS Ayrshire and Arran, the Planning Manager and Rehab-Coordinator & Managed Clinical Network Manager facilitate the local group.

What matters most is that the NHS professionals are committed to and value patient involvement, and that they can support the Neurological Voices to make their voices heard beyond local group meetings, ensuring patient and carer can genuinely influence service design and improvement. As one NHS Board states, “We need to ensure that a wide range of managers have the values, priorities and engagement and listening skills to develop the groups and individuals.”

3.3 Administrative arrangements

Administrative arrangements vary. For example, NHS Lothian provides full secretarial support for the group. NHS Greater Glasgow & Clyde organise the venue and contribute to the agenda but a Neurological Voices participant takes and distributes the notes. In some areas the NHS contact has served as Chair and group facilitator, e.g. NHS Tayside, while NHS GGC, NHS Lothian and NHS Western Isles are all chaired by a Neurological Voices participant.

Local groups can operate effectively in a range of ways, according to local NHS resources and requirements and the capacities of the local Neurological Voices representatives. In some areas, having a Neurological Voice as Chair or note taker for the group has been a positive choice, while elsewhere, no one has felt able to take this responsibility due to health status. It is essential that each health board area addresses terms of reference, no matter how simple, identifying the group’s purpose and how it can function effectively, with reference to The Neurological Alliance of Scotland’s ‘Guidelines for Effective Engagement with Neurological Voices’¹¹.

¹¹ [http://www.scottishneurological.org.uk/content/res/Guidelines_for_Engaging_with_Neurological_Voices.pdf](http://www.scottishneurological.org.uk/content/res/Guidelines_for_Engaging_with_Neurological_Voices.pdf)
3.4 Ongoing recruitment & induction

A final challenge affecting the strength of local groups has been the variable health status of participants which has affected attendance and commitment longer term. Groups were initially set up with a maximum of 10 participants so everyone could feel included, with time to have their say - but variable attendance has meant numbers can easily drop below a critical mass of around 5-6. Ongoing recruitment and induction of additional participants needs to be seen as integral to the maintenance of effective Neurological Voices groups.
4. **Recommendations and Future Priorities**

During 2013-14 the introduction of 'The 3 Step Improvement Guide – May 2013' ¹² has been helpful in consideration of the Neurological Voices programme.

The following recommendations are based upon the learning and evidence gathered from across NHS Boards and the NNAG and associated groups. Neurological Voices are now operating at a number of levels but without the continued central support of the Neurological Voices Programme this will not be sustainable.

### 4.1 Recommendations for Local Involvement of Neurological Voices

As discussed eight of the 14 NHS Boards have already received training.

- Training should be considered for all remaining NHS Boards; however, as consistent ongoing local NHS support is crucial to support and sustain involvement of local

Neurological Voices, it should only be delivered where there is a commitment to providing this support.

- Further recruitment should be undertaken and induction training delivered in active local boards who have already received Neurological Voices training. This will extend the range of conditions/perspectives represented in the existing groups and help to maintain effective group size.
- Encouragement and support should be provided to health boards with trained Neurological Voices where there is currently no active local group. This will increasingly be reinforced by the NNAG and OMG where Neurological Voices are actively championed.

### Current Neurological Voices Training Priorities

- NHS Borders and NHS Highland Neurological Voices new training
- NHS Ayrshire & Arran, NHS GGC & NHS Lothian further induction
- NHS Western Isles follow-up and further induction
- NHS Dumfries & Galloway, NHS Forth Valley, NHS Tayside support to re-establish existing group (+ further induction, as required)

### 4.2 Recommendations for National Involvement of Neurological Voices:

The NNAG is providing ongoing opportunities for national Neurological Voices involvement via its developing work streams and task specific groups. In order for this engagement to be as meaningful and representative as possible, Neurological Voices representatives at all levels of national involvement will need support briefings (e.g. clarifying agenda items and action points etc) as well as support to share information with local Neurological Voices groups and to gather relevant feedback.

### Current National Priorities

- All representatives on NNAG and associated groups should be supported as necessary by the Training and Support Co-ordinator via meetings and phone calls. This will help to ensure Neurological Voices have a good understanding of NNAG activities and support meaningful engagement at meetings.
- There should be increased involvement of Neurological Voices in the wider work of the Neurological Alliance of Scotland supported by the Training and Support Co-ordinator. This will enable Neurological Voices to engage with the wider strategic objectives of the Alliance.
- A national gathering for Neurological Voices from different health boards should be convened annually or bi-annually to support sharing of information and experiences regarding both local and national Neurological Voices involvement.
The Neurological Voices training programme enables people to identify and agree common and collective concerns and areas of priority beyond the experience of their own condition. Input at all levels of local and national involvement can be strengthened with improved sharing of information between all trained Neurological Voices in Scotland.

In 2012 a redesign of the Neurological Voices section of the Neurological Alliance of Scotland website was undertaken in consultation with some Neurological Voices volunteers. This area of the Alliance site was moved to its own linked sub site and information was included regarding the training programme materials such as the guidelines for engaging people with neurological voices, ground rules and training programme examples. Links to all relevant policy documents and guidelines were also added. As part of this re-design an online forum was established with the aim of providing all trained Neurological Voices with an area to post and discuss issues relating to their involvement work. It was envisaged that this would facilitate the sharing of information and experience locally and improve communication across the wider Neurological Voices network. A number of Neurological Voices signed up to the site and a couple of threads were posted initially with some exchange of comments. The forum, however, failed to be utilised despite attempts to promote and encourage its use by the Training and Support Co-ordinator. Feedback from the Neurological Voices was that whilst a mechanism for sharing information and enabling communication was welcome and seen as useful, a forum was not seen to be easily accessible and particularly user friendly. Social media was highlighted as a better way to achieve this aim. It was also agreed that a mechanism for regularly gathering information and seeking feedback would be useful and would require co-ordination by the Training and Support Co-ordinator.

The Training and Support Co-ordinator will therefore implement a wider communication strategy for gathering and cascading of information to Neurological Voices local groups and individuals across Scotland going forward.

### Priorities for Communication and Sharing Information

- Implementation of a system to enable consistent sharing of information between local Neurological Voices groups and through the NNAG structures to be developed and facilitated by the Training and Support Co-ordinator.

- Development of a mechanism to facilitate Neurological Voices reporting on key issues and action points. Information will be gathered and shared on regular basis.

- Email groups, Facebook page, Neurological Voices forum to be established, promoted and monitored.
From October 2013 - March 2014, the Neurological Voices programme was contracted by the Managed Service Network for Neurosurgery in Scotland (MSN) to deliver **Neurosurgical Voices** training at the four neurosurgical units: Aberdeen, Dundee, Edinburgh and Glasgow.

The Neurological Voices training programme was adapted to suit the needs of the MSN and patients and relatives who have used neurosurgical services. Participants were people who had previously undergone neurosurgery for a range of conditions (e.g. brain injury, tumour, epilepsy, Chairi malformation and stroke) and carers. Recruitment was via relevant NAoS member organisations, presentations to relevant local support groups and flyers distributed by NHS professionals in the units.

Training focused on sharing experiences of living with a condition; services and support; the remit of the MSN and the role of Neurosurgical Voices both nationally and locally. Groups also discussed effective communication skills, guidelines for involvement and shared areas of interest or concern that may be addressed going forward. Clinical staff from the local unit attended on the first day to meet participants and give an overview of their role in the unit.

The training evaluated very positively and there are now groups of Neurosurgical Voices established in all four areas who will be supported by their local MSN contact. Some of the groups have already met since the training and many of the participants have had a tour of their local unit to better understand the entire neurosurgical patient journey; visiting wards, outpatients, theatres and scanning.

The MSN Neurosurgery has recently established local hubs in the four areas which will comprise a lead consultant, MSN contact and multi disciplinary neuroscience staff. Neurosurgical Voices will be involved in the local hubs to ensure the perspective of those using neurosurgical services are incorporated into planning and improvement. There will also be opportunities for national involvement with the MSN where Neurosurgical Voices may help with the design of projects, making sure reports are ‘patient-friendly’ and helping identify priorities for improvement.

<table>
<thead>
<tr>
<th>Neurosurgery Unit</th>
<th>Training Dates</th>
<th>No. of Participants</th>
<th>No. of local Meetings</th>
<th>No. of hub meetings</th>
<th>National meetings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aberdeen</td>
<td>Oct/Nov 2013</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Dundee</td>
<td>Jan/Feb 2014</td>
<td>16</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Edinburgh</td>
<td>Nov 2013</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Glasgow</td>
<td>Feb/Mar 2014</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
6 Conclusion

The Neurological Voices programme has trained and supported over 100 people affected by a range of neurological conditions in eight NHS board areas. Many patients and carers, following training, have formed locally based Neurological Voices groups and have participated in local and national neurological health service improvement activity (this does not include Neurosurgical Voices, which was a separately funded initiative).

Neurological Voices have given many hours of their time participating in their local Neurological Voices meetings and providing representation at NHS Board Neurology Improvement Group meetings. A number of Neurological Voices have also taken on an additional role of becoming national representatives and have attended national meetings of the NNAG, OMG and associated work streams. As well as attending meetings, a significant amount of time has been spent reading and absorbing relevant documents and participating in specific work tasks. The Neurological Voices are motivated by a commitment to ensuring there is a patient and carer perspective on neurological service improvements. As one of the Neurological Voices states, ‘It is essential that patients and carers provide a lived perspective at all levels, including in consideration of strategy. Our voices need to be heard, ringing throughout the national and local frameworks. You won’t get it right without us!’

As evidenced in the report, Neurological Voices have been involved in a range of activity that aims to ensure neurological service improvements are aligned with patients’ priorities. All Boards where Neurological Voices are active are very positive about the programme and its benefits. As one Improvement Lead comments, Neurological Voices helped by ‘...pointing out that the vision that I had drafted was a vision for a way of working not for better services. Their kind and patient approach to my task and agendas have led us to a much clearer vision for services.’

Progress and achievements of Neurological Voices within participating NHS Boards have been variable and largely dependent upon the consistency and nature of NHS continued support. Personnel changes and resource constraints have proved a challenge in some boards and it is crucial that if Neurological Voices are to be effectively engaged, then sustained and appropriate support from their local NHS health board as well as support from the Training and Support Co-ordinator of the Neurological Voices Programme is required. This does not necessarily mean resource intensive support from NHS health boards but rather that the most appropriate NHS staff member is identified as the local contact, the terms of reference for the local group are clear and that meaningful areas for productive engagement are agreed. As one health improvement lead comments ‘They are excellent at keeping a focus on what’s important – or what matters, have energy and enthusiasm, and their challenges and discussions highlight how dysfunctional our internal
rhetoric and rule of thumb assumptions about patients views are, particularly when it comes to our use of resources.’ Rather than a one size fits all approach, there are various effective forms of modus operandi for involving Neurological Voices in local NHS board improvement and the Training and Support Co-ordinator can support local boards to find solutions tailored to their priorities, resources and constraints.

The NNAG is becoming established as an effective forum for collaboration and focused neurological health service improvement activity. It currently involves Neurological Voices in a range of its groups and offers further opportunities for future involvement. The NNAG can also share information, experience and examples of good practice regarding Neurological Voices involvement across local NHS Board improvement teams and can champion the value of including Neurological Voices in improvement activity.

Neurological Voices who have become national representatives require additional support to ensure they have a proper understanding of the agenda and outcome of meetings and are able to share information and seek feedback from the wider Neurological Voices network where appropriate. The Training and Support Co-ordinator has provided some support to national representatives to date and this role will increase as more Neurological Voices take up places on forthcoming NNAG subgroups. It will be increasingly important for the Training and Support Co-ordinator to facilitate the sharing of information and gathering feedback from across the Neurological Voices network to ensure that those Neurological Voices attending meetings are representative of wider patient and carer experiences.

In summary, the Neurological Voices programme is valued, both by the people affected by neurological conditions involved and participating NHS Boards, for its contribution to ensuring neurological health care services are truly person centred. New Interest in delivery of Neurological Voices training has been expressed by some of the NHS Boards yet to establish local Neurological Voices groups and requests for follow up training and additional recruitment/induction have been made by some of the already participating boards. Finally, national involvement of Neurological Voices will continue and expand with the development of the NNAG requiring ongoing support and co-ordinated facilitation regarding information sharing and gathering of feedback.
## Appendix 1: Table of activities by NHS board area

<table>
<thead>
<tr>
<th>NHS Board (A-Z)</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ayrshire and Arran</td>
<td>Improvement Plan – consulted and made changes to final version.</td>
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<tr>
<td></td>
<td>Public Information Leaflet - led on the development.</td>
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<tr>
<td></td>
<td>Implementation of Health &amp; Social Care agenda – consultation and discussion.</td>
</tr>
<tr>
<td></td>
<td>Research proposals – feedback and discussion.</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>Improvement Plan – consulted and discussed.</td>
</tr>
<tr>
<td></td>
<td>Condition specific care pathways considered against Clinical Standards.</td>
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<tr>
<td></td>
<td>Patient Health Record Books – reviewed.</td>
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<tr>
<td></td>
<td>Patient Information for newly diagnosed patients discussed.</td>
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<tr>
<td></td>
<td>Care Aware DVD – reviewed.</td>
</tr>
<tr>
<td></td>
<td>Participation at Neurology Services Group.</td>
</tr>
<tr>
<td></td>
<td>(No current local group activity.)</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>Presentation to Neurology MCN on Neurological Voices.</td>
</tr>
<tr>
<td></td>
<td>Involvement in Neurological Conditions MCN Strategy Stakeholder Event.</td>
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<tr>
<td></td>
<td>Participation by Neurological Voice(s) in Steering and Core MCN Group.</td>
</tr>
<tr>
<td></td>
<td>(No current local group activity.)</td>
</tr>
<tr>
<td>Greater Glasgow &amp; Clyde</td>
<td>Participation in update of Improvement Plan.</td>
</tr>
<tr>
<td></td>
<td>Review of patient information/website.</td>
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<tr>
<td></td>
<td>Review of outpatient facilities.</td>
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<tr>
<td></td>
<td>Redesign of patient survey.</td>
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<tr>
<td></td>
<td>Participation at Neurology Improvement Group.</td>
</tr>
<tr>
<td>Grampian</td>
<td>Participation by Neurological Voice (1) at Neurology Services Review Group.</td>
</tr>
<tr>
<td></td>
<td>(No current local group activity.)</td>
</tr>
<tr>
<td>Lothian</td>
<td>Stakeholder conference to develop Improvement Plan - Neurological Voices</td>
</tr>
<tr>
<td></td>
<td>gave a presentation to approx 100 delegates.</td>
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<tr>
<td></td>
<td>Identification of priorities explored and recorded in the local Improvement</td>
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<tr>
<td></td>
<td>Plan.</td>
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<tr>
<td></td>
<td>All aspects of the improvement group work and discussions shared with</td>
</tr>
<tr>
<td></td>
<td>local Neurological Voices group.</td>
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<tr>
<td></td>
<td>Input additionally sought from wider work on patient centred services.</td>
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<tr>
<td></td>
<td>Participation by Chair at Neurological Care Improvement Group.</td>
</tr>
<tr>
<td>Tayside</td>
<td>Review of Patient Information.</td>
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<tr>
<td></td>
<td>Rehabilitation review.</td>
</tr>
<tr>
<td></td>
<td>Patient Questionnaire.</td>
</tr>
<tr>
<td></td>
<td>(No current local group activity.)</td>
</tr>
<tr>
<td>Western Isles</td>
<td>Control of medication in the hospital, especially Parkinson’s Disease.</td>
</tr>
<tr>
<td></td>
<td>Annual reviews for long term patients - discussion.</td>
</tr>
<tr>
<td></td>
<td>Family briefings.</td>
</tr>
<tr>
<td></td>
<td>Video-conference Clinics – discussion and feedback.</td>
</tr>
<tr>
<td></td>
<td>Participation at Neurology MCN.</td>
</tr>
</tbody>
</table>
# Neurological Voices Case studies

## NHS Greater Glasgow and Clyde

G GC Neurological Voices meet every 6-8 weeks at the Southern General Hospital, Glasgow, which is currently undergoing a rebuild. The two Neurology buildings will not be moving to the new facility. Patients, carers and staff had raised concerns regarding the existing Neurology Outpatients Department (OPD). A small budget for refurbishment of the Neurology OPD was found to be available and has since been effectively utilised.

**AIM**

To improve the patient experience of Neurological Outpatients Department

**PROCESS**

- Short questionnaire about Outpatients Department (OPD) completed by Neurological Voices to identify preliminary issues
- Neurological Voices and Lead Nurses joint walk round of OPD, viewing facilities from the patients’ perspective
- Report on issues identified
- Discussions organised with architects/new service designers sourced by Neurological Voices to look at the best way to improve the OPD in the longer term

**OUTCOMES**

- Opportunistic improvements made short term, e.g., dropped kerb and new paving at entrance to building
- Removal of the sloping floor is planned
- Emergency pull cord in accessible toilet has been lengthened and the toiler roll holder relocated
- Priority issues reviewed by Estates, resulting in a planned programme of future improvements.

**BENEFITS**

- When familiar surroundings were seen through new eyes, different priorities were realised
- Staff became aware of the patient perspective – and vice versa
- Simple, practical exercise led to meaningful change that was implemented more quickly and readily than people might have expected
- Tangible difference sustained/raised motivation of Neurological Voices group;
- Improvements made and are ongoing.

**QUOTES**

‘Best meeting of the month!’ (NHS Staff member)

‘It is exciting to see, to physically see, that improvements have been made which we, as Neurological Voices, have suggested, that will benefit all patients using the department. However small those improvements may seem to be, it makes me feel valued and listened to!’ (GGC Neurological Voice)

## NHS Ayrshire & Arran

Ayrshire and Arran Neurological Voices meet as a local group every 8-12 weeks at the Douglas Grant Rehabilitation Centre at Ayrshire Central Hospital with consistent input from the Planning Manager and Rehab-Co-ordinator & MCN Manager.

After identifying a number of issues, the group decided to focus on two main areas.

**AIM(S)**

**Neurological Services 5 Year Improvement Plan**

To improve the experience of neurological patients and to clarify and standardize the implementation of services to all neurological patients by providing a patient and carer perspective on the 5 year plan.

**Improve Patient Information for newly diagnosed neurological patients in the local area**

To provide accurate signposting to relevant and correct information for patients at first referral or point of diagnosis.
### PROCESS

**5 Year Improvement Plan**
- Initial training on privacy policy and other issues.
- Invitation to review, reflect and advise on issues identified in the 5 Year Improvement Plan by the local Neurological Voices, with assistance and support from NHS facilitators.
- Neurological Voices were given a copy of the plan and studied each part carefully at home, making notes and observations. There was a commitment to better understanding issues relating to various conditions addressed in the plan. Meetings focused on particular sections of the plan, until all were addressed.
- The group also took part in a number of surveys to identify issues for discussion.
- Over many meetings, adjustments and suggestions were made to the plan and this information was carried forward to the Neurology Services Group.

**Improve Patient Information**
- Issue arrived at following discussion of Neurological Voices’ own experience. Lack of or incorrect information provided when patients with neurological symptoms were first referred or diagnosed. ‘The need for clear and simple information was overwhelming.’
- Neurological Voices discussed where information was most needed and decided on the GP practice. They proposed developing a small, easily understood leaflet to be issued by the practice nurse, GP or other healthcare professional. The group developed a simple leaflet which was refined and corrected over several meetings.
- After editing and checking for legal issues etc the new leaflet was sent for publishing.

### OUTCOMES

**5 Year Improvement Plan**
- Neurological Voices influenced the plan by suggesting adjustments and amendments, e.g. an amendment was adopted regarding the importance of carers in understanding conditions and assistance needed.

**Improve Patient Information**
- Leaflet produced and in circulation.

### BENEFITS

‘From working together, everyone involved with neurological conditions is more aware of expected treatment and care, whether health care professional, carer or patient. We are more able, by working together, to identify and build relevant local care packages for the patient. Everyone benefits.’

### QUOTE

‘To have the patients perspective on literature we produce is also crucial if we are to attract it to the patients’ attention and encourage them to read.’ NHS A&A

‘At the first NNAG annual conference, when Chairman Andrew Wynd made his opening remarks, the very first issue he referred to was one that the Neurological Voices had identified and passed on - this made many of us feel that at last we were being listened to and our concerns acted upon. Thank you.’ A&A Neurological Voice

### NNAG Annual Conference – Neurological Voices Plenary Presentation

Gill was invited to provide a Neurological Voices perspective as a patient representative on the NNAG at its first Annual Conference. Gill has complex epilepsy, lives independently, and has recently taken on an assistance dog, Holly, who accompanied her to the event.

**AIM**
To enable Gill to provide her Neurological Voice’s perspective with confidence and minimal stress.

**PROCESS**
Series of telephone and face to face meetings prior to the event:
- Initial telephone discussion regarding demands, practicalities, potential narrative/content
- Follow up telephone discussion, review and decision making based on demands of
- task and Gill’s current capacities, further discussion of narrative
  - Transcription of narrative by JA, sent to Gill for review
  - Initial meeting to consider and further develop message and content
  - Further crafting/polishing of copy by JA to reduce demand for Gill
  - Meeting for final redrafting with Gill, development of accompanying PowerPoint, presentation, rehearsal

At the event:
- Support on the day (for Gill and regarding Holly’s needs)

<table>
<thead>
<tr>
<th>OUTCOMES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gill successfully delivered her presentation</td>
<td>Feedback from across the range of participants was extremely positive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BENEFITS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gill demonstrated the capacity and commitment of patients to participate at a strategic level to a wide audience</td>
<td>Gill raised the profile of Neurological Voices</td>
</tr>
<tr>
<td>Gill communicated effectively, the support required to facilitate true Neurological Voices involvement</td>
<td>Gill and Jan modelled what can be achieved with a truly person centred approach.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QUOTES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I certainly wouldn’t have been able to do the presentation without Jan’s support in preparation and on the day.’ Neurological Voice</td>
<td></td>
</tr>
</tbody>
</table>
Thanks to:

The Scottish Government and The Hugh Fraser Foundation for funding this project

All Neurological Voices who have taken part

Craig Stockton (NAoS Chair) and Candice Dillen (NAoS Co-ordinator) for management support

Paula Aldin-Scott, Co-ordinator of the NNAG, Andy Wynd, Chair of the NNAG and Susan Walker, Chair of the NNAG’s OMG for championing Neurological Voices, nationally and locally

Irene Cameron (NAoS Administrator) for administrative support

NHS Scotland Neurology Improvement Leads and their colleagues who support the programme

Dave Bertin, Juliet McKellaig and Nicola Cotter of the Chest, Heart & Stroke Scotland ‘Voices Scotland’ team

NAoS member organisations, who have supported recruitment to the programme.

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