The Stroke Association
In partnership with South Central Cardiovascular Network

Stroke Patient and Carer Involvement project

Consultation document

December 2011

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1. Purpose

The purpose of this paper is to seek the views of all stakeholders in the patient and carer involvement project to shape the final stages of the project.

This will also give an indication moving forward of the sustainability and legacy of the project.

The paper looks at the successes and challenges of the project, and also outlines plans for 12-13.

Stakeholders receiving this document should also have been in receipt of quarterly reports for their own specified areas and the annual report, therefore this paper does not intend to repeat information unnecessarily. If you would like copies of the aforementioned documents please contact Carly Davey (carly.davey@stroke.org.uk).

2. Background

Engaging with the people who use services should be embedded into the very fabric of our systems. It should empower people to make improvements to services, for without the knowledge of how people view their care, how can we ever make things better.

The South Central Cardiovascular Network commissioned The Stroke Association to carry out a two year project to obtain patient and carer feedback on the stroke services they received at each stage of the recovery and rehabilitation journey. Two stroke patient and carer involvement coordinators were recruited; one for the south (Hampshire, including Southampton City and Portsmouth City, and the Isle of Wight) and one for the north (Milton Keynes, Berkshire East, Berkshire West, Buckinghamshire and Oxfordshire). It is hoped that the learning from this project will leave behind a legacy which will remain embedded in health and social care systems.

3. Project objectives to November 2011

The project started in June 2010 with 5 main objectives.

Questionnaires
To produce, distribute and collate responses for two questionnaires; one for the acute stage and one for post-discharge.

User involvement groups
To set up one user involvement group per health region to be linked in with professionals and commissioners to help develop and influence change.

Interviews
To produce an interview strategy and to appropriately conduct interviews across the region with those who have expressed an interest.

Engaging with seldom heard groups
To reach out and involve those from groups that are often seldom heard, for example, those discharged straight to nursing homes, those from ethnic minorities or whom English is not their first language and people with communication difficulties.

Feedback mechanisms
To establish feedback mechanisms to trusts, commissioning bodies, patients and carers and any other stakeholders in the stroke pathway, via a quarterly report.
4. Successes and Challenges to date

Since starting in June 2010, the work has developed from an initial plan in January 2010 to a project that is actively engaging with stroke survivors and carers at a number of different levels. People are able to feedback their experience of stroke, their ideas and their specific comments in a variety of ways. This allows the ‘patient voice’ to really contribute towards influencing the future stroke services across South Central.

‘Have Your Say’ events
These events focussed on engaging stroke survivors, carers and relatives in providing feedback about their experiences. The events were run in collaboration with the Trusts and helped develop awareness of the project and kick start engagement work across the region. The events were very successful and enabled to the project to recruit initial members for our user involvement groups.

Patient and carer representative development work
Through the careful mentoring of Wendy Gray, the project has been able to assist and run development sessions in collaboration with the South Central Cardiovascular Network. This training has ensured that we have ‘champions’ across the region who are expert representatives for their areas.

4.1 Questionnaires

Successes

An acute questionnaire has been developed for the region. Below outlines which trusts are using the questionnaire and what the return rate has been for each trust.

<table>
<thead>
<tr>
<th>Hospital Trust</th>
<th>Questionnaire</th>
<th>Distribution started</th>
<th>Project Questionnaires returned to date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Q1 11-12</td>
</tr>
<tr>
<td>Oxford Radcliffe</td>
<td>✔</td>
<td>March 2011</td>
<td>8</td>
</tr>
<tr>
<td>Buckinghamshire</td>
<td>✔</td>
<td>June 2011</td>
<td>0</td>
</tr>
<tr>
<td>Milton Keynes</td>
<td>✔</td>
<td>June 2011</td>
<td>0</td>
</tr>
<tr>
<td>Heatherwood and Wexham Park</td>
<td>✔</td>
<td>May 2011</td>
<td>0</td>
</tr>
<tr>
<td>Royal Berkshire</td>
<td>✔</td>
<td>March 2011</td>
<td>0</td>
</tr>
<tr>
<td>Basingstoke and North Hants</td>
<td>✔</td>
<td>March 2011</td>
<td>3</td>
</tr>
<tr>
<td>Portsmouth</td>
<td>✔</td>
<td>Pre-project</td>
<td>0</td>
</tr>
<tr>
<td>Southampton</td>
<td>✔</td>
<td>Pre-project</td>
<td>0</td>
</tr>
<tr>
<td>Winchester &amp; Eastleigh</td>
<td>✔</td>
<td>March 2011</td>
<td>5</td>
</tr>
<tr>
<td>Isle of Wight</td>
<td>✔ ✔</td>
<td>Pre-project &amp; Nov 11</td>
<td>0</td>
</tr>
</tbody>
</table>

*Project questionnaire = Based on original questionnaire pro-forma and adapted by the project team
**Trust questionnaire = Trusts own questionnaire, includes PDA in patient versions

Challenges

4.1.1 Scope of the questionnaire
Development of the questionnaire was a consultative process and was based on an existing pro-forma from Annette Murray, Stroke Specialist Nurse, Basingstoke and North Hampshire Foundation Trust. The questionnaire was tested with stroke survivors in the region to look at issues such as accessibility, length of questionnaire and the types of questions asked.

The end result is a very comprehensive questionnaire which should give a picture of a stroke survivor’s acute journey. However the timing of the distribution of the questionnaire can mean that participants will comment on their entire journey within this document.
4.1.2 Length of the document
The questionnaire is a 6 page, 26 question document with a series of optional answers and space to comment for example:

18. How **prepared** did you feel for being discharged from hospital?

<table>
<thead>
<tr>
<th></th>
<th>Very</th>
<th>Somewhat</th>
<th>Not very</th>
<th>Not at all</th>
<th>Can’t remember</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Please comment………………………………………………………………………………………………………..

Although a thorough consultative process was followed in the development of the questionnaire, there has since been feedback through various routes that people have found it very long and in some cases inaccessible.

It is understood that from a trust perspective the feedback needs to be detailed in order to act upon specific details of an experience, however from a patient perspective it may be that they will give the detail of experiences they were either particularly pleased with or particularly dissatisfied regardless of the questions asked.

4.1.3 Point of distribution of the questionnaire
For different reasons, the questionnaire has been difficult to distribute at a specific point in the pathway. Originally distribution was intended to be at point of discharge from hospital. In some trusts this has been an appropriate distribution method, but in others distribution has been problematic. As a result, the project team have taken a pragmatic approach to distribution wherever was reasonable to do so. In some trusts this has been at discharge and others at the 6 week or even 6 month review. Where there has been an existing method of obtaining patient feedback, we have systems in place to receive the report data from these Trusts so that some data is captured for the quarterly reports ”

4.1.4 Sustainable use of project questionnaires
As can be seen from the table above, the questionnaire developed by the project is being used in 7 of the 10 trusts. 4 trusts (including IoW who are now distributing both questionnaires) are using their own patient satisfaction questionnaires, which are passed to the project team to analyse. All trusts are therefore ensuring that feedback is sought from patients and carers who use services.

During the development of the project, it was originally planned that the questionnaire would be uniform across the region, however as some trusts already had their own systems this was not the end result. Since the aim of the project should be to facilitate and support this process to happen in the region, the project team feel that the objective of developing and distributing questionnaires has now been achieved.

The only area of concern where project questionnaires are not being used is around recruitment to other areas of the project. For example if a patient or carer does not receive a questionnaire, they may not have the opportunity to participate in an interview or user group either. This is further discussed in other sections of the document.

The issue of sustainability of the questionnaire is one which is more complex. Where trusts have implemented their own systems this will be embedded into the pathway and will be sustainable when the project ends. For other trusts, the project will need to support the process further, either by handing systems over to the trust or continuing to maintain the systems as a separate process.
Following the PPE steering group who met on 15th December 2011, it was felt that a complete redesign of the questionnaire was needed.

At the time of writing it is proposed that:

- The questionnaire is made much shorter—maximum 2 sides of A4.
- The questions are based around simple principles, such as satisfaction, areas for improvement etc.
- The questionnaire is given on discharge from hospital, and again at 6 weeks and 6 months where it is possible to facilitate the distribution of this.

The group felt that this would give people an opportunity to comment about each part of their pathway if they wanted to and that it would also give an opportunity for analysis across the pathway in a small number of cases, which would give a better overall picture of the stroke journey.

It was also recognised that providers of services should have their own satisfaction measures in place, and therefore that detailed feedback on particular provider services should potentially not be part of this project.

**Questions for consultation**

1. Should the project continue to support the process of distributing and collating responses to project questionnaires?
2. What is your view on the proposed redesign of the questionnaire?
3. What is your view on the frequency of distribution of the questionnaire?
4. Do you agree that detailed feedback on providers should not be included in this project?
5. Post project, should there continue to be a system whereby The Stroke Association (or other independent body) continue to support the process of distribution, collating and analysing feedback?

### 4.2 User Involvement Groups

**Successes**

Following a ‘Have Your Say’ event in each area, user involvement groups have now been established in eight areas of the region and are running bi-monthly where possible. Each group has had varying degrees of success in terms attendance and focus.

**Emerging themes**

There a number of themes emerging from the user involvement groups which are evidenced through quotes from the groups:

- **Discharge procedure** (poor communication at point of discharge, not providing relevant stroke information, and lack of confidence in the whole procedure). Minutes from all of the user involvement groups show regular discussions about the discharge procedure. It is thought by the groups that there is not enough useful/relevant information provided at the point of discharge. The questionnaire results show that some information is being given out on discharge. Perception of what is useful and what is actually given out seems to differ.
“Discussions took place around the sense of abandonment and perceived postcode lottery in the area……thought transparency at the discharge procedure and community service process would help with feeling isolated.”

“…frustrated that none of this information [about the stroke association and local stroke clubs] had been given to them at point of discharge from hospital.”

“…one of the main issues arising from the event was the discharge procedure at the hospital needing to be improved (members agreed this is linked to the above point about clarity of information).”

“…both had difficulty reading the information given out”

“…the group felt that there was a big issue around information and support for the children of stroke survivors”

“information can be contradicting depending on who you talk to.”

• **Provision of community services** (poor access to services, inadequate communication and lack information about services available). During the ‘Have Your Say’ events the ‘sense of abandonment’ came up several times. Minutes from many of the user involvement groups show some of the more animated discussions are around community services. Members of the groups have had some positive experiences, however some feel that feel it is unfair that this service isn’t available to them.

  “The group agreed that they struggled to find appropriate services after leaving hospital, including physiotherapy, speech and language therapy services and psychological support.”

  “…disappointed at the lack of physiotherapy once they were discharged from hospital. Members agreed they would all benefit from community physiotherapy services…… discussions were also had around the lack of psychological assistance.”

  “…the group felt that another main issue was lack of appropriate information about/access to community services”

  “No review at all after a year........don’t know what community service information is out there..............no support down the line; no speech therapy, no physio – general sense of abandonment...........no psychological support........ Alternative therapies should be considered e.g. singing, as there is evidence to suggest this benefits stroke patients’ recovery.”

• **Nursing home care standards** (lack of stroke specific training for care/nursing home staff). Minutes from user involvement groups detail the common discussions around standard of care within some care homes. It is thought by the groups that all care/nursing homes could benefit from receiving some in-house training in stroke specific skills.

  “…commented that there are obvious gaps between residential care and nursing care. [It was] highlighted that care homes see there clients as nursing home clients, not as individual stroke survivor clients.”

  “…raised the issue that if you don’t have a good support network of family and friends to flourish, then you slip through the cracks.”

  “Care home training was discussed as a concern of the group. Training is not right standard for stroke patients.”
Challenges

4.2.1 Refreshment of membership
Each group has had varying levels of participation. Some groups are becoming very large as new participants come along to have their say, others are a core group of individuals with few new ‘voices’ coming through the door, and one or two are struggling to get regular participation.

The lack of new ‘voices’ may be an issue, in that people’s experiences of the pathway at that particular point in time will become dated as services and systems change. This is not to devalue the participation of stroke survivors and carers whose experience of stroke may have been some time ago, and indeed some experience of services may be very recent, however the forum for sharing these experiences needs to be thought through. It might be that people are contacted through the project, network, trusts or commissioning bodies to consult on particular pieces of work that are going on, or it could be that they are asked to support newer ‘voices’ coming through the system.

Another issue that seems to be arising with the user groups, is that people are reluctant to attend such a forum early on in their experience, therefore it might be that the groups will never capture a recent experience in the pathway and their purpose should be redefined.

The groups need to remain at a reasonable size to allow people to have a useful discussion about experiences and comment on particular service developments, therefore we may need to look at limiting size and length of involvement with the groups.

4.2.2 Sustainability of groups
The project team is tasked with ensuring that the groups are sustainable beyond the life of the project. The project team has concluded that it is impossible to make these groups truly sustainable in terms of being self sufficient, because there is a need for continual refreshment of participation and there are aspects of the groups that need to be externally managed such as the administration and the feedback mechanisms. The groups however can become sustainable by being supported through the local health and social care architecture. This might be through emerging CCG structures, local authorities or trusts.

4.2.3 Ensuring a localised perspective
One issue that needs to be looked at is how we ensure people are given the chance to participate if they cannot access the current location of a user involvement group. For example if a group is held in the Reading area within the Berkshire West area, then participants will likely be from Reading and not neighbouring Wokingham or Newbury. With three different unitary authorities in this area as a whole, patient experience might be very different from one locality to another.

Proposals for dealing with this, include rotating the venue of the groups within the locality or setting up more user groups, so that in an area like Berkshire West there might be three groups. This would have serious implications on the workload of the project team and increase the complexity of feedback systems, however with the new CCG structures this could work moving forward.

Questions for consultation

6. Is 8-10 participants a reasonable sized user involvement group?

7. Should people be asked to attend for a maximum number of sessions?
   a. If yes, how many sessions would be enough to enable people to have their say?

8. What should the purpose of a user involvement group be?
   a. To gain feedback on recent experience of services?
   b. To act as a consultative group for service developments or issues?
   c. Any other purpose?
9. Should the user involvement groups continue beyond the life of the project which ends in 2012?

10. If yes, should they be supported by local health or social care structures?
   a. If yes, by whom would they best be supported?
   b. If no, should the user involvement groups continue to be supported by The Stroke Association or other independent body. Bear in mind that this will have funding implications.

11. Should user involvement groups be moved around within each area or would it be better to set up more locally based groups?

4.3 Interviews

Successes

To date 13 interviews have been requested and we are continuing to get requests for these. The project team are working with Wendy Gray (NHS Improvement) to carry out these interviews. There was an initial delay in setting up these interviews with regard to governance and staff training, however these have now been overcome.

Limited data has meant that it has not been possible to draw on themes as yet, but this will happen in due course. Individual quarterly reports will have information regarding the interviews relating to individual trusts.

Challenges

4.3.1 Sustainability of interviews
The project team is supporting and carrying out the interview process with people across the region. Interviews can take a considerable length of time and it is questionable how sustainable this method will be beyond the life of the project.

4.3.2 Accessing interviews
Most interviews thus far have been accessed through the questionnaires, which presents a problem for areas who are not using the project questionnaires. South Central Cardiovascular Network have now integrated a question to opt into an interview through the 6 month review tool being used in many areas. The project team will need to monitor these response rates as some areas are not carrying out 6 month reviews at the time of writing.

Questions for consultation

12. How can the interview process be sustained beyond the life of the project?
4.4 Engaging with seldom heard groups

Successes

A huge amount of research work has gone into locating/sourcing lists and contact details for all care/nursing homes across the area as well as lists and research about the various ethnic community groups.

The project now has extensive information which can be used to determine how and where the project will engage with in the New Year.

Challenges

4.4.1 Scope of the area
This area of the project has been challenging to work on for a number of reasons.

With regards to Black and Minority Ethnic groups, this area is so diverse that the project team needs to identify specific groups of people to approach and facilitate their involvement in each area. This work is ongoing. We are currently ensuring that demographic data is monitored to ensure we are collecting representative feedback from different communities in each area.

With regards to people with communication difficulties, the project team are actively involving people in user groups and have necessary skills and competency to be able to support individuals with aphasia through interviews.

With regards to care/nursing home residents, the project team are in the process of contacting each care/nursing home across the region and developing awareness of how their residents and/or family members can feed into the project. So far response to the projects contact has raised the issue of lack of stroke specific training for staff within the homes. These establishments will be put in touch with training providers and the information will be fed back into the network for further follow up.

Ongoing, we wish to ensure that mechanisms for the inclusion of ‘seldom heard’ groups of people are embedded into the project structures that are left behind.

Questions for consultation

13. We would welcome ideas and comments on this area.
4.5 Feedback mechanisms

Successes

A closed feedback has in principle been proposed in each area of the region and is demonstrated in this flowchart.

Challenges

4.5.1 Closing the loop
In some areas this loop works very well, this is usually where there is a regular meeting between local stakeholders including patient or carer representatives, where the project can feed into and see that actions are taken to remedy issues arising. There are however gaps in many areas and it is often left to clinicians to act locally on issues and feedback to the project. This can be difficult to track and feedback to participants in the project and we must ensure that Stroke survivors and carers who have commented know that their concerns have been listened to and acted upon where appropriate.

4.5.2 Acting on experiences
One issue for the project team is how to feedback experiences to trusts and commissioners without overload of information or making assumptions about whole systems on one person's experience. Every individual's experience is very valid to them and we need to find a way of feeding these into the overall picture and making adjustments to local service provision as appropriate.

4.5.3 PPE steering group
This group was set up to steer and monitor the project and also to provide a mechanism for feeding back to local providers and commissioners. Attendance at the group has been intermittent and has become more of a project update group.

The group met on 16\textsuperscript{th} December, discussed and agreed the following:

- The project team would speak with and agree who would represent particular areas and agree to be the link into the group and back to their local health and social care colleagues. It was agreed that this might not be consistent across the region as relationships worked differently in different areas.
- There would be a place for 2 stroke survivor/carer representatives at the group and that they would take on the role of feeding back to all of the user groups in the region and asking for feedback into the groups. The role of the reps would have to be very clearly defined.
Questions for consultation

14. How can we ensure that information is fed back more effectively to all stakeholders including social care?

15. Do you have any comments on the agreed membership of the group?

16. How can we involve patient and carer representatives more effectively within this group?
   a. How many representatives should attend?
   b. Should representation be rotated throughout the year?
5. Future project plans

**Questionnaires**
The project has achieved its objective to implement the process of questionnaire feedback in each locality. Moving forward, the outcome of this consultation will shape the ongoing work on this.

**User Involvement Groups**
The project will continue to work with the existing groups to keep membership refreshed and the focus locally based. How this is done and whether the project continues to support the groups will very much depend on the responses to this document.

**Interviews**
The project team will continue to process and carry out interviews to those who request them. The sustainability of this process needs to be carefully thought through.

**Seldom heard groups**
During the next stage of the project, our aim is to engage with the particular groups in each area and to embed mechanisms for engaging with groups of individuals into the project structures. We will also continue to monitor response rates to the various forms of feedback and highlight areas where particular communities are not being represented appropriately and act accordingly.

Nursing/care home responses will be monitored as and when we receive them and we will be proactively seeking to engage with nursing home communities to gain their feedback.

**Communication strategy**
The project team will develop a short communication strategy around the project to ensure maximum engagement across the region. This will include ensuring that all trusts give patients and carers an opportunity to participate in the project at some point in their journey and wider advertising of the project to primary care and other community locations.

**Expert people bank**
The project has been actively involved in the recruiting and support of people involved in the South Central Cardiovascular Network Peer reviews. This work has been carried out with the guidance of Wendy Gary (NHS Improvement) who has been pivotal in the facilitation of work.

A suggestion moving forward is that the project takes on the role of recruiting, supporting, training and facilitating the involvement of stroke survivors and carers within the region. This group of people would be supported and developed to be involved meaningfully in any aspect of engagement that was appropriate. The peer review has been a very successful example of this. We would envisage running a rolling training programme across the region for people to participate in as a gateway to the ‘bank’. This would not limit people becoming involved in other areas of the project if they had not been through this process, but would mean that people were better supported when undertaking representation in specific roles, such as representing at a regional steering group.
6. Next steps

Please let us know your thoughts and comments on what the project has achieved so far and how you would like to see it evolve over the next year.

It is important to have feedback from all stakeholders in this process so that we can make it work locally.

We are asking for feedback either by e-mail, letter or telephone by Monday January 30th 2012 so that we can move forward with the project in the most appropriate way in 2012. The feedback form is at the bottom of this document for you to answer the questions we have posed and also for any other comments.

Many thanks for your input into this project which should ultimately benefit stroke survivors and carers in the future.
7. Your response

Thank you for taking the time to read and comment on this document.

It would be helpful for us to know who the responses are from, so please complete the details section below.

Name:

Role:
(Stroke Survivor / Carer / Clinician / Commissioner in health or social care / Practitioner / PPE trust or PCT lead / other stakeholder – please detail)

Location in which you live/work:

Please comment on the following questions posed in the document:

4.1 Questionnaires

1. Should the project continue to support the process of distributing and collating responses to project questionnaires?

2. What is your view on the proposed redesign of the questionnaire?

3. What is your view on the proposed frequency of distribution of the questionnaire?

4. Do you agree that detailed feedback on providers should not be included in this project?

5. Post project, should there continue to be a system whereby The Stroke Association (or other independent body) continue to support the process of distribution, collating and analysing feedback from all sources of the project?
4.2 User Involvement Groups

6. Is 8-10 participants a reasonable sized user involvement group?

7. Should people be asked to attend for a maximum number of sessions?
   a. If yes, how many sessions would be enough to enable people to have their say?

8. What should the purpose of a user involvement group be?
   a. To gain feedback on recent experience of services?
   b. To act as a consultative group for service developments or issues?
   c. Any other purpose?

9. Should the user involvement groups continue beyond the life of the project which ends in 2012?

10. If yes, should they be supported by local health or social care structures?
    a. If yes, by whom would they best be supported?
    b. If no, should the user involvement groups continue to be supported by The Stroke Association or other independent body. Bear in mind that this will have funding implications.

11. Should user involvement groups be moved around within each area or would it be better to set up more locally based groups?
4.3 Interviews

12. How can the interview process be sustained beyond the life of the project?

4.4 Engaging with seldom heard groups

13. We would welcome ideas and comments this area.

4.5 Feedback mechanisms

14. How can we ensure that information is fed back more effectively to all stakeholders including social care?

15. Do you have any comments on the agreed membership of the group?

16. How can we involve patient and carer representatives more effectively within this group?
   a. How many representatives should attend?
   b. Should representation be rotated throughout the year?
Please feel free to make any other comments or suggestions about the project: