Oxfordshire

Stroke Patient and Carer Involvement Project

Final Report

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Distributed to

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Section 1 – Summary

Introduction
The NHS in South Central is committed to involving local people in how it plans, develops and delivers health services\(^1\). The South Central Cardiovascular Network (SCCVN) commissioned The Stroke Association to carry out the Stroke Patient and Carer Involvement Project to support stroke survivors and their carers to actively engage in the provision of feedback, specific to their experience of stroke services.

The purpose of the project was to drive forward the NHS agenda on Patient and Public Engagement and to focus on Quality Marker 4 of The National Stroke Strategy\(^2\), which seeks to involve individuals in developing services in the context of Stroke. The project also addresses other areas of NHS and Social Care policy including the NHS patient experience framework\(^3\), NICE quality standard for patient experience in adult NHS services\(^4\) and Our Health, Our Care, Our Say\(^5\).

In December 2011, the project consulted with all stakeholders and stroke survivors/carers across the South Central region. Clear recommendations for the final phase of the project were drawn from this consultation including plans for sustainability post project. The summary and recommendations are available from SCCVN.

This paper is the final report for the Oxfordshire area. It sets out the achievements of the project since June 2010.

Project overview
The aim of the project was to gather experiences from stroke survivors and carers across the stroke pathway – using a mixed approach of methods has helped us to achieve this. These methods included:

- Questionnaires
- User involvement groups
- 1:1 interviews
- Facilitated workshops with seldom heard groups

Organisations involved locally in the project have been:

Oxfordshire Primary Care Trust
Oxfordshire County Council
Oxford University Hospitals NHS Trust

Specific trends for the area have been identified and shared with participating organisations, stroke survivors and carers and SCCVN to support the continual service development and improvement of local stroke services.

The project has established a mechanism to engage stroke survivors and carers in sharing their experiences of local stroke services and shares learning and guidelines for continuing and sustaining this work.

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1. Patient and Public Engagement Toolkit for World Class Commissioning South Central WCC Collaborative PPI Programme p.3
4. NICE. Patient experience in adult NHS services – Improving the experience of care for people using NHS adult NHS services CG138 Feb 2012
5. Department of Health. Our health, our care, our say: a new direction for community services 2006
Participation
Questionnaires – 10% response rate
User Involvement Groups – groups held quarterly
Interviews – 3 patients, 1 carer

Main themes
Response rates from the questionnaires have been low at only 10% overall.

Responses from questionnaires from the John Radcliffe Hospital and Horton General Hospital have been largely positive with 68% (n=13) of patients reporting that they were felt their overall stay in hospital was excellent or good and particularly positive comments around privacy and dignity. Other themes of interest included:

- **Communication**
  Comments and data suggest that verbal communication and explanations were very good.

- **Discharge planning**
  30% (n=4) of carers and 21% (n=4) of patients felt that they weren’t prepared for discharge, 9% (n=3) of respondents felt that things weren’t in place when they got home.

- **Emotional support**
  From questionnaires 10% (n=2) of patients and 15% (n=2) of carers were very dissatisfied with the emotional care they received

Sustainability
Oxfordshire PCT and Oxfordshire County Council are keen to use a redesigned ‘Stroke Experience’ questionnaire which will be given out at 6 weeks and/or 6 months by the Stroke Reviewers. This has been designed in consultation with stroke survivors across the region and in particular the Oxfordshire area. This will be analysed locally.

The Stroke Forum will be organised by the Stroke Association’s Community Stroke Support service, and will meet on a quarterly basis.
Section 2 - Questionnaires

Questionnaires were developed in consultation with the Stroke PPE Steering Group members, hospital trusts and stroke survivors, based on a model developed by Annette Murray, Stroke Specialist Nurse, Hampshire Hospitals NHS Foundation Trust.

The focus of the questionnaire was based around the acute phase of the stroke patient pathway, however, it was intended that a further questionnaire would be developed to focus on other parts of the pathway, for example rehabilitation and life after stroke.

Across the region there has been variability in the uptake of the project developed questionnaire, as some sites had their own mechanism for surveying stroke survivors and carers.

Oxfordshire has used the project based questionnaire available as appendix 1a & 1b.

Distribution

The model agreed in Oxfordshire was for the stroke nurses to distribute the questionnaires to stroke survivors and carers on discharge from either John Radcliffe Hospital or Horton General Hospital. Distribution began in December 2010.

Questionnaire packs included:

- A covering letter – outlining the purpose of the questionnaire survey.
- A patient/carer questionnaire.
- A contact sheet – with opportunity to have 1:1 interview or attend local user group.
- An Stamped Addressed Envelope.

The table below describes the final position with regards to response rates at 31st March 2012.

<table>
<thead>
<tr>
<th></th>
<th>Average no. of Strokes per month&lt;sup&gt;6&lt;/sup&gt; Apr 11 – Jan 13</th>
<th>Questionnaire packs allocated (Dec 11 – Mar 12)</th>
<th>No. of returns</th>
<th>% return rate</th>
<th>Combined return rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>49</td>
<td></td>
<td>19</td>
<td>6%</td>
<td>10%</td>
</tr>
<tr>
<td>Carer</td>
<td>N/A</td>
<td>300</td>
<td>13</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
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<sup>6</sup> ASI measures – As submitted to SC Cardiovascular Network 2011-2012 – Denominator - Number of patients arriving at hospital with a stroke.
Summary of responses
The complete data set for the questionnaire return for the period December 2010 – March 2012 is available as appendix 2.

The following examples highlight the experiences of patients and carers with regards to their arrival at hospital, explanation of their condition, nursing care and written information.

Q5. How satisfied were you with the care you / they received on arrival at the hospital?

Generally respondents were satisfied with care on arrival.

Patient Comments
“I had a slight stroke and was extremely nervous, as in 2001 my husband had massive stroke and it left him paralysed down right side with no speech and I was put in bed that he was in before death, the staff and doctors were very professional, who moved me instantly when told them about my fears. Also, I became full time carer.”
“satisfied given that it was very busy.”
“Immediate treatment/ no waiting, efficient and very friendly.”
“Excellent, very professional.”
“Was severely depressed and was feeling traumatised by my time in JR”
“Everyone from the paramedics, porters, doctors, nurses were very attentive.”
“I felt very confident with the degree of care and assistance provided.”

Carer Comments
“…. was admitted in an emergency - it was unclear whether he had had a seizure or mini stroke (he had a significant stroke in 2009).”
“It appears that everything possible was done quickly and professionally.”
“Seen and attended to by several people (Drs/nurses) all very good.”
Q7. How satisfied were you with the explanation of their / your condition?

Data suggests that patients and carers overall were satisfied with the explanation of their condition.

Patient Comments
“I don’t remember any explanations. They explained to my relatives, but I had to be told by them.”
“Nobody explained anything.”
“We did not need explanation. The patient is a doctor. His wife a nurse.”
“The doctors were happy to answer questions. Only ‘satisfied’ because outcome not fully clear.”
“Clear and in layman's terms so I was not baffled with words I did not understand.”
“The doctors were unsure if I was suffering from a seizure or a mini stroke when I was admitted.”
“One doctor explained it.”
“It is more helpful seeing picture on computer of scan - areas of brain affected. Helped gain understanding from various different professionals and their different perspectives.”

Carer Comments
“They took into consideration the fact that …. had had Alzheimers for 6 years.”
“ Took time to explain test results / treatment etc.”
Q8. How satisfied were you with the care you/they received from nursing staff?

Overall data suggests respondents were satisfied but 2 comments state a perception of distracted and ‘inconvenienced staff’.

**Patient Comments**
- “I had to remind nurses about eye drops for glaucoma.”
- “Can't remember at the Radcliffe. Very satisfied at the Horton.”
- “although busy, care was very good when available.”
- “They all looked after me very well. Very professional, they all have to work so hard!”
- “No care received, too busy comparing ring tones on mobiles. Records etc not kept up to date.”

**Carer Comments**
- “…. was always treated as a person not as a number.”
- “Would not call it care!! My husband was an inconvenience.”
Q12. How satisfied were you with the amount of written information you were given about your/their stroke?

This is an area which needs further exploration, with a mixed response in this area.

**Patient Comments**

“Satisfied at Horton.”
“Can’t remember at the JR.”
“None received.”
“There was time for me to read written info had it been provided.”
“I haven’t received any.”
“General info pack given. No info on my stroke maybe in doctors letter.”
“Am aphasic, so don’t know what I was given was good or not? Couldn’t read it well.”

**Carer Comments**

“None received.”
“I am not sure that there is written information about seizures following stroke.”
“General leaflets. Copy of doctor’s letter. Not anything helpful to his
Section 3 - Interviews

Interviews with patients and carers were carried out as a second line method to explore issues highlighted by questionnaire responses.

Interviews were based on the Discovery Interview™ technique developed by NHS Improvement. Wendy Gray (NHS Improvement) acted as a consultant on the use and development of the technique and in mentoring and coaching of the project coordinators.

The focus of the interview provided an opportunity for patients and carers to describe their experiences of care across the whole pathway. This complemented the data gathered from the questionnaire returns which were acute phase focused.

The ability to offer interviews came later in the project. In part this was due to the need to develop the skill and competence of the staff carrying out the interviews, changes in the workforce, and delays to securing ethical approval.

Across the region interviews have been conducted in most areas. Overall more stroke survivors than carers have requested an interview.

4 interviewees (3 x patients, 1 x carer) were recruited with an experience in the Oxfordshire area.

Recruitment

The questionnaires provided an opportunity for respondents to request a 1:1 interview, flyers were also used to advertise the opportunity in areas of high patient footfall. The place of interview was usually the respondent’s residence. The project coordinators made telephone contact with prospective interviewees to outline what the interview would entail and agree date and time of when this would take place.

Interview packs included:

- A covering letter – outlining the purpose of the interview.
- Consent form
- Information sheet

Approach

All interviews were audio recorded. The use of open questions with some probing was the predominant approach to encourage interviewees to tell their story. The interviews allowed the interviewee to detail their experience fully across the whole pathway of care.

Following the interview the audio recording was fully transcribed. Summaries of each interview in addition to the full transcription were provided to SCCVN. The intention will be to share this information to commissioners and providers in the local area. Interviewees appreciated the opportunity to tell their story.

Findings

Whilst these interviews are the perception of 4 people’s experiences there are several areas of interest; mixed experience of care; lack of attention from staff; communication regarding follow up and tests. Some of these themes were supported through findings obtained from questionnaire returns.

We have included some extracts from interview transcripts below:
Positive experience of care
“…they were brilliant down there, they really were, you know, the girls and the nurses and the doctors” - (A&E) (Patient 1)
“…I would say they were good, you know, they looked after me well down there in A & E.” (Patient 1)
“…she was great because she sorted my food out…she ordered down special… If she was on, great” - (ward) (Patient 1)

Oxford John Radcliffe Hospital – perception of care was largely negative
“…And as for my feelins’ towards the services experience, yes I’m very disappointed. I think they could have been more caring towards him. Showed him a bit more respect and perhaps dignity in a sense. He hadn’t been offered a wash. right up until I was there on the Saturday. And I, I can’t remember when you first had a shower…personal care – he hadn’t been offered anything to clean his teeth with or the opportunity to do things like that…a little bit of personal dignity in keepin’ himself clean. So I wasn’t very happy with that.” (Carer 1)
“I got no care whatsoever” (Patient 1)
“They really don’t know what they’re doin’. I’m not sayin’ they don’t know medically, but each patient is different and have different symptoms and different health issues, they’ve got to learn this, and if they can’t learn it, what’s the point in bein’ there? Cause if I ever have to go again I will do my damnedest not to go to the JR.” (Patient 1)

Acute stroke ward
“…that took ages to get me up on the ward, nobody seemed to know what the hell was going off… took some time to get me up on to the ward and that is when trouble started” (Patient 1)
“…left me nothing whatsoever in terms of how to get hold of anybody in terms of, you know, if I needed a nurse or whatever, nothing wherever the buzzer was…so you know, if I’d needed to get someone I’d, I’d have to shout.” (Patient 1)
“…very little care from a nurses point of view, still no idea where buzzers was.” (Patient 1)

Diabetic needs
“I knew I was going into a hypo…and so it took some time to get them to understand that I wanted someone to do a glucose blood test, “what do you want one of them for?”…“I’m diabetic, I think I’m going into a hypo”, “oh, yep, we’ll sort that out in a minute”, “no I need it done NOW”. And you had to sort of push for something to happen” (Patient 1)
“…not once did anybody come and see how me bloods were, ask me what was going off, ask me if I’d given meself any injections, or anything” (Patient 1)
“…breakfast was non existent, yet bearing in mind I’m diabetic and have to have a high carbohydrate diet nothing, no toast, nothing, some sloppy cereal. And that was it. An I said, you know, I can’t carry on like this!” (Patient 1)

Communication about tests and follow up
“…don’t ever get any sort of results with anything, they don’t say “well you’ve got to have it because of your swallow and you could die if you don’t” type of thing, they just sort of leave it” (Patient 1)
“…me own GP, sorted me own physio out you know, up at Chipping Norton hospital. And then two months after that I get a call from the JR, you know, would you like the emergency physio that’s been organised for you?! “Er…I think you’re a bit late! Don’t bother with it”. And that’s the typical thing of the JR that rack you off.” (Patient 1)
“…that’s the way they plan everythin’. Erm, plan it? Couldn’t organise a… in a brewery! To be fair, to be truthful” (Patient 1)
“Get out and sort it out yourself, basically. I’m surprised that I’ve never, ever, had to have a follow up appointment, you know, that gobsmacked me in many respects, but I’m glad I haven’t cause I don’t want to have anythin’ to do with them because they did nothin’ for me when I was there…” (Patient 1)
Preparation for discharge

“If you read all the information they give you, they quite categorically states...that you will be away from the ward and in your own home, by lunch time. No ifs, no buts, that is exactly what they say. [I was] racked off, you know, typical JR stroke/heart department...left hand doesn’t know what the right hands doing.” (Patient 1)

“They have no coordination, no planning, and certainly no thought for a patient. Cause, I mean, you know, you’re going home, that’s great, you know, you’re keyed up, you’re out of it, you know, you’re on the way, oh hang on a minute, no you’re not going yet, you’ve got to wait to see so-and-so, and then, oh, I think we’ll do another test. How do you expect to feel after that? Totally, totally racked off...We walked out and Wife drove me home. And that was it.” (Patient 1)

“I think it, it prolonged the stress. Because like any person you just want to get your husband home... stress is the last thing he needed! I wanted to get him home and get him out of there because I knew he would relax better in his own home. And so I just felt it was just needless, they put him in this end room, ‘we’ll jus’ see to him you know, when we’re ready.’” (Carer 1)

After Care

“She gets a Gold Standard care package every single day, her nutrition is fantastic, her hydration is fantastic, she has brilliant speech and language therapy, by a fantastic speech and language therapist, both from the Acute sector, from the JR, well actually the Community one in Oxford” (Carer 2)
Section 4 - User involvement groups (UIGs)

An additional aim of the project was to establish a user group in each area of the South Central region where these did not exist for the target population i.e. stroke survivors and carers. The project coordinators consulted with stakeholders in each of the geographical areas to baseline existing groups to avoid duplication and participant fatigue.

The focus of the user group was to provide a forum for participants to discuss current issues and give opinions and views on local and regional service improvement work.

Across the region some areas had established groups which were accessed via the project, in other areas new groups were set up. A challenge has been in the ongoing attendance, small numbers and the recruitment of new faces at these groups.

A stroke user forum had just been started in the Oxfordshire area at the inception of the project. This was held each quarter rotating around the county. Historically it was a joint venture between Oxfordshire PCT and Oxfordshire County Council, and was passed over to the project for it's duration. Oxfordshire PCT and Oxfordshire County Council continued to have an active role in both the organisation and delivery of the forum.

Recruitment
Membership has been promoted through community groups and services and also via questionnaires.

Approach
UIGs were facilitated by the project coordinators with a standing agenda. Meetings were informal and the agenda included an opportunity for exploration of people's experiences and provided a forum for local stakeholders and SCCVN to consult. All meetings were minuted, circulated to participants, and included in quarterly reports. The reports were also included in the distribution to the Oxfordshire Stroke Network group. Venues sourced were free of charge and held in places which had good parking and were easily accessible, i.e. local libraries, community hospitals or council buildings.

Whilst the membership of the groups is predominantly intended to be stroke survivors and carers, staff working in health and social care were also encouraged to attend the meetings.

Findings
Meetings have been held quarterly and the attendance of the group has been high and consistent. All minutes from meetings are available from SCCVN.

The members of the UIG have been active in their discussions and have had a Patient Representative attend the Oxfordshire Stroke Network group.

The forum has acted largely as a consultative group since it’s inception and examples of work that has been developed with support from and approved by the forum includes county wide Communication Support, Early Supported discharge, Stroke Review service, long term support in the community and the soon to be adopted patient experience questionnaire.
Section 5 - Seldom Heard Groups

Many factors can contribute to being ‘seldom heard’. Some of these include; disability, ethnicity, sexuality or gender, communication disability, mental health problems, homelessness and geographical isolation.

The project aimed to facilitate the participation of seldom heard groups of individuals who it was felt might not be able to complete a questionnaire or participate in a user group.

A strategy for engaging with seldom heard groups was agreed focusing on:

Nursing home residents
Minority ethnic groups
People with aphasia

Across the region this particular area of the project has been a challenge. The main difficulties have been in trying to recruit people to participate in the project from minority ethnic groups and nursing homes.

Recruitment

- **Nursing homes**
  All nursing homes across the region were initially contacted by letter to explain the project and how they or their stroke survivor residents and carers could become involved. The project did not receive any relevant queries relating to this marketing drive. This exercise was revisited later in the project and a more targeted approach was used to reach nursing homes that advertise having stroke beds in their facility.

  Reports from the nursing homes contacted were that their residents were not willing, and sometimes unable to be involved in the project. With some further discussion it also became clear that the homes contacted were concerned that some areas of feedback might be particularly around care within their own establishments. The project also received a number of queries regarding lack of stroke specific training for their staff.

- **Minority Ethnic groups**
  The project recruited a volunteer to undertake a base lining exercise of all the minority ethnic groups across the region. Contact was then made with some of the groups offering the opportunity to participate and also to learn more about stroke. One member of staff who was multi lingual in several Asian languages, was available for the final phase of the project. Translations of questionnaires have been advertised and offered through the project.

- **People with aphasia**
  Questionnaires were originally designed in consultation with stroke survivors and carers some of whom have aphasia. Images were inserted into the questionnaires to ensure they were more accessible to people with aphasia. UIGs in most areas of the region have included people with aphasia and project coordinators have been trained in the techniques of supported conversation in order to facilitate active involvement of this group of people.

Approach

Facilitated workshop groups were offered in addition to the other methods the project adopted. The workshop groups consisted of supported and guided discussions to expand on experiences of stroke care across the pathway. Meetings were informal and all discussions were noted and are available on request from SCCVN.
Findings
Places of worship and Women’s groups attended by ethnic minority groups also been visited by the Project Co-ordinator. Chinese community and Afro Caribbean community groups have also been contacted. Unfortunately there was no interest from these groups to be involved in the work of the project. This was mainly due to there being no known stroke survivors in the Chinese and Afro Caribbean communities in Oxfordshire.
Section 6 - Overall trends and learning

This is a summary of information gathered across interviews, questionnaire responses, feedback from user involvement groups and workshops.

Responses from questionnaires from the John Radcliffe Hospitals and Horton General Hospitals have been largely positive with 68% (n=13) of patients reporting that they were felt their overall stay in hospital was excellent or good and particularly positive comments around privacy and dignity.

“The staff and doctors very professional.”
“Very satisfied at the Horton. Can’t remember for the Radcliffe.”
“Whenever the need, curtains were drawn. I had no issues.”

The interviews conducted were less positive about their experiences of care as detailed previously in sections.

It is of note that response rates for the project have been disappointingly low, however looking at the data as a whole there are still several arising themes which require further follow up by providers and commissioners in the area:

**Communication**

Comments and data suggest that verbal communication and explanations were very good.

“Everything was spoken in clear English without blinding you with science.”

But that people were less satisfied (25%, n=8 dissatisfied) with written information given.

“None received.”
“There was time for me to read written info had it been provided.”
“I haven’t received any.”
“General info pack given. No info on my stroke maybe in doctors letter.”

Questionnaire responses tell us 37% (n=7) of patients reported they did not receive information about stroke prevention and 32% (n=6) about resuming everyday activities. 32% (n=6) did not receive information about their follow up medical appointment and 32% (n=6) reported not being given contact details of community teams. 16% (n=3) reported not being given a transfer of care summary.

“Get out and sort it out yourself, basically. I’m surprised that I’ve never, ever, had to have a follow up appointment, you know, that gobsmacked me in many respects, but I’m glad I haven’t cause I don’t want to have anythin’ to do with them because they did nothin’ for me when I was there…”

**Discharge planning**

30% (n=4) of carers and 21% (n=4) of patients felt that they weren’t prepared for discharge, however 9% (n=3) of respondents felt that things weren’t in place when they got home. This could suggest that people feel very anxious at this point in time and that perhaps communication around what is happening could be improved to reassure them that necessary arrangements are in place for their discharge.

**Emotional support**

From questionnaires 10% (n=2) of patients and 15% (n=2) of carers were very dissatisfied with the emotional care they received, however as the numbers are very low it would be
worthwhile doing some more work around this within user forums with new discharged patients and carers to find out whether this is a wider issue.

The following challenges were identified during the life of the project. The table below highlights key learning in relation to each of these.

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Actions taken</th>
<th>Learning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses to the questionnaires have been relatively low.</td>
<td>Discussions concluded that this was most likely due to the fact that a generic patient experience questionnaire is given out.</td>
<td>Different questionnaire has been developed and will be given out a later stage in the pathway.</td>
</tr>
<tr>
<td>Difficulties accessing seldom heard groups of stroke survivors in the area.</td>
<td>Proactive contact and visits to ‘warm’ places.</td>
<td>This is a general area of difficulty, which needs further work. The coordinator focused on general health promotion to minority ethnic groups at the latter stages of the project.</td>
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Section 7 - Future sustainability

Questionnaires
The trust will discontinue the use of the acute questionnaire and the project has been working with Oxfordshire County Council and Oxfordshire PCT to design and embed a stroke experience questionnaire for to give out at 6 weeks and/or 6 months. It is intended that this will be distributed by the Stroke Reviewers and analysed through a research post within Oxfordshire County Council. Analysis will continue to be embedded into the Oxfordshire Stroke Network group for action.

Interviews
It was agreed early on in the project that it would not be possible to sustain the interview process post project.

User Involvement Group
The user forum will continue across in the area on a quarterly basis. The groups will be organised by The Stroke Association’s community stroke support service and will continue to be supported by Oxfordshire County Council and Oxfordshire PCT. Dates for the meetings have been set until the end of the year. The discussions from this group will continue to be fed into the Oxfordshire Stroke Network group.

Seldom Heard Groups
SCCVN is committed to continue the work with seldom heard groups.

Section 8 - Acknowledgements

We would like to thank those stroke survivors and carers who have taken the time to share their experiences with us, without whom this project could not succeed.

The Stroke Association and SCCVN would particularly like to thank Wendy Gray, NHS Improvement, who has given a significant amount of her time and effort to the development of the project and staff. Wendy has generously shared her expertise and skills and this has proved invaluable.

This project would not have been possible without the experience and assistance of the healthcare, social care and other professionals we have met with across South Central area. We would therefore like to thank all of the people who have contributed, so that the voice of stroke survivors and carers is put at the forefront of stroke service improvement.
Section 9 - Appendices

Appendices are held within a separate document:
Oxfordshire Stroke Patient and Carer Involvement Project – Appendix

List of appendices

1. Project questionnaire
   a. Patient
   b. Carer
2. Data Addendum
3. Questionnaire checklist
4. Questionnaire response template

Available on request from SCCVN (anita.soar@hampshire.nhs.uk)

User group minutes
Summary interview transcripts
Summary of workshop discussions