

The Impact of the Lambeth and Southwark Stroke Peer Support Network

Interim Report, October 2014



"I've become less shy and can now talk freely with friends I've made through the Network"

"People said I wouldn't walk again but now I don't use the wheelchair, only a crutch!"



"Swimming has helped me improve my health and now I'm going to the gym as well"



"If the Network stopped, people would have nothing to do or nowhere to go. They would become isolated, unhappy, depressed and in the end, more unhealthy, something we should be trying to avoid "



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October 2014

Lambeth and Southwark Stroke Peer Support Network is Funded by



Summary

Despite significant challenges, the investment in the Network has been a success. Feedback which has been collated from Network members through co-production events and a new survey of 20 respondents shows there is overwhelming support for the Network and what it does.

The Network currently has 98 members and 54 have taken part in activities in 2014, ranging from a weekly choir to one off trips to the cinema.

The evidence shows that membership has brought many benefits:

- 100% of respondents liked that it allowed them to socialise with other people who had the same problems as them.
- 90% liked that it enabled them to be part of a group so they didn't feel so alone and isolated.
- 85% liked that it both gave them an opportunity to learn and try out new things and made them feel better.
- Before joining the Network, 55% (11 of the 20 respondents) had taken part in no activities. Since joining the Network, 55% of respondents (11 of sample of 20 respondents) had also started taking part in activities additional to those provided by the Network, and 91% of these said being part of the Network helped them try these out.
- 70% of the survey respondents felt "a lot" more confident since becoming members of the Network.
- 55% felt "a lot" healthier since becoming members and all felt at least "a little" healthier
- 58% felt "a lot" happier since membership and all felt at least " a little" happier

If the Network was to stop user feedback suggests that these benefits would not be sustained in most cases. Seventy five per cent of respondents also said they would feel isolated, 95% would be unhappy and 100% said they'd miss both being part of a group and all the activities they took part in.

Introduction

Disability Advice Service Lambeth (DASL) first secured funding to run the Lambeth and Southwark Stroke Peer Support Network from Guy's and St. Thomas's Charity in 2008. A number of different services and activities were developed and reviewed for effectiveness between 2008 and 2011 and a separate report on this period of the project is available. By agreement with the funder, and in consultation with Lambeth Council and NHS commissioners, the project was relaunched in August 2012, enhanced by a new partnership with the Stroke Association, and offering a new menu of support, activities and volunteering / peer support opportunities to deliver health and wellbeing and social inclusion outcomes and offering.

This report highlights feedback from two engagement events with Network members and other stakeholders in December 2012 and December 2013 and reports on a new survey of Network members undertaken between August and October 2014. The survey participants were asked about their experiences of involvement in the Network's leisure, sports, cultural and social activities, any specific benefits they could identify from taking part in these and, more generally, the impact being

a member of the Network in contact with other stroke survivors had had on their lives. A self-assessment questionnaire was developed (see Appendix 1) which 20 participants completed or were supported to complete. These were analysed and the results are collated below.

This interim impact report is intended to give an insight into the benefits of participation in the Network as the project nears the end of its main funding through Guy's and St Thomas' Charity in March 2015 in order to provide a basis for further discussion about the value of the Network and the peer support principles which underpin it and how the service, or aspects of the service might be sustained and further developed in the future.

This is not a specialist assessment of any specific health and therapeutic benefits which stroke survivors might have enjoyed through their involvement. The emphasis of the survey has been on supporting participants to describe in their own words what they have gained from the Network using guided interviews to take people through a relatively simple and accessible questionnaire. The survey will continue to be used with an additional number of participants and the results updated. Over the next few months we hope to have further discussions with the Charity about their expectations of the final evaluation report for which we would hope to include, in addition to feedback from Network members, the views of key stakeholders, including other agencies with which we have worked to deliver the service.

Network size

There are currently 96 stroke survivors who are members of the Stroke Network. Of these, 15 are Southwark residents, 6 are from other boroughs (principally involved in the 'Out of the Blue' choir which is London-wide, and the rest are Lambeth residents.

The project is supported by 8 regular volunteers of whom 6 are stroke survivors.

Network activities



58 Network members tried one or more activities in 2013, 54 to date in 2014.

The following groups/ activities have been set up by the Network Co-ordinator and run regularly:

<i>What</i>	<i>2013 participants</i>	<i>2014 participants</i>
Fortnightly Aphasia Cafe at Caffe Nero in Morley's (Brixton)	22	15
Fortnightly Games Club at 'We are 336' (the Accord Centre)	21	15
Weekly Swimming Club using the Clapham Leisure Centre in Clapham Manor Street	19	20
Weekly choir - "Out of the Blue - the Stroke Survivors Choir" (open to stroke survivors from anywhere in London) at Morley College	24	23
Support for people to attend a Gardening Group at Brockwell Park [seasonal]	7	11
Support for people to cycle regularly with Wheels for Wellbeing at the Herne Hill Velodrome [ongoing]	10	

There have also been a number of one-off outings to enable people to take part in accessible sport activities and cultural visits. 2014 saw a larger programme of outings arranged, in response to members' feedback (see below).

	<i>2013 participants</i>	<i>2014 participants</i>
Art exhibitions	11	
Sportability – gliding & canoeing	7	
Bank of England tour	-	5
Beefeater Gin Distillery tour	-	6
Brighton	-	12
Cinema	-	6
Communicating without words – Art Exhibition	-	7
Daniel Lobb Exhibition	-	5
Kew Gardens	-	18

The Network also marked World Stroke Day in October 2013 with a joint awareness raising event with the Stroke Association at 'We are 336'.



Feedback from 2012 and 2013 coproduction events

At the Network's 2012 December consultation and social event, people were asked for their feedback to help steer activities for the following year. There were a wide variety of activities that people wanted to do, such as:

- Bird watching
- Going shopping
- Making art
- Swimming
- Going to church
- Gardening
- Exercise.

Barriers to people taking part in activities were about transport: “getting anywhere and back is difficult” and “dial-a-ride could be improved” were two comments. People also reported that accessing public transport was difficult, whether getting on and off the buses and trains or working out how to get somewhere.

Things which had helped Network members over the year included physiotherapy, speech therapy, the Stoke Support Group [provided by the Stroke Association until April 2014, thereafter the TOPAZ Team], and accessing activities at Connect, the national aphasia charity.

People had many ideas about what support they would like so they could do the activities they'd suggested. Some wanted a continuation or higher level of support of a service they already received such as speech therapy, others wanted more support to organise groups such as a cooking group, and others wanted support to help them get around or to solve problems such as benefits or housing issues, whether as a result of reduced physical mobility or visual impairment. Sharing expertise amongst themselves was also suggested e.g. advice on navigating systems they had to deal with; ‘buddies’ to accompany people to museums and galleries.



December 2013 saw a similar consultation and social event organised which also served to promote the Warm and Well in Winter campaign. Network members were again vocal in their “likes” and wishes, with issues raised similar to those in 2012, reflecting how energetic the participants were, but also confirming that the Network is impacted on by issues outside its immediate control e.g. in relation to travel barriers, and that the resources available to respond to members’ requirements and interests are limited.

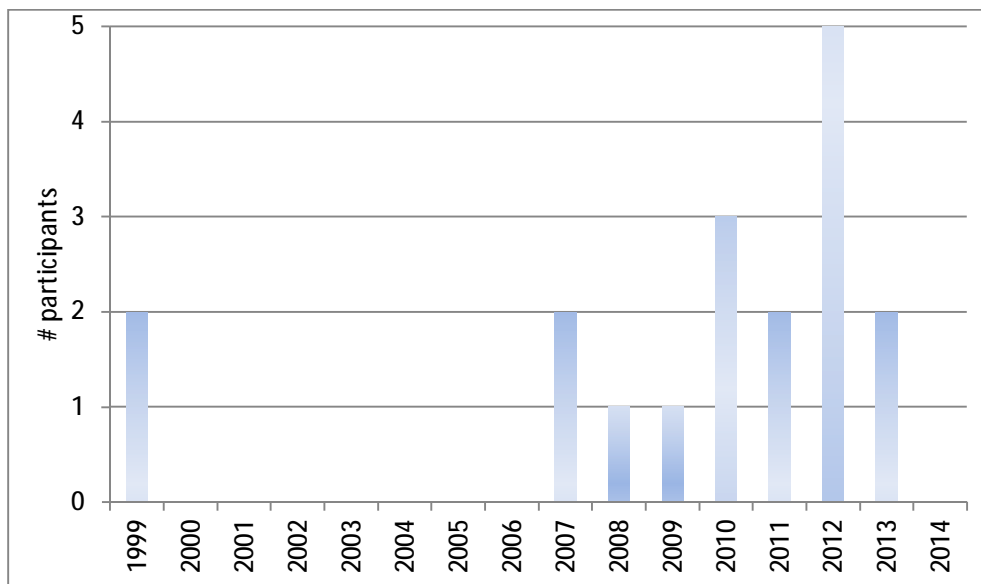


The 2014 survey

Twenty people took part in the survey carried out between August and October. The youngest was 46, the oldest 82. The mean average age was 61. 40% were women, 60% men.

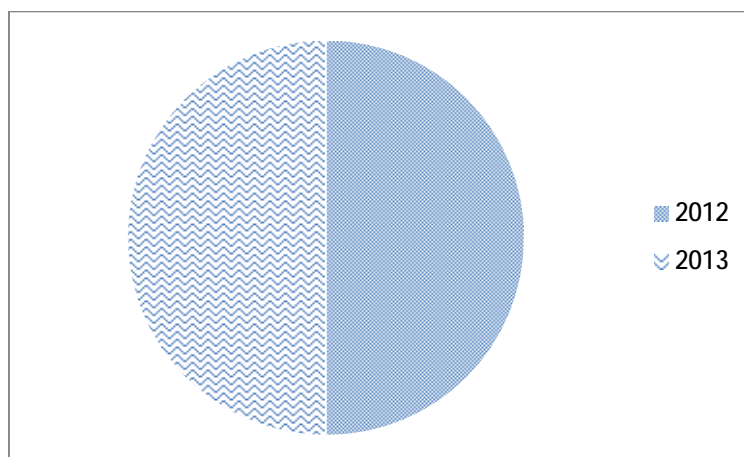
Only two people had had their stroke before 2007 (see Chart 1).

Chart 1: When participants had had their stroke



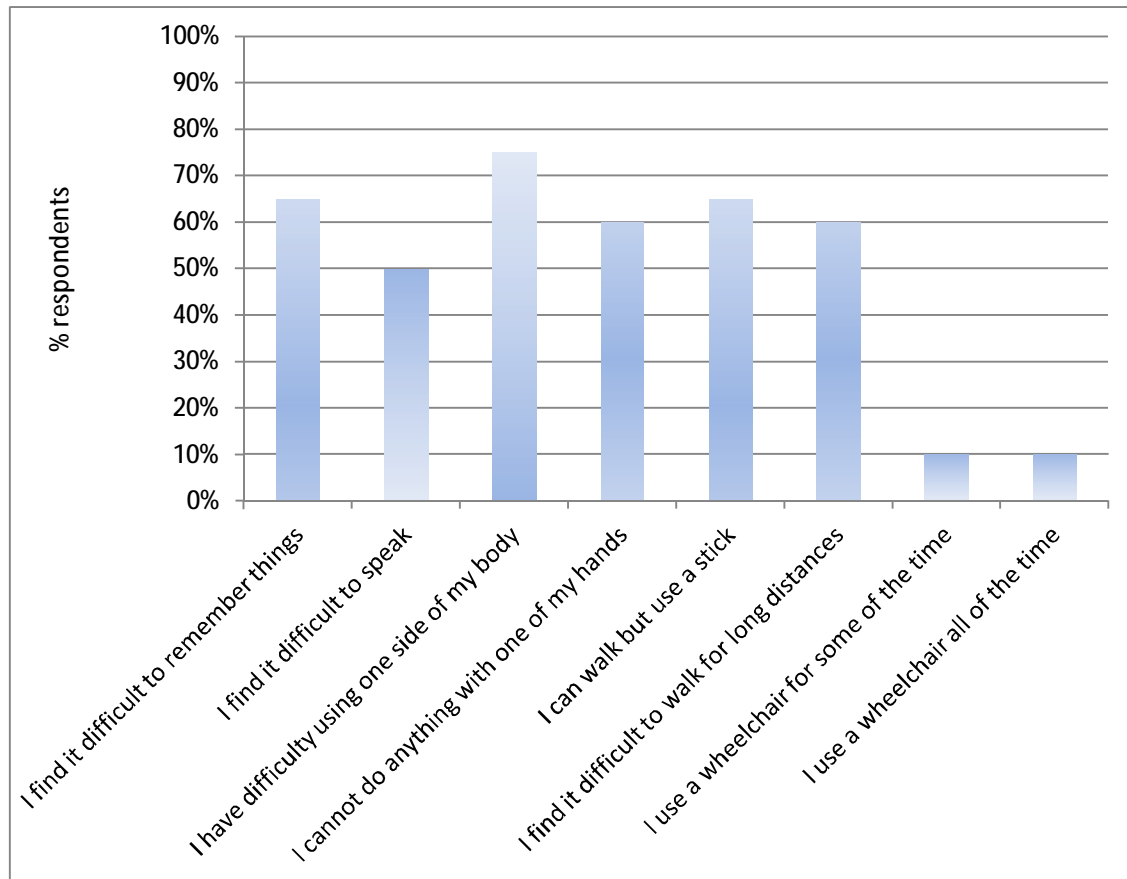
Half of the respondents joined the Network in 2012 and half in 2013 (Chart 2).

Chart 2: When participants joined the Network



Participants were asked how their stroke affected them. Seventy five per cent reported difficulties in using one side of their body, 65% used a stick for walking and 50% or more reported difficulties in remembering things, speaking, using one of their hands and walking over long distances (Chart 3).

Chart 3: How has your stroke has affected you?

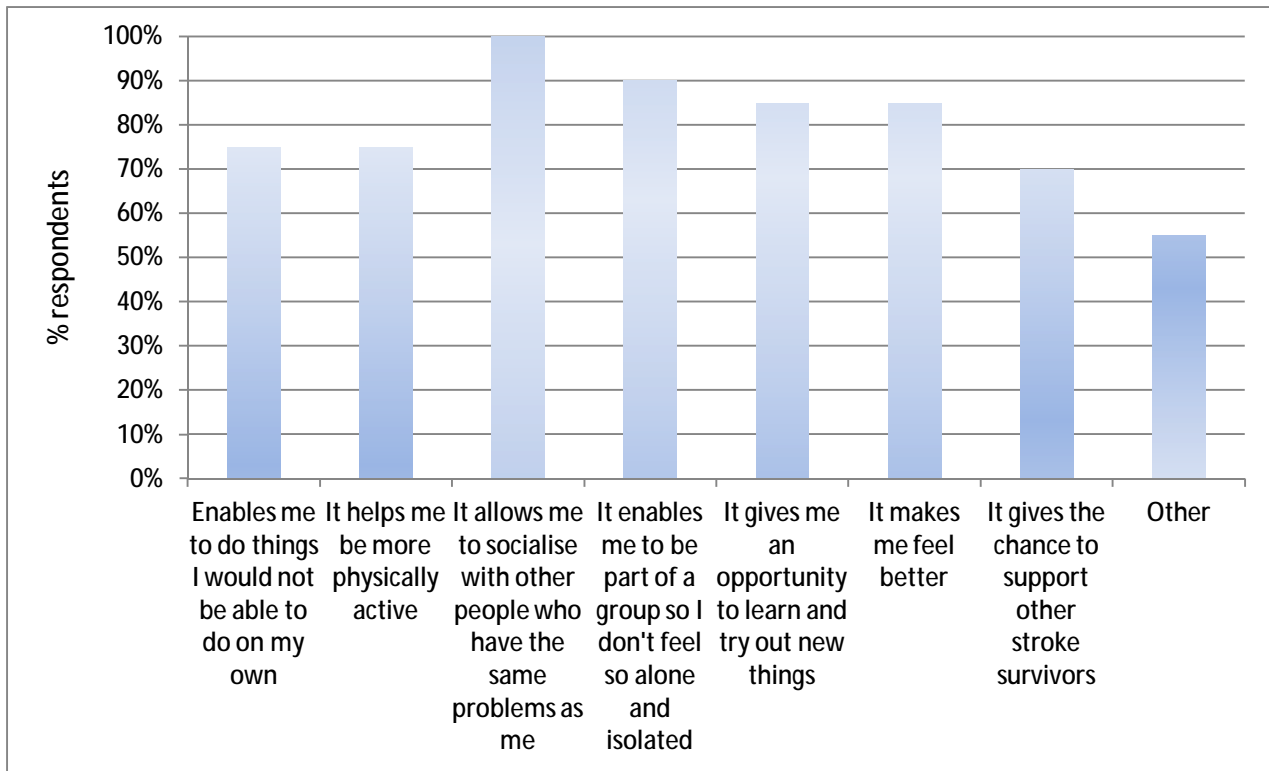


What participants liked about the Stroke Network

Participants were asked what they liked about the Stroke Network and were able to provide multiple answers (chart 4):

- 100% of respondents liked that it allowed them to socialise with other people who had the same problems as them.
- 90% liked that it enabled them to be part of a group so they didn't feel so alone and isolated
- 85% liked that it both gave them an opportunity to learn and try out new things and made them feel better.

Chart 4: What participants liked about the Stroke Network



55% had other reasons why they liked the Network (Table 1).



Table 1: Reasons people liked the Stroke Network

"One thing I have learned through the Network is to realise how lucky I am to have survived the stroke and to appreciate so many of the problems so many of the survivors have."

"I was abandoned by my family and friends after the stroke and being part of the Network has helped me immensely."

"Like meeting people - gets me out of the house - and I have a laugh which makes me feel better!"

"I volunteer."

"Good to get feedback from other stroke survivors & tips about things that work."

"Like supporting new people who join."

"As an artist I'm able to bring my strengths to the group."

"I like everything that you do."

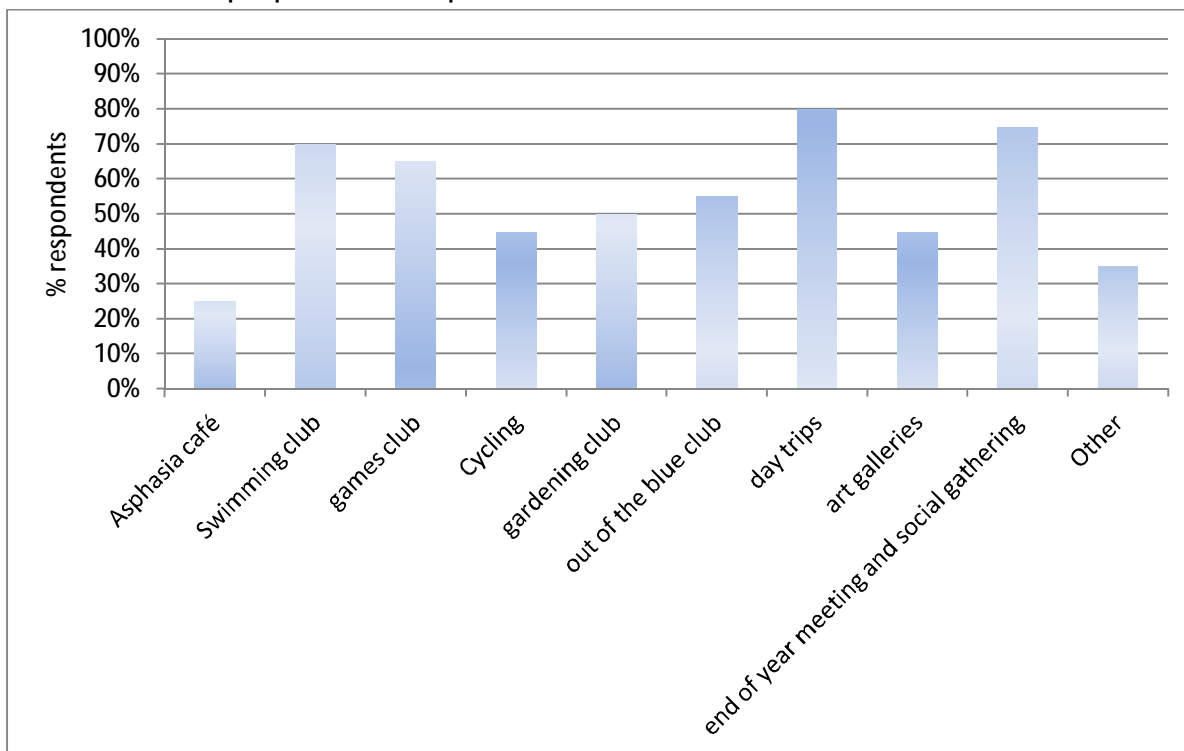
"I like everything about it."

"It breaks the monotony of being on your own, isolated and lonely. At least you are doing something."

Participant engagement

At least 5 survey participants had taken part in each activity enquired about. All participants had taken part in at least one activity. The most popular activity was day trips, which 80% of participants had undertaken, followed by the end of year meeting/ social gathering and games club which 75% of participants had enjoyed.

Chart 5: Activities people had taken part in



Before joining the Network, 55% (11 of the 20 respondents) had taken part in no activities. Since joining the Network, 55% of participants (11 of sample of 20 respondents) had started taking part in activities additional to those provided by the Network, and 91% of these said being part of the Network helped them try these out. Table 2 gives some examples of the non-Network activities participants have taken part in.

"What activities have you started doing since joining the Network?"

"I'm active in running the Stroke Support Group at Aspire."

Table 2: What activities have you started taking part in since joining the Network?

"Going out more, socialising more. Gives incentive to do more things."

"Computer training which Manuela told me about."

"Joined group called Remakers"

"I go to Connect, Alzheimer's group at Woodlands Centre (for the summer), Healthy Living Club at Lingham Court."

"Active in running the Stroke Support Group at Aspire."

"Walking, gym."

"Gardening in the allotment."

"Learning to use computer"

"Cake decorating and flower arranging at college."

"I now go the gym."

"Going to college. Mentoring with other organisations."

Participants were also asked if there was anything else they'd like the Network to do (Table 3). Many were happy with exactly how things worked; others were enthused to ask for more activities and events.

Table 3: Is there anything you'd like the Stroke Network to do/ organise that it isn't doing right now?

"Nothing, just more of the same"

"Happy with everything's that's happening now."

"More activities which would specifically help to improve speech."

"More day trips would be good"

"No. Happy with everything."

"Computer classes for people who are isolated. Then they could look for things to do."

"Yes, find me a wife! Maybe make links with groups in other boroughs, and organise social

gatherings such as going for coffee or dinner to create friendships and more!"

"I want you to continue doing everything you're doing now. More of the same."

"Provide transport to go to activities. Very difficult to get around. Learning how to cook - healthy eating. More swimming sessions would be good. More day trips throughout the year, not just in warm weather. More of - reminding/ chasing me to attend activities (I have poor memory so rely on this)."

"Exercise classes - pilates and tai chi just for stroke survivors. Organise "arty" things in Remakers where Lil can teach art etc to stroke survivors to culminate in an exhibition."

"I can't think of anything but would consider any new suggestions."

"More get togethers with fun things like Bingo, quiz days."

"Happy with the way it's running"

"No, happy with everything."

"Sailing in the summer, more visits/ outings - in winter to art galleries, museums, in summer, outdoor events."

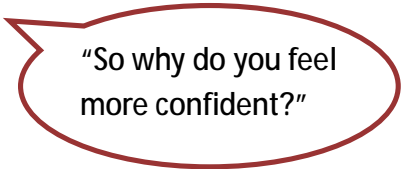
"Happy with everything. Would like it to continue! Maybe set up or organise somewhere to do things like pottery, crafts etc. Maybe organise film outings to the Ritzy or Streatham Odeon who have concessions for seniors."

How the Network has affected participants

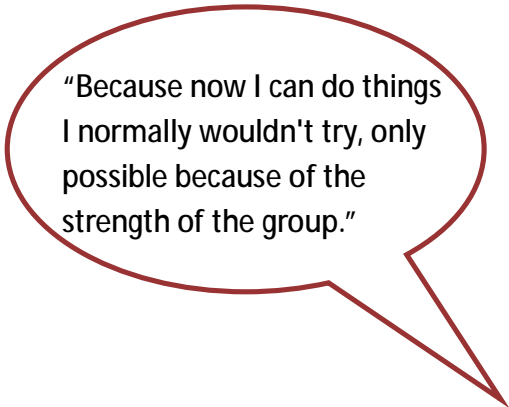
Participants were asked how they felt since they'd become a member of the Network.

Confidence

70% of the survey respondents felt "a lot" more confident since becoming members of the Network. All but one of the remainder felt their confidence had improved between "a little" and "a lot".



"So why do you feel more confident?"



"Because now I can do things I normally wouldn't try, only possible because of the strength of the group."

Chart 6: How people felt since they had joined the Network - confidence.

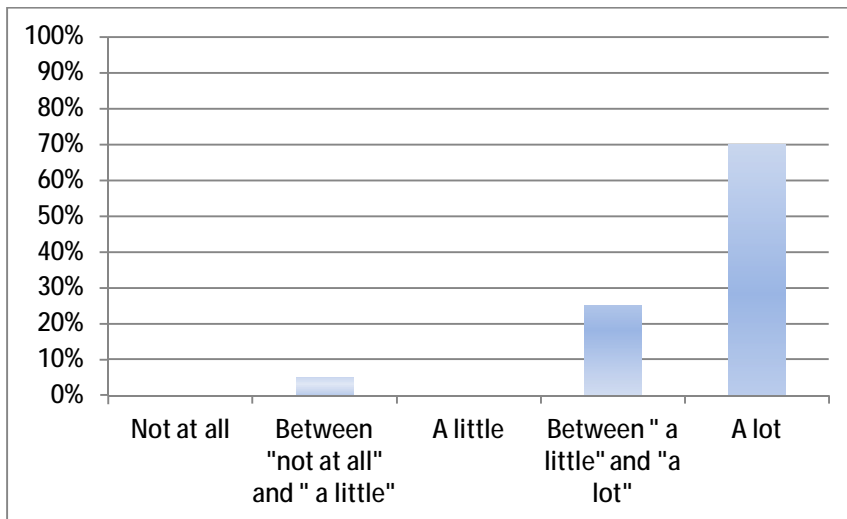


Table 4 gives some reasons why people have felt more confident.

Table 4: Tell us how you feel since you've been a member of the Network. I feel more confident – why?

"Because I am coming out and doing things with people who have the same problems as me."

"Making friends has made me feel like I'm no longer abandoned."

"Because I've tried many activities with the groups which I would never have done on my own."

"Working with people who understand my condition."

"Because I talk to a lot of people with the same issues."

"Try to participate in all activities and wouldn't have done before as nobody helping me."

"Because I used to feel more isolated. Didn't know how stroke affected everyone."

"Because now I can do things I normally wouldn't try, only possible because of the strength of the group."

"Because it makes me go and do things which I didn't used to do."

"Because before all I did was go to hospital appointments but now I do lots of things."

"Because I'm getting better and pushing myself to do more things and this helps me to move goalposts to do more."

"More comfortable going out and meeting people."

"Because I realise that once I start something, mostly I can achieve an acceptable result - if I can't, at least I've been able to try. To begin with, I could not try."

"Because I'm getting out a lot more, talking to people, doing things"

"Because I talk to people like me, some worse, some better."

"Because activities like swimming make me more sociable and confident."

"Because people treat me good. I'm not worried about going out. I know I can do things. People said I wouldn't walk again but now I don't use the wheelchair, only a crutch!"

"Because now I can do things I wouldn't have thought of before."

"Because I've been stimulated, lots of things to do, meeting people, getting sound advice and trying out new things."

Health

Fifty five per cent of respondents felt "a lot" healthier and all felt at least "a little" healthier since becoming members of the Network. There were a variety of reasons why (Table 5) and most referred to being more active.

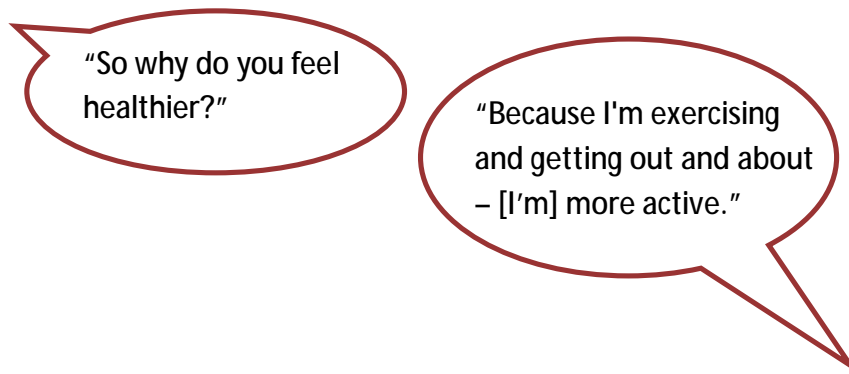


Chart 7: How people felt since they had joined the Network - health

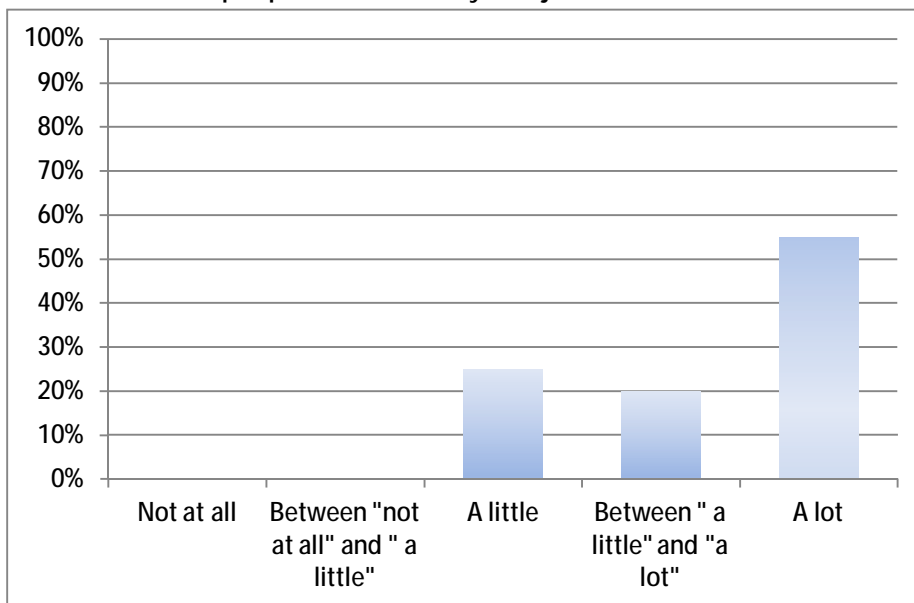


Table 5: Tell us how you feel since you've been a member of the Network. I feel healthier – why?

"Because I'm more active as well as going to the gym."

"My health is complicated as I've developed diabetes and kidney problems but in general I feel better than before I joined the Network."

"Because I've seen improvements in my right side which I think is to do with being more active."

"Because swimming has improved me physically - I like it a lot."

"Because activities have meant I'm walking better without a stick."

"Because I've become more active."

"Because I've been taking part in physical activity my health has improved."

"I can more things than I used to."

"I have more energy because of events and days out."

"Because swimming has been especially therapeutic for me, because if you can't speak fluently you can still make beautiful sounds even when you can't speak well and also it improves the ability to say words and also physically as you're moving a lot of muscles in your body."

"Thinking less about my ailments."

"Because starting out on something I realise that I can get there, achieve the object and still keep going."

"Going out and doing things has made me feel better."

"Mostly because I'm getting out and about instead of sitting and watching the TV"

"I am moving about more."

"Because I'm exercising and getting out and about - more active."

"Mobility has improved since I started swimming. Now I don't use the wheelchair."

"Because I'm able to do things which I couldn't do before."

"Swimming has helped me improve my health and now I'm going to the gym as well."

"Because I'm now more active."

Happiness

Fifty eight per cent felt "a lot" happier and all felt at least "a little" happier since joining the Network. There were a variety of reasons given for this, many about meeting other people.

"So why do you feel happier?"

"Because I'm socialising with people and learning new things."

Chart 8: How people felt since they had joined the Network – I feel happier

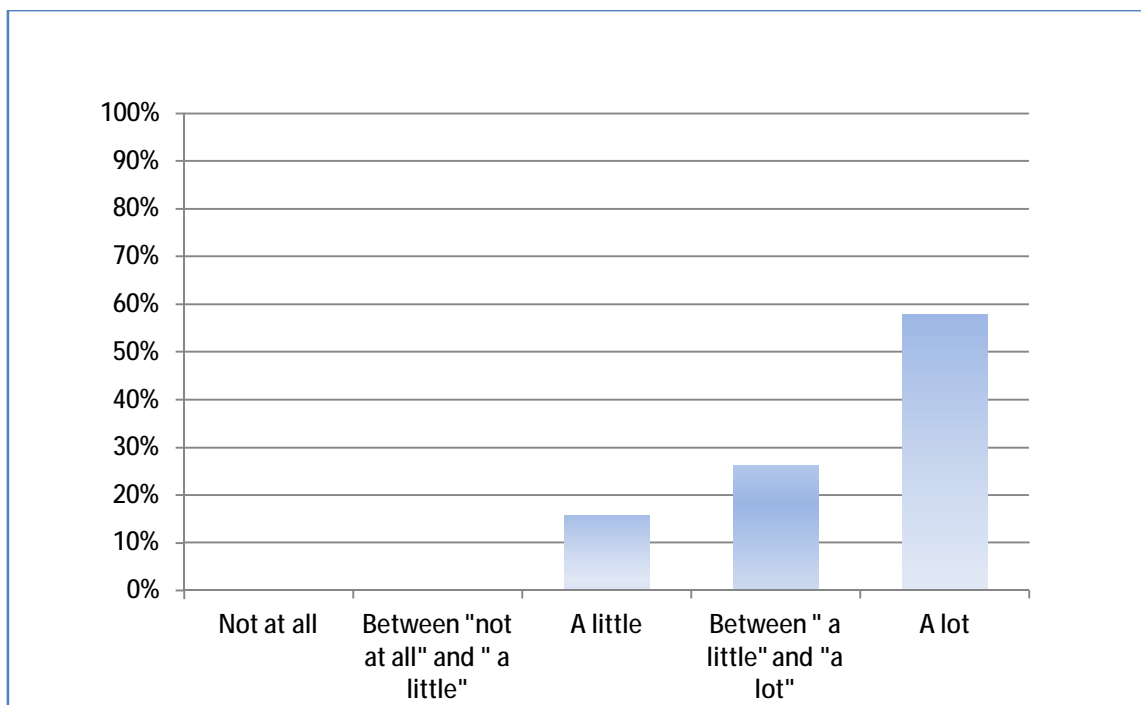


Table 6: How people felt since they had joined the Network – I feel happier

"I am a very positive person."

"Because I enjoy socialising in the groups I attend and we have a good laugh!"

"Because I feel less depressed and less isolated."

"Because there's people like me whom I can talk to."

"Because I'm socialising with people and learning new things."

"Because I go out, mix with people and not feeling lonely. I've become less shy and can now talk freely with friends I've made through the network."

"Only put a little because I have so many illnesses (kidney transplant, diabetes, gout, stroke) . This makes me unhappy but I enjoy all the activities put on by the Network."

"Because I look forward to getting up and doing things which I didn't before - I used to be very depressed and now it's a lot better."

"When I'm depressed all I have to do is go to one of the groups and it makes me feel better. There is always a goal to look forward to which makes me automatically feel better."

"Because I'm going out and meeting other people with the same problems as me."

"Because I know that there is still so much I can do and enjoy, as well as people who help in so many ways."

"Seeing other people like me makes me feel like I'm not alone. I had fun at Games club, beating a certain man at poker."

"Because I look to meeting people who I've become friends with through the group."

"The future feels brighter."

"Makes no difference"

"Because I'm getting better and I see this."

"Because going to the group, meeting people, laughing, etc."

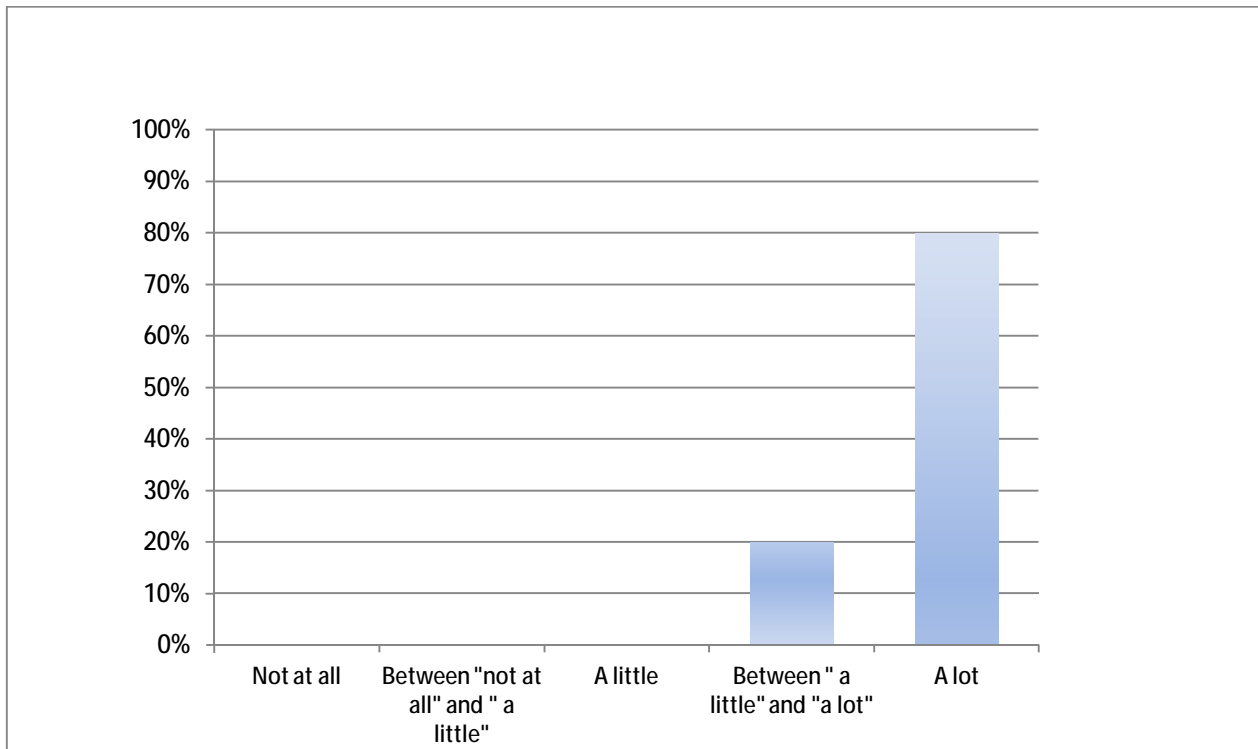
"I think that as I feel healthier, it makes me happier"

"I'm less depressed than I used to be. And I'm out and about a lot more."

"Like having something to look forward to"

80% of respondents said they liked having something to look forward to "a lot".

Chart 8: How people felt since they had joined the Network – "I like having something to look forward to each week"



Impact of stopping the Network

Participants were asked what difference it would make to them if the Network were to stop. 75% of respondents said they would feel isolated, 95% would be unhappy, and 100% said they'd both miss being part of a group and all the activities they took part in (Chart 9). No-one said it would make no difference to them. Many respondents elaborated on their views (Table 7).

"So what difference would it make if the Network were to stop?"

"If the Network were to stop, we would be like crabs going back into their shells - we would be lost. Not just me, but for everyone. Because there would be nowhere else to go, nothing to do, back to being bored and lonely. "

Chart 9: what difference it would make if the Network were to stop

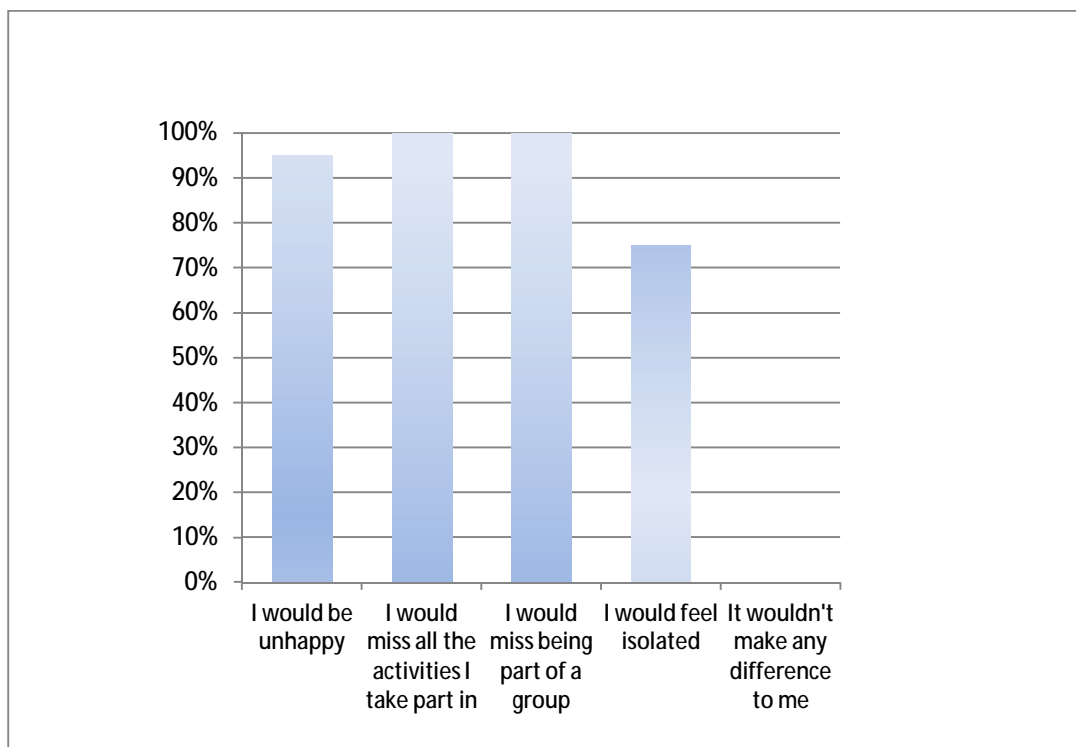


Table 7: The impact on participants of stopping the Network

"If the Network stopped, people would have nothing to do or nowhere to go. They would become isolated, unhappy, depressed and in the end, more unhealthy, something we should be trying to avoid. "

"I would be depressed I would go back to square one. If the network were to stop, it would hurt a lot of people because there's nothing else out there for survivors."

"If the Network was to stop I'd be back to square one - nothing to do! Would have to stay at home all the time."

"Would be completely isolated. Back to square one."

"If the Network were to stop, we would be like crabs going back into their shells - we would be lost. Not just me, but for everyone. Because there would be nowhere else to go, nothing to do, back to being bored and lonely. "

"It would be awful if the Network stopped. I really need someone to help me remember to go to the activities and events."

"I would be very bored without the activities because all I do is go to hospital appointments."

"It's imperative the people who have disabilities like us need a special place to alleviate our isolation, anxieties etc within a group of people who have the same problems."

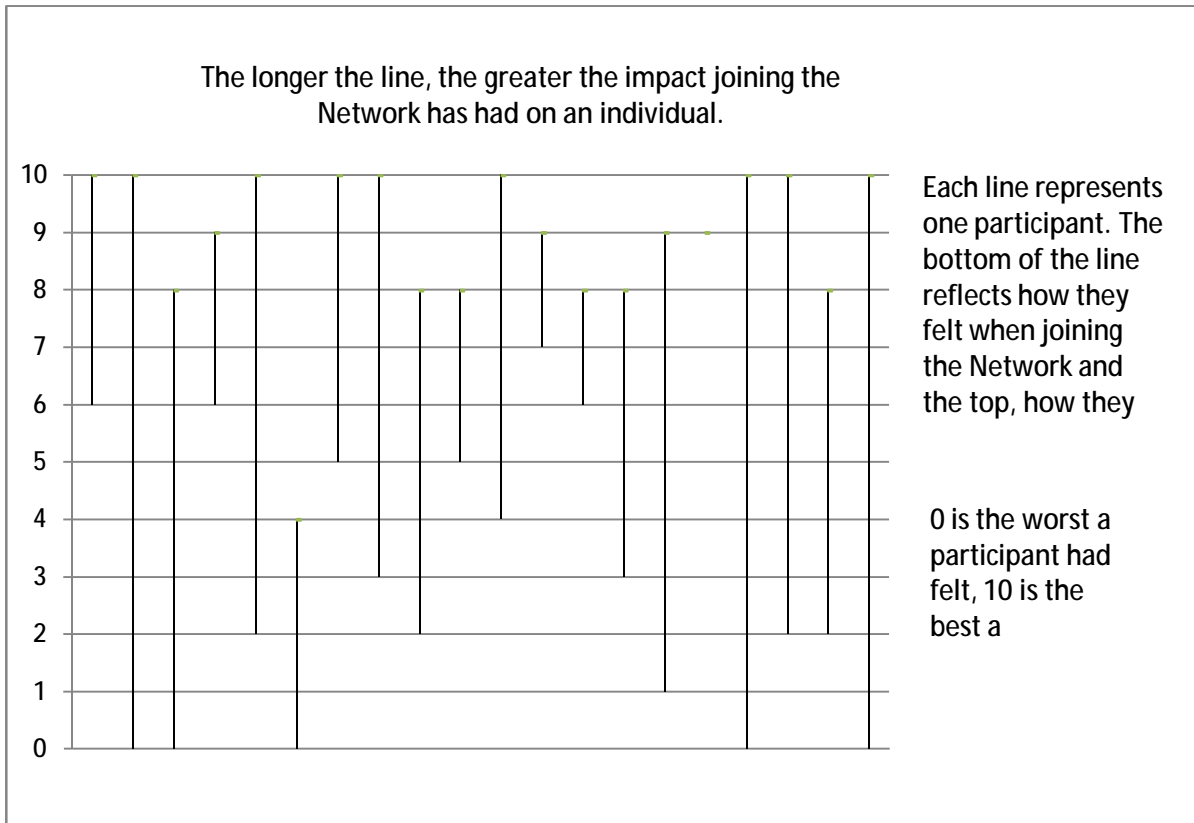
"The Network gives me the opportunity to look for interests that are not offered in any other way, that are in themselves within my capabilities as well as those of other people."

"It would be devastating if the group was to stop because we would go back to how we were before ie. Doing nothing! We need more support rather than less!"

Change in how participants felt as a result of being part of the Network

Participants were asked how they felt before they had joined the Network and how they felt after joining the Network, using a scale of 0-10, where 0 was the worst they had felt and 10 the best. The change was an increase of 5.7 points. Below (chart 10) shows the change each person felt, with each line representing a person. The worst someone felt before joining was rated as 0, the best was rated 7; the worst someone felt after joining was 4, the best was 10.

Chart 10: The change in how participants felt as a result of being part of the Network



Stroke Peer Support Network

EVALUATION OF THE STROKE NETWORK: What effect has the Network had on your life?

The Stroke Peer Support Network is run by Manuela who works for DASL and who organises activities for stroke survivors to help improve their quality of life, health and wellbeing, reduce social isolation, etc. This survey is aimed at getting an overall picture of how the Network has impacted on the lives of stroke survivors.

The information gathered will be used to produce reports for our current funders. It will also be used as evidence to attract new funders to keep the project going after March 2015 when the current funding runs out.

We will use the information you have given anonymously to produce these reports but it would be useful to quote some of your comments and use your photograph. Will you give your consent for us to do this?

Comments			
YES		NO	

Photograph			
YES		NO	

Thank you very much for taking part in the survey J

Manuela

Name:
(Optional)

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Signature:

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Gender:

Male		Female	
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Age:

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When did you have your stroke?

MONTH	YEAR

How long have you been a member of the Stroke Network?

Since	2012	2013	2014

1. How has the stroke affected you?

I find it difficult to remember things	
I find it difficult to speak (aphasia)	
I have difficulty using one side of my body	
I cannot do anything with one of my hands	
I can walk but use a stick	
I find it difficult to walk for long distances	
I use a wheelchair some of the time	
I use a wheelchair all of the time	
Other:	

2. How did you hear about the Stroke Network?

The Stroke Association's Advisory Service	
The Pulross Centre	
The Stroke Survivors and Relatives Group (Guy's & St Thomas')	
6 Month Stroke Reviewer	
TOPAZ	
Other:	

3. What do you like about the Stroke Network?

It enables me to do things I would not be able to do on my own	
It helps me to be more physically active	
It allows me to socialise with other people who have the same	

problems as me	
It enables me to be part of a group so I don't feel so alone and isolated	
It gives me an opportunity to learn and try out new things	
It makes me feel better	
It gives me a chance to support other stroke survivors	
Other:	

4. What activities have you taken part in?

Aphasia Cafe	
Swimming Club	
Games Club	
Cycling at Wheels for Wellbeing	
Gardening Club	
Out of the Blue Stroke Survivors Choir	
Day trips	
Art Galleries	
End of year meeting and social gathering	
Other:	

5. Before you joined the Network, what activities did you take part in?

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6. Since you joined the Network, have you started taking part in any activities other than those organised by the Network?

YES		NO	
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If yes, what are they?

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7. Does being part of the Network help you to try out these other activities?

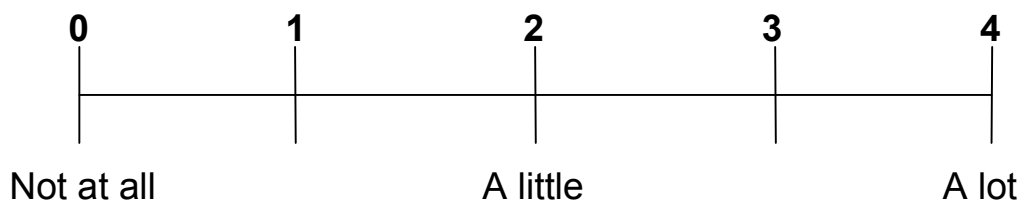
YES		NO	
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8. Is there anything you would like the Stroke Network to do/organise that it isn't doing now?

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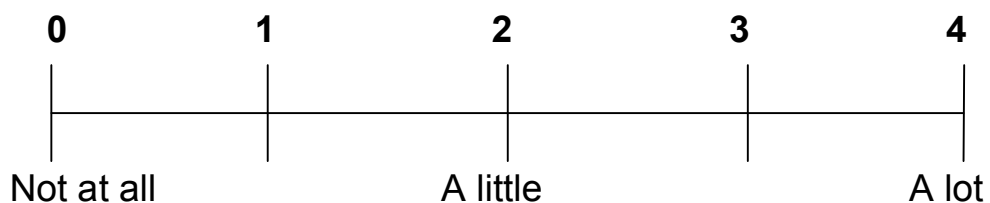
9. Tell us how you feel since you've been a member of the Network.

I feel more confident



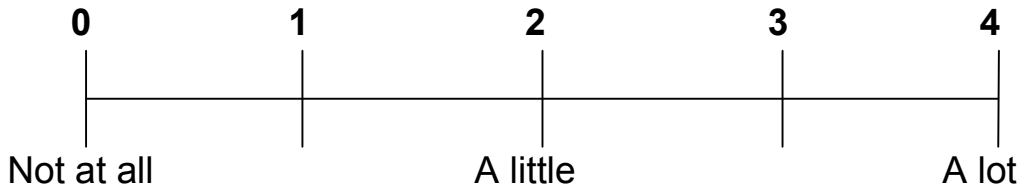
Why?

I feel healthier



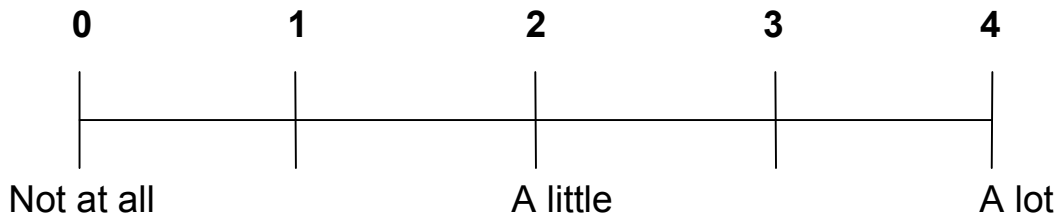
Why?

I feel happier



Why?

I like having something to look forward to every week





10. What difference will it make to you if the Network were to stop?

I would be unhappy	
I would miss all the activities I take part in	
I would miss being part of a group	
I would feel isolated	
It wouldn't make any difference to me	
Other:	


Thinking back to before you joined the Network:

if 10 on the ladder is the best you felt and 0 the worst you felt, where on the ladder best described you at the time?

10	
9	
8	
7	
6	
5	
4	
3	
2	
1	
0	

Thinking about how you feel now after joining the Network:

if 10 on the ladder is the best you feel and 0 the worst you feel, where on the ladder best describes you now?

10	
9	
8	
7	
6	
5	
4	
3	
2	
1	
0	