

Lambeth and Southwark Stroke User Network

LAUNCH EVENT

Friday 13th February 2009 ~ 10:30am - 4:00pm

Coin Street Neighbourhood Centre
108 Stamford Street, London SE1 9SE



Disability Advice Service Lambeth



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Disability Advice Service Lambeth (DASL)

DASL is a Lambeth based user-led voluntary organisation. We provide a range of services to enable disabled people to live as independently as possible:

- Advice and Information
- Direct Payments Support
- User Involvement for Disabled and Older People
- Lambeth and Southwark Stroke User Network



On 13 February 2009 DASL held an event to launch the Lambeth and Southwark Stroke User Network. The purpose of this report is to:

- Give **feedback** to event participants and other stakeholders.
- Say a big **thank you** to everyone who helped make the event a success.
- Enable **learning** from what happened.
- Pass on the **information** that participants exchanged.
- Share the **ideas** and suggestions that participants put forward.

Lambeth & Southwark Stroke User Network

The Network is funded for three years (2008 – 2011) by Guys and St Thomas's Charity, London Catalyst, NHS Southwark and NHS Lambeth.



The Network aims to:

- Promote self-care and self-management.
- Develop and improve services.
- Raise awareness of stroke.

By facilitating peer support and involvement, the Network aims to enable stroke survivors and carers to be:

- Less isolated.
- Better informed.
- More empowered.
- Well supported



Launch aims

The aims of the launch event were to raise awareness of the Network and bring together people who live with stroke, health and social care professionals and volunteers to

- Exchange information and views
- Share experiences
- Develop ideas for activities and involvement in the Network.

Focus

We wanted the event to acknowledge the **past**, reflect on the **present** and look to the **future**. We organised it around these themes:

- **Improvement:** Better outcomes for people living with stroke.
- **Involvement:** Professionals and service users working together.
- **Inclusion:** Reduced isolation of stroke survivors and carers.



Success!

The launch event was a fantastic success. More than 100 people attended. At times it felt quite crowded and noisy. For some this wasn't good as it was difficult to hear each other. The hall was lovely but not big enough for such a large number, especially for wheelchair users and those with mobility impairments.

44 professionals attended the event, representing a wide range of some 30 or so statutory and voluntary service-providing organisations and groups attended. Many more people would have come if we'd had room for them.

Three people came wearing dual service user/provider hats – from Connect and Different Strokes.

A list of the services represented is included at the end in Appendix 1

Staff and volunteers from Blackfriars Settlement (Stroke Network partners) provided invaluable specific practical assistance to disabled participants.

DASL staff were out in force on the day. One worker in particular took the lion's share of the multifarious administrative tasks which seemed to multiply in the days before the event.

Feedback from service users

56 service users came to the event. In the evaluation they said:

- I enjoyed it immensely.
- Let's do it again.
- Can't wait for the next event.
- When is the next one?



We asked what they liked best and were told:

- § The informality.
- § Sharing experiences.
- § Everything.
- § Lunch and exchanging ideas.

There is an EOP analysis of the service users who attended the launch in Appendix 2.

Appendix 3 details service user's feedback and comments on the launch

The three piece band Belatone was also very popular. They provided a soothing backdrop of calm during the otherwise potentially rather hectic lunch break.



It's good to listen

With more than a dozen discussion tables, we couldn't have managed the group sessions without the facilitation and note-taking support of the professionals. Several were given little or no notice of their role and therefore had no time to be briefed or to prepare.

Despite this they performed a magnificent feat. That we can report in some detail the content of the discussions is thanks largely to their hard work.

Staff and volunteers from Blackfriars Settlement (Stroke Network partners) provided invaluable specific practical assistance to disabled participants.

DASL staff were out in force on the day. One worker in particular took the lion's share of the multifarious administrative tasks which seemed to multiply in the days before the event.

A belated thanks to all the staff from DASL and other organisations who made it possible by helping with facilitation and many other tasks, including group facilitation and note-taking.

Good news!

Tom Penman from Lambeth PCT and Pip Hardy from Southwark PCT gave a lively **presentation** on how stroke services have changed. They described the way things used to be and what happens now.

We heard that, before the Modernisation Initiative, services for people who had a stroke were patchy and variable. Nowadays the hospitals and community based teams work together in a more structured and organised way.

As a result, treatment and support for stroke survivors are much better than in the past. It was acknowledged that there is always room for more improvement and more changes are planned in the way that stroke patients are treated in hospital.

These improvements show that good things happen when people who need services, carers and providers all work together for a common purpose.



It's good to talk

After the presentation there were two round table discussion sessions – one in the morning and one after lunch.

The morning session was entitled ***What life is like for me as a person living with stroke.*** To start the discussion, we asked people with experience of stroke to think about what was important in their lives, their responsibilities, interests, needs and choices.



Adjustment was a big issue for some of the service users. Stroke is life changing and sometimes devastating.

It wasn't all negative. We heard how stroke survivors and their families grow strong through their experiences, becoming skilled and resourceful.

The group facilitator's briefs for the morning and afternoon can be seen in Appendix 4

Barriers to independence

Participants were asked about their everyday challenges, how stroke affects their independence, the obstacles and frustrations.

We also looked at focus to other factors – the barriers *out there* that get in the way of doing what you need and want to do. Comments included:

- People don't give you time to express thoughts and opinions.
- Access with wheelchairs.
- People's ignorance – but since speech has improved I feel more assertive and stronger.
- People constantly asking how I am!



Some solutions

Stroke survivors and carers said it is important to:

- Believe in yourself and others who are supporting you.
- Actively follow interests despite the hurdles.
- Be given time to say what you want when communication is difficult.
- Focus on things you can do rather than things you can't do.
- Understand women's needs while recovering from stroke.

Services matter

Strong views were expressed by stroke survivors and carers – based on their own experiences - about the importance of services in helping them get their lives back together and maintaining independence.



Comments included:

- Professionals and carers need to take time, listen, respect.
- More physiotherapy and personal assistance.
- Transport -- better access, more co-ordinated, improved and monitored.
- More counsellors - they should have personal experience of stroke.



Questions for the Network

The afternoon session looked at **What we want from the Network and how we can get involved.**

We checked the Network's aims were the right ones (a resounding 'yes') then asked:

- How can the Network make a difference to the lives of people living with stroke?
- How can the Network take on the challenges talked about in the morning session?
- Who might get left out of the Network and how can we stop this happening?

What the network can do

There were a great many ideas and suggestions for what the Network should do, including:

- **Advocacy** - to have a voice and to access what I need.
- **Encouragement** to make lifestyle changes.
- **Lobby** for appropriate adapted housing locally.
- **Carers'** support group.
- Self-help - support and advice group
- **Meeting** people of similar age
- **Guest** speakers
- **1-2-1** with support worker
- **Learning** new skills
- **Information** - must be aphasia friendly

The complete notes from the group discussions are included at the end of the report in Appendix 5 for the morning discussion group and Appendix 6 for the afternoon discussion group.

How we can get involved

We asked participants how they could support the Network and how they wished to be involved:

- Share experiences
- Planning and consultations
- Campaigns
- Assist with finding venues
- Encourage other survivors



Feedback from providers

11 evaluation forms were returned. Professionals told us they valued the opportunity to learn more about the issues and challenges that people living with stroke have to deal with every day.

I thought it was very well organised, with great consideration for needs, and an opportunity for very thoughtful contribution by all. A brilliantly inclusive event.



As a service provider I learnt a great deal from the stroke survivors.

Hearing directly from stroke survivors was very powerful and highlighted a number of issues that I had previously been unaware of.

All feedback from professionals is included at the end in Appendix 7.

What we learned

The event showed there is a great deal of support and enthusiasm for the Network. Demand and expectations are high – of course.

Many people want to get involved although there were not as many concrete suggestions and offers as we might perhaps have hoped for. This is not to be taken as a sign of apathy or lack of interest.

Rather, it needs to be acknowledged that it isn't easy for people to know how to participate if they have no experience of involvement.



Of those who responded, influencing services is a high priority for some. Others have said they would like to support and empower other stroke survivors.

The key interest and need is in getting out beyond their four walls and mixing with others in a place where they feel supported and safe – where they are guaranteed a warm welcome.

We've been working hard to create a range of opportunities and different ways to include people in the Network.

What happened next?

12 stroke survivors who went to the launch have since become actively involved. All participated in at least one event.

17 people came to a Healthcare for London consultation meeting. Ten of these were people who had attended the launch.

20 stroke survivors came forward to become peer supporters. With the help of our more experienced volunteers, we're skilling-up the new volunteers.

Attendance list - Professionals

Name	Organisation	Position
Anna Norgrove	Southwark Neuro-Rehabilitation Team	Social Worker
Annie Schofield	Lambeth Council	
Cecilia Tsang	Lambeth Carers	Advocacy and Advice Officer
Christopher McKevitt	Kings College Health and Social care Research	Senior Research Fellow
Dave Morrison		Peer Supporter
David Strong	Disability Advice Service Lambeth	Director
Deborah Sowerby	Disability Advice Service Lambeth	Stroke User Network Coordinator
Elaine Hayward	SE London Cardiac & Stroke Network	Senior Project Manager
Faith Abbey	Age Concern Lambeth	Befriending Worker
Fiona Sheil	Lambeth Voluntary Action Council	Health and Social Care Officer
Funmi Oglunfinmi	Sickle Cell and Young Stroke Survivors	
Gaynor Smith	Guy's and St. Thomas'	Service Improvement Lead – End of Life Modernisation

Geraldine Girardi	Kings College Hospital	Stroke Pathway Coordinator
Gillian Hewitt	St George's University of London	Stroke Services Researcher
Greg Brown	Lambeth Adults and Community Services (Specialist Disabilities Team)	Social Worker
Harprit Lally	Lambeth PCT	Care Pathway Redesign Facilitator
Harry Clarke	Connect	Counselor
Janet Doswell	Lambeth Adults and Community Services (South East Team)	Case Coordinator
Jannett Ashley	Kings College Admission & Discharge Team	Broker
Jeffy Wong	Different Strokes	Regional Coordinator
John Martin	Disability Advice Service Lambeth	Advice Manager
Julie Corbett-Bird	Blackfriars Settlement	Director
Karen Williams	Lambeth Council	
Kate Dawson	Guy's and St Thomas' Charity	Head of Communications
Kate Walton	Disability Advice Service Lambeth	Direct Payments Worker
Kethakie Sumathipala	Kings College Health and Social Care Research	Research Associate
Kwasi Kamasa	Lambeth LINK	Manager

Leila Gharthey	Disability Advice Service Lambeth	Volunteer Information Worker
Linda Wright	Southwark Neuro-Rehabilitation Team	Communication Group Coordinator
Lucy Morley Williams	Disability advice Service Lambeth	Direct Payments Worker
Mala Fernando	Different Strokes	Central London Coordinator
Malvina Edwards	A4E Direct Payments Southwark	Direct Payments Advisor
Marcia Dillon	Lambeth Adults and Community Services (Sport and Recreation Department)	Healthy Lifestyles manager
Michelle Barber	Lambeth PCT / Lambeth Adults and Community Services	Commissioning Manager
Nanik Pursani		Peer Supporter
Natalie	Lambeth PCT	Occupational Therapist
Nick Harris	Southwark PCT	Public and patient Involvement Facilitator
Pip Hardy	Kings College Hospital	Therapy Lead
Prossy Nakirayi	Lambeth Adults and Community Services (North Team)	Social Worker
Rahkee Prema	SE London Cardiac and Stroke Network	Project Manager
Rasaq Alli-Balogun	Southwark Disablement Association	Advocate
Richard Farnos	Disability Advice Service Lambeth	User Involvement Worker

Robin Ramsdale	Disability Advice Service Lambeth	Advice Service Manager
Rosario Mincher		RLSB
Rukiye Ahmet	Lambeth PCT	Neuro Pathways Lead
Sally Wells	Age Concern	
Sam McKenzie	Lambeth Adults and Community Services (Specialist Disabilities Team)	Case Coordinator
Samuel Marrero	SE London Cardiac & Stroke Network	Project Manager
Susan Hamilton	Disability Advice Service Lambeth	Trustee
Tina Johnston	Blackfriars Settlement	Coordinator Older Peoples Services
Tirita Lemon	St Thomas' Hospital	Social Worker
Tom Penman	Lambeth PCT	Principal Therapist (Neurological Pathway)
Vasiliki Boutopoulou	Disability Advice Service Lambeth	Information Worker
Victor Willmott	London Catalyst	Director
Wasi Daniju	Connect	Speech & Language Therapist

Appendix 2

EOP Analysis of Service Users Who Attended the Launch

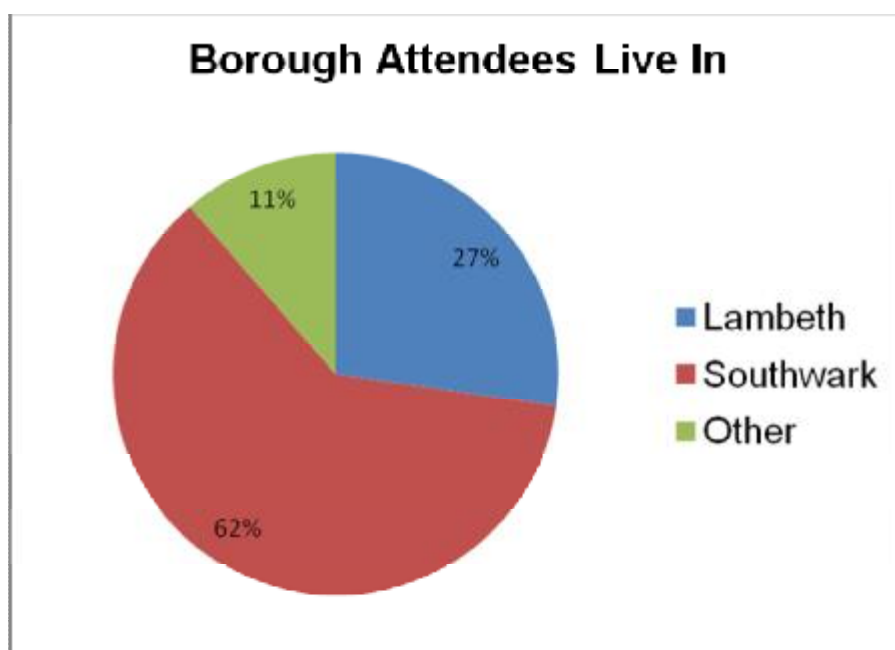
Data Source

This data has been compiled through using the Service User booking forms for the Stroke Launch which all attendees completed when reserving a place at the launch and from information held on the Lambeth and Southwark Stroke Network Membership Database. Information on age and ethnic origin have been solely obtained from the Lambeth and Southwark Stroke Network Membership Database therefore we do not have this information available for analysis for those who are not members of the network as these areas were not covered on the booking forms.

Which London Borough Attendees Lived In

Of the service users who attended the Stroke Launch 12 people lived in Lambeth, 27 people lived in Southwark and 5 people lived in other boroughs which included Haringey (2 people), Lewisham (1 person), Greenwich (1 person) and Barnet (1 person).

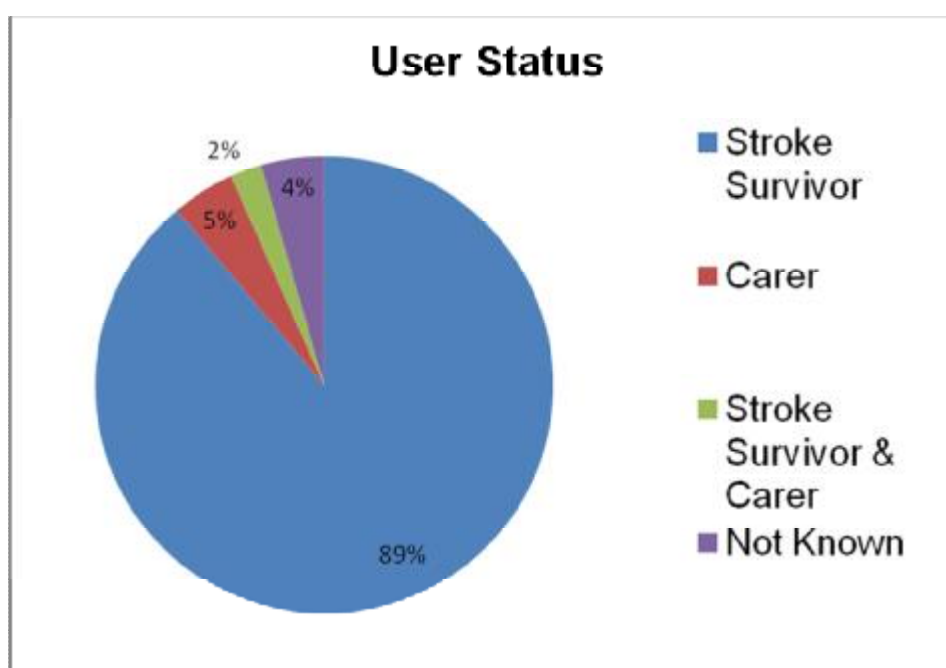
Borough	
Lambeth	12
Southwark	27
Other	5
Total	44



Attendees User Status

The majority of the users that attended the launch were stroke survivors (40 people). Two carers also attended the launch as well as one person who was a stroke survivor and also a carer. Of the people who attended we did not know whether two of the attendees were stroke survivors, carers or both.

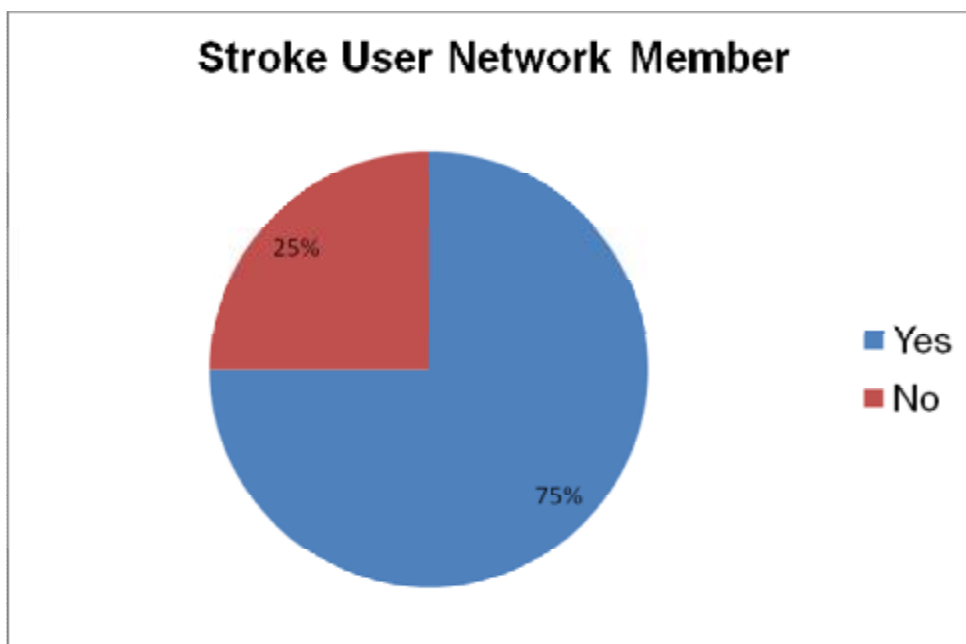
User Status	
Stroke Survivor	40
Carer	2
Stroke Survivor & Carer	1
Not Known	2
Total	44



Member of the Stroke Users Network

At the time of attending the Stroke Launch 33 of those who attended were already a member of the Lambeth and Southwark Stroke Users Network. Eleven of the people who attended were not members of the network.

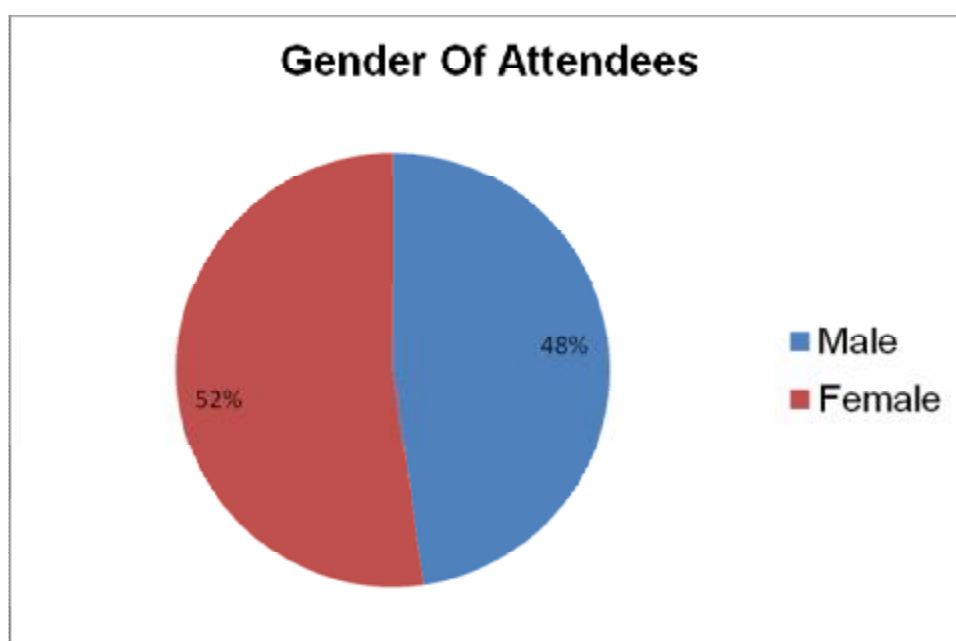
Network Member	
Yes	33
No	11
Total	44



Gender of Attendees

There was a fairly even distribution of male and female service user attendance to the Stroke Launch. 21 of those that attended were male and 23 were female.

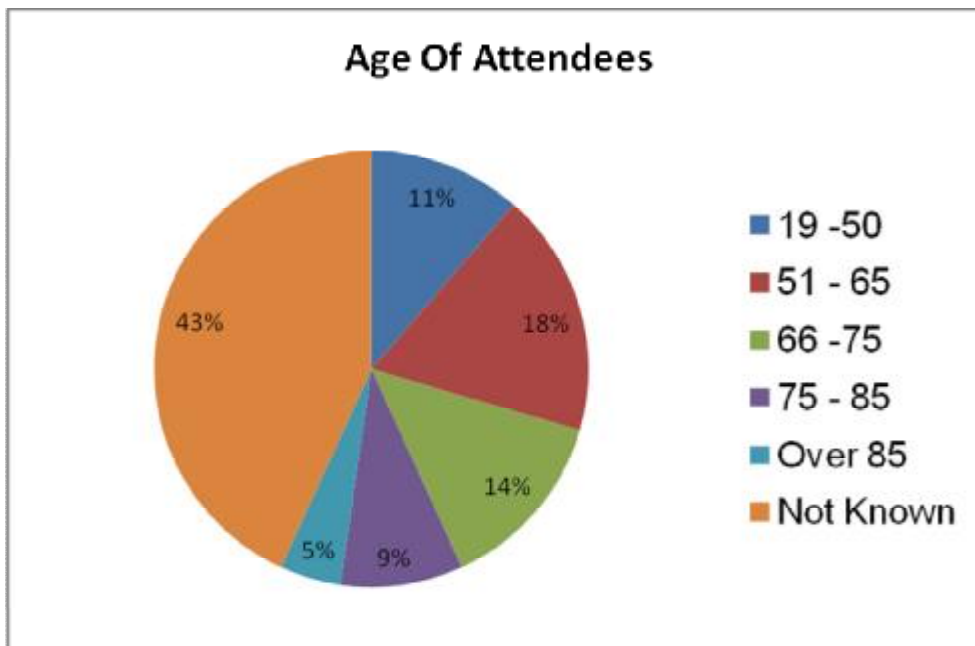
Gender	
Male	21
Female	23
Total	44



Age of Attendees

Of those that we held information on regarding age there was a fairly even distribution of attendees in the age groups between the ages of 19 to 85. Due to data source and attendees not wishing to disclose their age there are a large number of people (19) of whom we do not know their age.

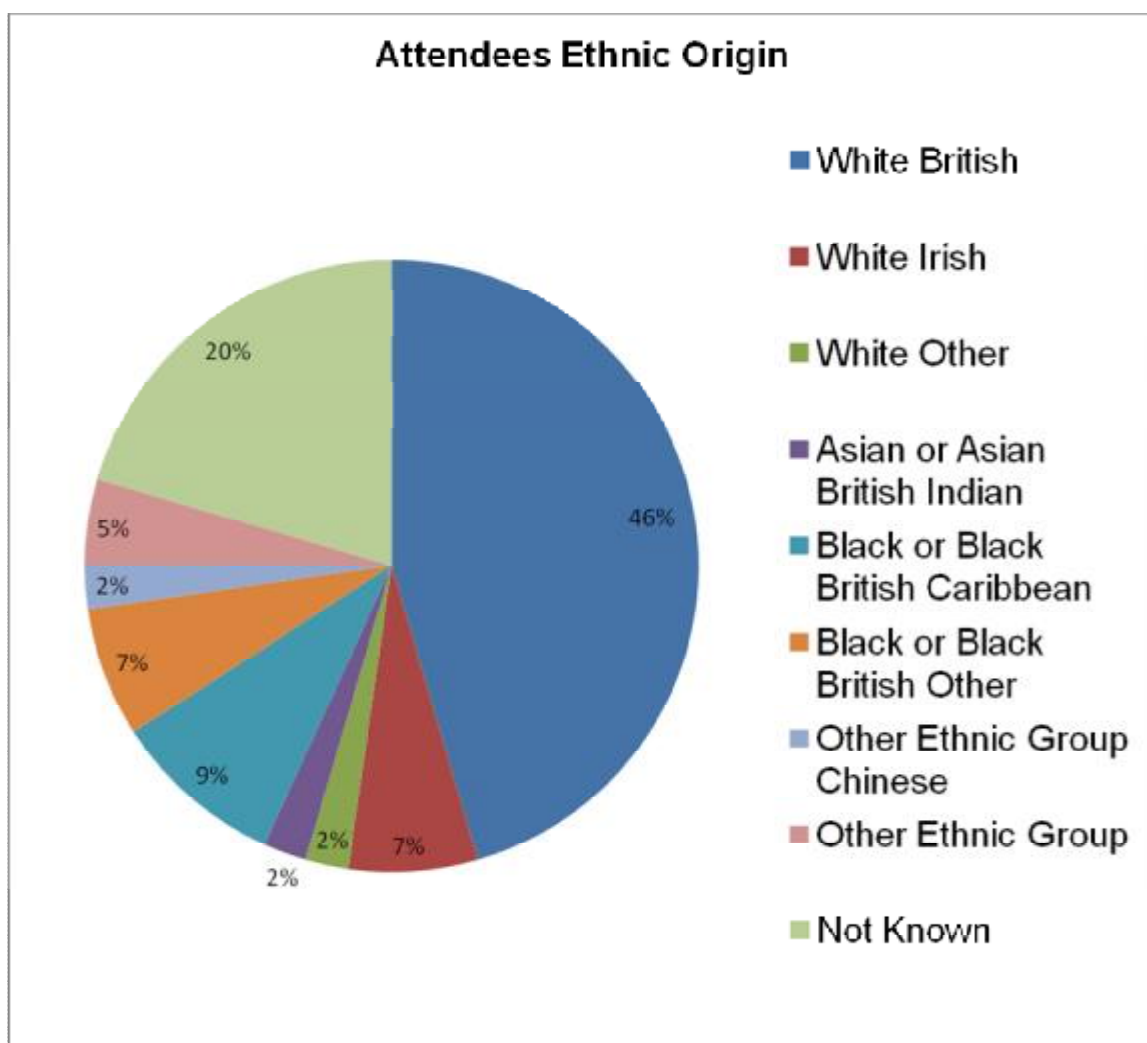
Age Of Attendees	
Under 18	0
19 -50	5
51 - 65	8
66 -75	6
75 - 85	4
Over 85	2
Not Known	19
Total	44



Ethnic Origin of Attendees

Just over half of the people who attended the launch were White British / Irish / Other. Eleven people who attended the launch came from other ethnic groups including Indian, Chinese and Caribbean. Due to data source and attendees not wishing to disclose their ethnic origin there are a large number of people (9) of whom we do not know their ethnic origin.

Ethnic Origin	
White British	20
White Irish	3
White Other	1
Asian or Asian British Indian	1
Black or Black British Caribbean	4
Black or Black British Other	3
Other Ethnic Group Chinese	1
Other Ethnic Group	2
Not Known	9
Total	44



Appendix 3

Service User Event Evaluation Feedback

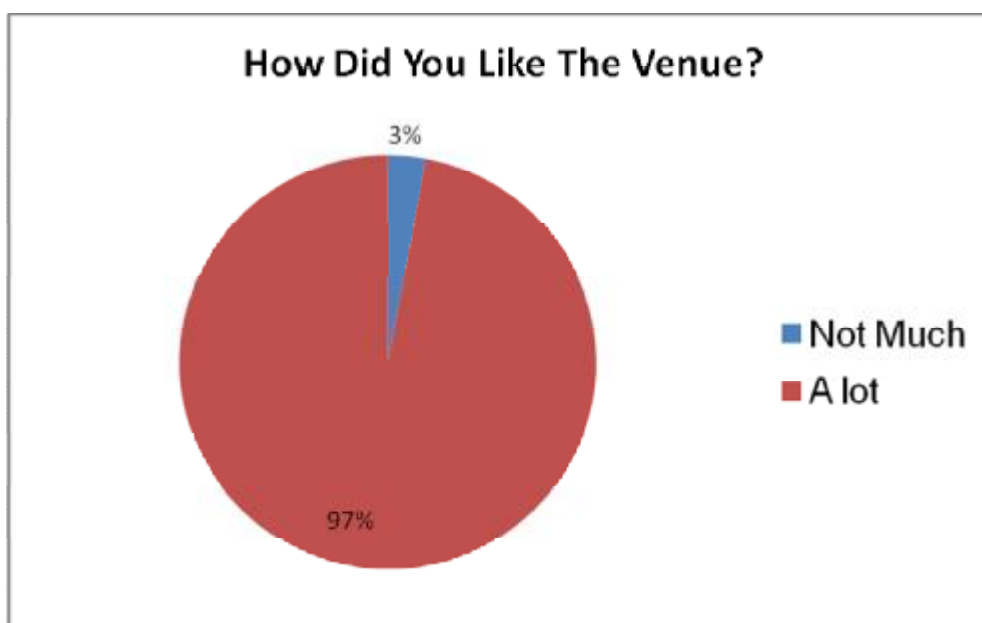
Of the 44 service users who attended the Stroke launch event 34 of them completed evaluation forms. The following outlines what the attendees thought of the event.

The evaluation form asked the following questions –

How Did You Like The Venue?

An overwhelming 97 % of those that attended the launch said that they liked the venue a lot; one person said that they did not like it much.

	Didn't Like	Not Much	A lot	No Answer
No	0	1	33	0
%	0	3%	97%	0

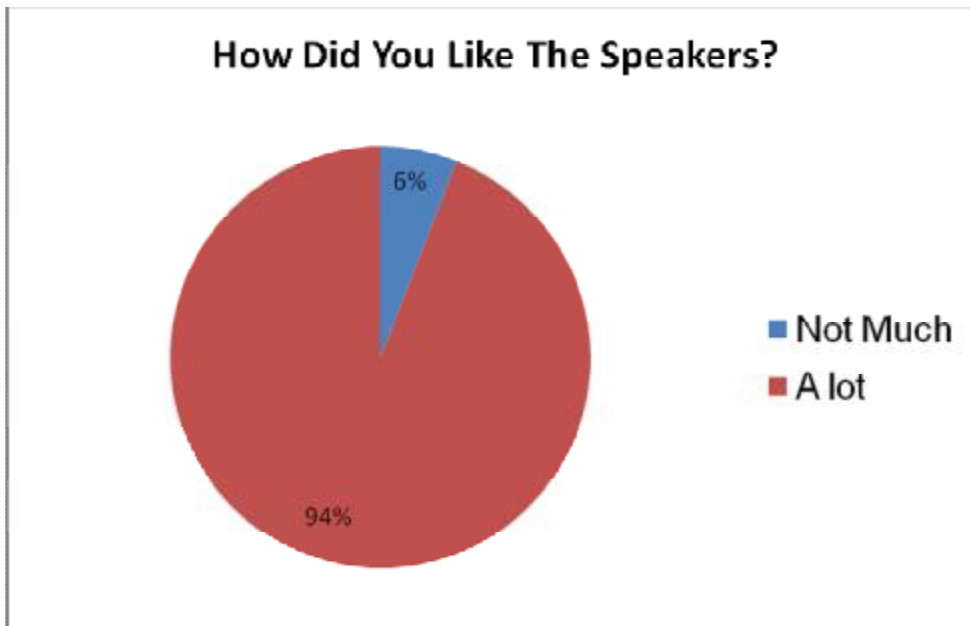


How Did You Like the Speakers?

The vast majority of the people that attended the launch enjoyed listening to the

	Didn't Like	Not Much	A lot	No Answer
No	0	2	32	0
%	0	6%	94%	0

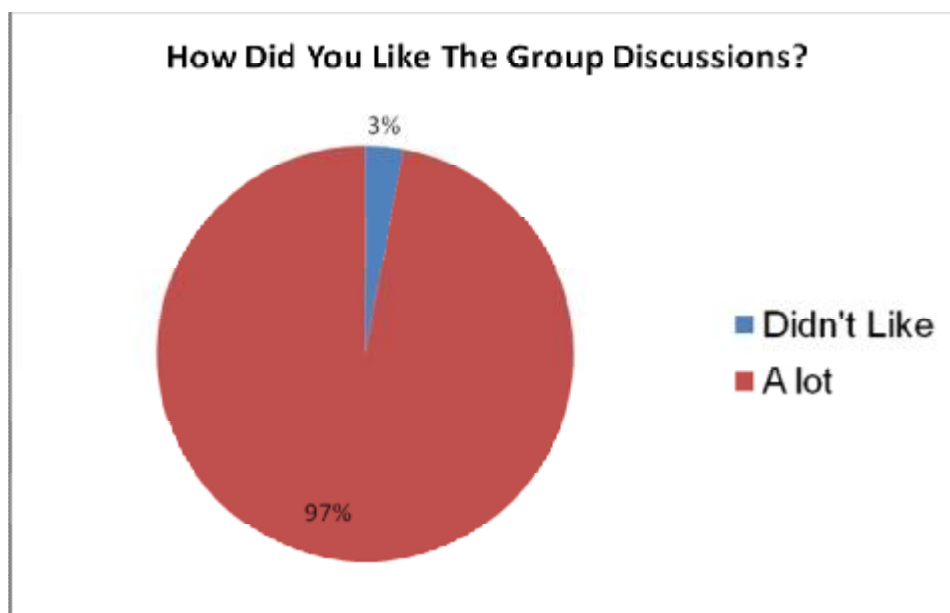
speakers and said that they liked it a lot (94%). Two of the people who attended the launch said that they didn't much like the speakers.



How Did You Like The Group Discussions?

Of those that attended the launch 97% said that they enjoyed the group discussions a lot, one person did not like the group discussions.

	Didn't Like	Not Much	A lot	No Answer
No	1	0	33	0
%	3%	0	97%	0

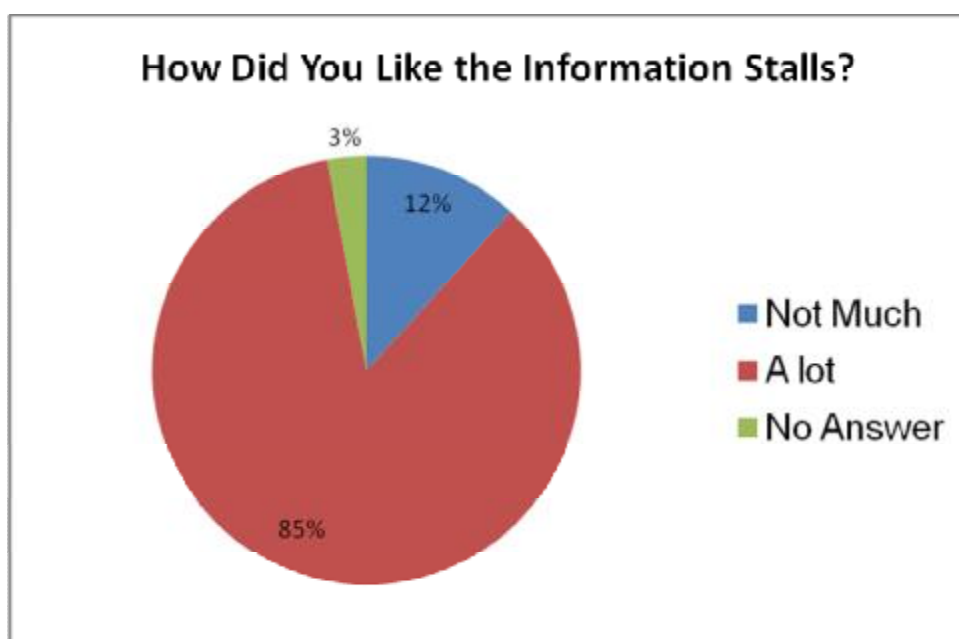


How Did You Like The Information Stalls?

The majority of people (85 %) who completed the evaluation form liked the

	Didn't Like	Not Much	A lot	No Answer
No	0	4	29	1
%	0	12%	85%	3%

information stalls and found them useful. Four people (12 %) did not like the information stalls much and 1 person did not answer the question on the evaluation form as they said that they did not look at the information stalls so felt that they could not comment.



What Did You Like Best About The Event?

- I met some friends
- It was informative
- The group discussions (5)
- It was a brilliant opportunity to speak to people
- Talking to and meeting new people, networking (6)
- Very exemplary
- It's about letting us know how we can help others
- It was well spoken
- The large venue
- It came together professionally – well organised
- Hearing and sharing peoples experiences (2)

- The live band – Belatone
- Everything about today, it's been good to talk to people (5)
- I enjoyed it immensely
- The informality of the event
- The food was very good (2)
- The exchanging of ideas
- People listening to what your needs are and the help and advice given to me
- Being able to talk to other people who have had a stroke and to service providers
- The venue was easy to get to





Any Other Comments

- There needs to be some extra information leaflets or posters on the network to promote its work to service users, carers, families and organisations (2)
- There was a cold breeze through the main door
- The taxi was amazing
- Carry on in this way so that know more about what to do.
- A good meeting
- Everyone was helpful
- When is the next event? – I really enjoyed it.
- It was a good day
- There should be a regular forum during the summer period
- The brochures were informative and useful.
- I had trouble finding the venue
- I am very motivated to keep going on making progress
- Can't wait for the next event
- Very glad that I came, I found it very informative
- Many thanks
- Looking forward to the report
- Good job
- The pavements were not good
- I use a wheeled walking frame and it was difficult to negotiate my way to the toilet due to lots of chairs.

- It was all very good
- More user speakers
- Everything was well above my expectations
- Let's do it again





Group Workshops Facilitators Briefs

Morning session
What life is like for me as a person living with stroke?

	2 mins	Welcome. Each say your name.
	10 mins	Think about what's important to you in your life, your responsibilities, your interests, your needs and your choices.
	15 mins	What are the challenges* you face in your everyday life as you try to stay as independent and active as possible? *Obstacles *Frustrations *Barriers
	15 mins	How does stroke affect your independence?
		What other factors affect your independence?
		What gets in the way, stops or makes it hard?
	5 mins	Three key points from the discussion – write on flipchart.

Afternoon session

What we want from the Network and how we can get involved.

	2 mins	Welcome. Each say your name.
	20 mins	Briefly outline the 4 aims of the Network
		Are these aims the right ones?
		How can the Network make a difference to the lives of people living with stroke?
		How can the Network take on the challenges talked about in the morning session?
	10 mins	We must make sure we include as many people as possible in the Network. *Who might get left out? *How might it happen? * How to stop it?
	10 mins	How would you like to be involved? *What are you good at? *What are you interested in?
	5 mins	Three key points from the discussion – write on flipchart.

Appendix 5

Group Workshop Morning Session

What life is like for me as a person living with stroke?

This is a summary of the main points made by attendees during the morning workshop.

Think about what is important to you in your life, your responsibilities, your interests, your need and your choices.

- The affect on family and carers should not be forgotten
- Having a carer that visits for more than just a few minutes.
- Family is important although you often lose touch with them.
- Keeping a normal pattern of life – going to the football, going to work
- Working is important – keep involved in work, having an understanding employer really helps.
- Helping other people.
- Keeping in physical condition and being active – exercising when you can is important.
- Hobbies and interests – being able to access art, dancing
- Going out
- Blackfriars Settlement
- Thinking positive is important.
- Church
- Having counseling – someone to talk to who understands you and can support you.
- Friends
- Doctor
- Participating in voluntary work
- Achieving activities that you have not done before – like knitting, computers, text messaging
- Physical, emotional and mental wellbeing
- Looking after my cat



- My grandchildren

What are the challenges, obstacles, frustrations, barriers you face in your everyday life as you try to stay as independent and active as possible?

- Difficulty getting up early in the morning – tiredness
- Loss of sight
- Not being able to concentrate for long
- Mood changes
- People do not give you time to express your thoughts, opinions or help you to express words or thoughts correctly.
- It is frustrating not being able to find the right word.
- Not being able to read for more than 5 minutes.
- Being made to feel stupid when you are having difficulty communicating
- Short term memory loss
- Being depressed and lacking motivation
- Not being able to cook
- Not being able to walk due to weakness in the legs
- Incontinence restricts activities you can do; you have to plan activities around where there are toilets.
- Not being able to speak
- Not being able to use your arms
- Recovering slowly
- Getting very emotional
- Getting frustrated with the things that you can't do
- Having to slow down
- Accepting support is difficult
- Having to adapt
- Learning to love yourself again.
- Not being able to be assertive and strong
- Accepting your disability



- Always losing things
- Accepting that every day is different, you can do things one day and not another.
- Low energy levels
- Aphasia
- Not being able to do the gardening
- Not being able to have a bath or a shower or shave without support
- People constantly asking how you are
- Not being able to run for a bus
- Dropping things and making a mess
- Not being able to turn over in bed
- Caring for a family – young children
- Not being able to use the telephone and having to physically go to places as a result
- Not being able to write
- Getting up and down stairs
- Not being able to use a knife or fork
- Changing my diet



How does stroke affect your independence?

- Has to rely on support from the community such as the green grocer dropping shopping around.
- People can't always see that you have had a stroke
- Makes me feel like I have lost my role within the family by not being able to do what I did before the stroke.
- Your world shrinks
- Become isolated

What other factors affect your independence?

- Not having access to accessible transport
- Living in a residential home takes away your control and independence, your life and timings are driven by the home.
- Having to rely on other people to help you so that you can do things.

- Having to forward plan if you going somewhere – is it a wheelchair accessible venue?
- Not having enough physiotherapy
- Restricted access to day centres due to transport.
- Other peoples ignorance
- Not having enough speech and language therapy

What gets in the way, stops or makes it hard?

- The environment can be intimidating or oppressive or negative
- Reading maps as they do not use signage that you can understand.
- Lack of dropped kerbs on pavements for wheelchairs.
- Shops aren't always accessible.
- Busy roads
- Fellow travelers are not always empathetic if you are causing delays for them.
- Not having everything you need in place before your discharged from hospital
- Organisations not being aware of the issues people with stroke face.
- Dealing with the DVLA
- Mistakes and delays by organisations.



Appendix 6

Group Workshop Afternoon Session

What we want from the network and how we can get involved

This is a summary of the main points made by attendees during the morning workshop.

What do we want from the network?

- Self help support and advice groups
- To meet people of a similar age
- Regular social groups
- Signposting of useful information
- Interesting guest speakers
- Information to be provided in various formats – written, oral etc
- Summer away days and Christmas parties
- Campaign on behalf of users
- Link in with other networks and organisations in local area
- Help make the public aware of issues that people with stroke experience
- Target young people who have had a stroke – make groups and events relevant to them.
- Tell people about resources in the community – talking books in libraries, mobile hairdressers etc.
- Influence other local authorities to do the same.
- A drop in service
- Help with transport
- Information on benefits, services and financial relief
- Breaks
- Peer support
- Influence policy developments and service provision
- Support and information on self care management



- Advocacy
- Information on adaptations
- Befriending
- Provide training on stroke to professionals e.g. Care providers
- Volunteer escorts
- To be a help point so that you don't get lost in the system
- Support groups for women
- Train bus drivers



How can the network make a difference to the lives of people living with stroke?

- Social groups so that people don't feel like their alone
- Support to learn new skills
- Make information aphasia friendly
- Peer support can help improve people's confidence
- By instilling positivity and coping strategies
- By making people feel more empowered.
- Learning things from each other
- Peer support for those most isolated
- Making the local community more aware and understanding of the needs of people who have had a stroke
- Give the stroke handbook to people
- Befriending



How can the network take on the challenges talked about in the morning session?

- Social groups so that people can get out and meet each other
- Through providing information to users and professionals
- Have a comprehensive list of useful telephone numbers and contacts of people and services that can help.
- Ensure there is continuity of services.

How do we include as many people as possible in the network?

- Make sure that GP's have information on the network to give patients.
- All local government, NHS and voluntary organisations should promote the work of the network
- Advertise outside the box
- Wardens in sheltered homes should be aware of the network.

How would you like to be involved?

- Help to promote the network using links in the community
- Help with finding appropriate venues
- Sharing experiences with others.
- Encouraging survivors to keep going with their exercises and mobility between physio visits and beyond.
- Can be an example to the success of programmes.
- Be a voice for new users
- Fundraising



Appendix 7

Service Providers Event Evaluation Feedback

Eleven service providers completed the evaluation feedback form. The following outlines what the attendees thought of the event and the comments that they have made in each section.

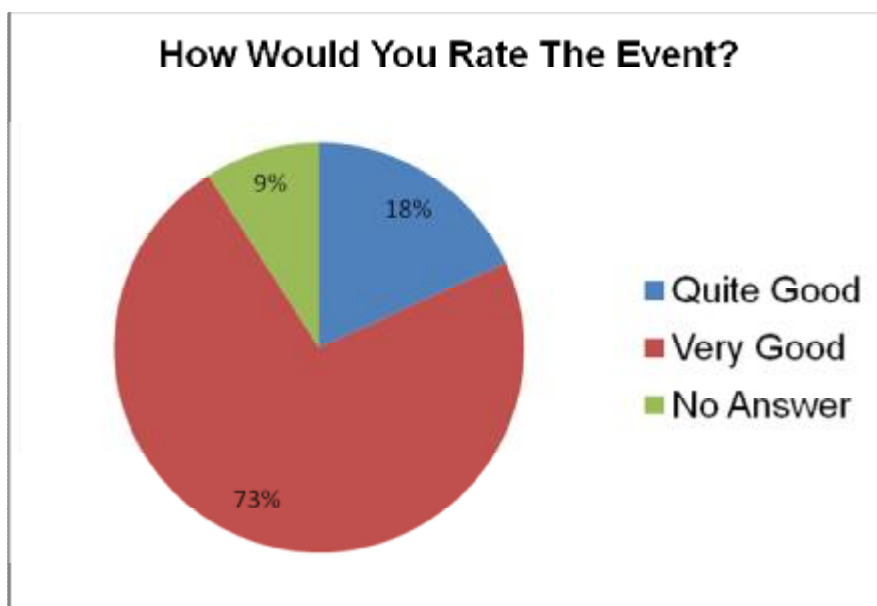
The evaluation form asked the following questions –

Overall, How Would You Rate The Event?

Of the service providers who attended just under three quarters of them rated the

	Not Good	Quite Good	Very Good	No Answer
No	0	2	8	1
%	0%	18%	73%	9%

launch as very good (8 people/73%), 2 people thought that the event was quite good (18%) and one person did not answer the question.



The service providers also made the following comments regarding how they rated the event -

- § The day was informative and enjoyable for the stroke survivors that sat at my table, Good chance for them to share their views and experiences.
- § It was a fantastic way of bringing people together to air not only their differences but their shared concerns.

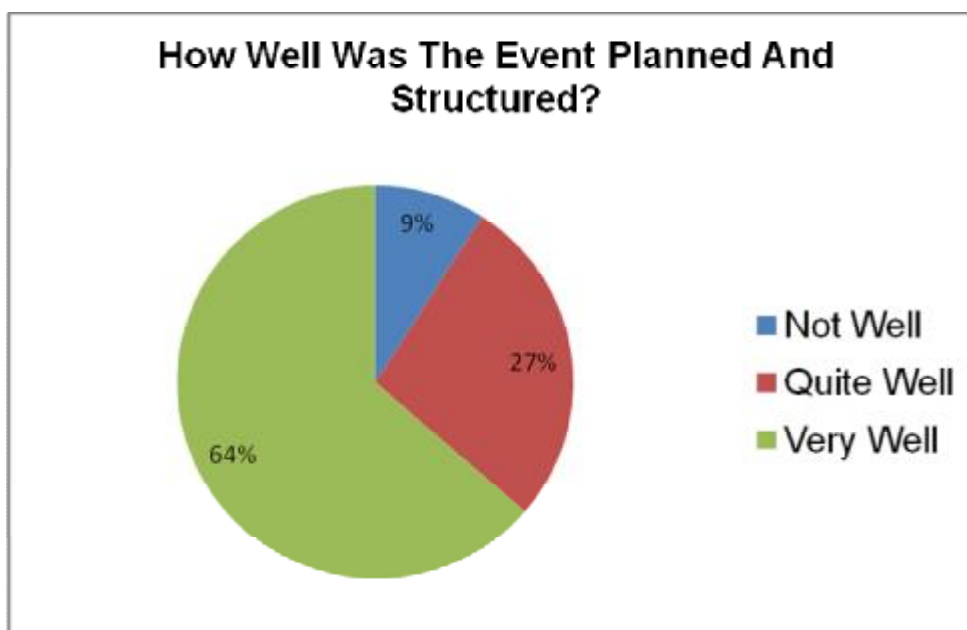
- § I thought it was very well organised, with great consideration for needs, and an opportunity for very thoughtful contribution by all. I thought it was a brilliantly inclusive event.
- § I thought the day provided a fantastic opportunity for stroke survivors to gather as a group to speak about their experience and gain support from one another. I believe the discussion topics were very topical and relevant and hopefully will help to develop support systems/knowledge relevant to stroke. As a service provider I learnt a great deal from the stroke survivors, particularly what they value from professionals and organisations.
- § I have spoken to a couple of my clients who attended this event and they have spoken very positively about it and have said that they would like to attend such an event again.
- § Brilliant opportunity to actually speak to service users outside of hospital environment.

How Well Was The Event Planned and Structured?

Two thirds of the service providers thought that the event was planned

	Not Well	Quite Well	Very Well	No Answer
No	1	3	7	0
%	9%	27%	64%	0%

and structured very well (7 people / 64 %). Three people felt that the event was organised quite well (27 %). However one person felt that the event was not organised well.



The service providers also made the following comments regarding how well they thought the event had been planned and structured –

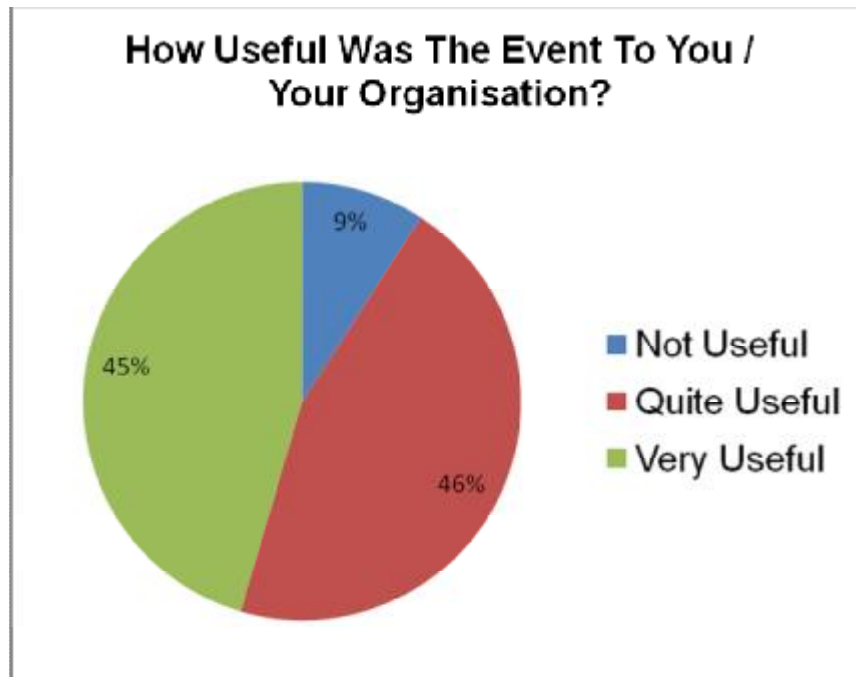
- § The event seemed well planned but the venue was cramped due to the amount of tables around.
- § A good location, a very nice room and well presented and tasty lunch.
- § Only attended in the morning but was a good mix of group work and presentation – would be interested in the feedback/actions agreed.
- § I acknowledge the huge level of organisation it takes to arrange such an event. I thought the level of communication/ correspondence sent to service providers and stroke survivors was very well done. The only points I would like to mention is the consideration given to people with mobility difficulties. Several of the clients I work with are wheelchair dependent and although provision was made for transport it was not until very close to the event that confirmation of this was given which was too late notice for some of my clients. Also given the number of people attending, particularly taking into account people with mobility problems – a larger room may have been more beneficial for some. For example a gentleman at my table who uses a stick found it difficult to negotiate his way to the toilet.
- § As a person who was asked to facilitate and note-take on the day it would have been helpful to have been made aware of this on the day as well as the topics of discussion.
- § I did not receive confirmation of the day until very close to the event- by which time I had assumed I wasn't needed and so had booked other things!
- § I think it was about the right length with enough breaks and opportunities for informal discussion and the right mixture of speakers and group work. The venue was a bit cramped, especially with so many wheelchairs. The final feedback session felt a bit rushed.

How Useful Was It To You/Your Organisation?

All but one (9%) of the professionals that attended the launch either found

	Not Useful	Quite Useful	Very Useful	No Answer
No	1	5	5	0
%	9%	45.50%	45.50%	0%

the event to be quite useful (5 people 45.5%) or very useful (5 people 45.5%) to either themselves or their organisation.



The service providers also made the following comments regarding how well they thought the event was to them or their organisation –

- § Because I was not there all day, but also because the day had quite a broad focus I think it had limited benefit to the Trust. I hope that once I see the feedback from the sessions and user's ideas that will help us formulate areas for improvement and work.
- § It was a good opportunity to meet both professionals and stroke survivors and see the range of professionals and groups involved in stroke care.
- § It was useful from the perspective of not knowing that many people who have had a stroke receive little or no support after they have been discharged from hospital.
- § Your work is a very valuable resource to the Neuro Rehab Team.
- § Was really useful to meet some stroke patients and hear about their experience firsthand. In addition was helpful to meet colleagues from other organisations such as Lambeth carers and the local authority.
- § I found it very relevant and helpful to my work with stroke survivors. I work in the Southwark Neuro-Rehabilitation Team, so I have been able to provide some feedback to therapists about some of the views expressed by service users, i.e. in regards to some of the positive

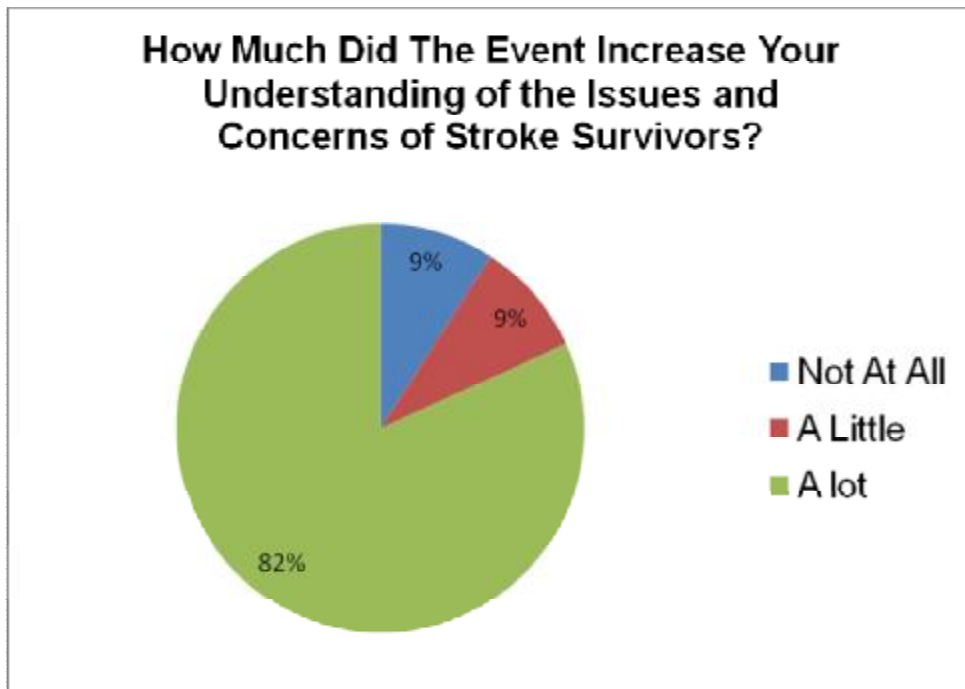
aspects and challenges they have come across when working with stroke services. It is also very good to know what the plans are in regards to forming a stroke network – and what I and my team may be able to do to contribute to this.

How Much Did The Event Increase Your Understanding Of The Issues And Concerns For Stroke Survivors?

The vast majority of professionals that attend the launch found that the event increased their

	Not At All	A Little	A lot	No Answer
No	1	1	9	0
%	9%	9%	82%	

understanding of the issues and concerns for stroke survivors a lot (9 people 82%) one person felt that it increased their understanding a little (9%) and one person felt that it did not increase their understanding (9%)



The service providers also made the following comments regarding how much they felt that the event had increased their understanding of the issues and concerns of stroke survivors –

§ I found the day very informative.

- § More so in terms of what issues are most important to survivors, rather than what the issues are.
- § Although I had a fair idea of what concerns stroke survivors I learnt that that London can be an extremely overwhelming and “disability unfriendly” place. I was left in no doubt that public awareness should be raised, as well as the useful tips established stroke survivors can pass on.
- § Hearing directly from stroke survivors was very powerful and highlighted a number of issues that I had previously been unaware of e.g. that they have their own carer responsibilities.
- § I found it very beneficial to listen to their views in this forum. The difference being that normally when I am working with clients I am listening and responding with regards to what support can be provided so it was interesting to just listen to their views and experiences.
- § I feel that I have a good understanding as I have worked across the pathway. However, the event served as a good refresher to keep these issues at the front of my mind.

How Could We Make It Better Next Time?

The professionals were asked to comment on how they felt the event could be made better, their comments were –

- § A bigger venue would be good for those with mobility problems.
- § I was selected as a facilitator/note-taker. There was very little notice of this and of what might be required of the job. Perhaps next time we could be given a little more warning and information? No other concerns, though. Well done!
- § The only suggestion is in regards to ... making provision for people’s mobility and care needs in a timely fashion prior to the event. Also, to inform professional prior to the event about the role they will be expected to take.
- § Thank you for organising such an event and I look forward to receiving feedback regarding the information gathered and the plans for the future with regards to the stroke network.
- § More notice of the final agenda
- § More focused focus groups – in a quieter environment
- § More talks from the users

- § Venue was easy to get to but it was hard to have discussion due to noise and space was difficult to use for people in wheelchairs.
- § Extend the range of invited voluntary agencies invited. For example there is an organisation in Southwark called Stroke Care and they were not even aware of Stroke Network.
- § I think it would be helpful to forewarn people what the group discussions are going to be about or at least give everyone a copy of the facilitator's questions as it was quite hard to get across the objective of the discussion, especially in a noisy room. Also people will have had more time to think about what they want to say if they know the topics in advance.
- § I thought it was an excellent event. I really learned a lot and would be very keen to come along to any more events. Well done to all involved.
- § Improved acoustics.