

Evaluation of Stroke Association Voluntary Groups

Knowing you're  
not alone:  
Understanding  
peer support for  
stroke survivors

*Research report*

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**Stroke**  
association

## About this report

Stroke Association Voluntary Groups (SAVGs) are volunteer-led, peer support groups based in local communities across the UK. They offer a range of activities for stroke survivors and carers such as exercise, art, music, gardening, talks and trips out. Peer support is a core part of these groups and 7 in every 10 of the volunteers who run the groups are themselves stroke survivors. Through the support they offer, the groups aim to contribute to a set of key outcomes for stroke survivors, as well as providing positive and largely similar outcomes for the carers who attend them.

The Nuffield Trust was selected to independently evaluate these SAVGs and to assess the value and impact of the groups for their beneficiaries. Our evaluation used a mixed-methods approach, which included a questionnaire of stroke survivors and carers to capture self-reported measures of health and wellbeing, interviews with stroke survivors and carers, and interviews and focus groups with staff and volunteers. The evaluation drew on the experiences and views of more than 200 stroke survivors and 100 carers from 30 local groups, as well as 20 Stroke Association staff and volunteers.

**For an accessible summary of this research, visit [www.nuffieldtrust.org.uk/SAVGs](http://www.nuffieldtrust.org.uk/SAVGs)**

## Acknowledgements

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## Who are the Stroke Association?

We are the UK's leading charity dedicated to conquering stroke. We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke. Together we can conquer stroke.

## Project funding

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## Executive summary

Stroke Association Voluntary Groups (SAVGs) are volunteer-led, peer support groups based in local communities across the UK. They offer a range of activities for stroke survivors and carers such as exercise, art, music, gardening, talks and trips out. Peer support is a core part of the groups and 7 in every 10 volunteers who run groups are themselves stroke survivors. Through the support they offer, these groups aim to contribute to the following outcomes for stroke survivors: reduced social isolation, improved mental wellbeing, increased knowledge and self-management, increased likelihood of accessing support and improved confidence.

The Nuffield Trust was selected to independently evaluate SAVGs and to assess the value and impact of the groups for their beneficiaries. Our evaluation used a mixed-methods approach, which included a questionnaire of stroke survivors and carers to capture self-reported measures of health and wellbeing, interviews with stroke survivors and carers, and interviews and focus groups with staff and volunteers. The evaluation drew on the experiences and views of more than 200 stroke survivors and 100 carers from 30 local groups, as well as 20 Stroke Association staff and volunteers. The evaluation began in January 2015 and ran for 18 months. Below we highlight the key findings, observations and reflections from this evaluation.

- In the UK, there are 130 SAVGs run by more than 700 volunteers. Stroke survivors can join a SAVG at any point after their stroke (in most instances people join around 12 months after stroke) and remain a member for as long as they want to. SAVGs are supported by the Stroke Association, but they are responsible for raising funds to run the group, usually through local grants or fundraising.
- There are common patterns in the way that local groups are structured (usually supported by a group of volunteers with different formal roles and responsibilities) and in the types of support that they offer. But the SAVGs do differ from one another, and are often shaped by the needs and preferences of group members and available funding.
- Group members were positive about being part of a group. They overwhelmingly felt it to be an essential part of their life after stroke and a source of ongoing support. Stroke survivors reported that joining a SAVG had had a positive impact on their social isolation and that the groups provided them with a way to access social networks and make friends. In interviews, social support was often given as a stroke survivor's primary reason for attending a SAVG. In addition, a number of stroke survivors reported having no other opportunity to regularly leave their home and interact with others.
- Previous research has demonstrated the negative impact loneliness and social isolation can have through its effect on people's wellbeing and quality of life. Therefore, our findings suggest that the social networks and interactions the groups offer is important for stroke survivors' broader recovery and wellbeing.
- Stroke survivors felt that their confidence was improved through participation in the SAVGs. Those interviewed reported that the groups provided them with many

practical opportunities to improve and build their confidence and that the overall atmosphere and culture of the groups also contributed.

- One of the biggest challenges stroke survivors were facing was changes with mental wellbeing and in particular feeling more emotional. Generally, people felt that attending a group had had a positive impact on their mental wellbeing. Some identified that the SAVG provided a space for people to tackle the ongoing 'ups and downs' that followed a stroke – in particular the heightened emotions experienced by many.
- Self-management was a difficult topic to discuss with stroke survivors in interviews; there was confusion around its meaning and in how improved self-management related to the groups. Stroke survivors reported that SAVGs provided ways for some to regain practical skills or functioning through learning and activities. Most commonly, the group had helped people with their writing, computer skills and with regaining their speech. A couple of interviewees also mentioned that the groups had helped them understand more about stroke.
- Although people generally felt supported by the groups, they didn't necessarily see the group as a way to access other types of support or services. However, this was challenging to capture in the interviews as people didn't know or couldn't remember who had provided them with support since their stroke.
- Carers felt positively about the groups, and were clear about the benefits the group had for themselves and those they cared for. Carers described improvements in mental wellbeing as one of their main reasons for accessing the group. In particular, they appreciated the friendly atmosphere and seeing success stories – people who had recovered from stroke – which gave carers a 'morale boost' regarding their own situation and future. The local networks and communities formed within groups were also appreciated by carers as a source of practical and emotional support when transitioning away from statutory services.
- Prior to this study, little research had been undertaken to understand the impact of peer support for stroke survivors. We found that, overwhelmingly, stroke survivors felt peer support had a positive benefit for them and they felt it made a real difference. Stroke survivors and carers found it reassuring and supportive to be with people who were going through similar challenges. It gave stroke survivors a more positive impression of their own recovery and also provided them with an opportunity to support others. We also found that there were times when people felt that peer support was not appropriate. This was identified as being mainly due to timing. In particular, in the immediate aftermath of a stroke it could be too soon for stroke survivors to attend a support group if they were experiencing strong emotions and anger.
- Staff and volunteers running and supporting SAVGs were facing numerous challenges in their roles. These were readily acknowledged and included: welcoming new group members, recruiting new group members, recruiting volunteers, training volunteers, managing pressures on lead volunteers, maintaining good relationships, providing adequate staff resource, sourcing funding and supporting the varying needs of stroke survivors. In addition, we observed that lead volunteers and volunteers in other formal roles were under great pressure to run the groups effectively and this was a key concern for the future of the groups. There was concern about how sustainable these roles could be without shared responsibilities and adequate staff support.

- Through a self-report questionnaire we attempted to capture measures of the following outcomes: reduced social isolation for stroke survivors, improved mental-wellbeing for stroke survivors, increased self-management for stroke survivors and improved quality of life for carers. We were unable to find any statistically significant changes over a three-month time period in any of the outcome measures for members of the SAVGs.
- This may have been because, for many stroke survivors attending SAVGs it had been several years since their stroke and they had plateaued in their recovery. Improvements in these outcomes were likely to have been seen sooner after their stroke and/or after joining the group. In addition, since the groups offer long-term support, leaving more time between questionnaires may have better captured the impact of groups.
- Despite not being able to detect significant changes in outcome measures over time, we still feel there is great value in using patient-reported outcome measures for groups of this nature. If these were to be used to capture the value of similar groups in future work, we would suggest:
  - stroke survivors complete and track their own outcome measures
  - capturing new group members as early as possible after joining a group, allowing more time between outcome measurements (such as 6 or 12 months)
  - groups to focus on a reduced number of complete outcome measures.

# 1. Introduction

There are around 1.2 million stroke survivors in the UK (Stroke Association, 2016) and each year stroke costs the NHS £4 billion and the wider economy £9 billion (Saka and others, 2009). The Stroke Association (Box 1.1) is a UK charity that aims to help stroke survivors make the best recovery they can.

For more information about stroke and its impact, see Box 1.

## Box 1.1: Stroke and its impact (Stroke Association, 2016)

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off and brain cells are damaged or die. Every year, there are 152,000 strokes in the UK.

Stroke is devastating and life-changing. It can affect people differently, depending on the area of the brain that is damaged.

A stroke can have an impact on the way the body works as well as how people think, feel and communicate.

Over half of stroke survivors have a disability and one third rely on others for help, making stroke one of the biggest causes of disability in the UK. Many stroke survivors experience fatigue, memory loss, low levels of confidence and self-esteem. They can become socially isolated from their friends, family and community. Stroke forces family members to become carers who are often left coping alone.

It is possible to recover to a certain extent after a stroke with the right care, support and treatment but despite having long-term and often complex needs, many stroke survivors and their carers have trouble accessing the support they need.

One source of support that is available to stroke survivors and carers is a Stroke Association Voluntary Group (SAVG) (see Box 1.2). These are volunteer-led peer support groups based in local communities across the UK. They offer a range of activities such as exercise, art, music, gardening, talks and trips out. Peer support is a core part of what the groups offer and around 72 per cent of the volunteers running the groups are themselves stroke survivors (Stroke Association, n.d.). The groups are financially self-supporting, but they operate within a national framework that enables them to access support from local, regional and national Stroke Association staff as well as training, resources and guidance.

## Box 1.2: What are Stroke Association Voluntary Groups (SAVGs)?

- Stroke survivors can join a SAVG at any point after their stroke, and they remain members as long as they want to. The Stroke Association reports that, in most instances, survivors join around 12 months after a stroke. This is the point at which statutory services tend to end.
- In the UK, there are around 130 SAVGs providing support to people affected by stroke.
- SAVGs are run by more than 700 volunteers. The majority of these volunteers have had a stroke or have cared for someone who has had a stroke.
- SAVGs are supported by the Stroke Association, but are responsible for raising funds to run the group, usually through local grants or fundraising.
- There are consistencies in the way that groups are structured and the types of support that they offer, but each group is different and is shaped by the needs and preferences of its members.



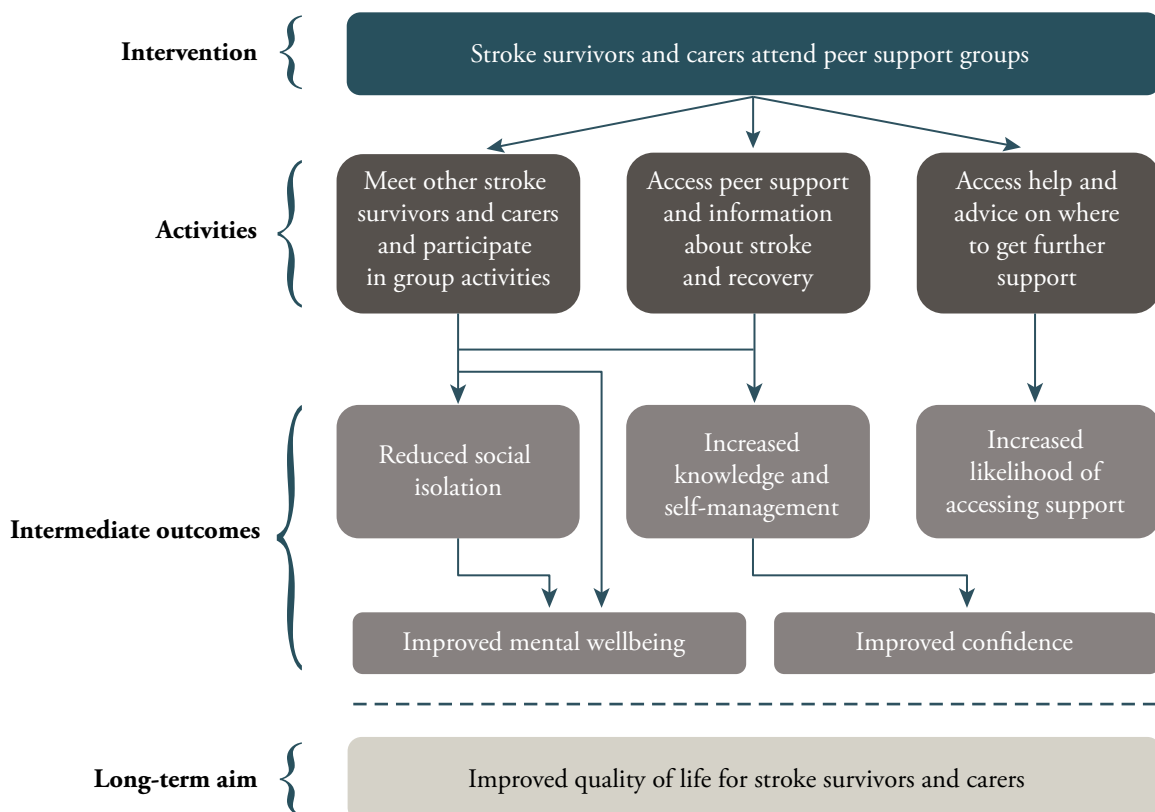
Although local groups vary in their activities and goals, the Stroke Association anticipates that the support offered by SAVGs will contribute to key outcomes for stroke survivors. These are:

- reduced social isolation
- improved mental wellbeing
- increased knowledge and self-management
- increased likelihood of accessing support
- improved confidence.

The Stroke Association also hopes that groups will contribute to positive and largely similar outcomes for carers who attend them.

Figure 1.1 provides an overview of the expected outcomes of being in a SAVG for stroke survivors and carers. These were captured in a theory of change prior to the evaluation. The evaluation subsequently considered whether these outcomes were being achieved, thereby testing the theory of change.

Figure 1.1: The activities provided by SAVGs and the expected outcomes for stroke survivors and carers



Notes: Diagram adapted and redrawn by report authors from original Stroke Association Voluntary Groups' theory of change

In 2014 the Stroke Association was awarded funding from Nesta and the Cabinet Office under the Centre for Social Action Innovation Fund's 'Long-Term Health Conditions' workstream to deliver the 'Peer Support Project'. The funding was provided in order to support the Stroke Association to increase its provision of community-based peer support for stroke survivors and their carers through SAVGs and to support groups to deliver increased – and more impactful – support by improving the training and development opportunities for volunteers (further details of this project are included in Box 1.3). Over a period of two years, the project set out to create 40 new peer support groups and to support over 100 existing groups for the benefit of more than 4,000 stroke survivors and carers (Nesta, n.d.).

### Box 1.3: What is the Peer Support Project?

The Peer Support Project was a two-year programme that was designed to increase the amount of support offered to Stroke Association Voluntary Groups (SAVGs), set up new peer support groups and fund evaluation work to look at what SAVGs do and what helps them in their work. The key areas of the project and the tasks involved are detailed below.

#### Quality improvement

- Development of a comprehensive quality framework and mapping tool to assist staff in focusing their support for Voluntary Groups to ensure the delivery of quality peer support in 101 groups.

#### New models of support

- Piloting new models of peer support in eight areas. These new models included: focusing support on physical activity and the creative arts, running groups by telephone, supporting people in their twenties and thirties, and creating groups in areas where there were no other Stroke Association services.

#### Resources and online platform

- Designing and implementing 12 new resources to assist volunteers in running clubs and groups. These included a welcome pack for new members joining a group, a communication toolkit to support people with communication difficulties and a fundraising resource pack to help SAVGs raise funds. Around 6,000 copies of these resources were distributed to groups.
- Launching an online platform for all group volunteers to connect and communicate. This platform includes 700 active users.

#### Training

- Additional training for 795 volunteers covering 470 clubs and groups. Training includes topics such as 'hidden effects of stroke', 'finance and fundraising', 'A–Z of running a group', and 'emotional impact of stroke and safeguarding'.
- Delivering the first comprehensive and at-scale 'train the trainer' programme for Stroke Association staff.
- Piloting the first Stroke Association Volunteer Trainer role, including providing training and support to the first group of volunteers in this role.

#### User engagement

- Recruiting 55 people from SAVGs to be active members of a new 'Voices in Partnership' user engagement group.

As part of the project (Box 1.3), the Stroke Association sought to independently evaluate its support for groups and to assess the value and impact of the groups for their beneficiaries. The Nuffield Trust was selected by the Stroke Association to conduct this evaluation, which began in January 2015 and ran for 18 months.

The evaluation was to focus on three strands of activity, reflecting an interest in process (exploring what it means to run and support these groups for volunteers and staff); impact (understanding the impact of groups); and learning (adding to understanding

of peer support, how to enable it, and its value to stroke survivors). The three aims of the evaluation were therefore to:

- explore how groups are delivered and supported – considering the effectiveness and value of the support given to groups
- assess the impact of support groups on stroke survivors and their carers – considering how they deliver support and the difference they make
- contribute to a better understanding of peer support for people with a long-term health condition and how peer support groups for stroke survivors and their carers can best be supported.

## Background

The charity sector's involvement in care service delivery has increased in recent years. This involvement was recognised in NHS England's Five Year Forward View (NHS England, 2014). As the health and social care system strives to improve productivity and reduce costs, the partnership between charities and statutory services is likely to play a key role in bringing about these changes.

Volunteers have been involved in providing health and social care services and support in the UK for a long time, and there is a large body of evidence that demonstrates the positive benefits of this work for volunteers themselves (Mundle and others, 2012). For example, a systematic review by Jenkinson and others (2013) found that "volunteering had favourable effects on depression, life satisfaction, wellbeing but not on physical health". A smaller number of studies have also provided evidence of the benefits for those receiving the support (Mundle and others, 2012).

It is believed that involvement in a community group has positive benefits for members – particularly in the case of older people. This is supported by a recent study conducted by Steffens and others (2016), which found that membership of social groups such as book clubs or church groups after retirement was linked with improved quality of life. This research followed recommendations from the National Institute for Health and Care Excellence (NICE) that local councils should do more to offer group activities to older people (NICE, 2015).

Peer support is one example of a volunteer-led service that is frequently offered in a community setting. Peer support is generally defined as the help and support that people with a shared lived experience can give to each other. A 2015 review conducted by Nesta and National Voices found that "peer support can help people feel more knowledgeable, confident and happy, and less isolated and alone" (Nesta and National Voices, 2015). However, the review noted that more research was needed in order to understand the impact of peer support on people with long-term health conditions.

For stroke survivors in particular there is a need for long-term support of the type a community support group could offer. Over 30 per cent of people have a persisting disability and will need long-term access to health and support services (NICE, 2013). Although the need for long-term support is well established, there is a lack of evidence regarding which types of support stroke survivors would benefit from. The 2013 NICE guidelines for stroke rehabilitation highlighted this lack of evidence on long-term health and social support for people following a stroke (NICE, 2013). To date, few studies (Kessler and others, 2014) have examined the impact of community support groups on stroke survivors.

## 2. Evaluation methods

The evaluation included qualitative and quantitative research components. A summary of the methods is shown in Table 2.1.

Table 2.1: Summary of evaluation methods

Evaluation area	Research questions	Methods	Timeline
Outcome	<ul style="list-style-type: none"> <li>What impact do SAVGs have on stroke survivors and carers?</li> </ul>	<ul style="list-style-type: none"> <li>Self-report questionnaire distributed at two time points to members of 30 SAVG groups</li> </ul>	<ul style="list-style-type: none"> <li>Data collection ran from April 2015 to June 2016</li> </ul>
		<ul style="list-style-type: none"> <li>Semi-structured interviews with stroke survivors and carers from four SAVG groups</li> </ul>	<ul style="list-style-type: none"> <li>Interviews were conducted between February 2016 and April 2016</li> </ul>
Process and learning	<ul style="list-style-type: none"> <li>What challenges do volunteers and staff face in providing peer support?</li> </ul>	<ul style="list-style-type: none"> <li>Semi-structured interviews with volunteers and staff</li> </ul>	<ul style="list-style-type: none"> <li>Interviews with volunteers and staff in June/July 2015</li> </ul>
	<ul style="list-style-type: none"> <li>What can we learn about effective peer support?</li> </ul>	<ul style="list-style-type: none"> <li>Focus groups with volunteers and staff</li> </ul>	<ul style="list-style-type: none"> <li>Focus groups were conducted in March 2016</li> </ul>

In total, the evaluation draws on the experiences and views of more than 200 stroke survivors and 100 carers from 30 local groups, as well as 20 Stroke Association staff and volunteers.

### Outcome evaluation: assessing the impact of SAVGs

We used two methods to help us assess and understand the impact of SAVGs on stroke survivors and carers. These were self-report questionnaires and semi-structured qualitative interviews.

#### Self-report questionnaire

A questionnaire was designed to collect information on a range of self-reported outcome measures (see Table 2.2). These outcome measures were selected to capture the outcomes outlined in Figure 1.1 (labelled 'intermediate outcomes').

Validated questionnaire-based measures were identified and considered for inclusion based on a literature search and consultation with experts. The following inclusion criteria were applied to select the final outcome measures:

- **Content.** Does the measure capture the outcome(s) of interest?
- **Validity.** Is the measure validated for stroke survivors or other populations with long-term health problems and their carers?

- **Practical issues for use.** How long does the measure take to complete? How many questions or items does the measure contain? Is the measure free to use, and who has to provide permission for its use?

Alongside these outcome measures, information was also collected on people's age, sex, ethnicity, their stroke and stroke recovery, and their involvement in a SAVG.

Table 2.2 summarises the measures included in the questionnaire.

Table 2.2: Self-report questionnaire measures

Outcome	Questionnaire measure*	Number of questions	Interpretation
Reduced social isolation for stroke survivors	Stroke impact scale, 'participation/role function' subscale† (Duncan and others, 2003)	8	Higher scores indicate lower perceived impact of stroke on ability to participate (scale: 0–100)
Improved mental wellbeing for stroke survivors	Short Warwick–Edinburgh mental wellbeing scale (SWEMWBS) (NHS Health Scotland and others, 2007)	7	Higher score indicates better mental wellbeing (scale: 7–35)
Increased self-management for stroke survivors and carers	Southampton stroke self-management questionnaire (SSSMQ) (Boger, 2014); specifically the 'capacity' and 'strategies' subscales	16	Higher score indicates greater self-management (scale: 9–54 and 7–42)
Improved quality of life for carers	Adult carer quality of life questionnaire (AC–QoL) (Elwick and others, 2010); specifically the 'support', 'stress' and 'satisfaction' subscales	15	Higher score indicates better quality of life (scale: 0–15)

\* Written approval was obtained from the owners of each measure for it to be used as part of this evaluation.

† This measure was used to provide an understanding of social isolation: although the measure approaches social involvement from a slightly different perspective than isolation per se, it was decided that, in combination with the other chosen measures, social experience would be adequately covered.

### Data collection

Participants were recruited from 30 SAVGs across England. Questionnaires were distributed by the Stroke Association either by post or in person to group members.

Stroke survivors were provided with a pack containing an information sheet, a questionnaire and a pre-paid envelope to return the completed questionnaire to the Nuffield Trust. The materials were designed to be accessible to stroke survivors with aphasia (communication difficulties) wherever possible; however, the use of validated scales limited the scope to develop a fully aphasia-friendly questionnaire. An additional supplementary questionnaire for completion by the stroke survivor's carers was also included. (Throughout this report, where we describe engaging with carers or consider the value of groups for carers, we are referring to unpaid carers – often a partner or family member – rather than professional paid carers, who were not the subject of this study.)

Questionnaires were distributed to stroke survivors at two time points – ‘initial’ and ‘follow-up’ – that were three months apart. The questionnaire was labelled with a unique reference number (URN) from the central Stroke Association database so that data returned to the Nuffield Trust did not contain personal information, such as the individual’s name or address. This URN could then be tracked to enable the same individual to be sent a questionnaire three months later.

A full description of how we prepared and analysed the data from completed questionnaires is included in the Appendix.

Invitations to complete a questionnaire were sent to 656 stroke survivors<sup>1</sup>. Questionnaires were completed by 246 stroke survivors<sup>2</sup> and 123 carers at the initial time point, with 115 of those stroke survivors and 57 of the carers completing a questionnaire at follow-up three months later. This gives a response rate of 37.5 per cent at the initial time point and 17.5 per cent at follow-up for stroke survivors. The drop off at follow-up was anticipated and, overall, the response rate is slightly better than other similar studies (Jenkins and others, 2012). Respondents were equally balanced in terms of gender, and ranged in age from 34 to 101 years.

Table 2.3 provides an overview of respondent characteristics.

Table 2.3: Demographics of respondents		
	Initial questionnaire	3-month follow-up questionnaire
<b>Stroke survivors</b>	246	115
Male	123 (50.0%)	59 (51.3%)
Female	123 (50.0%)	56 (48.7%)
Mean age, years (range)	68 (34–101)	68 (43–90)
Mean time since first stroke (years)	6.2	6.5
<b>Carers</b>	123	57
Male	104 (57.7% of total)	
Female	76 (42.2% of total)	
Mean age, years (range)	65 (16–90)	

#### Semi-structured interviews with stroke survivors and carers

Interviews were guided by a semi-structured framework that chiefly focused on the intended outcomes laid out in Figure 1.1. Two topic guides were developed to ensure that interviews did not become too burdensome for stroke survivors. Topic guides provide a framework for interview discussion by setting out the questions that the interviewer will ask. We reduced the duration of interviews by only covering 4 or 5 topics with each stroke survivor.

1 An additional 68 stroke survivors were included in the initial invitation but did not receive a questionnaire as they were either ill or no longer in a group. These 68 are excluded from the study.

2 An additional, small number of stroke survivors (8 at initial questionnaire and 6 at follow-up) returned a questionnaire but did not include valid demographic information (such as age or sex). They were therefore excluded from the analysis.

The topics covered were:

- experiences of having a stroke and joining a SAVG
- social isolation
- confidence
- mental wellbeing
- self-management and knowledge of stroke
- accessing support
- peer support.

Prior to the interviews, the research team undertook training in communicating with people with aphasia. Following this, a pack of aphasia-friendly images was created with support from the Stroke Association to support communication in the interview. The topic guides were piloted with a stroke survivor.

Carer interviews were also guided by a semi-structured framework. The topics covered were:

- experiences of being a carer and involvement in the group
- the role of the group in supporting carers
- impact of the group on the stroke survivor they care for.

Participants were recruited from four SAVGs selected for in-depth study. Stroke survivor interviews were conducted face to face at the time and location of a stroke survivor's usual SAVG meeting. Side rooms at these venues were used to provide privacy. Interviews were audio recorded and transcribed verbatim where possible. For stroke survivors who had communication and/or speech difficulties, interviews consisted of a mixture of verbal conversations, gestures and pictures. For these interviews, a list of topics and ideas discussed were recorded following the interview instead of a verbatim transcript.

Carer interviews were conducted over the phone at a time convenient to the carer. Interviews were audio recorded and then transcribed verbatim. One carer chose to send their answers by email.

Interviews were carried out with 11 stroke survivors and 5 carers (two of whom chose to be interviewed together). One additional interview with a stroke survivor was stopped part of the way through and their responses were not included in the analysis.

A thematic approach was used for analysing interview data. We identified themes by comparing data with the expected outcomes of the SAVGs (Figure 1.1). This analysis used the common phased approach recommended by Braun and Clarke (2006).

### **Process evaluation: Understanding what it means to run and support the groups and the value of peer support**

We conducted two activities to help us understand more about the structures and support for volunteers and to capture different perspectives on the value of support offered to SAVGs. These were semi-structured interviews and focus groups with staff and volunteers.



### Semi-structured interviews

Four SAVGs were chosen by the Stroke Association to take part in semi-structured interviews. These SAVGs were chosen because they represent different levels of development on an internal framework used by the Stroke Association. This internal framework is used by the Stroke Association to help assess and subsequently respond to the group's capacity and support needs. The interviews were conducted with group volunteers and local, regional and national Stroke Association staff.

The interview field work was conducted in June and July 2015. Nine volunteers and staff took part. The interviews were either carried out face to face at the SAVG locations when group visits were taking place, or via the telephone.

### Focus groups

Two focus groups were delivered in two different parts of the country. The two areas were chosen specifically where new groups had just been set up or where they were in the process of setting up. These areas were different from the places where the interviews took place.

The focus groups were conducted with:

- lead volunteers or volunteers with significant involvement in running a group (from five different SAVGs)
- local staff who had roles supporting these groups
- national staff.

It was felt that capturing new groups/volunteers would be of particular interest as they were likely to be experiencing different challenges to long-standing groups. The organisation of the workshops was managed by the Stroke Association.

The focus groups used a scenario approach to present common challenges for the SAVGs that had been identified early in the project. Participants discussed their experiences of common issues and solutions. These scenarios covered:

- welcoming new group members
- recruiting volunteers
- maintaining good working relationships.

The focus groups were held in March 2016 and each involved 6 or 7 participants. The groups consisted of volunteers (from five different SAVGs) and local and national staff. Both focus groups were chaired by the same moderator and were aided by one or two assistants. They took place face to face at a pre-arranged time and place. The focus groups were tape recorded (with the explicit permission of participants) and transcribed prior to analysis. Notes taken by assistants on the day and mind maps created during the focus group were all also used to support analysis.

### Project oversight

A project advisory group was set up to guide and support this evaluation, and in particular to provide the perspective of stroke survivors and carers. The group consisted of Stroke Association staff, stroke survivors and carers, and academic researchers with specific expertise in stroke research.



### 3. How do Stroke Association Voluntary Groups support people affected by stroke?

SAVGs are community-based, volunteer-led interventions (see Box 1.2). They aim to provide stroke survivors and carers with peer support by creating a space where people can be with others affected by stroke and share their knowledge and experience. In this section of the report we outline some of the key characteristics of groups, consider the support they offer, and look at how they are experienced by group members and volunteers. Our findings are drawn from our visits, interviews and group discussions with 14 different groups around the UK. These 14 groups include those who took part in interviews and focus groups as well as an additional small number of groups visited as part of the questionnaire distribution.

#### Meeting people's needs and expectations

We began each interview by asking stroke survivors to describe the journey they had been on, from their stroke, to joining the group, through to the present day. This allowed us to gather a sense of what it had been like to have a stroke and its impact on the stroke survivors' lives. For almost everyone we interviewed, it had been well over a year (most commonly several years) since they had had their stroke. People shared the various ways that their stroke had affected them, including physical disabilities (such as problems walking or with writing), emotional difficulties and problems with speech or communication. People also talked about how much their lives had changed after having a stroke, describing the things that they couldn't do and the impact it had had on them:



Your life changes completely after stroke. In fact, you're upside down, you know, but once you get used to it, the things you can do, the things you can't do... you've got to learn to manipulate and work with [it].

*(Stroke survivor)*



Before my stroke, I was active; I had a good job; I was driving all my life for forty years – I had one job for forty years seeing all kinds of people... I had a wonderful life till my stroke.

*(Stroke survivor)*

We asked people to tell us how they had come to join a group. This seemed to be specific to each group and dependent on the way that it recruited members. Some had joined soon after their stroke with group volunteers meeting them before they had left hospital. Others had been encouraged to contact the group by their hospital or physiotherapist. Another group of stroke survivors had joined much later in their

recovery, with some not knowing for years that the group existed. The majority of stroke survivors we interviewed had been attending their group for many years.

Very few people expressed clear motivations for joining the group and for almost everyone their reasoning was simply that they had been invited to join or had had the group recommended to them by a health care professional. A small number of stroke survivors interviewed mentioned they had had hesitations about joining. For some, this was related to their perceived abilities at the time: one stroke survivor in particular described their concern about joining a group when they were unable to speak. Others expected not to stay in the group, or were worried that the group members would be much older and that they might find it a sad place.

In some instances, although not always, the things that members wanted from a group were linked to individual needs. Needs that were highlighted included practical needs, such as access to community transport to attend the group, as well as stroke-specific needs, such as communication or exercise sessions during the group meetings.

### Providing a variety of support and activities

The activities that people engaged in and the things that they liked most were key discussion points. This varied by group. The biggest differences between groups occurred in those whose activities centred around regular meetings at their own venue compared with groups that organised more frequent visits to external locations. Conversations with volunteers and group members revealed that this was determined by the characteristics of people in each group – for example age and mobility of stroke survivors – and also by what group members wanted, what volunteers wanted and the level of funding available. Here, one stroke survivor describes the activities they did in their group:



They do painting, keep fit... I love jigsaw puzzles, they do lots of board games, the table top games; and we do flower arranging and all sorts, we've had music sessions and people come in and do music with us. As I say, there's a lot.

*(Stroke survivor)*

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Volunteers and staff consistently stated across the interviews that a group should offer the type of support its members wanted:



The key thing is that they provide the right kind of support for the stroke survivors in their group and... everyone is different.

*(Stroke Association staff member)*

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Staff members encouraged groups to undertake different activities, and the presence of a wide range of activities was viewed by staff as an indicator of an effective group:



If [we] have people who have aphasia within the group, we do encourage activities that help specifically support and improve them in their stroke recovery.

*(Stroke Association staff member)*

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It was also recognised that group benefits extended beyond merely providing activities and that, ultimately, a group may still be meeting members' needs if it served a predominantly social function for stroke survivors and carers. This was frequently referred to as a 'traditional stroke group' by staff. The importance of the social function of the groups for members was highlighted by a number of the volunteers interviewed:

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“ With some people, especially those who are living on their own, it's the only time that they actually do socialise with anyone else: we have one lady who says it's the only day in the week that she goes out and she looks forward to it all week. And with others who aren't on their own I think it's just socialising generally and being with other people who have had the same experience.

*(Stroke Association volunteer)*

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### Providing structures and support for volunteers

Although the groups are commonly supported by a group of volunteers, different formal roles and responsibilities exist for volunteers. We observed variation among the groups, particularly in terms of leadership. Some groups had a 'lead volunteer', while others were more reliant on a committee of volunteers. There were mixed messages across the interviews regarding the value of a strong chairperson or lead volunteer versus the role of a broader committee with shared responsibilities. A number of the staff interviewed talked about how having a full committee with well-defined roles was important for groups to be effective. One person suggested that, as well as encouraging more democratic decision-making, if tasks were shared, it could minimise the burden placed on specific volunteers:

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“ So what we say as a core is that you would have a treasurer, a chair and a secretary of a group, and then you would have additional volunteers who would go on the day and support daily activities, but the ones that are most effective or the ones that work the best are where you have quite a few volunteers who have specific tasks.

*(Stroke Association staff member)*

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These 'specific tasks' could include roles such as group treasurer, secretary or first aider.

Another issue that was often discussed in the context of volunteer roles was how sustainable groups could be, that is, whether they would be able to stay operational over time. The impact of the SAVG chairperson on group sustainability was commonly mentioned by interviewees. Despite the perceived importance of the group chairperson from a sustainability perspective, though, the influence of the group chairperson on the way that the groups ran was not always seen as positive:

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“ Although there's always that structure of having a chair or an organiser, you want them not to be the person making all the decisions and in control of everything.

*(Stroke Association staff member)*

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At times, a more dominating chairperson was seen as a barrier to the groups' evolution, with the chair's interpretation of the needs of the group being prioritised ahead of the actual needs of the group. One example given was when a member suggested a new activity, the chairperson might say no, based on what they thought the wider group wanted.

The impact of the group chairperson and committee was also discussed in terms of the effect they could have on group cohesiveness: one interviewee highlighted how important it was for members to feel it was "their group". If the feeling of community was not apparent, it could lead to people not returning to the group.

Although shared responsibility was thought to be essential, many discussed the difficulties inherent in making it work in practice – particularly the reluctance of volunteers to take on more responsibilities:



It's not that we don't want to delegate; some people say it's because you're not happy to give other people jobs, but that's not it at all. All our members, because they are older, our volunteers, there is not a role that they want to take on.

*(Stroke Association volunteer)*

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## 4. What is the value and impact of Stroke Association Voluntary Groups on stroke survivors and carers?

### Experiences and outcomes for stroke survivors

#### Reduced social isolation

For many of the stroke survivors we interviewed, having a stroke had been an isolating event. In particular, people felt that they had lost friendships and the reasons were often linked to those around them either not understanding stroke or not being able to adapt to the changes it had created. This was especially true for one younger stroke survivor:



Maybe I don't do what [my friends] used to do: I don't drive so you lose a lot of people through that. I don't drink so you lose loads of people through that.

*(Stroke survivor)*

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Others also noted how having a stroke had led to a loss of independence, particularly through having to give up work or driving, and that this in turn had had an impact on people being able to access the relationships and networks they had before. Although people frequently reported losing friendships after stroke, many mentioned that they still relied on close relationships with their family for support.

Joining a SAVG represented a turning point for many stroke survivors in terms of isolation and in being able to access social networks. Overwhelmingly, stroke survivors saw the social aspect of SAVGs as the main purpose of the groups, and this was often their primary reason for attending:



I suppose it's like a social gathering; that's what it is, really – a social gathering for us all... I just like being with people... They're just like your best group of friends.

*(Stroke survivor)*



It's just like a social event. It gets me out, [we] have a laugh. I'll have little chats with the people out there.

*(Stroke survivor)*

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Interviewees described how it gave them an opportunity to spend time with others and a route back to having a social life. In particular, people felt that their group was a place where they could 'have a laugh' and make friends.

However, a couple of interviewees (younger stroke survivors) felt they were different to others in the group, and would not necessarily have chosen to spend time with them, although they were able to see the positives:



It's a bit formal. I wouldn't choose these people but I make the most of it.

*(Stroke survivor)*

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Others acknowledged that building relationships in a group takes time regardless of the type of group:



You need to come to a few meetings to get almost accepted I suppose, but if you're prepared to put some time and effort into it, like with any group, you know, you'll get something out of it.

*(Stroke survivor)*

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Feelings of isolation beyond the group were highlighted as an ongoing issue for many. Stroke survivors frequently reported that attending the group was their "lifeline to get out of the house" or their way of not being "stuck in their four walls at home". For many, this was the only time of the week that they left their home and were able to spend quality time with other people.

Since reducing social isolation is a key ambition of the groups, this was one area we attempted to explore further in the questionnaire. In order to do this, we used the participation subscale of the stroke impact scale (Duncan and others, 2003). The subscale asks stroke survivors how, over the previous four weeks, their stroke has affected their ability to participate in the activities they usually do, things that are meaningful to them, and the things that helped them find a purpose in life over the previous four weeks. Each stroke survivor was invited to complete these questions at two time points, three months apart, so we could measure change over time.

Overall, when combining both time points, stroke survivors had an average score of 49.7 (95% confidence interval 47.0 to 52.3) of the participation subscale. The scale ranges from 0 to 100, with higher scores indicating a lower perceived impact of stroke on one's ability to participate. This score is generally lower than other studies that have used this scale (Duncan and others, 2002; Guidetti and others, 2014; Huang and others, 2010), which suggests that people in the groups felt that stroke was having a greater impact on their ability to participate. However, there were clear differences between our cohort characteristics and those of the other studies, which makes it difficult to draw conclusions: for example, Duncan and others (2002) evaluated the use of this measure in 287 stroke survivors and found the mean score of the subscale to be 58.9. Although this is higher than our finding, that study looked at stroke survivors within 28 days of their stroke, and the cohort had a mean age of 72.6 years. For our cohort the average time since stroke was 6 years and the mean age was 68 years.

The mean score of the subscale at the initial questionnaire was 49.3 (95% confidence interval 46.4 to 52.2) and 49.6 (95% confidence interval 45.6 to 53.6) at the three-month follow-up. This shows a very slight increase, but this difference is not statistically significant (see Figure A5).

#### Increased confidence

Confidence was a topic that was frequently discussed in the interviews. When asked, all of the stroke survivors felt that having a stroke had affected their confidence in a negative way. People often mentioned this in relation to coping with lots of new and different challenges following their stroke:

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“ Of course, with stroke you can't see it... I'm clumsy, I drop things, knock things over and all that sort of thing... you know, it destroys your confidence. (Stroke survivor)

“ I just, basically, sat there with a cup of tea and [my husband] did all the talking because I suppose my bit of confidence had gone from having a job for 17 years to doing nothing. And I think it took all my confidence away. (Stroke survivor)

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The groups provide many practical opportunities for people to improve and build confidence. The opportunity to become a group volunteer was mentioned by a few as a great way to build one's own confidence as it allowed people to take on extra responsibilities and to try new things. Many of the stroke survivors we interviewed identified themselves as having an additional role (although not necessarily formal) within the group, such as running the raffle or helping with the tea and coffee. Some reflected that these opportunities gave them a way to regain confidence to do things they had done previously:

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“ I think the most, in terms of helping me... in my job pre-stroke [I] was involved in doing presentations... we had to do a five minute presentation to a local group and I was absolutely petrified about doing it, but I did it and we got the funding, so that's in one respect how it's helped me to overcome those sorts of fears of standing up and talking in front of a group of people. (Stroke survivor)

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For others it was the overall atmosphere and culture of the groups that they felt improved confidence. People talked about the group being a place where they could feel safe and with the acknowledgement that they could 'go at their own pace', without pressure. One person in particular felt the confidence they had gained in the group had a positive impact on their life outside of the group:

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“ Well, as I say, coming to the group, I'm more outgoing. I don't feel as embarrassed as I did when I was in the wheelchair. Coming to this group, I'm up and down to the shops now, from the home. And before, I never did that. I was just sitting in the home and wait[ing] till someone else goes down the shops. But now I've got the confidence: put my coat on, off I go, down the shops.

*(Stroke survivor)*

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### Improved mental wellbeing

Since one key intended outcome for the groups is to improve stroke survivors' mental wellbeing, we asked those interviewed about their mental wellbeing and whether the group made a difference to this. Those interviewed consistently highlighted the impact that having a stroke had had on their emotions, with many feeling they were much more emotional and much less able to control their emotions following their stroke. This was felt to be quite a character change for some:

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“ I do find myself after my stroke, I get very, you know, emotional. That comes with the stroke. I wasn't like it before.

*(Stroke survivor)*

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Some described their struggle to accept what had happened to them as a result of stroke and the changes it had caused. Many acknowledged that the period immediately following their stroke was their lowest point:

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“ What happened was I blamed everyone and I accused everyone... I was so down. When I was in hospital, I didn't want to get out of bed or do nothing. I was so down. I was in a dark place.

*(Stroke survivor)*

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Despite the progress made in some areas of the stroke survivors' lives, issues related to mental wellbeing were still ongoing. Depression was commonly mentioned, and some of the interviewees noted that they had been on, or were still on, antidepressants. Many explained how they were coping with the loss of the life and the person they were before their stroke. Alongside the more obvious physical and mental changes stroke survivors mentioned, we observed that people were often facing more subtle changes, particularly in their familial/societal roles. This was frequently mentioned in the context of people having to give up driving:

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“ You get very depressed because you can't do things the way you used to. I found that I couldn't drive, which was the biggest blow of all really, because it stopped me from getting out anywhere.

*(Stroke survivor)*

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Some of the men we interviewed in particular felt that by having to give up driving they had lost a way they could 'take care of' their partners. They noted that this had affected the contribution they made in that relationship and the independence they had previously had as a couple.

Generally, people felt that attending a group had had a positive impact on their mental wellbeing. Some recognised that the group allowed a space for people to tackle the ongoing 'ups and downs' that followed a stroke, in particular the heightened emotions experienced by many. People paid tribute to the atmosphere the group had created and that it made them feel better. One stroke survivor describes what the group gave them as follows:

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“ Oh, self-respect for a start – I feel differently when I come [here], like I'm undergoing change, I look differently in my clothes. I don't feel so old fashioned like some people are... My life has turned around, coming here; I try to do my best. Otherwise I'm very happy, very happy.

*(Stroke survivor)*

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As well as using interviews, we also collected information on people's perceived feelings of mental wellbeing using the short Warwick–Edinburgh mental wellbeing scale (SWEMWBS). For this measure, higher scores indicate greater feelings of mental wellbeing and scores range from 7 to 35. Again, this information was captured at two time points to detect any change over time.

Overall, the average score for all respondents was 21.6 (95% confidence interval 21.1 to 22.1). This is lower than the general population when compared with the national mean score of 23.6 captured in the Health Survey for England in 2011 (Health and Social Care Information Centre, 2011). The mean score at the initial survey was 21.5 (95% confidence interval 21.0 to 22.0) and was the same at 21.5 (95% confidence interval 20.8 to 22.2) at the three-month follow-up. This change is not statistically significant.

#### Increased self-management and knowledge of stroke

In a pilot phase of interviews we found 'self-management' to be a difficult topic to discuss, and this reflects observations made by others (Boger and others, 2015). For the purposes of these interviews, we asked people how they felt about looking after themselves and how in control they felt of their own health and recovery. We also used some examples to provide context to these questions where appropriate. These included support with getting washed and dressed, taking medication or trying to stay healthy.

The majority of people we interviewed felt that they were able to take care of themselves and needed little support from others. Some talked about the need for support in the early stages of recovery, but felt they were able to take care of themselves without much support later on.

People reported that the group provided ways for some to regain practical skills or functioning through learning and activities. Most commonly, the group had helped people with their writing, computer skills and with regaining their speech:



I couldn't speak really, not like this. If I take my time I'm all right, but coming here has made me talk with different people and that's how I've learnt how to talk again. Very slowly...

*(Stroke survivor)*

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A couple of interviewees mentioned how the group had helped them to understand more about stroke. However, the majority of people we asked struggled to recall or remember things related to knowledge or information since it had been a long time since their stroke for the majority of interviewees. When discussing this, we also observed that people found it challenging to untangle 'the group' from statutory services and wider support from the Stroke Association. However, one person did feel that coming to the group had given them a better understanding of stroke:



I didn't realise there were so many different types of stroke people, whether it's disabled ones like myself – which is paralysed down the left side or the right – but there's also aphasia, which I intend to learn more about, because if I can understand what happens to that type of person, then I can understand other people in the community and also in the whole country.

*(Stroke survivor)*

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Feelings about self-management were also captured in the questionnaire using two sets of questions about capacity to self-manage and strategies to self-manage from the Southampton stroke self-management questionnaire (SSSMQ) (Boger, 2014). Scores range from 9 to 54 for 'capacity' and 7 to 42 for 'strategy'. Higher scores in each case indicate greater feelings of self-management in these areas. As with other measures, scores were captured at two time points.

For capacity to self-manage, the overall average score was 32.0 (95% confidence interval 31.4 to 32.7) and for strategies to self-manage the score was 31.2 (95% confidence interval 30.1 to 32.3). For questions related to capacity, the mean score at the initial questionnaire was 31.7 (95% confidence interval 31.0 to 32.5) and at three months it was 32.6 (95% confidence interval 31.5 to 33.6). This difference was not statistically significant.

Similarly, for questions related to strategy, the mean score was 30.9 (95% confidence interval 29.7 to 32.0) in the first survey and 30.6 (95% confidence interval 29.2 to 32.0) at follow-up. Again, this difference is not statistically significant (see Figures A7 and A8 in Appendix). This evaluation is the first study to use these subscales in isolation and we are therefore unable to make comparisons with other research.

### Increased likelihood of accessing support

Another topic that we were keen to capture in the interviews was whether people felt the groups had helped them to access support from other organisations external to the group. Initially, we asked about the support people had received following their stroke. Stroke survivors frequently discussed the support they had received in hospital immediately following stroke in a positive light. However, many noted that they were lacking in long-term support, particularly from statutory services:

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“ I think the thing about the help that you get is there seems to be a two-year maximum time period, certainly from the health professionals, and at the end of that you're out. (Stroke survivor)

“ I find that I don't like the aftercare we get from doctors and hospitals, it's almost as though they've done their bit and that's it. (Stroke survivor)

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Although people generally felt supported by the groups, they didn't necessarily see the group as a way to access other types of support or services. A couple of people also noted that they had received support from the Stroke Association but not from the group per se.

For many, coping with the impact of emotional and physical changes was still ongoing and there were clearly areas where it was felt that they would still benefit from support. Although people said they would like more support, they didn't necessarily feel that this should come from the group.

### Other reflections

To end the interviews, we asked people what advice they would have for people who had been through a situation similar to their own and about whether they should join a group:

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“ Oh yes, definitely come to the group: if you are any worse off than me, try and get another group, same type of thing but they might do different things to help you but for God's sake don't stop coming, you must come, come to these groups because they are excellent. Really for anybody. (Stroke survivor)

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Others responded to this question by describing the group's impact on their own lives:

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“ The Stroke Association and this group gave me my life back. My family gave me my life back. And things are better now. (Stroke survivor)

“ You need structure when you've had your life disrupted like that, and I found that coming here. (Stroke survivor)

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## The experiences and outcomes of carers

### Improved mental wellbeing

When we discussed the broad impact of the groups with carers, the change emphasised above all others was the positive effect on emotional health and mental wellbeing, for the carers themselves and the person they cared for. Specifically, carers felt that peer interaction gave them a better understanding of how to cope. All carers were keen to highlight the upheaval caused by stroke and the initial feelings of being stuck or isolated, not knowing how to move forward. A typical comment from carers was that stroke had “turned their life upside down”.

One carer described getting advice on how to cope with issues related to mental wellbeing as a motivation for accessing the group:



[The stroke survivor] won't take anti-depressants, but he had bad days, you know. I thought it would be helpful to meet people in the same situation and grasp any information about dealing with things better.

(Carer)

Carers linked improvements in their own mental wellbeing to the friendly atmosphere they found at the group. This was seen as a welcome alternative to more serious and focused interactions with care providers. One carer described a previous experience of seeing a psychologist as “patronising”, and compared this with the more positive experience of interacting with others who have real-life experiences in line with her own. The “light” nature and sense of humour of groups were particularly valued as a coping mechanism for carers.



It's refreshing when you go there. You have a laugh. It's light. It's kept light.

(Carer)

Seeing success stories, such as people who have survived and recovered from stroke, gave carers a “morale boost”, about their own situation and future. Volunteers and group leaders in particular, who were themselves often stroke survivors, were perceived to be role models in this way.

### Increased enjoyment due to stroke survivor recovery

Alongside improvements in mental wellbeing, carers perceived the groups to be a setting where stroke survivors could improve and develop new skills. They often spoke about people being able to “practise” speaking, listening and physical functioning in a way that wasn't possible at home. In this respect the groups were also viewed favourably over more formal speech therapy support, which tended to be shorter – “just one hour a week” in one case.

Groups were also seen as a more “natural” environment for recovery where several different people had the opportunity to interact together, rather than the one-to-one nature offered by more formal care. For carers, understanding that the group was a place where their relatives were making significant steps to recovery was integral to their own enjoyment of the group.

### Increased access to knowledge, information and support

Although the formal training opportunities on offer to carers themselves varied between groups, many carers spoke about going to the groups in order to gain knowledge that might help them in their day-to-day life. One person who cared for her husband explained that she enjoyed listening to local speakers who were invited to the group, especially when she learned about new services and opportunities, such as in a talk by a police officer.

One carer highlighted the lack of support services on offer to people who had had a stroke and their families. In this context the groups were seen as an important “lifeline” and “the only way you can meet other people in the same position as yourself”. The local networks and communities formed within groups were also appreciated by carers as a source of practical and emotional support when transitioning away from statutory services.

Most of the carers interviewed spoke of home visits and professional support that lasted up to 10 weeks after hospital discharge. It was felt that groups filled some of the gaps left when people felt their formal care had become less frequent. Many of the carers we spoke to felt that the support offered by these peer networks moved beyond the scope of formal care in terms of its benefits – for instance, volunteers helping each other with transport or providing more effective emotional support.

### Measuring support, stress and satisfaction

Using the carer questionnaire, we collected information on carers' perceived quality of life using three subscales from the adult carer quality of life (AC-QoL) questionnaire. The questions asked carers how they felt about the support they received, their stress levels and their satisfaction in their caring role. The number of carer responses was relatively low and so we were restricted in the analysis we were able to conduct; in particular, we were not able to compare how these scores changed over time. Each subscale ranges from 0 to 11+. For these subscales, scores less than 5 indicate a lower reported quality of life for that issue and may suggest problems or difficulties; scores between 6 and 10 indicate a mid-range reported quality of life; and higher scores (11+) indicate a higher quality of life.

We found that the overall mean scores for support for caring was 6.4 (95% confidence interval 5.7 to 7.1). For caring stress, it was 10.2 (95% confidence interval 9.7 to 10.8) and for carer satisfaction was 10.6 (95% confidence interval 10.1 to 11.0) (full details, including the number of respondents and standard deviations, are available in the Appendix).

## 5. What can we learn about peer support from Stroke Association Voluntary Groups?

A valued aspect of SAVGs is that they offer peer support. This means that the majority of the volunteers and other group members have shared similar experiences to each other – most commonly either having had a stroke or having cared for someone who has experienced a stroke. We were keen to understand more about peer support and what, if any, difference this aspect of SAVGs made to the overall impact of the groups for stroke survivors and their carers.

### Peer support provides positive benefits

All the stroke survivors we interviewed reported that 'peer support' had a positive benefit for them and felt it made a real difference. In one way, having a shared experience meant that the group provided a 'safe space' where people understood what they were going through with no judgement:



You understand what people have been through and [are] perhaps more, as I said, sympathetic, so that if somebody stands up and walks up, walks off whilst you're in the middle of a conversation with them, you don't think 'Well how rude is that?', because you accept that sometimes it's maybe how the stroke has affected them... I think coming to the group helps with that because you're then in another environment where people understand what you've been through and the impact that it's had on you.

*(Stroke survivor)*

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For others, it meant they were not alone and could be with other people similar to themselves. One stroke survivor in particular expressed how reassuring it was to be with other people who couldn't speak. A volunteer describes the commonality of understanding of the different ways people had been affected by stroke:



They know that their [stroke] isn't worse than anybody else's. One new lady who came showed us her card that said 'I'm sorry, I've had a stroke, I can't speak', and you're kind of like 'Yes, that's fine, we all can't speak, we're all doing various amounts of gesture and sign and having to repeat a lot and having to wait a lot'.

*(Stroke Association volunteer)*

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Some members felt that this shared understanding meant that they weren't pushed too far:

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“ It helps being with other people who have been through similar experience. It's helped me a lot, speech-wise and communicating. Again, people don't try and push you too far. 'Cause sometimes you can go a bit too fast...

*(Stroke survivor)*

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Frequently, those interviewed reported that 'peer support' gave them a more positive impression of their own recovery. People commonly reflected on how lucky they felt they were and that being around others made them grateful for the things they had not lost following stroke – for example retaining their speech or mobility. There was also an additional benefit for some as the groups gave them an opportunity to help others:

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“ It makes a big difference in myself because when I see them, some of these young girls, there's...one girl there, she comes, you know, kind of a Zimmer frame, that's why it's upsetting, but I'm glad I come to see her because there are people here worse off than me and those are the people I try to help as well – just to talk to them and get their response, it is overwhelming.

*(Stroke survivor)*

“ Some of them are worse off than me. I was lucky, wasn't I? I had all the support, me brother and sister, so they came and got me out of the hospital and back home.

*(Stroke survivor)*

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Carers were particularly expressive about the benefits of peer support for them and for the person they were caring for. They said that the opportunity to meet a group or community affected by stroke was useful to them. Seeing this variation among people experiencing stroke recovery gave an important context for carers to understanding their own situation and emotions:

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“ Some people get really angry, there's a whole range of emotions. Not everyone is the same as you, but you get to see the range.

*(Carer)*

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Interestingly, carers tended to speak about their most valued learning coming directly from their peers:

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“ You get to see other people from all walks of life and how they just get on with life and everyone understands.

*(Carer)*

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Having been asked what they had learned at the group, another carer's response again suggested that it is the perspective on other people's lives that is the most powerful part of the group experience:



It's been brought to me rather unexpectedly that we've been very lucky and it could have been a lot worse. I see that every Tuesday when I go to [the group]. It's made [me] appreciate life.

(Carer)

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### Peer support needs to be offered at the appropriate point of recovery

Although most stroke survivors and carers reported a very positive experience of peer support, there were some comments from staff and volunteers about scenarios where peer support may not be appropriate, with this perceived to be mainly down to timing. It was felt that, for some stroke survivors, in the immediate aftermath of a stroke it could be too soon for them to attend a support group since they could be experiencing strong emotions and anger.



## 6. What challenges do Stroke Association Voluntary Groups face and what are the possible solutions?

Throughout this evaluation a number of challenges for groups were identified. These were initially evident in the early interviews with volunteers and staff but their importance was reinforced through informal conversations at groups and in interviews with stroke survivors.

These challenges fell under the following broad headings:

- welcoming new group members
- recruiting new group members
- recruiting volunteers
- training for volunteers
- pressures facing lead volunteers
- maintaining working relationships
- providing staff resources
- sustainable funding
- varying needs of stroke survivors.

The decision was made that the focus groups held with volunteers and staff towards the end of the project would centre on these topics and possible solutions. We cover each of these topics in turn in what follows by describing the issues more fully, then sharing the solutions offered by staff and volunteers.

### Welcoming new group members

The point at which a stroke survivor joins a group was considered to be a challenging time, and a point at which potential new members were often lost. It was felt that welcoming new members in the right way could lead to people getting the greatest benefit from the groups and could set the tone for their time in the group. Volunteers and staff discussed the different ways in which they welcome new group members. These discussions revealed some practical solutions, which are outlined in Box 6.1.

### Box 6.1: Volunteer and staff suggestions for ways to welcome new group members

- The lead volunteer could meet one-on-one with the stroke survivor before meeting the rest of the group to build relationships – a home visit would be most useful.
- The lead volunteer could build relationships with stroke survivors on the phone before attending the group.
- A stroke survivor could bring someone – such as a family member or carer – along to their first few meetings.
- A stroke survivor could introduce themselves to the group and explain a bit about themselves at their first meeting.
- The lead volunteer could introduce the new member at the start of a meeting.
- Groups could establish a buddy system, where a new member is partnered up with a long-standing group member.
- Groups could have a new member's corner (particularly for larger groups) where new members sit together.
- Groups could make use of the Stroke Association 'Welcome Pack'.
- Groups could set aside the first meeting of every month for new members only.
- Groups could offer a transport service where an existing group member brings a new member to the group.

In the context of welcoming new members, people felt that, in order to properly include someone into the group, they needed to have a clear idea of that person's needs and to understand their expectations of the group. In learning about this, it was felt that sometimes, either by choice of the group volunteers or the potential new member, that joining that group may not be the best fit:



There was a lady wanting to do very much more active things – my group is more passive... it wasn't quite for her because she wanted more active things.

*(Stroke Association volunteer)*

Capturing feedback on how groups were meeting people's needs and expectations was seen as a useful ongoing process. Some suggested that an annual questionnaire to a group's members was a good way to capture feedback and would allow people to make anonymous suggestions. Staff and volunteers also felt that it was important to understand why people chose not to join the groups at the start. It was felt that telephone conversations may be a way of learning about this.

#### Recruiting new group members

Successfully accessing and recruiting new members – primarily stroke survivors – frequently came up as a key concern. It was clear that this was one of the biggest challenges facing the groups, and the issue was raised by volunteers, staff and stroke survivors alike. Many felt that there were people in the community needing help or who would benefit from group support but were missing out. In particular, it was felt that capturing people when they were still in hospital was key:



We're all battling to talk to people and get them [to] become members and make the group successful, but we're still failing in getting to the people at the time they need, [reaching] the stroke survivors when they're in hospital or just coming out of hospital.

*(Stroke Association volunteer)*

Volunteers and staff offered some suggestions on ways to recruit new stroke survivors to the groups. Some felt that they could be active themselves in recruitment by going out into the community or on to hospital wards to raise awareness of the groups by doing talks, sharing posters and leaflets, and meeting people. Others felt the link to statutory services and health care professionals was essential. For some local areas the link to services acted as a barrier. In particular, some noted that the handover time from a professional service to a group did not work well and that many potential new members could be “lost in transition”.

Other barriers to stroke survivors joining a group included people being unable to access support with transport or finding it hard to access the group's venue.

### Recruiting volunteers

Another aspect that groups were often concerned with was having enough volunteers to support a group. When staff and volunteers were asked about ways groups could recruit new volunteers, it was overwhelmingly felt that encouraging group members to evolve into volunteers was the best starting point, and one that could have huge benefits for all those involved. It was felt that developing group members in this way could also allow the volunteer to develop skills, particularly for those wanting to return to work.

Alongside developing members into volunteers, staff and volunteers suggested several other ways to recruit volunteers. These are outlined in Box 6.2.

#### Box 6.2: Volunteer and staff suggestions for ways to recruit volunteers

- Attend volunteer fairs in order to attract people interested in volunteering.
- Target free publications that advertise for volunteers.
- Tap into volunteer centres and build links with Rotary International in Great Britain and Ireland (an organisation that links up volunteers with community projects).
- Use universities to recruit students, particularly those with an interest in stroke, studying speech and language therapy, social work or psychology.
- Give talks at companies or organisations that have part-time workers to build relationships and to showcase the work of the group.
- Access the University of the Third Age (an organisation that provides opportunities for retired or semi-retired people).
- Ask people you know to volunteer for you.

There were frequent discussions about the skill mix and the balance of volunteers' experience in a group. There were some disagreements in what people felt was necessary to make a 'good' volunteer. Some felt that the volunteer needed to have an understanding of stroke and, therefore, a personal experience of stroke. Others felt that this perspective was important, but that groups worked well with a balance of volunteers, which would include those who were not stroke survivors. For instance, some noted that groups needed volunteers to help with practical things such as lifting tables or helping people into the building and that stroke survivors may not always be able to do this.

There was also a difference of opinion regarding the number of volunteers a group needed. Some felt there were too many 'general volunteers' without specific roles, but one volunteer believed having a larger pool of volunteers was essential:



You need the volunteers. I personally feel the more volunteers you have the better because there's going to be times when people don't turn up.

*(Stroke Association volunteer)*

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For most, though, the issue came down to having clear roles and responsibilities delegated properly. Some of those asked didn't feel that they were doing this effectively and were looking to the Stroke Association for more support. Staff highlighted how important it was to be clear about the type of volunteer role needed in order to successfully recruit for a post that would meet the group's needs.

### Training for volunteers

One key way that the Stroke Association aimed to support the groups was to offer support and training to volunteers. This training ranged from understanding more about stroke and its impact to improving practical skills, for example in running a group.

Staff felt that enabling volunteers to meaningfully access and use the training was key to the successful future of the groups. Staff and volunteers discussed some of the barriers people experienced in attending training. Common reasons included travel limitations (particularly in rural locations) as well as the time commitment required for training alongside other responsibilities. In addition, some volunteers did not feel the training was relevant to them or had not been told about the training. It was felt that overcoming these challenges seemed likely to stem from clear communication between staff and the group, and achieving effective integration between groups and the Stroke Association.

Alongside these barriers, people also raised concerns about how the training, taken in isolation, could be limited in its impact:

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The majority of the volunteers are stroke survivors, so still even after doing the training we'll come back and want to clarify things, so they might do the risk assessment training, but then when they come to do a risk assessment they've forgotten what they have to do, so it's important for us to still support that and make sure they do it still independently, but just giving them a little bit more confidence.

*(Stroke Association staff member)*

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### Pressures facing lead volunteers

The clear demands of holding a committee post (particularly a chairperson/lead volunteer) were highlighted by both staff and volunteers. Several factors were mentioned, such as the time commitment, the range of activities that had to be undertaken, and the pressures of paperwork. It was felt that others were not always fully aware of the commitments lead volunteers were subject to.



Some people don't really understand that there is more than 'Oh I just run a group on a Monday and have a coffee for a couple of hours', there's an awful lot more that you need to do to make your group more successful and for people to want to continue to come to that group.

*(Stroke Association volunteer)*

In some groups the chairperson was seen as integral to ongoing success because of the amount of work they did to keep the group operational. This often meant that some groups remained with the same chairperson and key committee members for many years. In a number of instances, the potential loss of the chairperson was seen as a real threat to the group's ongoing future.

Another concern raised in the focus groups was that the nature of the lead volunteer role meant they were often "stuck in the middle" between group members and the Stroke Association. This could leave them feeling under pressure as they tried to manage different expectations regarding their role.

### Maintaining working relationships

It was clear that the groups involved many different relationships, including links between members (stroke survivors and carers), volunteers and staff. Having good working relationships was therefore seen as essential to the successful running and future of the groups.

Many volunteers described various tensions and conflicts they had come across in their time in the groups. Some felt that tensions often arose due to "a mismatch in expectations and what is possible". This was particularly seen to be the case in terms of group members' expectations. Others felt that the reasons for tensions could simply be down to different personalities. It was also mentioned that the way stroke had affected people could have an impact on their interactions within the group, either for members or volunteers, and that this in turn could lead to conflicts.

Staff and volunteers discussed possible ways of dealing with conflicts in the groups. These are outlined in Box 6.3.

#### Box 6.3: Volunteer and staff suggestions for ways to resolve conflict or tension in the groups

- Understand reasons for conflict and context
- Start informally: talk to the person you're having difficulties with
- Use a third party/bring in an outsider
- Volunteers can go 'higher up' if needed – to their line manager/staff member
- Ask a volunteer committee to back up lead volunteers
- Put things to a group vote
- Compromise – try things once every few meetings
- Use the Members' Charter to manage group member behaviour and expectations
- Other solutions – Consider whether the group is the wrong place for someone (either a member or a volunteer)

It was clear from staff and volunteers that the Stroke Association as an organisation had a role to play in fostering good relationships. This was particularly noted in the context of group setup, but also at times of change. One staff member noted the importance of starting groups off “on the right foot” to ensure everyone understood where responsibilities lay and where support came from in the organisation. It was clear that good communication was essential to maintaining these relationships.

### Providing staff resources

Interviews with staff highlighted a number of issues relating to pressures experienced in the job that had an impact on their dealings with the groups. There was some concern over how effectively staff felt they were able to support groups given the number of groups they were responsible for in addition to other aspects of their role:



They have no understanding of all the other things the service coordinator is doing. I've been in situations where people have said 'I only see [them] once a week and it takes three days to call back', and they think 'What are [they] doing?', and they have no concept that that poor coordinator is charging round the borough trying to do 15,000 things at once.

*(Stroke Association volunteer)*

The implications of such pressures on staff were acknowledged in that, ultimately, some groups received more support than others. One staff member mentioned that, in some instances, this prioritisation occurred as a result of how vocal different groups were:



We quite often get caught in the trap of 'those who shout the loudest get the most attention'.

*(Stroke Association staff member)*

Due to their limited capacity, staff had to rely predominantly on remote communication to keep in contact with groups, but many staff (as well as volunteers) said that more in-person visits would be helpful. The majority of staff interviewed (from a total of six staff) said that it would be helpful to have a full-time job role focused on supporting the groups. This was thought to be particularly important in areas with a higher number of groups.

### Sustainable funding

Volunteers and staff also faced the ongoing challenge of achieving sustainable funding for the groups, and this topic arose a number of times. It was clear that the volunteers felt very responsible for sourcing this support for their groups, expressing particular concern over how to cover the cost of the venues they use. As mentioned previously, paying for transport for group members also came up as a funding worry.

### Varying needs of stroke survivors

Stroke survivors' varying ages also posed a challenge, since people at different stages of life may want and/or need different things from the group. For example, some younger stroke survivors recognised that they felt different from older group members, either

in their needs or experience. In particular, we observed through the interviews and informal conversations that younger stroke survivors mentioned particular goals and aspirations for their recovery that were not mentioned in interviews with older stroke survivors. These goals included things such as being able to return to work, to support their families/children more and to improve their mobility. Here, one younger stroke survivor describes this ambition:



As I say, that's my main aim: is to get out of this chair and walk. I'd love to get off the bus here and walk in when it's all packed like that, I know everyone will stop. It'll be a crowd-stopper sort of thing, everyone stopping and looking. But that's what I want to do is just walk.

*(Stroke survivor)*

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Meanwhile, older stroke survivors reflected that they were dealing with more common issues associated with old age alongside their stroke. This was also frequently acknowledged in conversations by group volunteers, particularly in terms of the need to support people with their hearing and balance.

A smaller group of interviewees highlighted that they were dealing with other health needs (not connected to age) alongside their stroke. For some, this was unconnected to the stroke and was related to medication for other conditions, such as diabetes, but for others it was more closely related to their stroke – for example brain tumours. It was clear this small group were facing additional challenges that could add additional complications to the support they wanted from the group.



## 7. Reflections on this evaluation

In order to understand the value and impact of SAVGs for those who attend them, we analysed findings from interviews with stroke survivors and carers alongside results from a self-report questionnaire. We also drew on interviews and focus groups with staff and volunteers to understand how groups are delivered and supported, and the challenges and learning to be drawn from providing peer support through groups. Below, we draw out some of our key reflections on this evaluation, including the importance of the findings, the key challenges we experienced and their implications, and our suggestions for future work.

### Reflections on the findings

The finding that stroke survivors felt being in a group reduced the social isolation they experienced following their stroke is particularly important, as loneliness and social isolation is known to have broader negative implications. Previous research has demonstrated the negative impact loneliness and social isolation can have by affecting people's wellbeing and quality of life (Masi and others, 2011). A study conducted by Hilari and others (2010) found that, for stroke survivors specifically, low social support and loneliness were among the main predictors of psychological distress.

Our findings suggest that the social networks and interactions the group offers are important for stroke survivors' broader recovery and wellbeing. Additionally, one very powerful finding from the interviews is that many of the stroke survivors reported having no other opportunity to regularly leave their home and interact with others besides the group. This demonstrates how essential the groups are in providing this regular opportunity to access social support.

Similarly, the finding that stroke survivors felt their confidence improved through participation in the groups is very important. In 2010, the stroke community (including stroke survivors, carers and professionals) came together to identify the top ten priorities for stroke research. 'Finding the best ways to improve confidence after stroke' was one of the priorities identified (Pollock and others, 2012). It was clear from our interviews that this is an area where people felt that being in the group had made a positive impact. Our findings suggest that being in a support group of this type offers a way for people to improve their confidence following stroke.

Prior to this study, little research had been done to understand the impact of peer support for stroke survivors. One small case study had found positive benefits of peer support for stroke survivors (Kessler and others, 2014); however, a literature review conducted by Nesta and National Voices (2015) reported that further research was needed to understand more about how peer support affects people with long-term health conditions. Our findings show that stroke survivors overwhelmingly felt that peer support had a positive benefit for them, and people felt it made a real difference. Stroke survivors and carers found it reassuring and supportive to be with people who were similar to them. It clearly gave stroke survivors a more positive impression of their own recovery and provided them with an opportunity to support others.



The finding that volunteers and staff felt that a key challenge for them was recruiting new members to groups is of particular interest to the future of the groups. Interviews with stroke survivors revealed that many came to join a group through an invitation or recommendation from a health care professional. Therefore, it is evident that strong links with statutory services and health care professionals is essential for reaching new stroke survivors who could benefit from the support that groups offer.

The finding that lead volunteers and volunteers in other roles were under great pressure revealed a key concern regarding the future of the groups. There was a worry about how sustainable these roles could be without more shared responsibilities and adequate staff support. We observed that having a committee would be one way of helping with this, but the majority of staff interviewed felt that there needed to be a full-time job role focused on supporting the groups.

Finally, it was evident throughout this evaluation that staff and volunteers were incredibly engaged and invested in the future of the groups and displayed real ownership in wanting to develop and improve them. Volunteers and staff expressed a keenness to know more from their members – about their needs, but also to receive feedback on the support they provided. It is hoped that some of the learning from this evaluation can help to address these needs and offer possible ways to achieve this in the future.

### **Additional analysis**

We undertook a number of additional analyses in this evaluation that are not reported here.

We compared the relationship between outcome measures and people's perceived stroke recovery. People's perceived stroke recovery was captured using a scale from 1 to 100 (from the SIS) and asked people to rate how much they felt recovered from stroke. This was asked at both time points. For all measures, there was a positive correlation between the scores of each outcome measure and perceived stroke recovery. This means that people who report a greater recovery from stroke also score more positively on outcome measures (such as higher mental wellbeing) and vice versa.

We also compared how the scores of different groups of respondents varied by gender, age, time spent in hospital and time spent in group. The mean scores for all measures were not statistically different from average. This indicates that there were no systematic differences in scores according to these characteristics for any measure (full details are given in the Appendix).

### **Challenges of measuring the impact and value of Stroke Association Voluntary Groups**

As evaluations of this nature are rare and the learnings have wider value, we have outlined below the key challenges faced in this study to give additional context to the findings and to provide a source of information for future research.

#### **Capturing the early value or impact of groups**

We experienced a challenge in capturing any initial benefits groups might offer stroke survivors. In this evaluation, for the most part we captured the experiences and outcomes of stroke survivors and carers who were already part of a group and receiving support. We felt that the process of joining a group would in itself contribute to some

of the positive outcomes groups hope to achieve for their members – in particular, reducing social isolation and increasing confidence.

We had therefore hoped to capture more new group members using the self-report questionnaire as they joined a group. It was hoped that capturing new members might allow us to better observe the initial impact that the groups have. However, the reality was that only 8 per cent (n=29) of respondents were 'new' and had been in a group less than 3 months. The majority of respondents (over 70 per cent, n=250) had been in the group more than 12 months. Our sample of new members was too small to conduct meaningful analyses and so we were unable to look at how their outcome measures changed over time. Without being able to capture information about people's outcomes and experience just prior to and just after joining a group, we were not able to test our assumptions about the initial benefits groups might offer stroke survivors.

#### Capturing change over time

We did not detect any meaningful differences in any of the outcome measures over time for the questionnaire element of the evaluation as a whole. We offer a few observations on this:

- Through our group visits and interviews with stroke survivors, we observed that many group members had plateaued in their recovery, as it had been several years since their stroke (the mean time since first stroke was 6 years). This posed a particular challenge for capturing a change in these outcomes over time, since many stroke survivors were likely to have seen improvements sooner after their stroke and/or after joining the group.
- As groups offer long-term support, we feel that a gap of three months between questionnaire collections restricted the impact we were able to capture. It is likely that leaving a longer time (such as 6 or 12 months) between collection points may have better captured the impact of the groups.
- For all the outcome measures used, scores were similar at both time points, which means that although we did not detect any improvements over time, we also didn't detect any decline. While groups aim to have a positive impact and see improvements on the intended outcomes (such as increased mental wellbeing or reduced social isolation), we suggest they may also have a value in supporting stroke survivors and their carers to maintain their wellbeing and levels of social interaction with others over time.

#### Choice of outcome measures

One key consideration at the onset of this evaluation was a desire not to overburden stroke survivors with a lengthy and onerous questionnaire. As a result, we chose to include relevant subscales of certain measures in order to capture different aspects of support rather than including full measures (which tend to be lengthier). Although this successfully reduced the length of the questionnaire while also allowing us to capture information about several aspects of the support offered, it did limit our ability to comment more fully on the intended outcomes. For example, as we were the first study to use the two subscales of the SSSMQ, we were limited in drawing meaning from these scores compared with other research.

The use of the participation subscale of the SIS as a measure of social isolation also posed a challenge for adequately capturing social isolation. This subscale captures feelings about how stroke has had an impact on participation in roles and activities.

It does not capture other aspects of social isolation, such as social networks, social connectedness and particularly social relationships that are also linked to social isolation.

#### Suggestions for measuring the value of peer support groups

Based on our reflections of this evaluation, we now offer some suggestions for how SAVGs and other similar support groups could measure their value and impact in the future.

Firstly, despite being unable to detect significant changes in outcome measures over time, we still feel there is great value in using patient-reported outcome measures for groups of this nature. Used in the right way, capturing the changes of stroke survivor outcomes could have benefits for both stroke survivors and volunteers and staff in understanding more about the impact of the support they provide. If groups were to use outcome measures in the future, the following points may be helpful to consider:

- We suggest that stroke survivors (with support from the group) could use, complete and track their own scores using outcomes measures over time. We suggest that, by allowing people to have ownership and involvement in using these measures, this could bring additional benefits to the stroke survivor by increasing their understanding of how they are changing after stroke. This could also mitigate some of the practical challenges of using outcome measures in groups of this nature, such as keeping scores confidential and keeping track of which score belongs to which member.
- Timing is also key to better understanding the impact of the groups. We described above the challenges of capturing the likely initial positive impact stroke survivors and carers could experience by joining the groups. Our suggestion would be to capture new member outcomes as soon as possible – either before they join or as they join a group – and use this to compare against in order to detect change over time.
- As the groups provide long-term support to their members, allowing more time between outcome measurements (such as 6 or 12 months) may be a more appropriate timeframe for detecting group impact.
- Although groups aim to have an impact on many things, we suggest reducing the number of outcome measures used and focusing on one complete measure. This would keep the burden of administering and completing the outcome measures smaller. As these would likely be administered by volunteers or staff in the group, we suggest using a scale that is easy to analyse and calculate a score from. One example from this study would be the short Warwick–Edinburgh mental wellbeing scale (SWEMWBS). We suggest this example given the nature of the tool – not necessarily the outcome it captures. It would be essential to pick an outcome most relevant to the support on offer and that group volunteers feel able to use.

Beyond the use of outcome measures, it is important to capture members' voices to enable them to have genuine ownership of, and influence on, how groups run. In addition to the mechanisms the Stroke Association already has in place to ensure that groups are genuinely led by their members, one additional suggestion made in this study was to implement an annual survey of group members with a few key questions asking people whether they were happy and what they liked/disliked about the groups. This would give volunteers a way to learn about the value of the support they offer and

the needs of their members. It would also allow members to contribute to the group in an anonymous way.

There is also great value in asking people about their experiences, and people really value being asked. The interviews revealed important findings that described some of the more intrinsic value of the groups, which otherwise might be hard to capture.

### Concluding thoughts

In this evaluation, we set out to:

- understand more about Stroke Association Voluntary Groups
- build a picture of the impact and value they have for stroke survivors and carers
- understand how groups are delivered and supported by volunteers and staff.

Alongside this, we also looked at the challenges of delivering peer support through groups.

Our findings suggest that group members felt very positive about being part of a group. They overwhelmingly saw it as an essential part of their life after stroke and a source of ongoing support. We found that people felt the groups had had a positive impact on their social isolation, mental wellbeing and confidence. Stroke survivors and carers also felt that peer support was an essential part of the groups and made a real difference in how they viewed their own recovery and provided an opportunity to support others.

We were unable to find any significant changes over a three-month time period in any of the outcome measures used in this study. Despite this, we believe there could still be great value in groups using outcome measures to capture impact if used at the right time and in the right way.

We gained important insight into how groups are structured and how they run and operate. We also highlighted some of the key challenges that groups will continue to face in the future. In response to some of these challenges, we elicited some suggestions for finding and recruiting new stroke survivors so they are able to access the support offered.

While evaluations of this nature are still rare, they do offer insights for the wider charity and research sector as well as the groups themselves. This work tells us about the value and impact of these groups, but also provides a deeper understanding of the most appropriate ways to measure and capture the value of support on offer.

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# Appendix:

## Additional information on outcome measure analysis

### Methods: data preparation

When completed questionnaires were received at the Nuffield Trust, all responses were recorded in a spreadsheet against the person's unique reference number (URN). Initial and follow-up responses were differentiated by a time field. Missing fields, obvious errors in responses and spoiled data were recorded with different codes.

Before analysing the data, checks of approximately 10 per cent of entries into the Excel spreadsheet were made against the original questionnaires to check the accuracy of data entry. This identified errors in one particular field (gender) of a small group of questionnaires filled in on a particular date. All fields of all questionnaires around this date were subsequently checked, with data corrected where appropriate.

Data were imported into SAS statistical software to prepare the data for analysis:

- Outcome measures were calculated from their constituent component questions.
- Data cleaning was carried out for demographic and other characteristic variables.

For individuals with both initial and follow-up responses, if any of the following pieces of information were complete for one the time points but missing for the other, we replaced the missing value with the completed value. This was done for sex, age band, time since stroke, self-assessed recovery, time in group, and hospital length of stay.

We used mixed linear regression to model each of the outcome measures in turn. Demographic and other characteristic variables were included as predictor variables (fixed effects). All valid initial (T1) and follow-up (T2) entries were entered into the model. To test for systematic changes in outcomes over the three months, we included a time (T1 or T2) variable as another fixed effect. Random effects were included at the person level to account for the fact that some individuals were included twice and their responses may be similar at each time point.

The carer outcome measures were modelled in a similar way, but also included the carer's responses. Time was not included as a fixed effect for the carer outcome analyses since sample sizes were too small.

For both stroke survivors and carers, mean scores were calculated to describe variation in outcomes across a range of characteristics.

### Findings - Additional information on outcome measure analysis

Tables A1 and A2 show the scores for all outcome measures (stroke survivors and carers, respectively) in this study alongside the number of respondents, standard deviation and 95 per cent confidence intervals of the mean scores.

Figures A1–A4 display adjusted means of the stroke survivor outcome scores for various groups (initial and follow-up responses are used together). Adjusted means tell us what the mean would be for particular groups of interest (e.g. men and women) if all other characteristics were set to be the same. The figures also display 95 per cent confidence intervals on the adjusted mean values.

Figures A5–A8 display the changes between initial and follow-up in adjusted and unadjusted means of the stroke survivor outcomes.

<b>Table A1: Stroke survivor outcome measure scores</b>				
	<b>Stroke impact scale, 'participation/ role function' subscale</b>	<b>Short Warwick–Edinburgh mental wellbeing scale</b>	<b>Southampton stroke self-management questionnaire 'strategies' subscale</b>	<b>Southampton stroke self-management questionnaire 'capacities' subscale</b>
<b>N</b>	323	327	285	294
<b>Mean</b>	49.7	21.6	31.2	32.0
<b>Standard deviation</b>	24.2	4.4	9.6	5.7
<b>95% confidence intervals</b>	47.0 to 52.3	21.1 to 22.1	30.1 to 32.3	31.4 to 32.7

<b>Table A2: Carer outcome measure scores</b>			
	<b>Adult carer quality of life questionnaire support subscale</b>	<b>Adult carer quality of life questionnaire stress subscale</b>	<b>Adult carer quality of life questionnaire satisfaction subscale</b>
<b>N</b>	133	146	142
<b>Mean</b>	6.4	10.3	10.6
<b>Standard deviation</b>	4.2	3.4	2.6
<b>95% confidence intervals</b>	5.65 to 7.07	9.72 to 10.81	10.13 to 10.98



Figure A1: The stroke impact scale, 'participation/role function' sub-scale by different group characteristics (N=323)

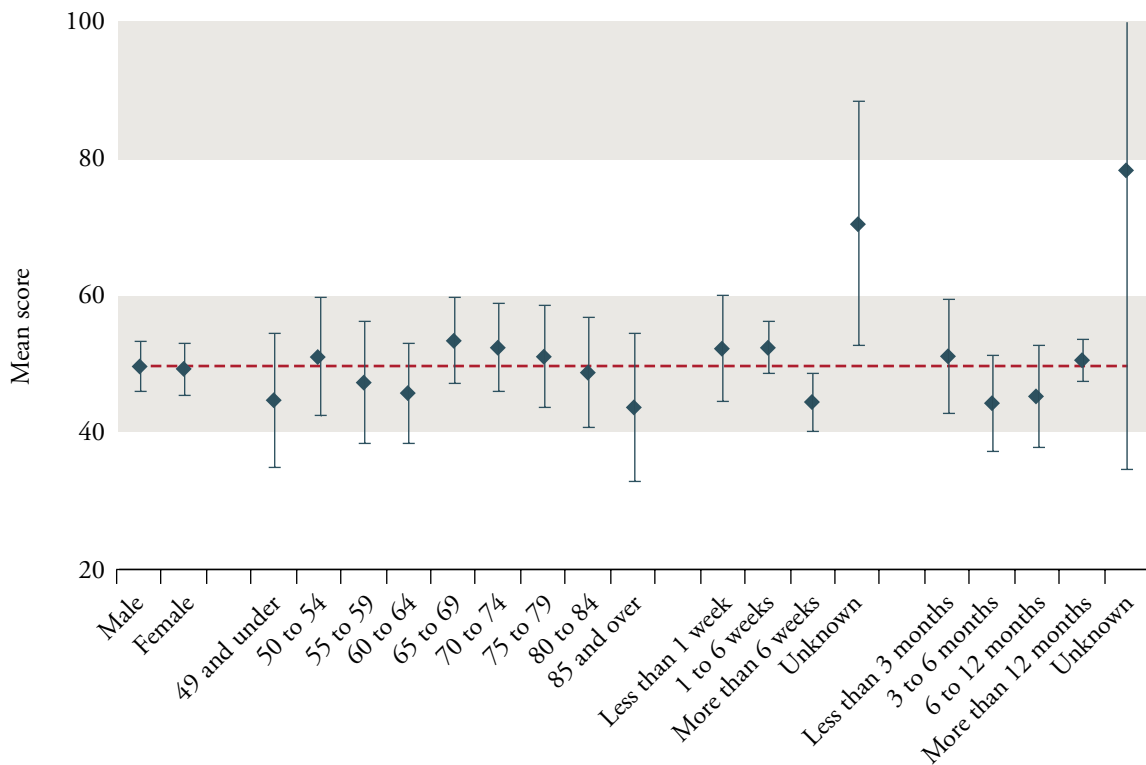


Figure A2: The short Warwick–Edinburgh mental wellbeing scale by different group characteristics (N=327)

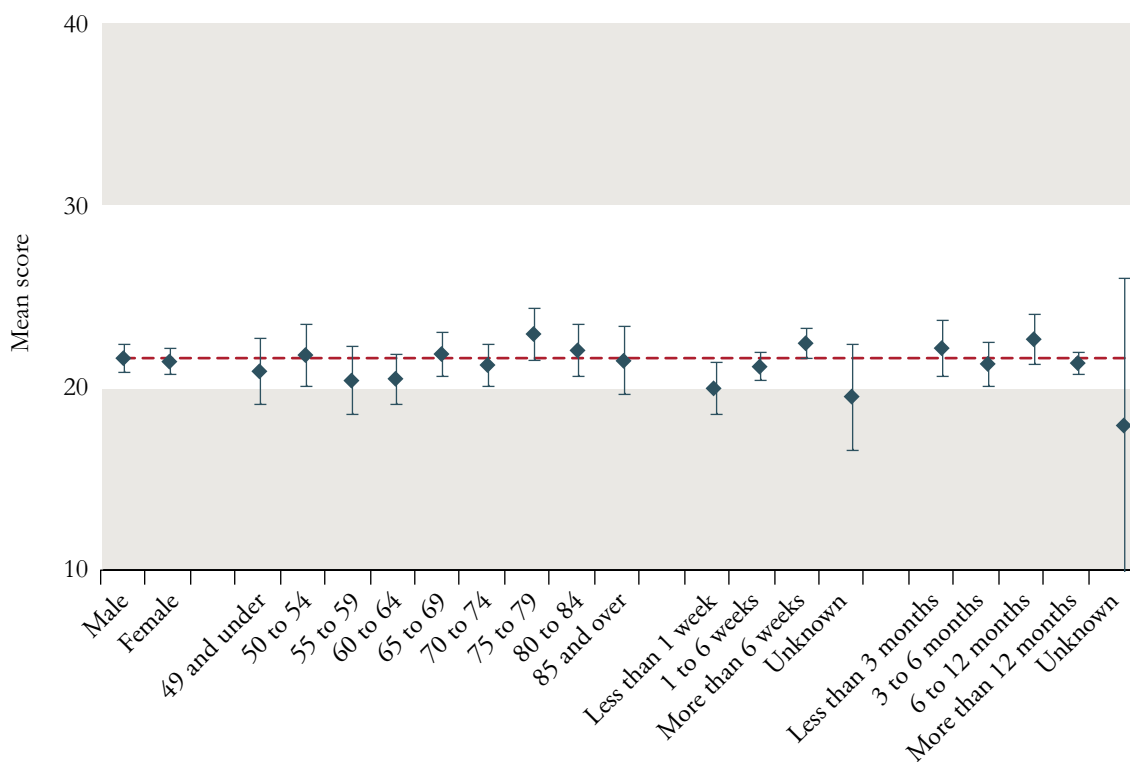




Figure A3: The Southampton stroke self-management questionnaire 'strategies' subscale by different group characteristics (N=285)

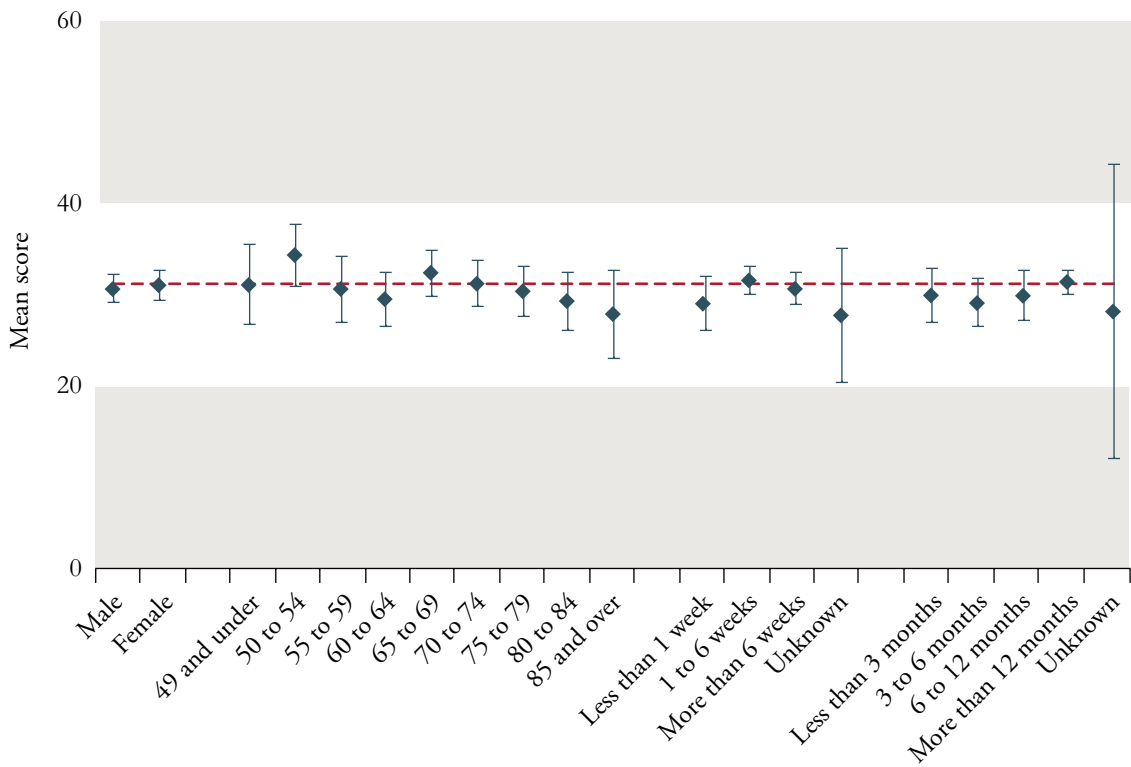


Figure A4: The Southampton stroke self-management questionnaire 'capacities' subscale by different group characteristics (N=285)

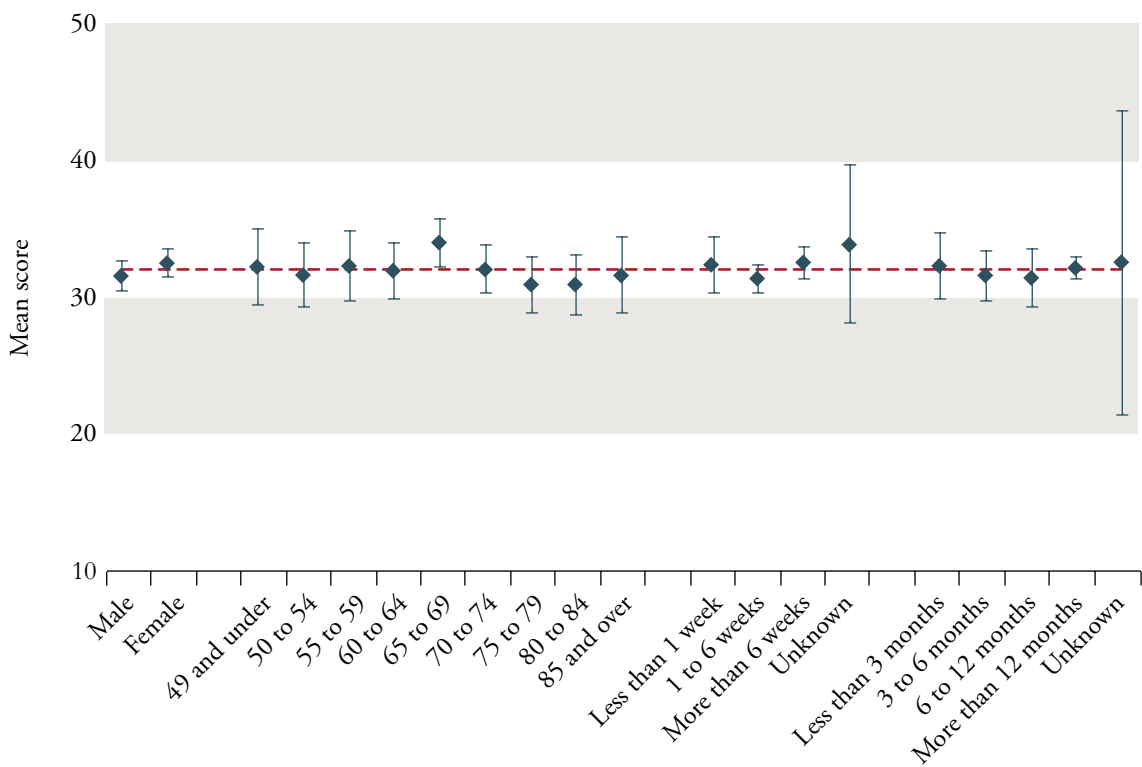


Figure A5: Adjusted and unadjusted mean of the stroke impact scale, 'participation/role function' subscale at initial (time 1) and follow-up (time 2) (N=323)

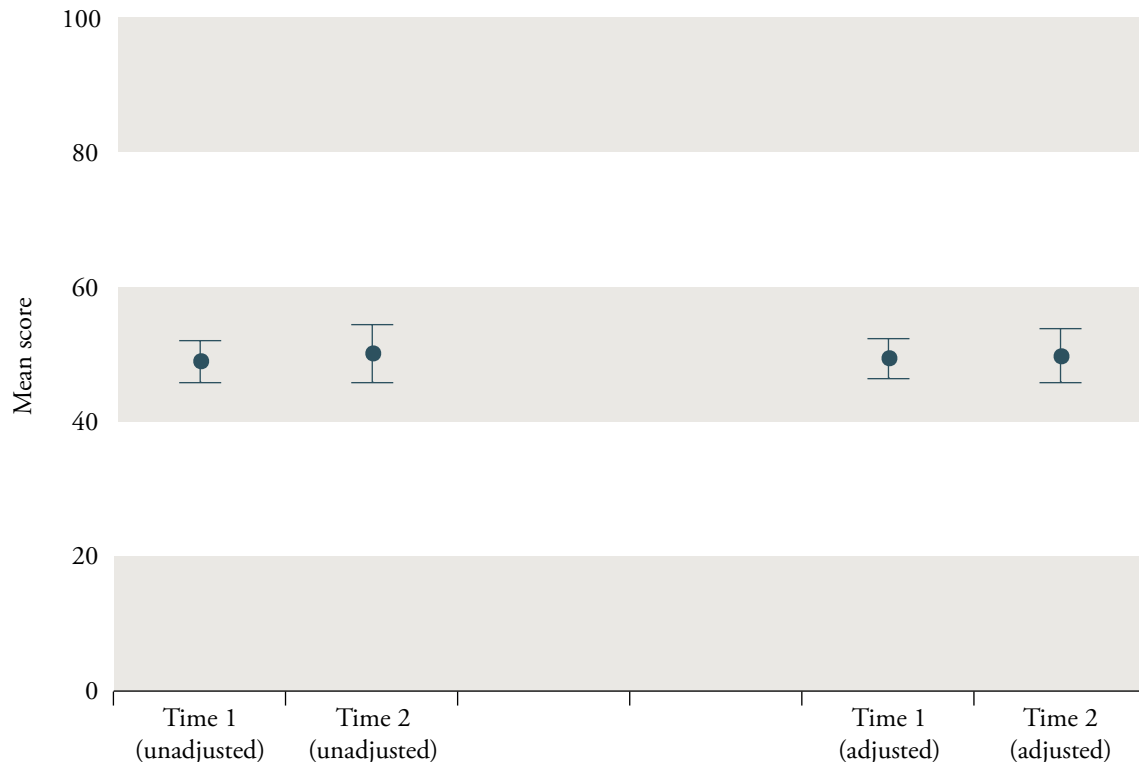


Figure A6: Adjusted and unadjusted mean of the short Warwick–Edinburgh mental wellbeing scale at initial (time 1) and follow-up (time 2) (N=327)

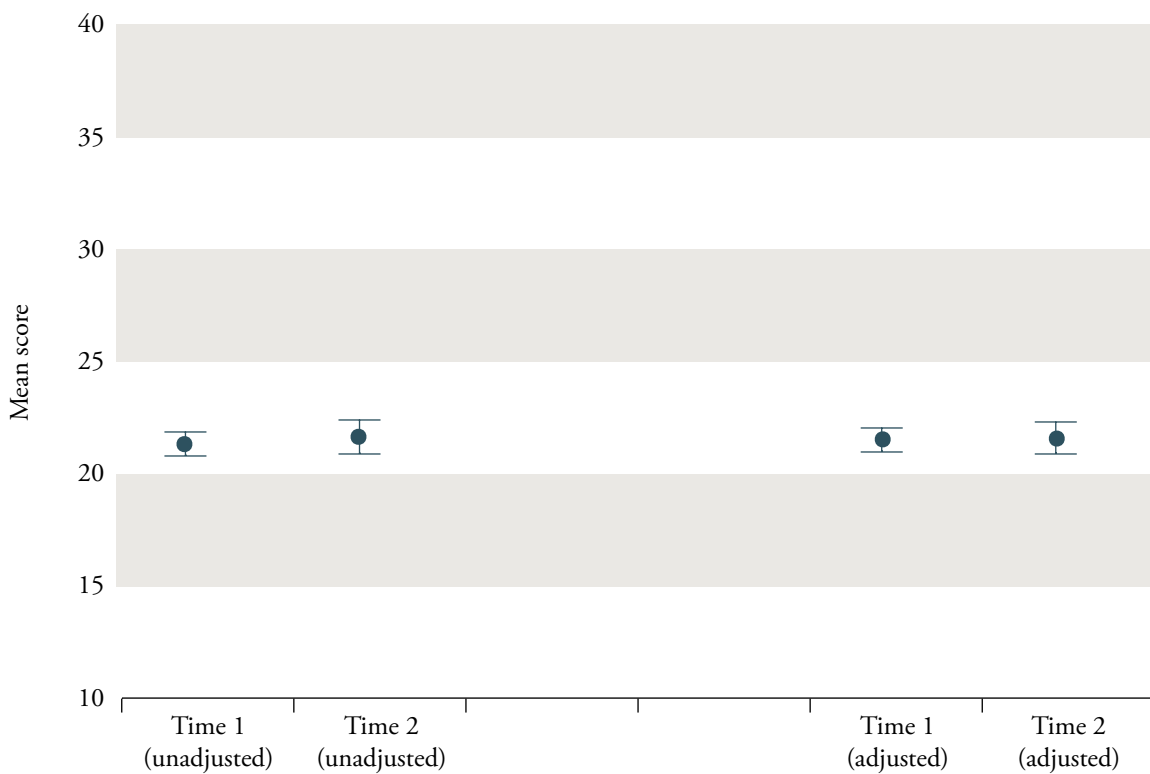


Figure A7: Adjusted and unadjusted mean of the Southampton stroke self-management questionnaire 'strategies' subscale at initial (time 1) and follow-up (time 2) (N=285)

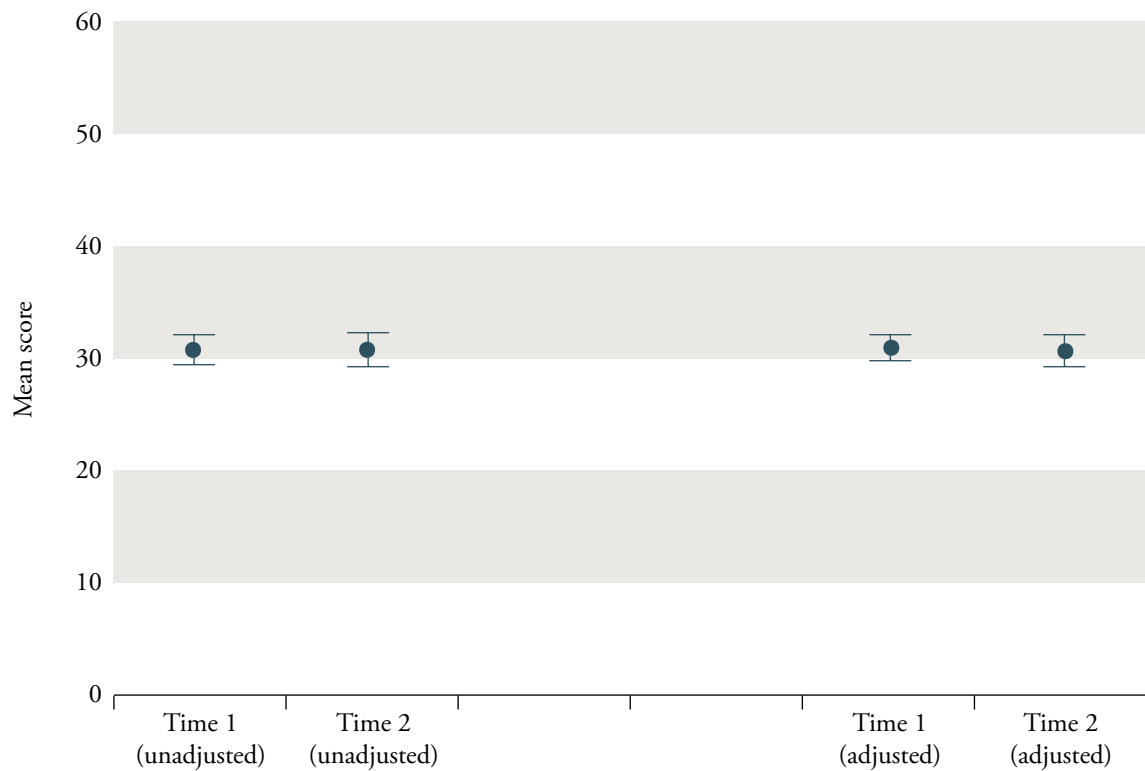
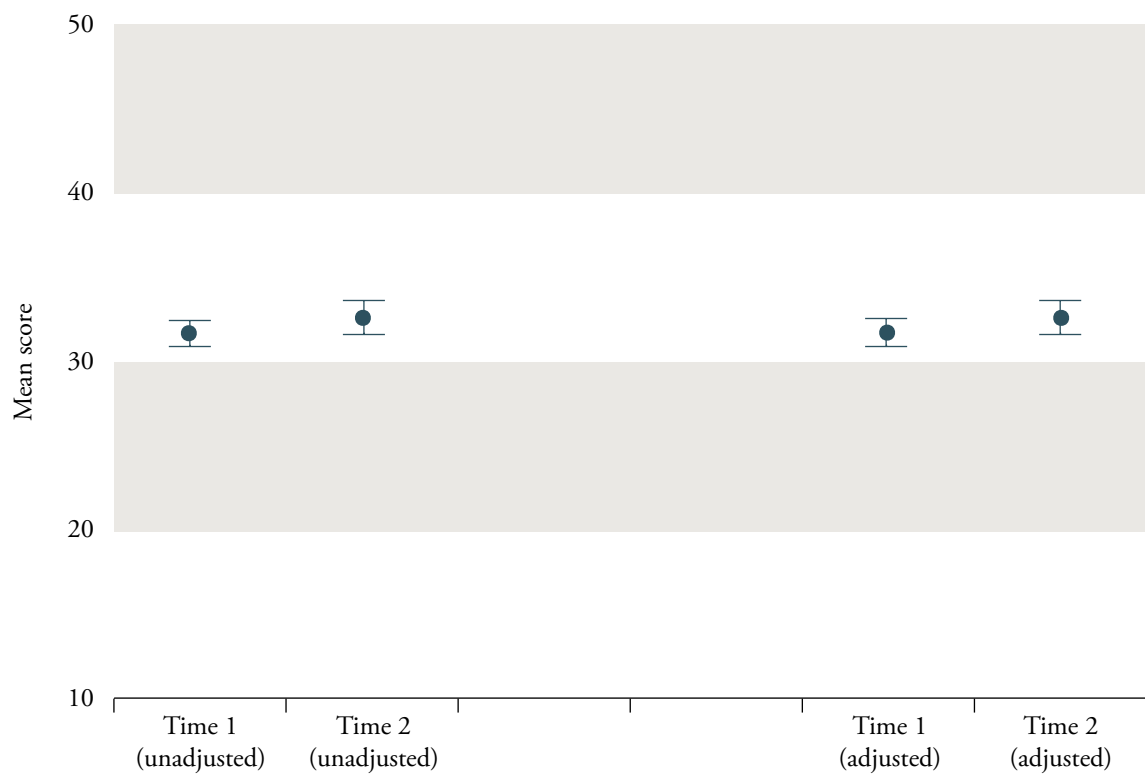


Figure A8: Adjusted and unadjusted mean of the Southampton stroke self-management questionnaire 'capacities' subscale at initial (time 1) and follow-up (time 2) (N=285)



# About the authors

**Holly Dorning** is a Senior Research Analyst at the Nuffield Trust. Holly joined the Trust in May 2013. Holly started her career in medical research charities and worked at the Multiple Sclerosis (MS) Society before joining the Trust. She worked on a number of research projects and initiatives at the MS Society, including leading the analysis of the 'My MS, My Needs' project, which is the largest survey of people with MS in the UK and explored whether people with MS were getting what they needed from health and social care services. The results of this project were used to develop 'A lottery of treatment and care – MS services across the UK'. Prior to this, Holly worked in the research team at Prostate Cancer UK and has a degree in Physics from the University of Warwick, where she had a particular interest in medical physics.

**Miranda Davies** is a Research Analyst at the Nuffield Trust. She joined the Trust in July 2014 from Brunel University, where she worked as a Research Fellow on a number of projects in the health sciences research field. Her key interests include quantitative research methodology and aspects of health in older age. Miranda holds an undergraduate Psychology degree from the University of Plymouth, and an MSc in Health Psychology from London Metropolitan University. She is a Chartered Psychologist with a PhD in Health Sciences from Brunel University. Miranda's PhD research area was elder financial abuse; she conducted a mixed methods research project exploring how professionals from different sectors identify elder financial abuse. In her first post-doc role she helped develop online training for professionals to enhance detection of abuse. Subsequent post-doctoral roles have focused on exploring health professionals' decision making.

**Cono Ariti** is a Lecturer of Medical Statistics at the London School of Hygiene and Tropical Medicine (LSHTM). He was previously employed as a Senior Research Analyst at the Nuffield Trust. He is currently involved in applied and methodological research on measuring the impact of complex interventions in health systems, primarily the UK NHS. Recent work has included the evaluation of the effectiveness of telehealth and the ability of the voluntary sector to reduce pressures on hospitals over the winter months. He is also currently designing a clinical trial to evaluate the effectiveness of telephone coaching on patients with long-term chronic illness. Previously, when he was a lecturer in Medical Statistics at LSHTM, he was involved in the design and analysis of clinical trials in focussing on cardiovascular research.

**Dr Kerry Allen** is a Lecturer at the Health Services Management Centre, University of Birmingham. She has over ten years' experience of applied health and care research and evaluation. Kerry is a Fellow of the National Institute for Health Research School for Social Care Research, and of the Higher Education Academy. Kerry is a health sociologist by background with strong experience of designing and conducting research in a health and care context. Her recent studies include: an evaluation of approaches to home therapies for people with chronic kidney disease (Department of Health); Research into prevention in older people's services (NIHR); and a Cancer Research UK study of treatment decision-making for older people with cancer. Her relevant specialisms and interests are: the experience and management of chronic conditions; prevention services and the delivery of adult social care; integrated care models, older people's services; shared decision-making and participatory methodologies.

**Theo Georghiou** joined the Nuffield Trust in 2008 as a Senior Research Analyst. His interests include predictive risk techniques, methodologies for evaluation of complex care interventions, and end of life care services. He is currently leading a number of studies to evaluate the role of voluntary sector organisations in helping to avoid unplanned hospital admissions, and has been documenting variations in the use of hospital care at the end of life. Theo has extensive experience using large administrative datasets from primary and secondary health care and social care services. In his previous role at The King's Fund he was part of the team that developed the Patients at Risk of Readmissions tool (used by commissioners to identify patients at high risk of an emergency readmission), and at the Trust he has extended these methods to make use of a wide range of data sources (including those from social care and GP systems). He has also been involved in the development of person-based resource allocation models, evaluations of a palliative care nursing service and studies of the use of health and social care at the end of life. Prior to his work at the Nuffield Trust and The King's Fund, Theo worked at the Healthcare Commission and the Commission for Health Improvement. He has a master's degree in Experimental and Theoretical Physics from the University of Cambridge.

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