

**Evaluation of Active Lives after Stroke**

**Final Report**

**June 2020**



Research & Evaluation Services

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## Executive summary

This evaluation of the Stroke Association's Active Lives After Stroke (ALAS) project draws together multiple sources to comment on the way in which services were developed and delivered and their impact on stroke survivors, carers and volunteers. The aims of the project were to improve attitudes towards physical activity and for beneficiaries to change their behaviour to integrate activity and exercise into their daily lives more regularly.

We observed that, at all locations, participants have found ALAS to be a supportive environment for exercise and the encouragement of physical activity by stroke survivors and their carers. The peer support and social aspects of the sessions were regarded as critically important and attendees reported improvements in managing their day-to-day activities, physical strength and overall wellbeing as a result of their participation. These benefits combined had led to numerous examples of people being more mobile around the house and more engaged with their families and friends.

The investment of time by co-ordinators and volunteers in understanding the needs of participants was an important driver of the success of the project and also enabled them to maintain high levels of motivation and attendance. Text messages and reminders were an important part of this, although other interventions – such as MyStrokeGuide – were not well used.

As mentioned, 1-1 peer support was a key element of the service and group members were prompted to help motivate and encourage each other through informal budding schemes which also created a friendly and social dynamic among the groups. For example, we spoke with a number of people who came along to sessions to be part of the group even if they felt unable to partake in the activity that day. Allied to this was having instructors and session leaders (including volunteers) who understood the needs and challenges of working with stroke survivors and could therefore offer specific support.

Attendees typically reported that they intended to remain active after the sessions and there were examples of group members who had invested in equipment or joined a gym in order to do so. However, for many, remaining active would be dependent on relevant activities being available in a safe social environment. The stroke specific nature of ALAS was felt to be key, not only in terms of the activities but because it brought together people facing similar challenges who were thus able to support and motivate each other as a group and as 'buddies'.

Looking to the future, we observed that volunteers feel supported and are motivated to continue to be involved, although this will depend on the exit plans in each area. However, we did note that recruiting volunteers in Newham was more challenging than in other areas. The training and recruitment of volunteers is therefore likely to be an important element of future project design.

Other lessons from the project include the benefits of multi-activity formats, the benefits for (and importance of) carers, the importance of relationships and also to be sensitive with the language of physical activity. For example, we noted that attendees typically referred to ALAS as a social activity that gave them enjoyment rather than physical activity that allowed them to reach 'goals'.

Finally, we also observed that the most compelling advocates for the project are the attendees themselves thanks to their enthusiasm and ability to articulate the difference the sessions have made within the context of their own life and challenges. As such, we consider that there is potential to use participants as an important resource for promoting this and similar services in the future.

## Introduction

### Background

The Active Lives after Stroke (ALAS) project was developed by the Stroke Association in 2018 and began delivering services in 2019. It was intended to have a positive impact on the attitude of stroke survivors towards physical activity and change their behaviour to make it a regular and beneficial part of their life. While the focus of the project is on stroke survivors, carers are also able to attend the sessions. The service is aimed at stroke survivors who do less than 30 minutes of exercise a week and aims to support them to become more active. There is an ambition that people supported by Active Lives will continue to be active after 12 months and that the Stroke Association will encourage and help them to continue to meet for this purpose either as Stroke Association voluntary groups or independently operated group within the local community. It is also hoped that anxiety and loneliness among participants will decrease and that they will feel more confident to get involved with group activities in the longer term.

The Stroke Association received funding from the National Lottery awarded by Sport England to develop the project, which runs in four areas of England: Grimsby, Central Lancashire, North Devon, and Newham. Locations were chosen to reflect geographically different areas (rural/urban) with mixed demographics (affluence) and high prevalence of stroke and obesity. Locations were also selected in parts of the country where Stroke Association had existing peer support groups and those where the organisation did not have a significant presence.

The project started in Summer 2018 with the first wave of activities starting in January 2019. The project received funding until summer 2020, however sessions ceased in March 2020 due to the onset of the covid-19 epidemic. The overview section of this report details the response of the organisation to the crisis.

### Methodology and data analysis

Figure 1 sets out a timetable for our data analysis. We used a mixed-methods approach to the evaluation, combining self-reported quantitative data using established measures (e.g. active lives survey and GAD-7) with qualitative evidence (notably the qualitative evaluation and carers tools) both of which were designed and validated by Cloud Chamber through field visits. The use of multiple sources enabled the evaluation to consider different perspectives and understand the mechanisms for changes in behaviour and outcomes at both an individual and group level. This approach also provided real world examples of change that could be used to inform both the ongoing development of the project and future service development. The quantitative tools were designed by the Stroke Association in consultation with Sport England.

Each wave of analysis informed monitoring reports in May 2019, November 2019 and February 2020 as well as an interim report produced in August 2019. This final report is based on all available inputs. Details of these evidence inputs (surveys, etc.) can be found in Appendix 1.

**Figure 1: Evidence inputs and evaluation reporting**

<b>Analyses of evidence inputs</b>	<b>May 2019</b>	<b>Aug 2019</b>	<b>Nov 2019</b>	<b>Feb 2020</b>	<b>June 2020</b>
Self-assessment survey (incl. Short Active Lives Survey and questions around self-efficacy and quality of life)	X	X	X	X	X
CRM/registration forms	X	X	X	X	X
Qualitative evaluation tool	X	X	X		X
Carers tool		X			X
Learning log		X			X
Volunteer review form		X			X

### ***Impact of covid-19 outbreak on evidence sources***

The covid-19 epidemic had the following impact on the availability of data and evidence.

- **Self-assessment surveys** were completed where practical, however due to the early completion of the project the number of 12 month surveys was limited to 17. Due to low sample size, we have not presented 12 month matched survey data as we do not believe it to be statistically robust. Where appropriate we have commented on any relevant trends where we believe the 12 month matched data sample is consistent with the six month matched data sample (which is used throughout this report).
- **CRM/registration forms** were completed up to the end of the project and we consider that they provide a representative sample of service users
- The **qualitative evaluation tool** (focus group) and **carers tool** were carried out for two waves in each location but were not able to be carried out for the third wave. Due to the strong level of consistency in responses between waves of activity and the four locations, we do not consider that this has had a detrimental impact on the quality of evidence available
- The **learning log** was updated at each stage of the project and we have reviewed all entries. A learnings day building on this analysis and focussing on project lessons and future plans was held in May 2020.
- **Volunteer reviews** were carried out in two stages after the first and second waves. The commonality of themes emerging from volunteers at these two points means that we feel that the information is representative despite the absence of the a third review point at the end of the project. This supplemented regular informal 'check-ins' with volunteers to understand and address any issues which were, in turn, reflected in the learning logs.

### ***Limitations of the fieldwork***

Surveys and focus groups have been conducted with, and completed by, the majority of attendees at each location and are therefore considered to be representative of the groups. While generally the qualitative fieldwork and the qualitative self-assessment surveys have been directionally consistent, responses in the focus group format have typically been more positive than for the questionnaire based survey. The reasons for this might be twofold, firstly, there may be challenges in terms of the methodology such as:



- People may be more likely to give positive responses in a group setting and reluctant to highlight some of their day-to-day challenges
- Some degree of over-reporting of activity levels may also be a factor in the written questionnaires. This may be more apparent in the baseline survey which is conducted before the participants have established trust with the group and activity leaders
- It is sometimes the case that, when learning new skills, people's self-reported achievement levels are lower at the end of a course than at the start. This is because they have begun to benchmark themselves at a higher level than was previously the case

Secondly, the questionnaire design and sampling approach might not fully reflect the lived experiences of stroke survivors with regards to changes in physical activity levels. Example of this might be:

- Sample sizes may not be sufficient given the large number of variables and range of individual circumstances.
- The survey asked for reflections on the past 7 days, 2 weeks, 6 months and general observations. This creates the potential to bias responses unintentionally
- The point at which the survey is administered may influence results. If surveys are completed in week 11 or 12 of the programme, the activity in that week may influence the result.
- The length of the questionnaires and terminology used can be difficult to understand for stroke survivors, among whom Aphasia is a common condition. Local co-ordinators and volunteers reporting having to help many group members to complete the surveys due to their complexity.

Overall we consider that the different sources of evidence allow us to draw reasonable conclusions regarding the efficacy of the interventions on people. However, we note that the wide variety of abilities, stroke effects and personal circumstances of attendees should be considered when evaluating the outcomes and impacts of the project as a whole.

## **Logic Model**

A logic model is a systematic way to describe a project to understand what drives change. A logic model can serve as the basis for an evaluation framework and inform planning on how to capture relevant evidence. Definitions for the terms we use in logic models are outlined in Figure 2 overleaf.

**Figure 2: The logic model - some definitions**

Rationale	The rationale defines the fundamental reasons behind the creation of a project, including evidence of demand or need, and the identification of the problem the project was created to solve
Objectives	The objectives are statements of the results that a project is expected to achieve
Inputs	The inputs are the resources that are contributed to the delivery of the project (financial and other resources)
Activities	The tasks undertaken using the resources of the programme and which are designed to meet the programme's objectives
Outputs	The quantifiable measures of activity
Outcomes	The immediate change that the programme participants experience as a result of the project
Impact	The longer term change brought about as a result of the programme – directly to participants and/or to the wider population – which should address the rationale

A logic model for the project is presented in Figure 3 overleaf. This has been adapted from the original project logic model presented to Sport England in the application for funding and following a review of documentation provided by the Stroke Association (including the Stroke Association Evaluation plan for ALAS). We have omitted the rationale and objectives elements from the draft logic model for simplicity given that these elements are covered in existing project documentation.

**Figure 3: Logic model: Active Lives after Stroke**

<b>Inputs</b>	<b>Activities</b>	<b>Outputs</b>	<b>Outcomes*</b>	<b>Impact</b>
Sport England Funding	Physical activity sessions	# of physical activity sessions delivered	Increased physical activity	Enhanced quality of life
Stroke association staff and volunteers	Stroke survivor consultations	# of users of My Stroke Guide	Increased physical mobility* Increased motivation to participate in physical activity as a result of digital interventions	Long-term/sustained increase in physical activity Sustained health improvements
Instructors	Personal digital interventions (Activity reminders by SMS and My Stroke Guide)	# of 1-1 peer support relationships established	Feeling reassured and motivated about staying active	Sustained lifestyle and behavioural change
SA Voluntary group framework		# of peer support groups established	Reduced anxiety and loneliness	Carers reduce levels of care-related stress or anxiety
Physical resources	1-1 peer support	Evaluation insight and reports	Increased confidence in stroke survivors to engage in group activities/community activities	Carers feel less lonely Volunteers improve their skills, confidence, and networking
Local community resources & equipment	Peer support groups			Contribute to strategic goals of Sport England, SA and the Richmond Group
Behaviour change theoretical frameworks (Health Belief Model and Nudge Theory)	Evaluation Governance			Economic development (e.g. whole system benefits arising through maximising independence, reduced healthcare interventions, etc)

\*physical change in how participants move in their immediate environment and complete daily activities e.g. getting out of bed)

## Key evaluation questions

Figure 4 sets out the key evaluation questions that we have sought to address through the evaluation and how they are linked to the relevant part of the logic model.

**Figure 4: Key evaluation questions**

Logic model element	Key evaluation questions
Inputs	<p>Were the inputs sufficient to meet the stated objectives?</p> <p>Were any additional inputs needed to deliver the project?</p> <p>Did established behaviour change theoretical frameworks lead to improved outcomes/impacts?</p>
Activities	<p>Do specific features of the delivery model (i.e. peer support or digital interventions) lead to a supportive environment for exercise, and sustainability of improvements?</p> <p>Is membership and motivation of groups aided by personal digital interventions?</p> <p>Could activities have been delivered more efficiently or effectively?</p>
Outputs	Has the project met its expected KPIs and targets?
Outcomes	<p>Are the stated outcomes of the project being met?</p> <ul style="list-style-type: none"> <li>• Is physical activity increased among participants?</li> <li>• Is physical mobility* increased among participants?</li> <li>• Is there increased motivation to participate in physical activity as a result of digital interventions?</li> <li>• Do participants feel reassured and motivated about staying active?</li> <li>• Is anxiety and loneliness reduced among participants?</li> <li>• Are stroke survivors more confident in engaging in group activities/community activities?</li> </ul> <p>Do outcomes vary by delivery area and, if so, can this be explained?</p>
Impacts	<p>Has participant's quality of life been enhanced?</p> <p>Is physical activity sustained over the long-term?</p> <p>Is the health of participants improved and is this sustained?</p> <p>Are co-morbidities reduced?</p> <p>Are changes in lifestyle and behaviour sustained</p> <p>Are Carers levels of care-related stress or anxiety reduced?</p> <p>Do Carers feel less lonely?</p> <p>Do volunteers improve their skills, confidence, and networking?</p> <p>Does the project contribute to strategic goals of Sport England, SA and the Richmond Group?</p> <p>Are there wider economic benefits (e.g. reduced healthcare interventions)?</p> <p>Do impacts vary by delivery area and, if so, can this be explained?</p>

## Overview of Active Lives after Stroke

### Project set-up

The project started in Summer 2018 with the key activities being to establish relationships with stakeholders, recruit staff and volunteers and put in place the key project processes ahead of the initial launch of activities in January 2019. Key challenges during this period including ensuring alignment of administration and reporting with Sport England and updating processes such as internal guidance on physical activity. These issues were being dealt with at the same time as delivery staff were recruited and onboarded during what was a very busy period for the project.

In each area a coordinator was recruited and contracted for seven hours a week to plan and deliver the project in their area. In each area the project coordinators were responsible for working with existing support groups to raise awareness of the project, develop sessions in consultation with Stroke survivors, and promote and recruit people to participate in the sessions. In Devon, time was also devoted to networking and seeking opportunities for activities to involve people in as part of the ‘taster session’ approach used in that area.

During this phase, local coordinators found that the ability to leverage existing services and support groups was very important to developing Active Lives, as was spending time getting to know and understand the needs of potential users. The pace of development of the project was cited as a challenge in many cases because stakeholders and users were engaged before activities and supporting documentation had been finalised and this required careful expectation management.

- “Promoting Active Lives has been difficult with no supporting information. It has at times felt less professional and I feel that it creates less of an impact”
- “I feel that the key policies and procedures should have been in place at the onset of the project and not be being developed at the same time as the project sessions”

It should be noted however that these issues appeared to have been resolved by the time the project started to deliver activity sessions.

### Project delivery by location

ALAS started delivering sessions to stroke survivors and their carers in January 2019 in three locations, while the activities in Devon got underway at the end of March. The slightly later start date for Devon reflected the need to establish relationships in a part of the country where the charity had a relatively small presence with no active volunteers and only one support group (which had two attendees).

Figure 5 summarises the timing of the three waves of Active Lives sessions in each of the four locations. Note that only two waves took place in Newham.

**Figure 5: Activity schedules by location**

Wave 1	Wave 2	Wave 3



Newham	January to March 2019	October 2019 to March 2020	N/A <sup>1</sup>
Grimsby	January to April 2019	September to December 2019	February to March 2020*
Central Lancashire	January to May 2019	August to November 2019	February to March 2020*
Devon	March to May 2019	July to December 2019 <sup>2</sup>	March 2020

Source: Stroke Association (\* indicates wave incomplete due to covid-19 crisis)

The first session in Newham was run with an existing Stroke Association Voluntary Group in a room at Plaistow library and consisted of instructor led week-long programme of specific exercises adapted for the needs of the group (which contained wheelchair users and independently mobile stroke survivors) with an emphasis on building exercise tolerance and mobility. The second group brought together new participants at a local leisure centre running low level activities including table tennis and skittles delivered by the coordinator. Participants had also organised induction tours and gym sessions on a number of weeks to familiarise them with the leisure centre facilities available.

Following a taster session on 5<sup>th</sup> December 2018, a 12 week programme started in Grimsby on 9<sup>th</sup> January. The sessions were run by a local specialist instructor at a sports hall in a community centre. Sessions included peer support at the start and end of each week as well as a 25 minutes of low impact circuit training session and 25 minutes of team building games. Following the first session, subsequent waves were facilitated by the coordinator and volunteers, with around 4 sessions delivered by the instructor to bring in higher level activities. The second group of participants were noted to have gelled very well and expressed a desire to continue meeting. The third wave sought to re-engage with participants from earlier sessions who were no longer active as well as new group members. At all sessions participants were offered the opportunity to be inducted into the onsite gym for free, and become members at a reduced rate.

The first wave in Central Lancashire started in Preston with a launch event where participants could meet staff, instructors and each other. Activities consisted of 16 sessions, each session was delivered by an instructor and consisted of a warm-up, circuits and a cool-down. The second wave of activities was held in Chorley, with the aim of capturing people in a different part of the geography. The sessions were again delivered by an instructor and supported by a number of volunteers from a local university. The sessions followed a similar structure to the first wave of activities. For the third wave of activities the sessions became leisure centre based (West View Leisure Centre, Preston) and were led by a volunteer with an exercise qualification, as well as being supported by other volunteers.

In Devon, the approach taken was slightly different. The first sessions were run as a series of taster activities to show stroke survivors what was available in their area and possible for them to do. Activities included wheelchair basketball, seated yoga, tai chi and table tennis. Wheelchair basketball and table tennis were very popular with the group. The group bonded well so it was decided to continue running the group as a multi activity group and invite new members in as a second wave. The second wave of activities also consisted of a golf group which ran concurrently with the second multi-activity group. A surfing taster day was also organised. Communication and planning were an

<sup>1</sup> Plans for a further wave of activities with an existing group in Newham were cancelled due to the covid-19 outbreak

<sup>2</sup> The North Devon activities evolved into rolling sessions as part of a local Stroke Association Voluntary Group at the end of the second wave. It is intended that these will continue after the covid-19 outbreak



important focus for the local coordinator because the activities of the Devon group were delivered at two separate venues and involved different instructors for the activities. The multi activity group continued to run and people could join on a rolling basis. Finally in March 2020, an existing group in Plymouth was engaged and equipment purchased but they did not have the opportunity to have many meetings due to the covid-19 outbreak.

### **Project exit strategies**

Project exit strategies were considered on a location by location basis to reflect local dynamics, resources and the needs of the various groups. Overall, two key themes of establishing relationships and ensuring sustainability were emphasised.

- In Central Lancashire, a development grant was submitted with the aim of working with a supportive local leisure centre to develop monthly drop-in sessions providing information about being more active after stroke and taster sessions of activities available in the leisure centre
- In Grimsby the group coordinator was unsuccessful in securing local funding to maintain the group in its existing format. As an alternative, the co-ordinator was considering self-funding for a low level exercise qualification to enable her to deliver sessions independently with attendees paying a small weekly charge.
- In Newham they were exploring Life After Stroke grants with individuals and were also seeking to obtain discounted memberships with a local leisure centre. While the groups run had expressed a desire to keep meeting, a lack of suitable volunteering was seen as a key challenge to sustainability
- In Devon, the multi-activity group is aiming to be run on a voluntary basis with training being planned for group members and attendees sharing the cost of court hire. Meanwhile many of the golf group members continue to meet independently. Discussions had also begun with a partner organisation in Okehampton to look at co delivering an initial 12 week block of sessions. A development grant for surfing sessions has been submitted and further funding streams are being considered. In addition, the group co-ordinator has organised a free 2 day sailing taster session for May 2020 although this is unable to take place due to the covid-19 epidemic.

Overall, the key challenges in terms of the sustainability of groups that were commonly identified were ensuring volunteers felt comfortable taking responsibility for sessions and also reservations among some group members regarding making sessions non-stroke specific.

### **The impact of covid-19 crisis on the project and its participants**

All group and community projects run by the Stroke Association ceased on 17th-March 2020 due to the covid-19 crisis and it is not expected that those ALAS groups still running at that time will restart in the coming months. The subsequent lockdown restrictions announced on 23<sup>rd</sup> March meant that all sports facilities and group gatherings had to stop with immediate effect, thereby having a significant impact on the ability of stroke survivors to exercise. However, after discussions with Sport England a new plan for ceased activity to be restarted when safe to do so has been developed. Grimsby and Central Lancashire will restart the groups for a full 12 weeks while Devon will restart with the voluntary group, and also look to set up the sessions in Okehampton followed by surfing,

golf and Sailability sessions. Newham will not resume sessions but will continue to support participants to access Life After Stroke grants.

All of the co-ordinators have attempted to contact group members to understand how they are getting on and whether they have been able to keep active. Of over 30 people called, there was a fairly even split between those who had been able to keep active and those who had not. Lack of access to facilities and low mood and motivation were proving to be important barriers for some, while there were also examples of people who had had to fulfil a caring role for a relative. Among those who had kept active, many had been focussing on household tasks including painting, gardening and building a shed. Others had been doing online videos or practicing routines and exercises that they had learned from the Active Lives sessions.

Similarly, there was an even split between group members who had kept in touch and those who had not; in some cases those who had not been in contact did not have the details of others or didn't have online access or group messaging services. Those who remained in touch with other members saw it as a good way to support each other and have a chat to share their experiences.

Those people contacted did typically state that they were motivated to participate in activities again when the situation allowed as they missed the exercise sessions and, in particular, meeting up socially. For some, the restrictions on exercise had brought home the benefits of being more active and so they felt highly motivated to pick things up again as soon as they were able. Those who were less motivated to participate in activities again had been struggling with their health more generally and had low mood. Friends and family were cited as people who could help support that person to get back to being more active once restrictions are lifted. In Grimsby the coordinator has facilitated online movement sessions and peer support meetings via Zoom as participants expressed that wanted to stay connected.

## Review of activities and outputs

In total the project engaged approximately 170 people, versus an original target of 288. Prior to the covid-19 crisis, project coordinators were prioritising attracting increased engagement with a revised target for the project of 200-220 people. Activities to increase engagement were based on lessons learned to date and included:

- A renewed approach to targeting existing groups, providing lighter touch support and engaging with groups who had a greater mix of active and inactive members, where previously the focus had been on largely inactive groups.
- A telephone recruitment drive in Central Lancashire. Of 29 people approached, 8 intended to attend sessions while 12 had declined due to a variety of reasons including challenges with transport, not being able to leave the house, already being active and being back at work. A further 8 individuals had been approached but conversations had yet to take place.
- In Newham an approach and presentation was made to a local aphasia group who subsequently decided not to attend as they were happy with their existing group. A lesson from this was that a trial day might have been a more successful way of improving understanding regarding the nature of ALAS. Two other local groups had also been identified as potential partners for purchasing equipment and supporting activity sessions, however initial conversations were curtailed due to the covid-19 outbreak.
- Networking with a social prescribing service in Grimsby (Thrive) after which successful referrals to the group were made.

### Key delivery data and KPIs

Participants in Grimsby and Central Lancashire attended more frequently, with over 8 sessions on average compared with 5.3 and 6.7 in Devon and Newham. The relatively low number for Devon may reflect the wider range of activities and ‘taster sessions’ organised, some of which may not have appealed to all members. We also noted that the average number of sessions attended was lower for the second wave of activities (6.5) than the first (8.4).

Coordinators noted that session attendance was typically lower around holiday periods such as Easter due to people spending time with their families or going away.

Figure 6: Session attendance

Area	N	Ave number of sessions attended
Central Lancashire	21	8.3
Devon	31	6.3
Grimsby	25	8.9
Newham	22	6.7
<i>Grand Total</i>	<i>101</i>	<i>7.5</i>

Source: Stroke Association

## Project reach and participant characteristics

Data regarding the characteristics of 126 of the project participants was recorded by the CRM data and is considered in detail in Appendix 2. This data shows that 60% of attendees were male across the project as a whole. Devon had the lowest level of female participation at 33%.

There were larger differences in the age profiles of participants by location. The average (mean) age of participants in Central Lancashire was 72 compared with 64 in Devon, 62 in Newham and 61 in Grimsby. Over 40% of the groups in Grimsby and Central Lancashire were accounted for by 65-74 year olds compared with 29% and 26% for Devon and Newham respectively. A further key difference between local groups was in terms of ethnicity where Newham was significantly more diverse than other groups reflecting local demographics.

A large majority of respondents (87%) had another long-term condition in addition to being a stroke survivor. High blood pressure and arthritis were the most common other conditions. Moreover, nearly two-thirds of participants reported communication problems while half disclosed mobility issues. This reflects the comments of project coordinators who highlighted that groups contained people with a wide variety of needs and that activities needed to be conducted in a way which was sensitive to this.

The profile of participants was broadly consistent between waves in each location, although as mentioned above, there were significant differences in group profiles between locations. Group co-ordinators did however note that the different groups did take on slightly different dynamics; as an example the Wave 2 Central Lancashire was felt to have a more positive and engaged outlook than the Wave 1 group at the same location.

We are unable to comment on the extent to which the profile of participants is representative of local stroke survivor populations. We note, however, that project coordinators have sought to raise awareness of the service through a wide range of promotional activities with the aim of reaching as many people as possible rather than focussing on particular demographic groups.

## Features of a successful delivery model

The following section highlights the main drivers of success and challenges encountered during the project to date considering the feedback from attendees (qualitative tool), learning logs completed by project coordinators, and volunteer review forms.

### ***Understanding individuals needs and motivations***

Feedback from group members in all locations consistently showed that they felt their own personal needs and challenges were understood and that this gave them confidence that the sessions were appropriate for them and that they were a safe environment to try new exercises and learn.

- “*It gave it a personal touch with Laura coming to the house to complete the initial paperwork and talking to us about the group*”
- “*The gentle way Sonya has two or three goes at encouraging us to come along and then, when you’ve got people, they stay*”
- “*Encouragement to start is really important*”



This was also supported by our observations from visiting group sessions in Grimsby, Devon and Newham where there was a very good rapport between individuals and the group co-ordinators which enabled the sessions to be well managed in an informal way.

Volunteers also had an important role to play in supporting the group co-ordinators and helping to manage the sessions by focusing on individuals specific requirements.

- *"I liked having the volunteers there. It felt good knowing that they accepted me and were there to support me"*

When asked more about this aspect during our service visits, we noted that this early investment in understanding the needs of members meant that they had realistic expectations regarding the sessions. This is likely to be a reason why only a small number of people were reported by coordinators to have dropped out of the sessions after joining.

Nevertheless, there were also some examples of people who had considered dropping out of the group but had stayed following personal encouragement from coordinators.

- *"I would have stopped attending if the coordinator had not encouraged me. I had given up and she persuaded me to restart and try again"*

A further example was someone who had left the group due to mental health issues but who was still in touch with the coordinator with a view to attending later in the year.

The importance of understanding individuals needs and investing time in this when setting up the group was also highlighted by coordinators and volunteers, with the latter group finding this a particularly rewarding aspect of their role.

- *"Completing consultations on a one-to-one basis has been useful as enabled me to support the stroke survivor to discuss and consider what they would really like to try and what their barriers are, perceived or actual"*
- *"I believe the visits are required to ensure the coordinator fully understands the challenges the client is trying to overcome .... but this is time consuming with the limited hours available."*
- *"I have really got to know all of the individuals in the group [in my role as volunteer]. Encouraged and praised them. Become a lot more confident in myself"*
- *"He [the volunteer] found this enabled him to get to know their needs better which enabled him to tailor how he worked in order to provide the support"*

### **Quality of the instruction**

In all areas, the sessions have been developed using instructors, staff and volunteers who understand the needs and challenges of working with stroke survivors and were able to build on the understanding of individuals' needs provided by the co-ordinators. They also received guidance and support in this area from the coordinators to ensure the sessions were specifically targeted. Group members commented on these aspects and a number of them also noted how exercises and stretches could be adapted for them to use in the home.

- *"The tutors know about stroke and the effects, this is helpful"*
- *"Exercises are adaptable and there are some movements we can do at home as part of our day to day"*

- “I adapt what Ralph [the trainer] does with us to do my own routine”
- “The type of exercises we were doing in the sessions made me realise that doing anything is important as long as I am moving”

Some group members also commented on the role of having volunteers alongside the instructors.

- “A trained instructor was important to motivating physical activity”
- “Having the volunteers supporting as well as the instructors provided more support”

Volunteers were able to learn how to run sessions from the instructors and increasingly were able to lead activities themselves as the project progressed, thereby reducing the reliance on instructors. Although we did not specifically test for it, we did not observe a difference in group feedback between co-ordinator/volunteer led session and those delivered by instructors.

In three of the four areas, exercises and sessions were developed to be progressive and encourage development over the duration of the project. In Devon, the emphasis was on trialling different activities and we noted that the reaction to these sessions in terms of enjoyment and outcomes was in line with the other areas. The only exception to the positive feedback regarding instructors came in Devon during the early stages of the project where some group members felt the badminton instructors hadn't really adapted the session to the needs of the group or appropriately shown them what to do.

In contrast, the surfing sessions (also run in Devon) which took many of the group very far out of their comfort zones were very well received indeed with significant praise for the instructors. That particular session was used to generate more awareness of the project in the local media.<sup>3</sup>

- “I felt very safe, even relaxed, although unable to swim. Actually enjoying my best experience in this decade”

### **Peer support and buddying**

Groups felt that they supported each other informally at the sessions and in terms of encouragement and motivation as well as, in many cases, speaking in between sessions on the phone. While this was not regarded as a ‘formal’ buddying approach, people found that they were able to develop links to share practical hints and tips with each other (and volunteers) in an informal way. People reported that they found this one of the most beneficial aspects of attending the sessions. In some cases, such as Grimsby, co-ordinators encouraged informal buddying particularly when encouraging newer members to feel welcome and more confident within the group.

- “I do not have a buddy but I am meeting up with another member to keep active, walking together.”
- “I was buddied with a volunteer initially to attend the gym. I then naturally buddied with another group member. We meet up to go to the gym.”
- “We are all buddies, it’s like a big family”

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<sup>3</sup> <https://www.northdevongazette.co.uk/news/stroke-survivors-go-surfing-wave-project-national-lottery-1-6183958>

When asked whether they would like to be paired with a buddy, group members typically did not feel this was necessary given the support that they had from both other participants and the volunteers/ coordinators.

- “We share experiences, watching others achieve aspires us to push ourselves”
- “Prompting other people in the group to get involved”
- “I came to be put back on my feet and it helps me when people say to me ‘well done’”

One group member did highlight that the size of groups was an important factor in ensuring the group dynamic is welcoming and supportive.

- “An important factor is that the group size isn’t too big – this can be daunting and off-putting as it may be too noisy”

The importance of the peer to peer discussions among participants was also referenced by the project coordinators and in Devon it was observed that the opportunity to have time before or after the session was important.

- “Not everyone stays at the end of every session for refreshments but those that do have built stronger friendships within the group”

In response, the coordinator had tried to mix up groups for some activities so that people could get to know each other and this had had a positive effect. In other locations it was observed that people formed friendships due to the informal nature of the activities themselves and this social aspect was key to people’s overall enjoyment.

Finally, it is worth noting that English language skills were felt to be a barrier for some of the participants at the second Newham activity sessions, possibly reflecting the demographic characteristics of the area. However, one member of the group did highlight that the sessions had improved their English language skills and they now felt more able to express themselves as a result.

### Digital interventions

Text reminders from co-ordinators or other group members were felt to be an effective way to engage, remind and motivate participants to attend, particularly as some had issues with memory loss.

- “Communication via texting is good”

One volunteer did however note that continued intervention from a coordinator was needed when it came to reminders and encouragement between group members.

- “Everyone exchanged phone numbers to stay together and keep active. This has faded to nothing. It needs a coordinator to continue to encourage”

One coordinator also sounded a practical note of caution regarding reminders, highlighting that some members of their group had mobile phones so were unable to respond to text or email reminders. Consequently, reminders had to be conducted via phone and this was found to be very time consuming as group members were often lonely and wanted to talk to someone.

This was emphasised by the feedback from the group members contacted during the covid-19 crisis; those members with limited online access or no access to group messaging services were finding it difficult to stay in touch with group members.

In contrast to text messages, very few group members had experience of other digital interventions and, where used, these did not seem to be a contributor to the success of groups. In Newham, only one person had heard of MyStrokeGuide<sup>4</sup> and that was because their friend had come across the website when trying to research activities for him to do. None of the group reported receiving text reminders. MyStrokeGuide was not referenced by the group in Devon.

In Grimsby the group had been introduced to MyStrokeGuide but take up was low. Only one participant had downloaded information and they didn't use the goal setting feature. In Central Lancashire, only one person had joined MyStrokeGuide, however everyone felt that the phone calls, texts, letters and reminders had been really useful in getting them to come along.

## Challenges encountered and responses

### Administrative burden

As previously mentioned, coordinators reported that there was a significant amount of administration in terms of processes and data gathering in order to get the project under way and that this was time consuming. They did appreciate that this was inevitable when trying to get the project set up and were positive about they received centrally from the Stroke Association, however concerns were raised that administration did create a significant burden given coordinators are only contracted for seven hours a week.

This concern reflected the fact that coordinators considered that spending time understanding group members' needs and building relationships with stakeholders (including trainers and potential activity leads) were critical to the successful running of ALAS in addition to the time spent leading the sessions themselves.

In addition to the project administration, the evaluation requirements were also viewed as challenging for both the Sport England self-assessment questionnaires and the qualitative evaluation tool.

- “Questionnaires are not suitable for our members: complicated; too long; too many options.”
- “I found it difficult to capture everything that needs capturing when you discuss as a group”

Although co-ordinators got more comfortable with the administrative requirements of the role, including the evaluation, as they became more familiar with them, the time pressures on them continued to be challenging as they typically wanted to focus on the relationship aspects of their role including engaging with group members and trying to attract volunteers. At busy times, the multiple aspects of administration were still a challenge.

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<sup>4</sup> MyStrokeGuide is an on-line information and self-management tool to support people who have been affected by stroke

- “I am struggling with the getting my head around all the admin for the various parts. For example, volunteers recruitment, volunteers CRM, becoming a SAVG and supporting the group well enough and keeping them information. Sometimes I’m not convinced I know what is going on either!”

### **Mixed ability sessions**

Volunteers initially highlighted that it could be challenging to look after everyone in an activity when there was a range of high to low level functioning such that everybody felt included and supported. This was particularly felt to be an issue in group or team activities, and less so for circuit style exercises when someone could opt out of an exercise if they were unable to do it. Over time however, this tended to become easier as volunteers got to know individual members better and the groups themselves started to gel.

While this process did represent a challenge for coordinators and volunteers, group member feedback suggested that this was well managed and this supports our own observations at the sessions we attended which were very inclusive with the groups themselves helping to make sure that everybody was included.

- “You may be able to do things they can’t and they may be able to do things that you can’t at the moment, but it gives you motivation”
- “I’ve met lots of people, all affected by stroke. We have various levels of severity but we can all talk. Even if you can’t join in you can come along and talk to the others and watch”
- “The sessions were at the level we need to maintain motivation”
- “You can do as much or as little as you can”
- “We all work at a pace that suits ourselves”

Overall, we observed that the inclusive nature of the group activities was a real strength of the project and in part reflected the social nature of the groups. However, while some group members may struggle with activities, there are others for whom the sessions can be a reminder of skills and capabilities that they had prior to their stroke

- “I feel that there has been improvements and I have seen a change in myself. I still struggle with frustration that I can’t do the same level of exercise that I could do before my stroke. I feel this ends up balancing the positives as I want to be at the same point of normality I was before my stroke”
- “I was really disheartened at first as the others are lot more severe [in terms of stroke effects], that depressed me”

This challenge in part reflects how individuals frame their challenges and the extent to which people adapt their expectations after their stroke. For one group member in particular, the sessions had been supportive of this process.

- “It’s made me realise I need to stop focussing on what I could do before my stroke, because I am still able to do things now but they are different”

## Sustainability

The final challenge that was raised by project teams and volunteers was regarding the sustainability of the project in terms of both maintaining the availability of activities and the motivation of stroke survivors to continue to access them.

- “We have looked at sustainability for the project and feel in order to keep stroke survivors active they will need to receive support from us and signposting may not be sufficient.”
- “Volunteers do not want the responsibility of running the sessions”

While group members demonstrated considerable enthusiasm for physical activity and the benefits that this was having, many did express reservations about their ability to participate in other non-stroke specific activities. This was felt to be a function of both the availability of suitable sessions and also individual confidence levels.

- “At the time of the sessions people got active. I am concerned that some people haven’t kept it up. I believe this is because of a lack of confidence”
- “Some of the clients have stated that other services available do not cater for their complex needs after a stroke”

There were different perspectives as to what could help to address the issue of sustainability in the longer-term, with some project members feeling that their role should be on supporting and encouraging individuals in the longer-term while others felt that a key challenge was to improve the availability of physical activity sessions.

- “I am hoping that the PT instructor would like to continue with the sessions independently once the project has finished and the sessions are established and that I would be able to refer into this with new clients.”
- “[I long for] a better platform and more availability to keep people engaged and support them to access existing community assets. In order to do this, we need to have time to build relationships with existing providers and educate them to make sessions more stroke friendly and remove unnecessary barriers”

The potential benefits of longer-term support were explored in Devon where the group was successfully developed into a voluntary group through sustaining the sessions and the relationships with participants over a longer period of time.

## Review of outcomes and impact

The following section considers the evidence provided by participants at ALAS sessions gathered using both the qualitative evaluation tool and the self-assessment surveys. We have also included comments from carers. Further details about these sources can be found in Appendix I.

### Has physical activity increased among participants?

Our discussions with stroke survivors and carers suggested that physical activity has increased among the majority of participants and we found that the examples provided and reasons for this were consistent across locations. These give us some confidence that the project is having a positive impact on activity levels. However, the survey analysis suggests that the extent of this positive change is modest. This may reflect both the wide variety of individual circumstances that make up each group along with limitations in the survey regarding its complexity and the terms used; for example some group members viewed the groups as a social activity rather than a physical activity.

#### Qualitative analysis

Groups in all locations reported being more physically active since starting the project.

- In Grimsby, all respondents reported being more active with the majority stating that they were much more active
- In Newham, four of the first group reported that their physical activity levels were the same as before starting Active Lives but the remainder of group were all more active. At the second session, one considered that they were more active while the remaining four respondents stated they were much more active.
- In Devon, a majority of people reported being more active, for the remaining people activity levels were felt to be about the same with only one exception who considered that they were less active.
- In Central Lancashire there was a more even split between those who felt their activity levels were about the same and those who were more active

In all locations, group members reported having more confidence in being active due to a combination of volunteer support, their peers and being in a safe environment as a stroke survivor. Motivation to be active was also reported to be higher.

- “*I was already active through golf, it was about confidence*”
- “*I feel more confidence to get more active*”
- “*I am more confident in doing things now*”

When asked how coming to the sessions had helped them become more active, similar themes were identified at all locations:

- “*The interaction with each other is what is motivating for a lot of people and why they come to the session*”
- “*I adopt a more positive approach to other activities*”



- “Previously I didn’t know what to get up for, it’s about making yourself do something. The motivation is to keep going.”
- “I have more information about techniques and approaches”
- “I used to play badminton and it gave me a boost to find out I can still do it, I can still hit that shuttlecock”

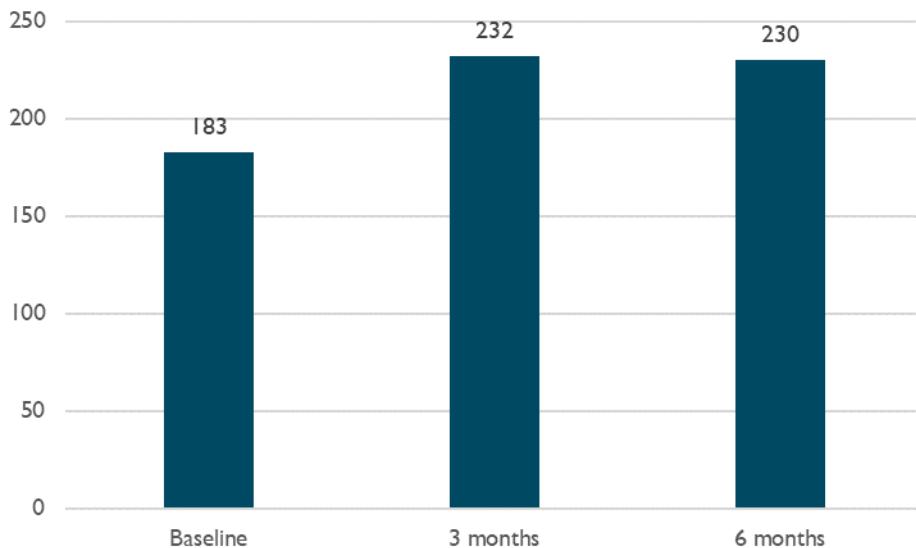
In line with the comments regarding the quality of the instruction and the tailored activities, many participants also remarked that the stroke-specific nature of the sessions was a key element in encouraging them to be more active, further

- “I might not have come if wasn’t just Stroke survivors. I put on a confident front as a way of survival but often don’t feel confident in front of others”
- “I didn’t think I could do it, now I can”
- “Everyone is in a similar position so you don’t have to feel embarrassed. Non-judgemental”

### **Survey analysis**

There are notable differences between the trend in physical activity as reported by the baseline and follow-up physical activity surveys and what was reported by the groups themselves using the qualitative evaluation tool.

Physical activity is measured using Sport England’s Active Lives survey which asks respondents to state in the last 7 days how many minutes of physical activity per day (on average) they undertook within the follow three categories: walking, cycling and sports or fitness classes. We analysed reported activity minutes across three types of activity as determined by the Active Lives survey. The following table reports the baseline and 3-month and 6-month follow-up total activity minutes (without accounting for breathlessness), categorised using the Sport England definitions of inactive, fairly active and active. The mean average of physical activity minutes at baseline was 183 minutes, 232 minutes at 3 month follow-up, and 230 minutes at 6-month follow-up. We noted from the small number of responses at the 12 month follow-up point that activity levels had declined to close to the three month level, though it is not known if this representative of the broader group.

**Figure 7: Physical activity minutes (n=62)**

Source: Stroke Association

### **Has physical mobility increased among participants?**

Our focus group evidence highlighted that physical mobility had increased for the majority of participants and that this was helping them to manage with day to day activities. The nature of these improvements and the examples provided were suggestive of small but positive changes in day-to-day activities rather than significant 'step changes' in symptoms. This was also reflected in the survey analysis with 50% of respondents reporting no problems managing day to day activities at the six month point compared with just over 30% at baseline.

#### **Qualitative analysis**

Group members across all locations reported a very positive view of changes in managing day to day activities as they relate to both to day-to-day living and also adopting, or returning to, a more active lifestyle.

- “I’m doing more. I cook, I clean, do the laundry. I wasn’t doing any of them before. I was going to the gym a lot before my stroke but afterwards I stopped doing things”
- “I can now wash my own hair which I couldn’t do before I started to become more active”
- “My dexterity has improved as well as the range of movement on my weaker side, I am now able to stir my cup of tea which I couldn’t before”
- “I have been going for more walks outside “After the surf session my walking improved, but I realise I need to get back in the water to keep this up”
- “Stairs are easier to manage”
- “I’m not using my walking stick [anymore]”
- “I shake less and my muscles have got stronger, my family have noticed”
- “It’s slow but it’s getting better. I’m going out a bit more with my daughters.”
- “I can now take the dog out for a walk”

- “I’m more able to get into the wheelchair on my own”

Examples like the above were also noticed by volunteers at each of the location.

- “... people were no longer using their hands to sit and stand because they were more confident in their movements”
- “Many people had to use their dominant arm to support the other limbs when exercising but now they are not needing to or doing it less frequently”

The nature of the changes observed by participants varied from person to person but we did note that balance and movement were both important factors in improved physical mobility.

- “I feel that I have seen an improvement of my general strength and balance”
- “Balance has become better, I have also learnt to adjust my ways and take more time”
- “I have learnt to take more time doing things and think about the movements involved”
- “I’ve only been coming a few weeks, doing the bowls, and I’ve noticed I’m able to move both arms better”

A number of people also highlighted improvements in coordination and concentration as being very important and resulting directly from the ALAS groups they attended.

- “I’ve always done a lot of exercise, I always walked. What really helps is coordination and concentration. Watching the ball come across, even if I don’t hit it every time. (table-tennis)”
- “For me the impact on my limbs wasn’t great but my cognitive improvement was much greater.”

Unique to the Grimsby focus group was a discussion on the impact of the sessions on people’s weight and this was felt to be an important success indicator.

- “I feel very good in myself and I’ve been swimming, lost weight. The people help keep me going and I like it”
- “With their [the group’s] help I can do more than I did and I’ve lost weight; a stone and a half”

A volunteer in Grimsby also mentioned weight when giving an example that they felt demonstrated the improvements in physical activity levels that people in the group can achieve.

- “He has increased his activity by 100%. He has lost nearly a stone in weight and is exercising every day. He has increased his walking distances and frequency and is very motivated to keep active. He has joined a gym.”

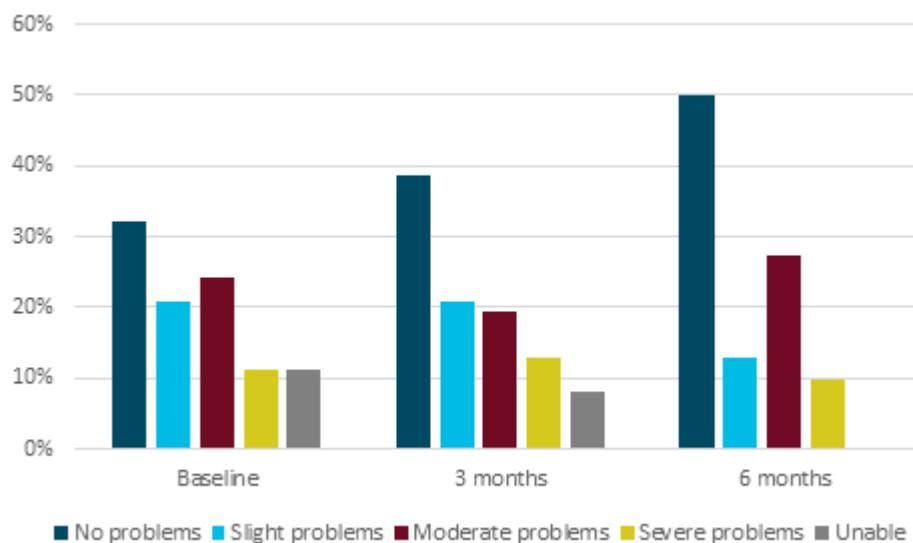
However, despite the overwhelmingly positive responses, we did also note a couple of more nuanced comments which suggested that people’s expectations and experiences within the group can differ depending on the extent of their symptoms.

- “I’ve been exercising for 8 years but I’ve not got any better.....The exercise has not made me better but it has improved my wellbeing”
- “I wanted to move my arm more but it has not done that”
- “A key learning [for volunteers] is that everyone is affected differently”

### **Survey analysis**

Over time, increasing proportions of respondents reported having no problems in managing day to day activities increased from 32% at baseline to 50% at 6 months. Moreover, the number of reporting that they were unable to manage day to day activities fell from just over 10% at baseline to zero at the six month point.

**Figure 8: Managing day to day activities**



### **Is there increased motivation to participate in physical activity?**

Confidence and motivation were highlighted consistently by group members on an unprompted basis and there was considerable enthusiasm for the groups themselves. There was, however, a greater reluctance to engage in other groups and, in particular, non-stroke specific activities and this is likely to account for the differences in motivation levels identified between the qualitative and the survey analysis. While both showed positive change, the survey analysis suggests a much more nuanced picture. It is also worth noting that while text messages and reminders were found to be helpful, other digital interventions were not widely used and did not appear to have a noticeable impact on individual's confidence or motivation levels.

### **Qualitative analysis**

Confidence was a key theme in all locations during the group discussions about motivation and in particular how it related to group settings, with comments such as “I’m raring to go”, “It’s given me a boost” and “it’s broken a negative mindset” indicative of the way in which people felt the sessions had changed how they approached both social groups and activity. This was particularly the case when groups discussions concentrated on the fun aspect of activities.

- “*You don’t have to be the best, let’s be honest, when we play bowls it’s hilarious*”
- “*Being more active doesn’t mean needing to do a marathon!*”
- “*I enjoy the social side, we have a laugh together (and at ourselves) and motivate each other*”

- “The social element is just as important. Helped my attitude to getting active because it’s encouraging being with others and I look forward to coming more”
- “Reassuring that you haven’t got to be the best – getting us to have the confidence to start and sharing our own experiences.”

Underpinning this was a sense that confidence had come from sharing experiences and stories as well as supporting each other in sessions to move forward. However, while many people felt much more confident, not everybody felt as confident about engaging or being more active in a non-stroke specific environment.

- “I would attend another block of sessions in this environment, but I am not going to pursue anything else. It has highlighted what I can’t do”

Two of the volunteers highlighted that a key part of their role was to help maintain motivation and encourage people to be more confident about participating where appropriate.

- “.... gave up completely half way through. We encouraged him to continue and he came back and completed the course”
- “I’m concerned that some people haven’t kept it up, I believe that this is because of a lack of confidence”

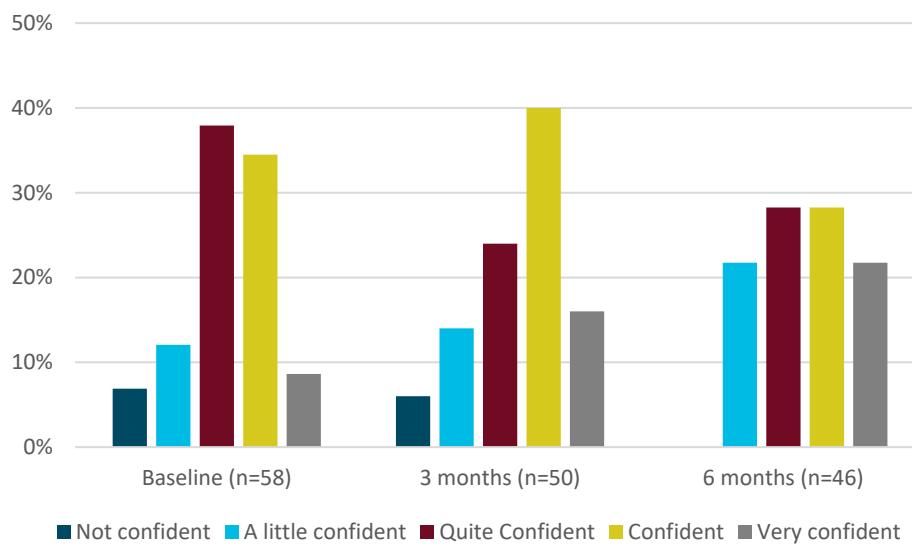
It is worth noting however that comments regarding limitations or barriers were not observed to the same extent in Devon where participants had engaged in a wide mix of activities. While some had reported that certain activities were not for them, it seems that all had enjoyed at least one of the activities and this had improved motivation, resilience and perseverance according to the group. However, some participants in Devon did feel that it may have been helpful to split the group for certain activities if some members were more experienced than others.

There were also examples of people who have been motivated to do more exercise individually since starting ALAS. This was particularly the case in Devon, where one participant had started using equipment including a football and basketball hoop to exercise more in her garden.

- “I bought an exercise bike for home and have been going on that”
- “I have been doing some of the chair based exercises at home whilst sat down”
- “I’ve done a lot more walking and I did the Couch to Coast programme (relates to building up to complete a walk around Westwood Ho on the SW Coastal Path)”

### **Survey analysis**

There is an increase between baseline and 3 months in confidence, with higher proportions feeling confident or very confident in groups, and fewer feeling ‘quite confident’, ‘a little confident’ or ‘not confident’. At the six month point, there is an increase in participants who are ‘very confident in groups’ and a fairly even spread across the different categories with the exception of ‘not confident’. No respondents stated that they were ‘not confident’ at the six month point.

**Figure 9: Confidence of being active in a group**

Source: Stroke Association

## Is anxiety and loneliness reduced among participants?

The social aspect of the group was generally held to have been positive for the anxiety and loneliness of participants. This positivity was most apparent in the group discussions while the findings from the follow-up survey data were more nuanced.

### **Qualitative analysis**

In the majority of focus group discussions, the issues of anxiety or loneliness did not arise explicitly, which likely reflects the reluctance of people to talk openly about these issues in front of others. However, where people did respond, these issues were commonly highlighted and recognised by a majority of group members to some degree.

- “Initially I was feeling alone and not realising there are other people in the same boat. Working as a group helps each other along”
- “Being active in a group means I am less isolated as I live on my own and this is the only chance I get to be with others”
- “Before I started attending the group I felt a little bit isolated from the stroke and the group really helped me to start doing things again because I really wasn’t doing anything. I was sitting on the sofa doing nothing all day and it got me to actually get off my backside and do something to help myself”
- “Yes I liked being with other people. I feel happy when I am here”

Having people to talk to and share challenges with was felt by many to be a major benefit of attending sessions and in some cases people did refer to be benefits this had on their mental wellbeing.

- “I’m relaxing more with my meditations after doing chair based exercise. It reduces anxiety, I do the exercises every other day”

- “I feel a lot better and calm. I talk to other people like me”

In addition to these specific comments, focus groups also highlighted the related social benefits of the group when discussing the impact of ALAS on their quality of life which is covered in a following section.

### **Survey analysis**

As part of the self-assessment questionnaires, participants were asked the extent to which they felt four different emotions over the past two weeks to indicate general levels of anxiety. Responses were mixed regarding a sense of anxiety appears to have worsened over the course of the project with no clear trend. However, this was not the case for ‘worrying too much’ where the proportion saying ‘not at all’ increases from 31% at baseline to 39% at 3 month and 48% at 6-month follow-up.

A small number of participants did become worried about becoming more active over time with greater proportions worried or quite worried at both 3 months and 6 months, compared to baseline. However, there was a decline in those feeling very worried and just under 60% respondents stated that they were ‘not at all worried’ about becoming more active which was a slight increase from the baseline level.

### **Are stroke survivors and carers more confident in engaging in group/community activities?**

There was a varied response by groups to questions regarding their engagement in other group or community activities since getting involved with ALAS. In Central Lancashire, only one group member had enrolled on another course while other group members were focusing on keeping activity individually. However, in Grimsby there were examples of people joining other groups as well as some group members joining the gym together. In Newham two group members had started to get more involved in their local community while a further individual was investigating courses he could attend to learn new skills.

There were also examples of people going out more with existing friends and family.

- “I feel more confident to walk around town now”
- “I’m more social now and I talk to more people. Before I didn’t want to. I walk out my front door more, I don’t want to stay in”
- “I’ve been going swimming and doing ‘chair keep fit’. I walk with my daughter and friends”

Participants in Devon, where the project involved taster sessions of a variety of activities, had shown the most engagement in other community activities including signing up for golf lessons, swimming and Tai Chi. The Devon group also commented how supportive the local golf club had been when they had a session there and that they felt people had the club had been very keen to involve more people in their sport. This also highlights that, as well as differences in the age profiles within each area, the ability to engage in other group/community activities will be dependent on the availability of such opportunities in each area.

As a final remark, one group member did highlight that, as someone who was still employed, it was challenging for her to be involved in other suitable activity groups as they are typically held during

the day. The timing of sessions may therefore preclude some people from joining the activities and contributing to the older demographic profile of some of the groups.

## Has participants' quality of life improved?

Participants felt that their quality of life had improved in a number of different aspects and common themes around wellbeing, social activity and friendship were enthusiastically highlighted in all locations. Although the survey analysis suggested more limited change, this may reflect the more closed nature of those questions compared with the free ranging nature of the qualitative analysis which provided numerous rich examples of positive impacts.

### Qualitative analysis

The majority of respondents in all locations reported a positive or very positive impact on the quality of life and gave examples of the way in which this manifested itself. Generally day to day well-being was the most commonly cited benefit of attending the sessions.

- “It boosts your confidence and then your attitude changes. You want to do more, not just sit around”
- “What benefits did I find? You generally just had an uplift of a purpose and a better understanding of what's going on”
- “You realise you're still you”
- “I have the confidence to go back to work”
- “I feel happy when I am at the sessions”

Very closely linked to individual well-being and quality of life was the social aspect.

- “The group is like a family”
- “I don't have a social life as such but I enjoy coming here”
- “It's all about group therapy”
- “Coming to a group with others who have something in common encourages you even if you stay quiet”

The sharing of experiences within the group was commonly cited as beneficial, as was the welcome given to carers and friends. One participant had brought her granddaughter along to one session and remarked how it was both nice for them to do something together and also how it had helped the granddaughter to understand more about her condition. Also mentioned was the way in which Active Lives gave people something to look forward to and a focus point for the day.

- “The whole format of the session is beneficial. It provides structure - so it means I have to make sure I am ready and here for a certain time, I get out and drive here and know I will be catching up with like-minded people whilst doing the exercises”
- “On the day, yes [it does improve my quality of life]. I want to be involved but at home I can't be bothered. This gives you a push”
- “I never went out before these sessions”
- “[If it wasn't for the sessions] I would be sat home alone”
- “Without it I wouldn't do anything, it's ever so easy to do nothing”



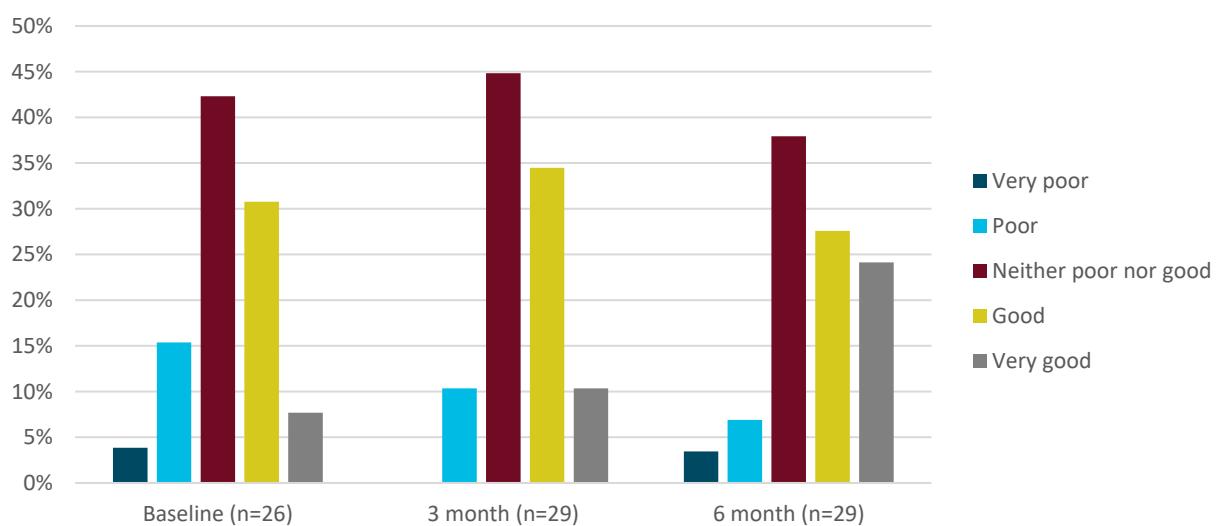
Finally, a recorded interview from a participant at the Grimsby group also highlighted the broader benefits of the project.

- “I’m at a position where I’m returning to work, I’ve got a back to work date, and without the group I’m not sure I’d have got to that point because I’ve been physically getting up, becoming active and walking. My problem was that I couldn’t physically get to the bus stop and I wouldn’t have got there without the help and support of everybody at the group”

### **Survey analysis**

A greater proportion of participants stated that their quality of life was ‘very good’ or ‘good’ at the 6-month stage (52%) compared with 3 months (44%) and baseline (39%). Trends within related questions regarding confidence asking for people for help and satisfaction with relationships also showed also showed a positive trend over the period.

**Figure 10: Quality of life**



Source: Stroke Association

Data for other quality of life metrics, such as achievement of self-set goals and happiness with relationships did not show a clear trends. Both of these metrics declined at the baseline to three month period and improved from the three to six month periods, but these changes were not felt to be significant and may be impacted by other factors such people setting more challenging goals as a result of the ALAS sessions. While Sport England uses the achievement of self-set goals as an indicator of self-efficacy, we felt that attendees provided clearer and more details responses regarding their ability to manage their condition what asked about their use of health and social care services.

## How has participants' use of health and social care services changed?

Both the qualitative and quantitative analysis does suggest that many participants use of other health and social care services has declined following their involvement in Active Lives after Stroke. A key theme cited for this was the sharing of advice and tips among group members themselves which had improved their self-efficacy. However, the nature of these changes and reasons for them do differ significant on a case by case basis.

### Qualitative analysis

While group members in Newham and Central Lancashire were generally reluctant to explore the extent to which they were using health or support services differently since starting Active Lives, those in Devon and Grimsby were more forthcoming, most notably regarding their use of GP services.

Access to GP services was cited as a problem by a number of respondents in Grimsby with three stating that they were unable to get appointments. We did not feel it appropriate to further explore these issues in a group setting. However, some group participants did state that they felt they didn't need to see the GP as a result of attending Active Lives sessions.

- “I have been [to see the GP] but now I can come here”
- “Managing the effects of my stroke is something that I’m learning all the time”
- “I’m a lot better at managing my diabetes and blood pressure.... I have more get up and go in me”
- “I haven’t need to go to see my GP since I’ve been coming here because of the confidence in myself and I don’t feel so ill”

In Devon, there was a high level of consensus that the sessions had led to improved understanding of their condition and therefore the type of support that they needed.

- “I get hints and tips from the group and know what is normal so don’t need to go to the Doctor so much”
- “The consultant doesn’t know how it feels but the group knows what it’s talking about”
- “If I go to the GP I just get a pill, that doesn’t help really”

In addition, one member highlighted that their movement had improved despite their physiotherapist previously telling them that they had reached their maximum level of capability after their stroke.

- “The physio said ‘you’re the best you can be’ but I’ve had more improvements at the group”

Another participant also commented that they had been told off by their Stroke Consultant for participating in a bungee exercise session; the participant had been wearing a heart rate monitor which got up to 180 bpm during the activity.

- “they told me, “you can do everything but not bungee jumping!””

## Survey analysis

Self-assessment questionnaires at the six month follow-up period showed a decline in the usage of all categories of health and social care services compared with the baseline level with the biggest falls apparent in visits to A&E, an occupational therapist and a physiotherapist. This overall fall was despite an increase in the usage of some services, particularly occupational therapists, speech and language therapists and mental health/counselling services at the three month period versus baseline.

## Are participants motivated to sustain physical activity?

The final questions of the qualitative evaluation tool explored in a group setting whether participants were intending to remain active after the sessions had finished and how they intended to do so.

In Newham, all participants have stated that they intended to stay active unless physical symptoms prevented them from doing so. The main ways in which people intended to do this were by carrying on with the attending the sessions and by going to the gym. One participant intended to carry on walking which she had been doing more since starting Active Lives while another was looking for ways to integrate the exercises at home. One group member did mention that they would like to carry on with the sessions but would not be able to do so if there was a fee involved. Despite this members have highlighted that the gym facilities and some of the sessions run at the nearby Olympic Park are suitable for stroke survivors.

In Grimsby, most of the participants indicated that they would continue to be active. At the first focus group session there was a discussion about the role of the weather and the importance of the group dynamic in this. Regarding the weather, some group members felt that the winter was a harder time to get motivated to be active while others felt that it was a good time to run the sessions as it was a much needed reason to get out.

At the second focus group in Grimsby, all but two of the group intended to remain active. Those two who did not intend to stay active stated that they would like to continue but would not do so if the group was no longer running.

- *“My confidence has grown but I will not join another group. I would come back here but I’ve not got the confidence to go anywhere else”*

There was a mix of different activities that group members were planning to do in order to remain active including chair-based exercises, walking, swimming, going to the gym and attending other groups such as gardening clubs.

- *“I will attend other groups, everything we have done makes me feel stronger”*
- *“I will continue exercising at home”*

Some of the respondents indicated that they had found out about the other activities via the group leader and via information leaflets, adding that they would go along to these sessions with other group members.

In Devon, all but one of the participants at the two focus groups indicated they would continue to be active with many expressing a preference for a social group. The social aspect appeared to be particularly popular with participants in Devon and some people highlighted a desire to join a broader range of groups including a singing group. Some members also stated that they enjoyed the social aspect so much that they would still attend even when their symptoms prevented them from



actively participating in the sessions. One member also highlighted that their GP was very supportive and actively encouraging them to be more involved in groups of this nature.

In Lancashire, there was a difference between the views of the first and second groups of participants in terms of how they responded to this question in the discussion. The first group discussed the possible barriers to continuing to being active. Physical barriers such as stroke effects and fatigue were highlighted as well as concerns that other activity sessions in their community were not stroke specific. The second was more positive, although the subject of locally available facilities was again an important issue.

- “I still want to concentrate what I do on my weaker areas so that I can carry on strengthening them”
- “I want to carry on doing more things in the house”
- “Do hope to attend a gym which is something I wouldn’t have previously even thought about”
- “I am looking to go to a specialist gym and have been referred there, think that being with others and having something with structure will make me more likely to carry on”
- “It’s finding where these facilities are and what is accessible for us, I didn’t know that I had a local leisure centre”



## Conclusions

### Changes observed through the project

Stroke survivors and carers across all four locations reported that they have found the Active Lives after Stroke project to be beneficial in terms of supporting and encouraging them to partake in physical activity and achieving improvements in managing day to day activities as a result.

Improvements in physical strength as well as co-ordination and balance were experienced by many participants which they felt was as a result of participating in activities. These improvements taken together had led to many people being more active around the house as well as stating that they were able to enjoy family interactions such as walking and playing with grandchildren.

The sessions have boosted confidence and motivation with the social aspect and peer support seen as critical to this, even among those participants and carers who have not reported benefiting from the physical activities themselves. The positive impact on mental wellbeing for stroke survivors and carers who attended groups has been clearly and consistently highlighted during our fieldwork. This was also true for volunteers who reported very positively on their experiences and greatly valued the skills that they had developed and have the opportunity to practice.

The stroke-specific nature of the activities has been crucial in terms of both the support people get from within the group and the tailored nature of the programme which, in many cases, has provided people with exercises to do at home. The investment of the project coordinators and volunteers in understanding each individual's needs and motivations was cited in many cases as being an important factor in ensuring that the activities are relevant and beneficial to the group as a whole.

While participants stated a desire to stay active, many barriers were highlighted including a lack of other stroke suitable exercise classes or facilities. While this raises some questions regarding the extent to which health improvements and behaviour change will be maintained in the longer term, many people were being more active in their daily lives in ways which are likely to be more sustainable, such as housework or domestic chores. The number of group members who had maintained activity levels in this way during the covid-19 epidemic suggests that many participants have both the skills and inclination to sustain changes made as a result of the project.

We have also observed that participants have very different interpretations of what constitutes physical activity. Many members appeared to classify their involvement as a social activity as distinct from a physical activity and this may reflect some of the more modest changes observed in the quantitative analysis compared with the qualitative evidence. Moreover, the normalisation of increased activity levels in day to day life makes it challenging to monitor the extent to which changes are sustained in the longer term.

To this end, the project can be seen as consistent with the strategic goals of Sport England, the Stroke Association and the Richmond Group in that it has enabled and normalised a more active lifestyle for many participants with a subsequent impact on their overall wellbeing. However, we are concerned that the 'breathlessness' measure used by Sport England is not an effective way of understanding the progress of stroke survivors in this context. This is because improved strength and mobility has led to many daily tasks becoming more achievable which can reduce 'active minutes' using the breathlessness despite the individual being both more active and healthy.

As a final observation, many participants reported using other health and social care services less as they become more active. While it is very challenging to measure the economic impact of this, the way in which groups shared knowledge and experience appeared to have an impact on individuals' self-efficacy which in turn might be expected to lead to less demand for other services.

### Sport England behaviour change model

Another way of considering the Active Lives project is to consider it in relation to the Sport England behaviour change model shown in the below figure.

Figure 11: Sport England behaviour change model



Source: Sport England: Towards an Active Nation 2016-2021

In the Sport England model, there are three overlapping phases:

- **Tackling inactivity:** pre-contemplation and contemplation. These stages cover recruitment to the project and one of the key lessons has been the need to understand individual requirements and give people confidence to come along and try the session to see it is for them. The different profiles of each location in terms of population density and social-demographic characteristics allowed comparisons to be made about context specific factors which also included Stoke Associations existing profile and groups within the area.
- **Creating regular activity habits:** contemplation, preparation and action. A key success factor for ALAS has been establishing rapport and trust between the individual and the coordinator/volunteers to help encourage regular attendance. The friendly and stroke specific dynamic of groups can help get people to start attending sessions and to feel comfortable that this they are in a suitable and safe environment to start to become more active. To this end, it is helpful to think about regular habits in terms of attending sessions as a first step with participating being a second step.

- **Helping those with a resilient habit stay that way:** action and maintenance. The relatively low levels of attrition from the groups as reported by coordinators suggests that the sessions are well targeted and that participants are benefiting from being more active. Coordinators have quickly engaged and followed-up with people who have missed sessions to offer support and encourage them to return without pressurising them. The understanding that coordinators have of individuals allows them to reinforce the benefits of activity on the day to day life of that person. The social aspect of groups is also important in this regard, many participants commented during focus groups that they would attend even if they were struggling that day and unable to participate in the activities themselves.

As well as considering the project in terms of the Sport England model, it is also important to consider it in the broader context of people's behaviour after the project has finished. The completion of the sessions effectively marks a break in the 'maintenance' phase and the individual might be expected to move back to an earlier phase of the model.

Our observation of the groups is that participants are actively contemplating other forms of activity and are broadly aware of local options. Project exit strategies have encouraged people to try other sessions (often together) and taster sessions have also been organised. In some cases (e.g. Devon) the group is trying to continue in its current form while in others that is not practical and so the focus has been on trying to get people to the action stage with other services.

Due to the covid-19 crisis and sudden cessation of services, it is difficult to assess how successful the project has been (or is likely to be) regarding migrating participants to other forms of activity. Nevertheless, it is also important to recognise that the action and maintenance phases can be maintained in the home and that many participants were doing just that despite the lockdown conditions.

## Recommendations

We have observed that the co-ordinators and the central team have been sharing their experiences as the project has progressed and, as such, that many of the operational lessons have been captured. Considering all the available evidence, there are some issues that appear to be consistent across all four locations and we make the following recommendations for future service developments relating to activity for stroke survivors and their carers.

- **Multi-activity formats are considered where appropriate.** Feedback from the Devon multi-activity group was very positive, particularly regarding the extent to which members had enjoyed trying new things and the way in which this had energised the group. The Newham group also provided feedback that multiple activities would mean using different muscles and that having a mixture of safe alternatives would be better than going to the gym. It is also worth considering whether exposure to multiple activities is more likely to lead to an increased willingness to participate in other groups.
- **Volunteer availability and training is recognised a key component of project design.** Volunteers played a key role in many areas and were able to establish strong relationships with participants and ensure that they enjoyed and benefit from the activities. Volunteers also fed back that they benefited from the training. However, challenges recruiting and encouraging volunteers were encountered, particularly in Newham.

- **Informal buddying helps build connections within the group.** Encouraging people to support and motivate each other builds strong connections within the groups and a sense of fun and enjoyment which participants consistently cited as a key reason for attending sessions. This social aspect was very important, with people often regarding other attendees as friends and numerous examples of people starting to meet up outside of the groups.
- **Carers are considered as a key audience.** Carers who attended sessions reported similar feedback and outcomes to stroke survivors in terms of improved activity levels and factors related to broader health and wellbeing. As well as indirectly benefiting stroke survivors, carers are likely to be key influencers of the behaviour of stroke survivors with regards to activity levels and are also, through attending the sessions, likely to learn from other group members in terms of helping to overcome day-to-day challenges and managing stroke effects.
- **Participants are used to help promote the service.** We observed that participants are very positive about the sessions and are able to emphasise the social and supportive nature of the groups in a way which resonates with others. However, one limitation of this approach is that it can reinforce any demographic biases within a group (e.g. by age profile or gender) as awareness improves among groups of friends of a similar background or outlook. As such it is important that awareness raising is considered within the context of the wider population of stroke survivors within an area.
- **The language of physical activity is considered sensitively:** we observed a number of examples of participants stating that they were not more physically active, yet demonstrating enthusiasm for the fact they were able to do much more as a result of the sessions, such as walking with family. Phrasing such as physical activity did not appear to resonate with many participants, whereas discussing activity within the context of an individual's capabilities and daily life was a consistent theme in the many success stories that we heard. We also noted that participants often referred to groups as being a 'social activity' rather than a 'physical activity'. It will be important to consider this in the organisation's information resources and toolkits.
- **Relationships that have been built are maintained:** significant resources have been invested in relationships to build awareness among organisations of the needs of stroke survivors and their carers, and to encourage people to engage at a local level. Examples of relationships established include RYA Sailability and Active Newham at a local level, and Table Tennis England and Swim England at a national level. These efforts appear to have been successful in building support and establishing practical advice. Given that organisation's priorities and resources are likely to be impacted by the covid-19 crisis, continuing to develop these relationships will be important to ensure that progress is maintained.
- **The consequences of covid-19 on people's motivations to be active are understood:** the comments from participants contacted at the start of the crisis in March and April 2020 suggest that many were continuing to practice exercises learned as part of Active Lives and were missing the social aspect of the groups very much. Many of these people were also doing online exercise classes, the awareness of which has been heightened by media coverage. In contrast, low mood and a lack of motivation as a result of the lockdown situation was also commonplace among other participants. There is a risk that the least confident and most anxious stroke survivors and their carers will be reluctant to engage in social activities for an extended period. The organisation will need to be sensitive to very different perspectives regarding social interaction and exercise among stroke survivors when services are able to resume.

## Appendix I: Description of data inputs

This monitoring report is based on three sources of evidence.

### Self-assessment survey

A self-completed survey of participants is administered by Stroke Association staff (and/or volunteers) at four time points: pre-intervention, 3, 6 and 12 months post intervention. The survey includes the following instruments:

- **Short active lives survey:** a Sport England designed and advocated survey for all projects in the Movement for All Programme. The survey assesses the number of days and the total time spent doing physical activity in the past seven days (walking; cycling; and sport, fitness or dance). It also asks respondents to indicate whether the activity raised their breathing rate, in order to determine whether it was at least moderate intensity.<sup>5</sup> It is based on the longer Active Lives survey, Sport England's more in-depth measure of physical activity in the population
- **Stroke Survivor survey:** a Stroke Association designed instrument that measures stroke survivor outcomes before activity and capture change against these outcomes (long and short term) that occur after physical activity group ends. This survey was also developed to provide measures relevant to the Traverse evaluation of the broader Sport England evaluation. It includes:
  - Managing with day to day activities
  - Self-confidence
  - The motivations for physical activity (referencing peer support and digital services)
  - Anxiety and loneliness (four adapted items from the GAD-7 instrument)
  - Quality of life
  - Service use (e.g. adult social care, GP, acute/emergency health services etc)

### CRM/registration forms

The registration form that beneficiaries complete when signing up to the project records:

- Ethnicity
- A self-declaration of whether an individual does fewer than 30 minutes of activity per week
- Medical conditions
- Mobility
- Communication

This provides information on the demographics of participants, particularly if this can be linked to the CRM system. It can also indicate co-morbidities among participants.

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<sup>5</sup> Milton K, Engeli A, Townsend T, Coombes E, Jones A (2017) The selection of a project level measure of physical activity. London: Sport England.



Stroke Association's CRM system provides data on all referrals into the project and tracks those who become participants and the types of activities they participate in, including if they choose to leave the programme. Metrics include:

- Number of participants regularly attending a group
- Number of sessions attended
- Duration/intensity of activity

## Qualitative evaluation tool

Working with the Stroke Association project team, Cloud Chamber have developed a qualitative evaluation tool to enable group leaders to facilitate a semi-structured focus group with stroke survivors and carers who attended the sessions towards the end of the activity programme. The tool comprises a mix of questions which seek to understand qualitatively the impact that Active Lives After Stroke has had on them. The key questions that the evaluation tool has been designed to explore are shown in the below table.

**Figure 12: Key questions for the evaluation tool**

Theme	Purpose and practical considerations
Physical activity	Establish self-perceived changes in PA, and attribution to the intervention Understand motivations for changes in physical activity Understand features of the delivery model that contribute (including peer support and digital interventions) Establish longevity of effects Independence of physical activity uptake (i.e. taking a walk, going for a swim) Attitudes towards physical activity
Mobility	Explore changes in physical mobility Attribution to the project
Mental wellbeing	Anxiety and loneliness Quality of life
Individual development	Confidence in engaging in group activities Civic participation (engagement in volunteering) Exploring self-efficacy Encouragement of other stroke survivors to join and remain active in groups
Other	Explanations of service use changes Exploring other achievements (work, education, civic participation)

Using the qualitative evaluation tool alongside the survey forms will enable the evaluation to consider different perspectives and understand the mechanisms for changes in behaviour and outcomes at both an individual and group level. This approach will also provide us with real world examples of change that can be used to inform the development of the project and future service development.

The qualitative evaluation tool was tested in Grimsby and Newham in April 2019 at which the session was led by the Group Leader with Cloud Chamber supporting and observing the sessions. These experiences were used to develop a user guide for the group leaders to run the sessions independently.



## Carers tool

Following a similar process to the qualitative evaluation tool, Cloud Chamber developed a set of questions to be used with carers who have attended the group with the person that they care for in order to understand any changes arising as a result of attending the sessions on both the person that they care for as well as the carers themselves in terms of physical activity, loneliness, stress/anxiety and their ability to look after their own health.

## Learning log

Learning logs are kept by project staff. These capture feedback from volunteers on their interactions with stroke survivors and their carers, and their thoughts on how responsive stroke survivors have been to activities. This is completed quarterly by staff responsible for each project area. The form includes:

- Progress in the quarter
- Reflections on what has gone well and what can be learned from this
- Improvements and barriers
- Sustainability and scaling considerations
- Celebrating success
- Plans for the next quarter

## Volunteer review form

The volunteer review meeting form is both a supportive and an evaluative tool. Volunteers meet with a member of Stroke Association staff (a volunteer manager), using the form to have a structured conversation about the both the impact of the project on them, and on participants they support. At the same time, the activity is an opportunity for volunteers to reflect what they have learnt, and how things might be improved in future. There are 8 open-ended questions which are shown overleaf.



**Figure 13: Volunteer review form questions**

- What activities have you been involved with since your last review meeting? Is there anything that has gone well or that you have particularly enjoyed?
- Has there been anything that hasn't gone so well? Is there anything we can do to help?
- You have been supporting participants to make changes and become more active, have you seen this in the sessions? Can you give examples?
- Has the role been what you expected? In your interview/last review you said you wanted to XXX? Have you achieved this?
- What have you learnt in your role so far? Have you completed any learning or training since your last review? If yes, what did you do and was it beneficial?
- What would you like to achieve during the next review period e.g.: develop in your current role or try a new role? How can we help you to do that?
- Is there any further training or support that you need?
- Any other matters that you would like to talk about? This could include any updates about the charity, ways of working or any upcoming events or campaigns



## Appendix 2: Project reach and participant characteristics

The following section outlines the profile of group members at the four locations based on the baseline survey for survey for all waves, which was completed by 126 people. Differences in the demographic profile within each area for different waves were not significant.

### Service area

Overall, the project has engaged with over 100 individuals, 54 in Wave 1 and 57 in Wave 2. 15 individuals had taken part in wave 3 for whom baseline data was collected. See Figure 14 for an overview of participants by service area and wave.

Figure 14: Participants by service area and wave

Service area	Wave 1	Wave 2	Wave 3	Total
Central Lancashire	14	7	5	26
Devon	14	25	0 <sup>6</sup>	39
Grimsby	11	15	10	36
Newham	15	10	0	25
All areas	54	57	15	126

Source: Stroke Association

### Gender

Across all four services, 60% of clients were male and 40% were female (n=126). The higher number of men than women was common to each service area, as shown in Figure 15.

Figure 15: Participant gender profile by service area

	Central Lancashire	Devon	Grimsby	Newham	All areas
Female	42%	33%	39%	40%	40%
Male	58%	67%	61%	60%	60%
N	26	39	36	25	126

Source: Stroke Association

### Age

The average age of participants was 64 (mean average, n=123). The average age was highest in Central Lancashire (72) and lowest in Newham (62) and Grimsby (61).

Figure 16: Participant age profile by service area

Metric	Central Lancashire	Devon	Grimsby	Newham	All areas
Mean average age	72	64	61	62	64
Maximum age	89	83	77	79	89
Minimum age	50	39	27	40	27

<sup>6</sup> The baseline data for 12 people who planned to attend the next waves of activity in Devon was collected but has not been included in our analysis as these sessions did not take place due to the covid-19 outbreak



Range (years)	39	44	50	39	62
N	25	38	35	25	123

Source: Stroke Association

Figure 17 shows how the age distribution differs for each location.

**Figure 17: Age distributions of participants by service area**

	Central Lancashire (n=25)	Devon (n=38)	Grimsby (n=35)	Newham (n=25)	All areas (n=123)
25-34	0%	0%	3%	0%	1%
35-44	0%	5%	11%	12%	7%
45-54	12%	26%	11%	28%	20%
55-64	12%	21%	29%	12%	20%
65-74	40%	29%	43%	28%	35%
75-84	20%	18%	3%	20%	15%
85+	16%	0%	0%	0%	3%

Source: Stroke Association

## Ethnicity

The majority of project participants were White (87%, n=124). In Newham the proportion of people in the White ethnic category was 40% compared with Central Lancashire and Devon where the corresponding statistic was 100%. The ethnicity of participants by area is shown in Figure 18.

**Figure 18: Participants by ethnic category and service area**

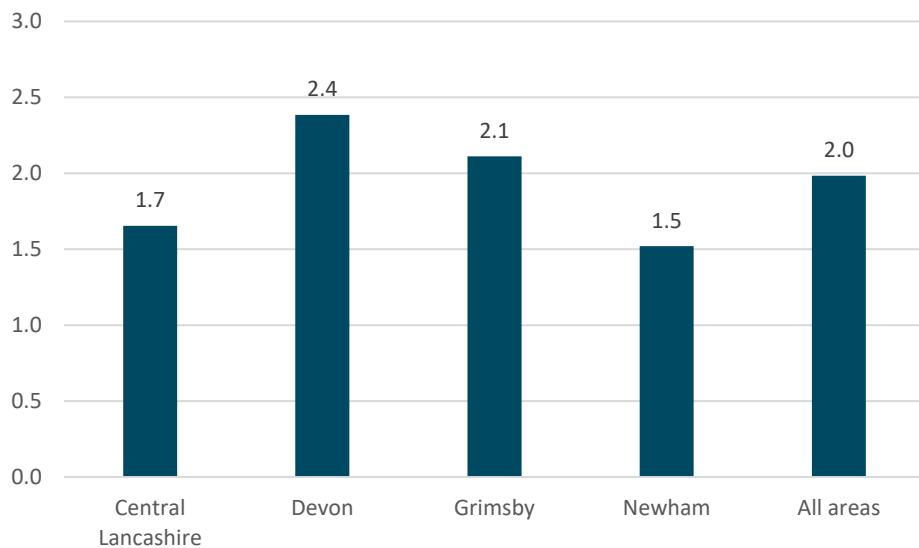
Ethnic category	Central Lancashire	Devon	Grimsby	Newham	All services
White	100%	97%	97%	42%	87%
Mixed/Multiple ethnic group	0%	0%	0%	4%	1%
Asian/Asian British	0%	3%	0%	13%	3%
Black/African/Caribbean/Black British	0%	0%	0%	42%	8%
Other ethnic group	0%	0%	3%	0%	1%
N	100%	97%	97%	42%	87%

Source: Stroke Association

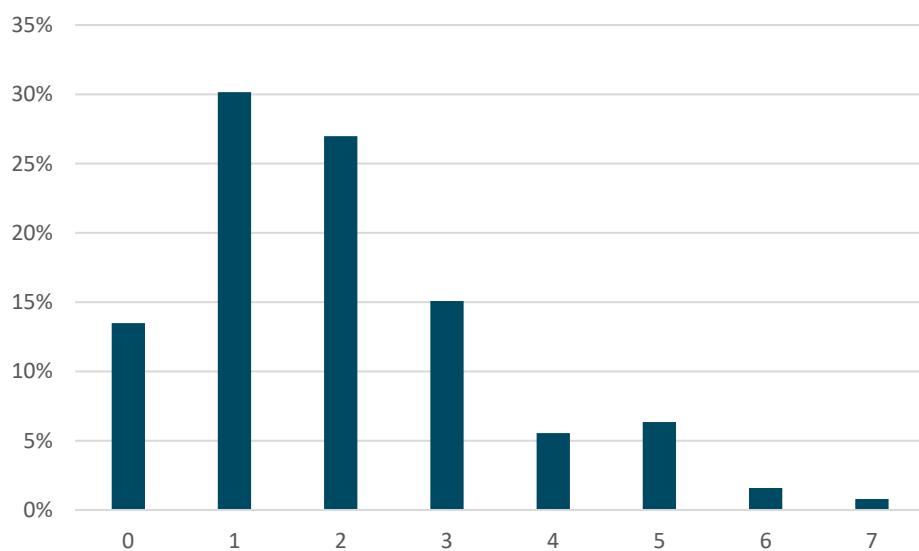
## Other long-term health conditions

A large majority of respondents had another long-term condition in addition to being a stroke survivor (87%, n=126). Newham had the lowest proportion with another long-term health conditions; this is likely to reflect the younger age profile of participants in that service (76%). In Grimsby, 94% of participants reported long-term conditions.

Of those reporting conditions, on average each had 2.0 long term health conditions. This was highest in Devon (2.4) and lowest in Newham (1.5).

**Figure 19: Average number of LTCs reported per participant by area**

Nearly a third of participants had one other long-term condition (30%) and a further quarter (27%) had two. See Figure 20

**Figure 20: Number of LTCs (n=126)**

The most common long-term condition affecting participants (aside from stroke) was high blood pressure, with almost a quarter suffering from this issue (n=249). This might be expected given the associations between hypertension and stroke. Other common conditions include arthritis, diabetes, heart conditions and breathing conditions (

Figure 21).



**Figure 21: Other long-term conditions affecting participants (multiple responses were possible)**

Condition	N	% of all conditions reported
High blood pressure	60	24%
Arthritis, or back or joint problems	46	18%
Heart condition	35	14%
Diabetes	28	11%
Breathing condition	22	9%
Mental health condition	19	8%
Other	15	6%
Neurological (e.g. epilepsy or Parkinson's)	14	6%
Cancer	10	4%
All conditions	249	100%

Source: Stroke Association

## **Mobility and communication**

Half of all participants disclosed a mobility issue (50%, n=126). This included use of walking sticks, wheelchair, and support needed (i.e. when transferring). Nearly two-thirds (64%, n=126) reported communication problems including aphasia, deafness, use of hearing aids, and speech difficulties.

## Appendix 3: Analysis of participant self-assessment survey responses

### Introduction

This appendix presents results from a ‘matched’ sample of ALAS participants, completing pre and post (3 month and 6 month) surveys connected with their involvement with the Active Lives project. Overall we analyse 30 matched responses with these all drawn from the first cohort of the project. Figure 22 shows respondents by project area, there is a fairly even split between the four areas with marginally greater representation in Grimsby compared to other areas.

**Figure 22: Respondents by project area**

Area	Respondents	% of total
Central Lancashire	13	21%
Devon	21	34%
Grimsby	18	29%
Newham	10	16%
All areas	62	100%

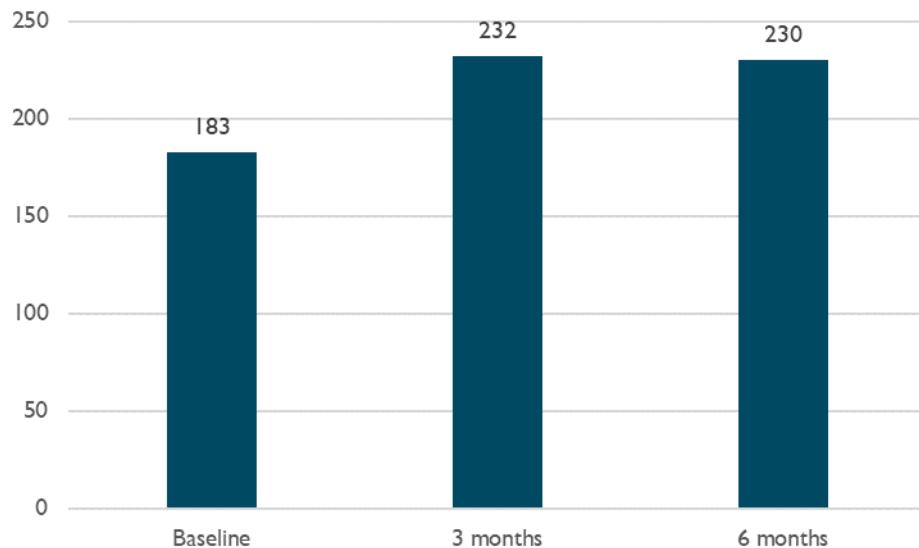
Source: Stroke Association

### Physical activity

#### **Unadjusted for breathlessness**

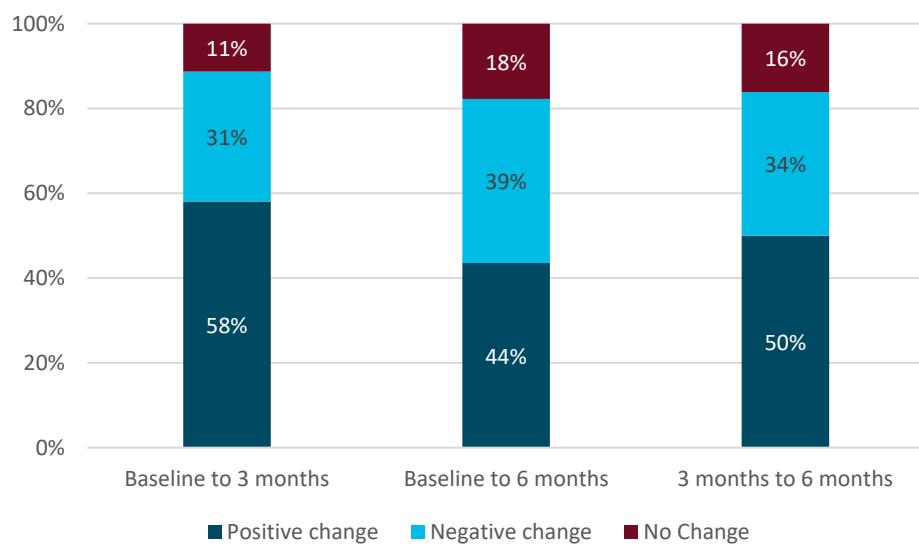
We analysed reported activity minutes across three types of activity as determined by the active lives survey (walking, cycling, and other organised fitness session). The following table reports the baseline and 3-month and 6-month follow-up total activity minutes (without accounting for breathlessness), categorised as per the Sport England definitions into inactive, fairly active and active. The mean average of physical activity minutes at baseline was 183 minutes, and 232 minutes at 3 month follow-up and 230 minutes at 6-month follow-up. We noted from the low number of responses at the 12 month follow-up point that activity levels had declined to close to the three month level, though it is not known if this representative of the broader group.



**Figure 23: Physical activity minutes**

Source: Stroke Association

The following chart summarises how each individual's physical activity level category changed between baseline and the two follow-up. Positive shifts in physical activity are more common between baseline and 3 months, with 58% reporting an increase. This diminishes over time, with 44% reporting positive change between baseline and 6 months.

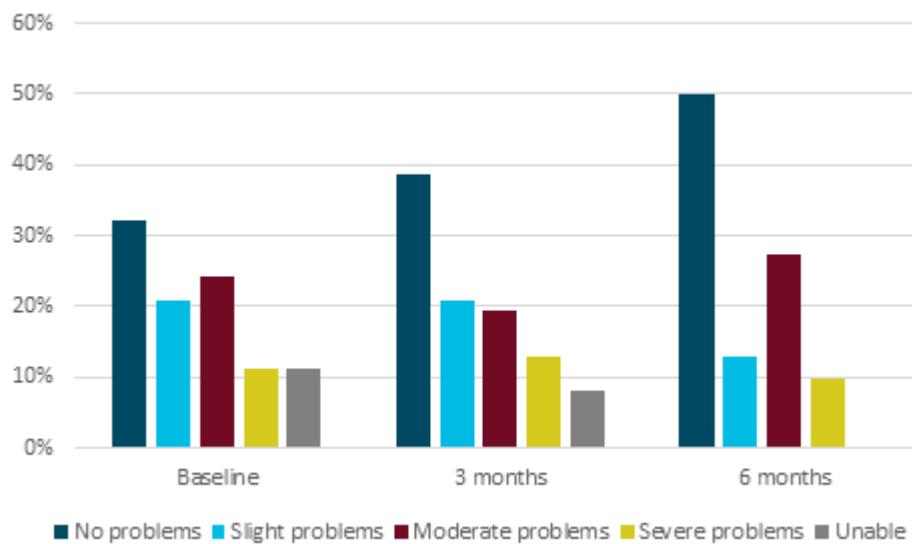
**Figure 24: Changes in matched responses (n=62)**

Source: Stroke Association

## Managing day to day activities

The chart below shows the differences in ability to manage day to day activities between the baseline and follow-up surveys. Over time, increasing proportions had no problems in managing day to day activities increased from 32% at baseline to 50% at 6 months.

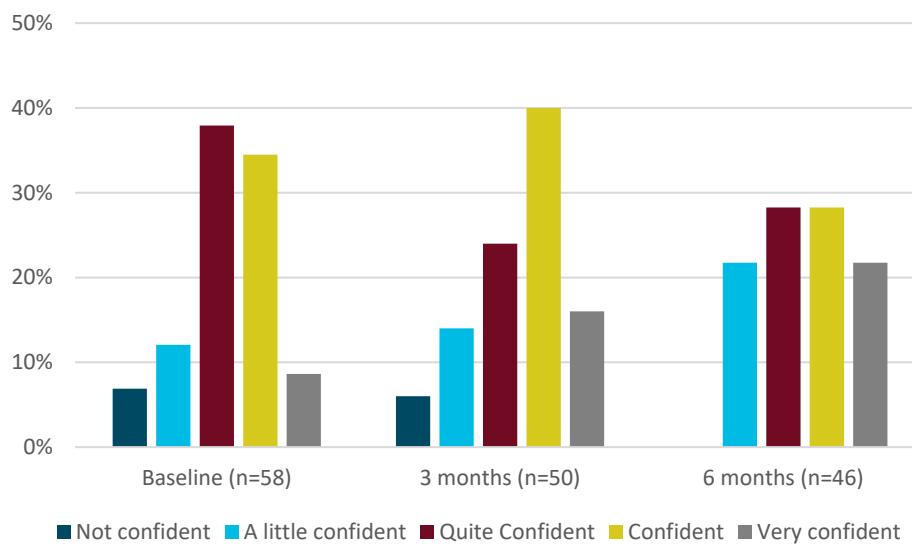
Figure 25: Managing day to day activities



Source: Stroke Association

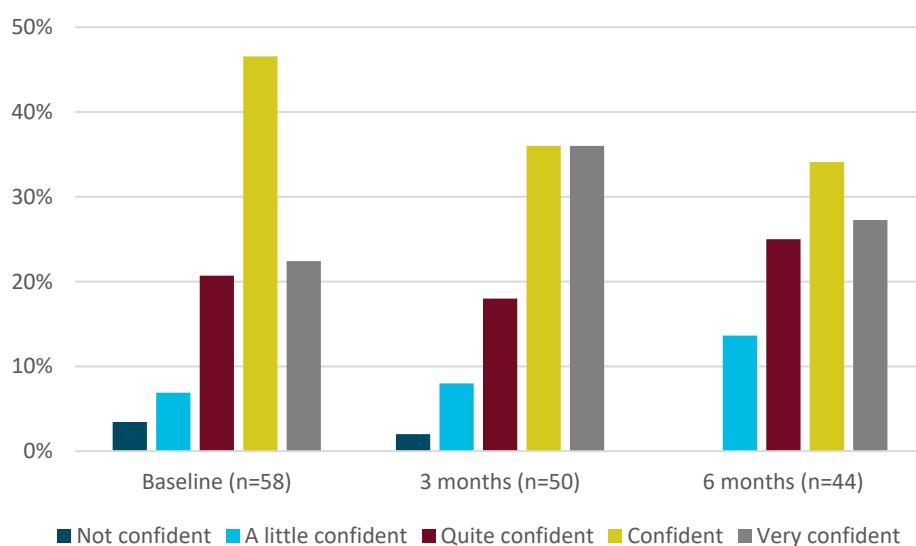
## Confidence

There is an increase between baseline and 3 months in confidence, with higher proportions feeling confident or very confident in groups, and fewer feeling ‘quite confident’, ‘a little confident’ or ‘not confident’. At the six month point, the shape of the distribution changes and while there is an increase in participants who are ‘very confident in groups’ (which increases from 9% to 16%, to 22%), there are equal proportions who are ‘quite confident’ and ‘confident’ at 6 months post intervention (28% respectively). There was no observable trend in the matched responses for the limited number of respondents for the 12 month survey which likely reflects the low sample size.

**Figure 25: Confidence of being active in a group**

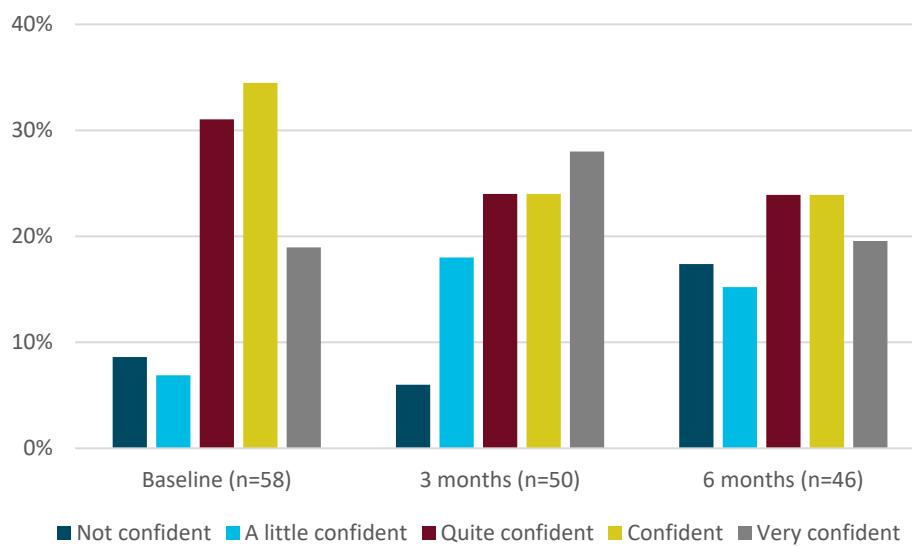
Source: Stroke Association

Confidence in meeting other people with stroke shows no clear trend over time (Figure 26).

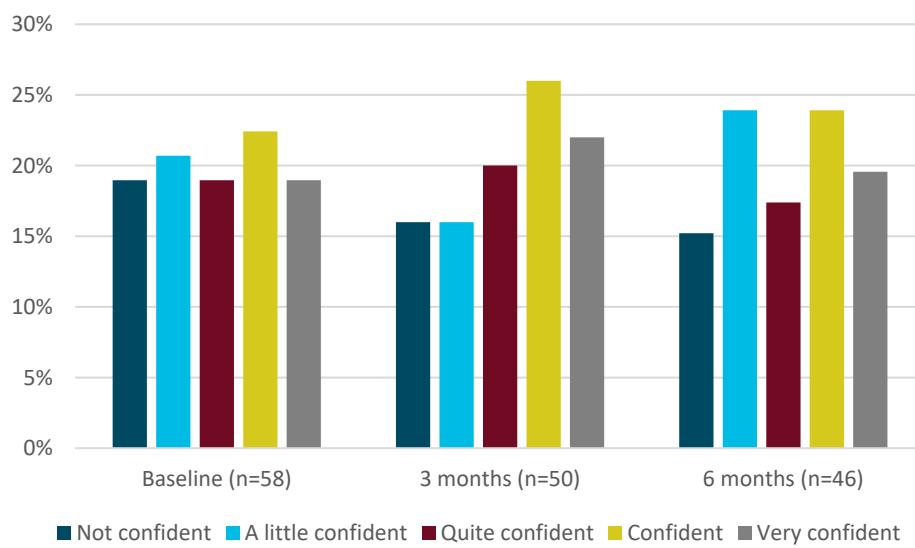
**Figure 26: Confidence in meeting other people affected by stroke**

Source: Stroke Association

While the proportion who are very confident in trying new things has increased from the baseline position to 3 and 6 months post intervention, there are a greater proportion who are not or a little confident at each of the follow-up points compared to the baseline.

**Figure 27: Confidence in trying new things**

Source: Stroke Association

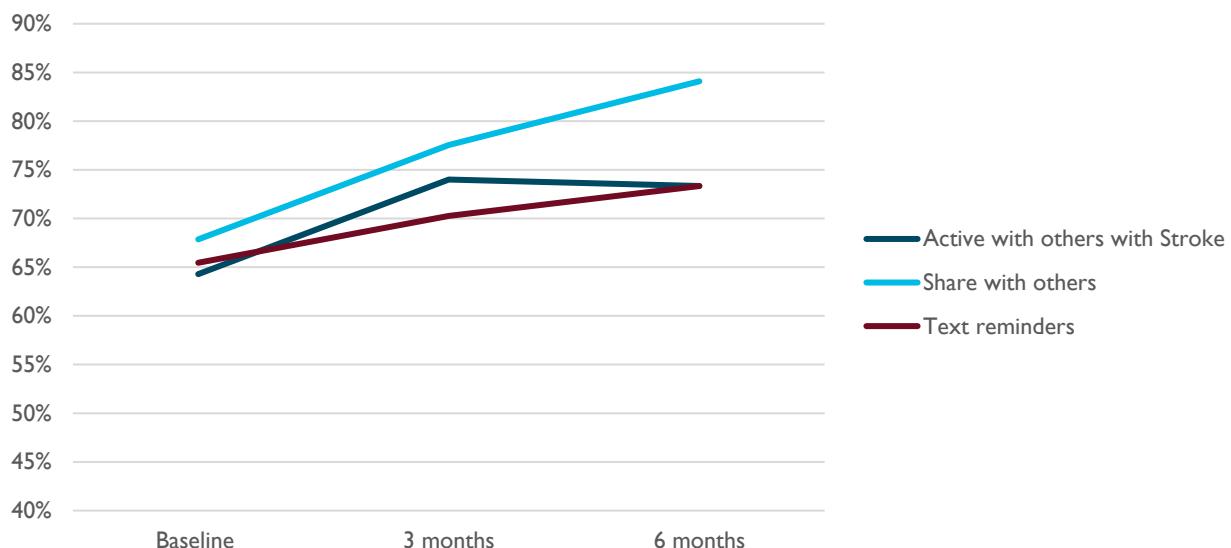
**Figure 28: Confidence in going to social or leisure activities in the community**

Source: Stroke Association

## Motivation

Various forms of motivation to be active are explored in the survey. In general, respondents show higher levels of motivation over time in all three of the scenarios prompted by the questionnaire.

**Figure 29: Proportion of respondents citing they would be more motivated to be active if... (% of respondents)**

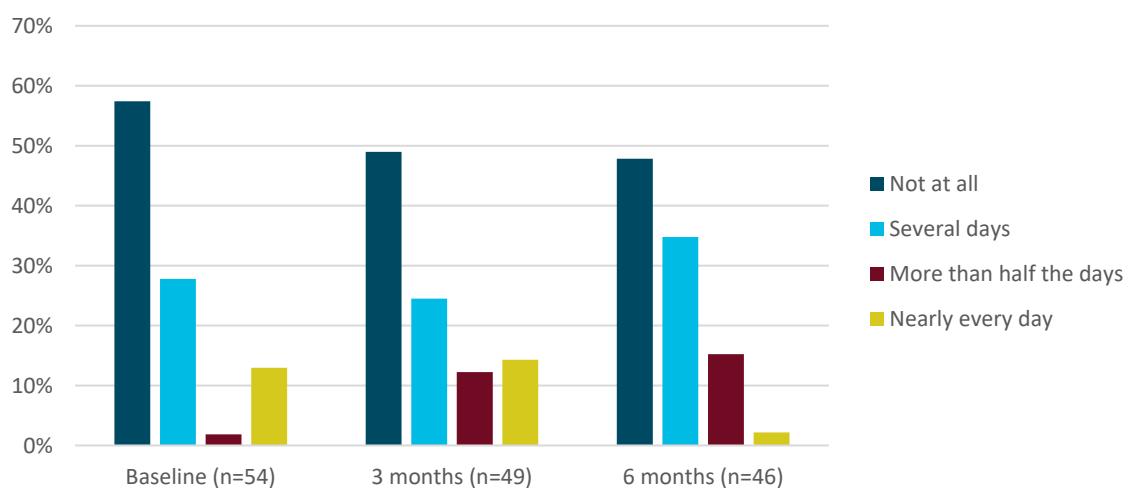


Source: Stroke Association

## Feelings and emotions

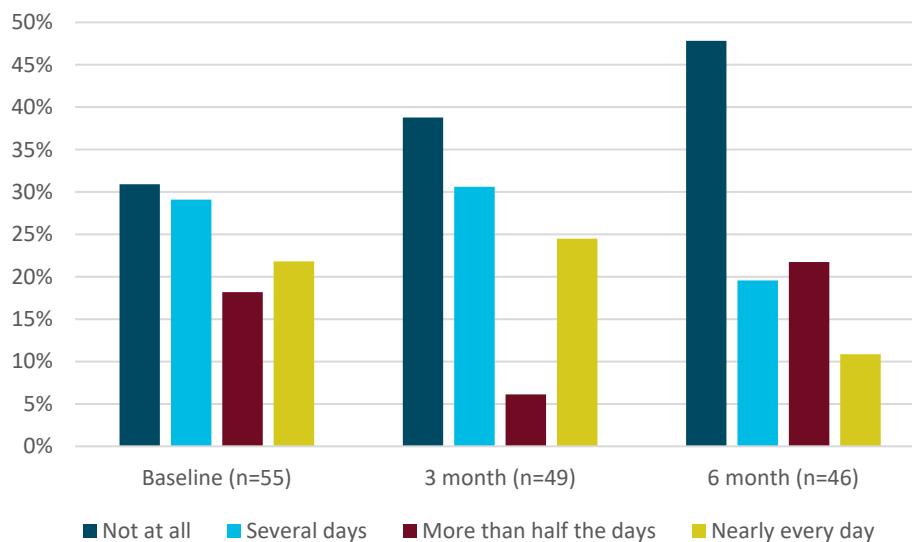
There are no discernible trends in the proportion of people feeling nervous, anxious or on edge.

**Figure 30: Nervous, anxious or on edge**



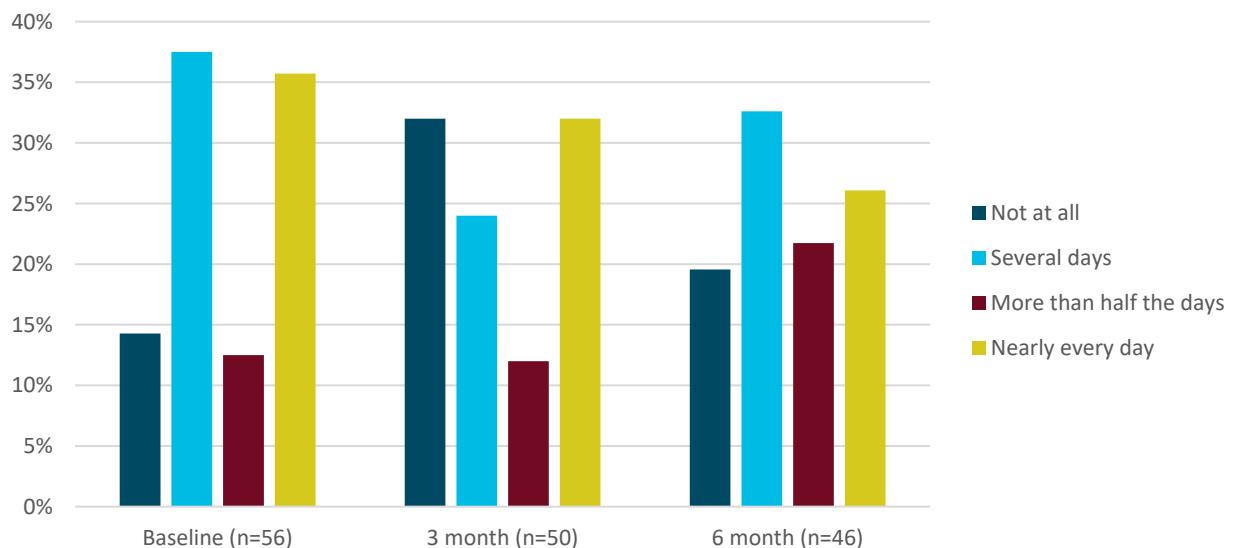
Source: Stroke Association

This is not the case for 'worrying too much' where the proportion saying 'not at all' increases from 31% at baseline to 39% at 3 month and 48% at 6-month follow-up.

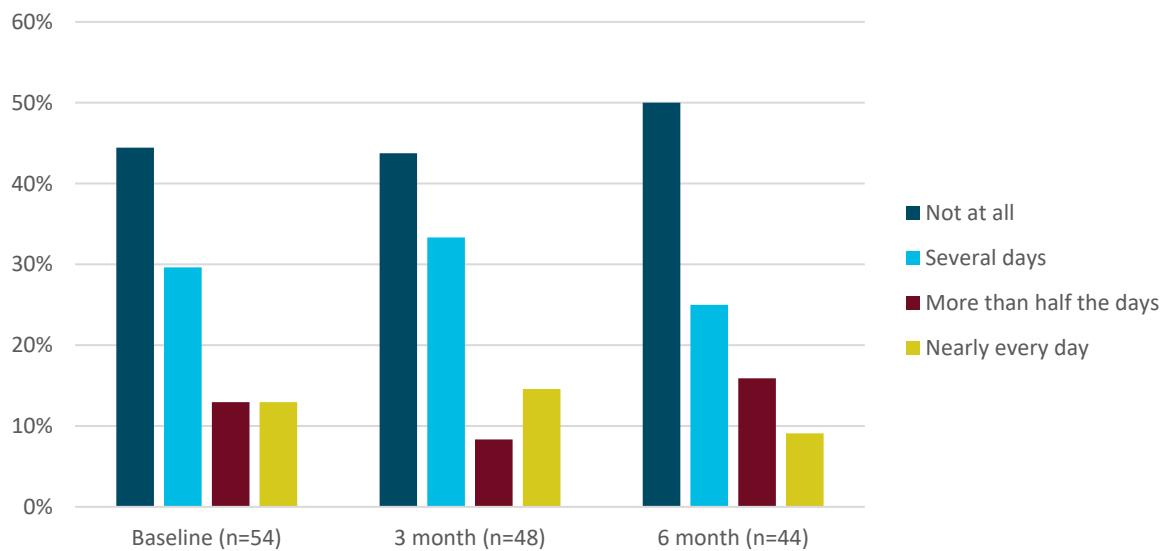
**Figure 31: Worrying too much**

Source: Stroke Association

There is no clear trend in 'feeling relaxed' but the proportion 'easily annoyed' as shown below shows an increase in the proportion stating 'not at all'; increasing from 44% at baseline and 3 months to 50% at 6 months.

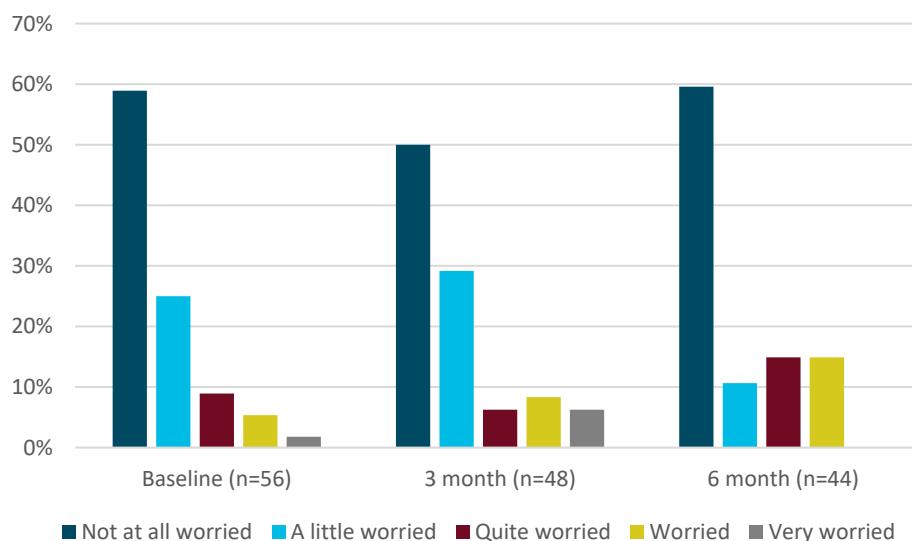
**Figure 32: Feeling relaxed**

Source: Stroke Association

**Figure 33: Easily annoyed**

Source: Stroke Association

Participants become worried about becoming more active over time with greater proportions worried or quite worried at both 3 months and 6 months, compared to baseline. There was some evidence that this trend towards increased levels of worry about becoming more active over time continued at the 12 months point for the small number of respondents completing that questionnaire, although this should be treated with caution due to the low sample size and is not presented here for that reason.

**Figure 34: How worried are you about becoming more active?**

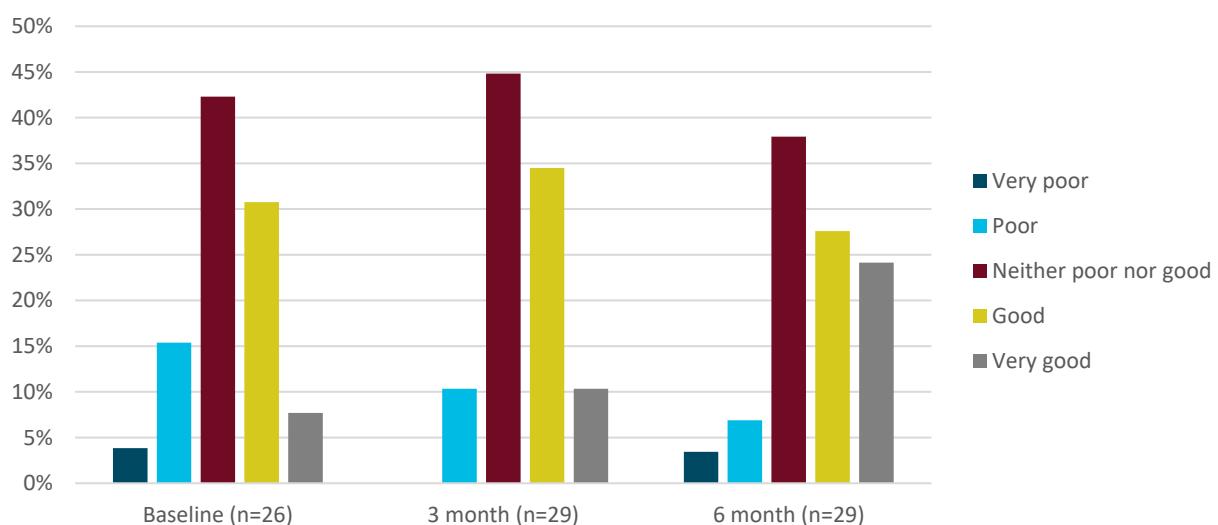
Source: Stroke Association

## Impact

### Quality of life

A greater proportion of participants say their quality of life is ‘very good’ or ‘good’ at the 6-month stage (52%) compared with 3 months (44%) and baseline (39%). There was no change in this trend when comparing the small number of matched responses at the 12 month point.

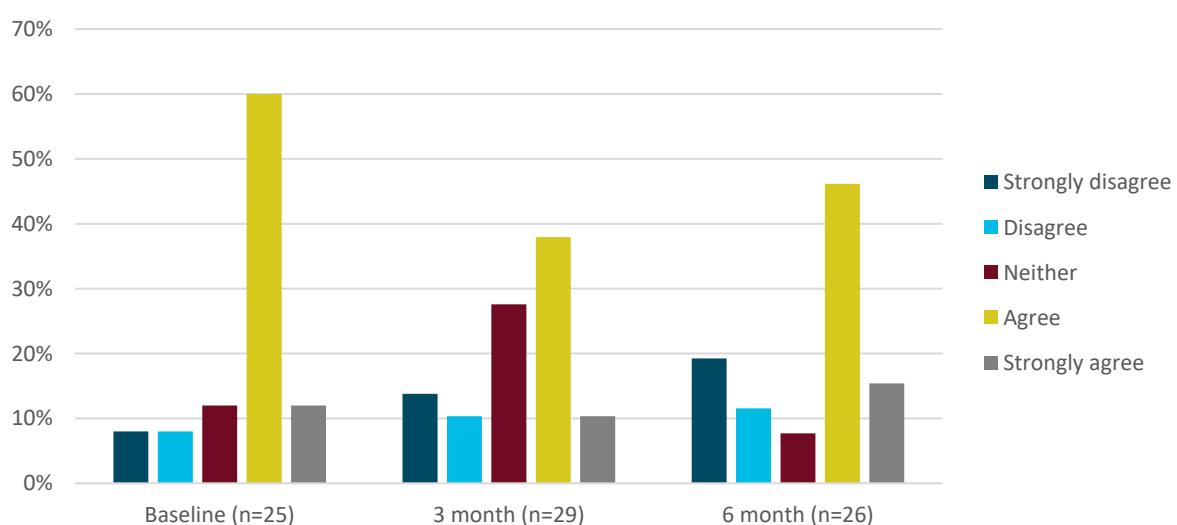
**Figure 35: Quality of life**



Source: Stroke Association

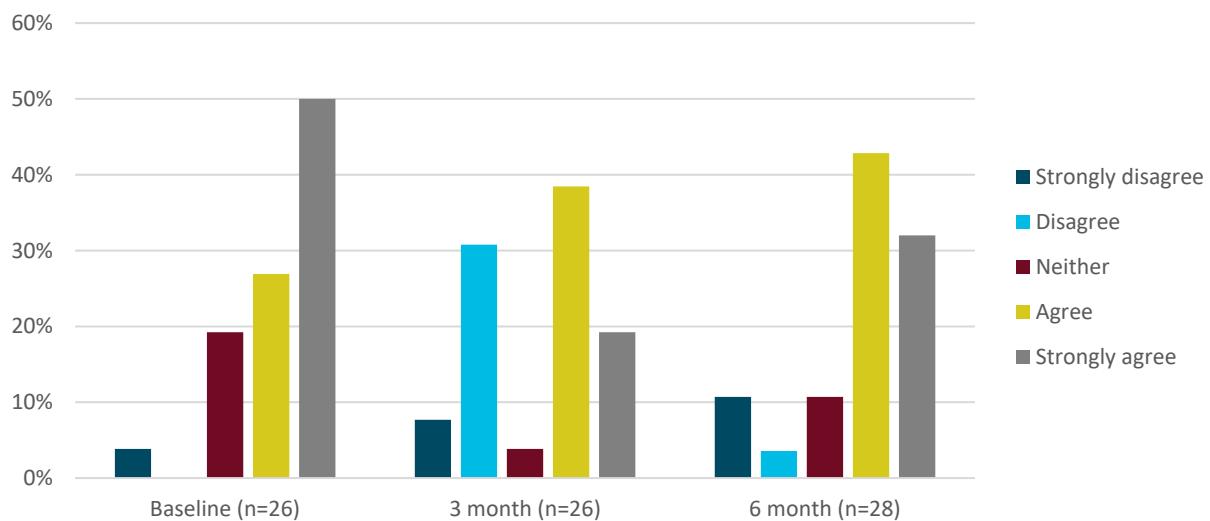
Greater proportions disagree or strongly disagree that they can achieve most of the goals they set for themselves over time (16% at baseline c.f. 31% at 6 months). The distributions become more dichotomous over time.

**Figure 36: I can achieve most of the goals I set myself**



Source: Stroke Association

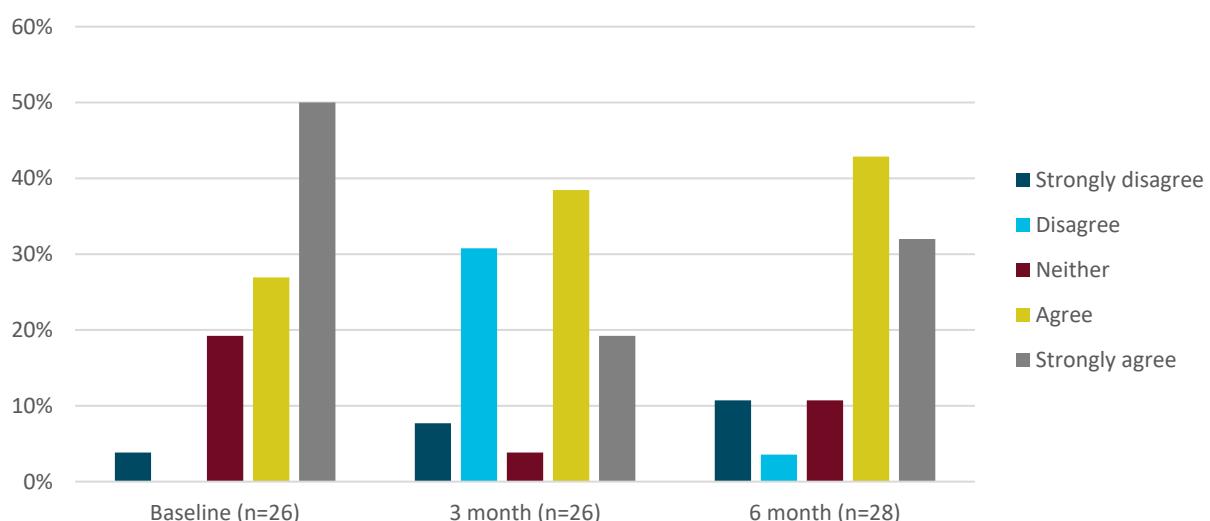
There is no clear trend regarding happiness with friendships and relationships (Figure 37), but over time greater proportions strongly agree that they have enough people to ask for help (



Source: Stroke Association

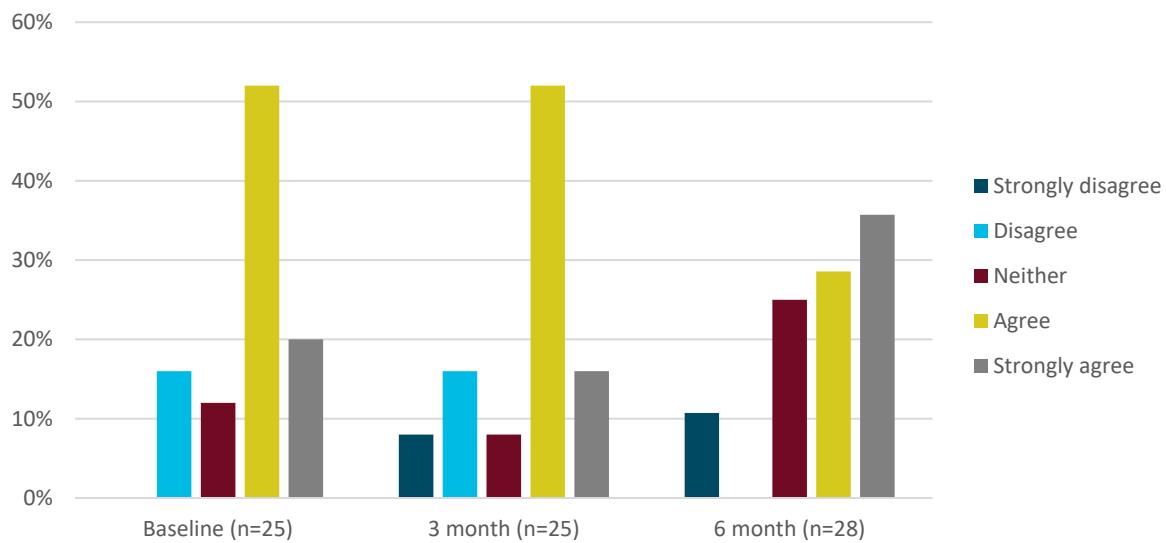
38). This trend was also reflected in the limited number of 12 month responses received.

**Figure 37: Happiness with friendships and relationships**



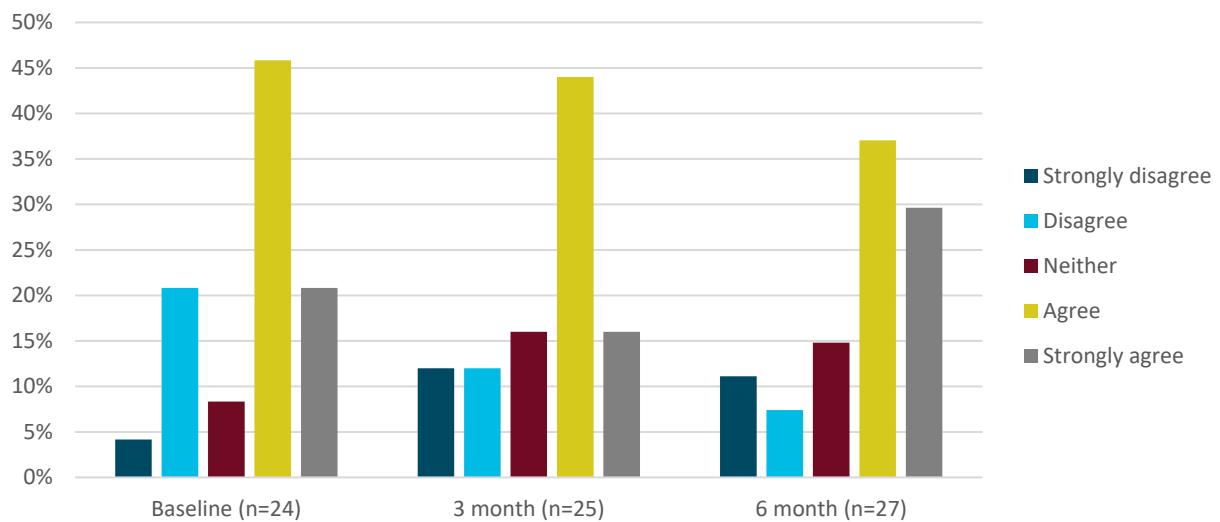
Source: Stroke Association

We also observe no clear trend regarding comfort levels when asking for help, instead noting a switching between strength of agreement/disagreement at the different survey points and which we do not feel to be reflective of real shift in people's views.

**Figure 38: I have enough people I feel comfortable asking for help at any time**

Source: Stroke Association

There is, however, an apparent increase in relationship satisfaction over time, with greater proportions saying they agreed or strongly agreed at 6-months compared with previous time-points. The limited data available at the 12 month point suggests that this increase in satisfaction may be sustained in the longer term.

**Figure 39: My relationships are as satisfying as I would want them to be**

Source: Stroke Association

### **Use of health and social care services**

We report usage of health and social care services in the below table, and Figure 41 to Figure 43 show change in resource use. There is an increase in resource use between baseline and three months (see Figure 41), but this reduces overall from both the baseline and 3 month point to 6 months (see

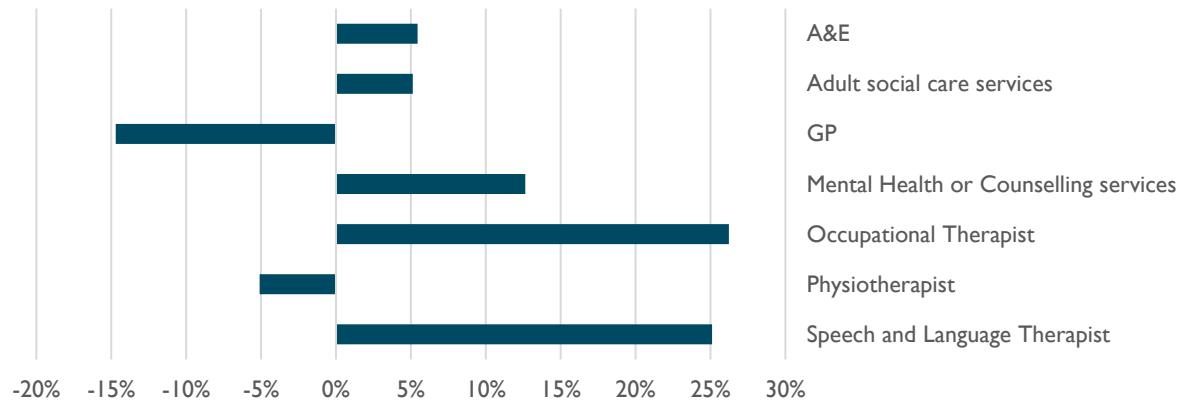
Figure 42). We have not presented data from the 12 month survey due to the low level of responses but noted that, for those respondents who did complete the survey, the baseline to 12 months trend was consistent with the baseline to 6 month trend for all service types.

**Figure 40: Use of health and social care services**

Resource use category	Baseline		3 months		6 months	
	Average	N	Average	N	Average	N
Adult social care services	4.9	16	5.1	12	4.8	8
A&E	2.3	17	2.5	10	1.5	12
GP	3.7	40	3.2	39	3.1	35
Speech and Language Therapist	4.2	16	5.3	9	4.5	11
Physiotherapist	6.7	23	6.4	12	4.2	13
Occupational Therapist	4.6	19	5.8	13	2.8	9
Mental Health or Counselling services	4.6	10	5.1	8	3.9	7

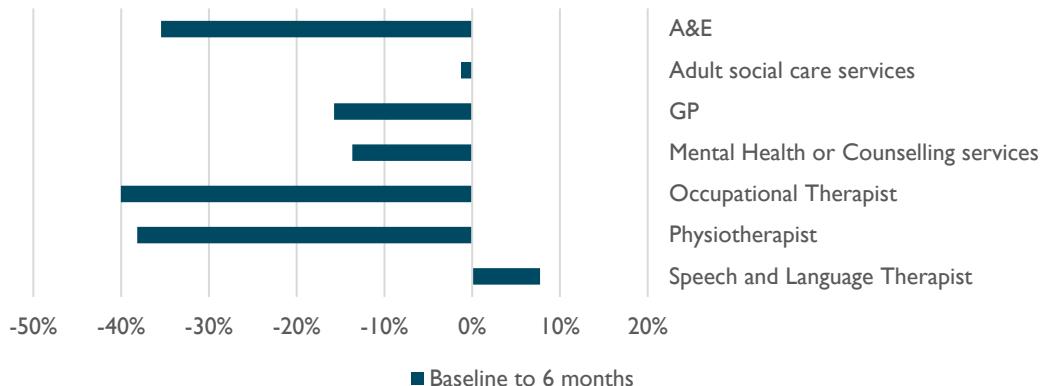
Source: Stroke Association

**Figure 41: Change in resource use baseline to 3 months**



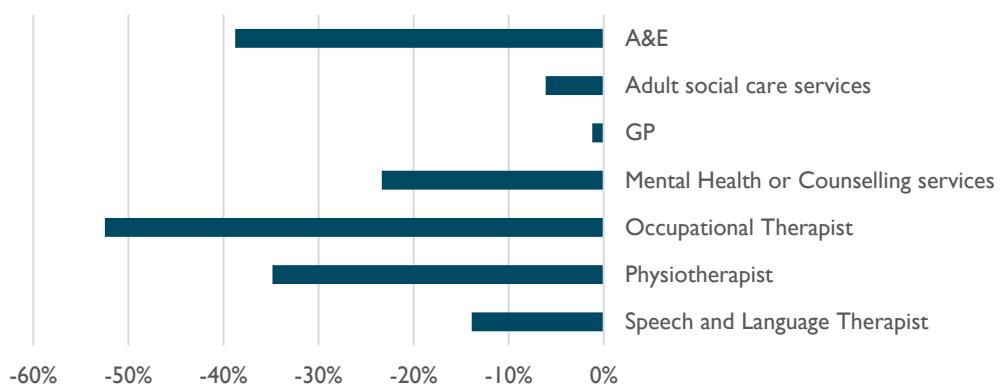
Source: Stroke Association

**Figure 42: Change in resource use Baseline to 6 months**



Source: Stroke Association

Figure 43: Change in resource use 3 months to 6 months



Source: Stroke Association

## Appendix 4: Analysis of Carers' responses

We received feedback from four carers who help the person that they care for attend ALAS sessions. Three were connected to the Devon group and one was connected to the Central Lancashire group.

Three of the carers attended the session, and one did not attend the session. Of those who provided feedback and had attended the session, these carers had attended all the 12 week sessions. Most frequently, the coordinator approached the participant to attend, in one case through an existing group.

### ***Impact on the carer***

We sought feedback on the indirect effects on carers of participation:

- **Stress/anxiousness:** The majority (3 out of 4) felt there was no effect on their own level of stress and anxiousness, while one said they were a lot less stressed/anxious
- **Loneliness:** Three carers report that they were less likely to feel lonely as a result of the person that they cared for attending the session
- **Own physical activity participation:** there did not appear to be an effect on a carers on physical activity

While the sessions were considered to be an extra task by one carer, there was no adverse impacts reported on their caring role and many found the sessions enjoyable and beneficial. One carer notes:

- *"I have company for the morning which makes me less isolated for that period. Usually I don't see anyone but the carer, although we do see friends and family when we can. It's good to meet with people who really understand."*

### ***Impact for the person cared for***

Three carers offered observations on the impact on the level of physical activity of the participant:

- *"He has been able to take part in things he would not normally do"*
- *"He wouldn't exercise if it wasn't for the group"*
- *"Slight increase in walking when encouraged"*

Carers noted that it was the positive encouragement of the group that helped affect this change (particularly seeing what others can do) as well as the opportunity to meet people and take part in structured activities, getting out of the house and meeting others with similar difficulties.

Three of the four carers stated the participant had increased their awareness of the benefits of physical activity. Attitudes were less frequently changed as a result of the project, with one comment noting the participant had always 'been keen' on physical activity, another noting the motivation that comes from the carer and a final comment that the participant 'is still not keen'.

Health and wellbeing impacts cited by carers included:

- *"Improved confidence in balance and will attempt more things. Definitely benefitted from being on the course"*

- “He looks forward to going and meeting the group every week. The coordinator makes the activities enjoyable”
- “He has become more positive in general”
- “He has enjoyed being with people in a similar situation and has made new friends, and enjoyed a coffee with them all at the end of the session”



## Appendix 5: volunteer review forms

### Introduction

Eight volunteers for the project have completed two reviews of their experience after the first and second waves of activities in three locations (Central Lancashire, Devon, Grimsby). Information from these reviews, which took the form of conversations between the local service coordinators and the volunteer have been made available to Cloud Chamber for analysis.

### Activities

Volunteers were involved in a wide-range of activities as part of the project. This included:

- Induction
- Driving participants to sessions
- Using social media on behalf of the project
- Activity set up
- Marshalling
- Interacting with the group, supporting and encouraging
- Focus group

Many of the volunteers had completed the course themselves and participated in the activities as well as supporting the co-ordinators and trainers.

Volunteers commonly enjoyed all aspects of their involvement, but specific highlights included a seeing participants start to see the benefits of physical activity as well as enjoying the social aspect. Typical comments included:

- “*I have enjoyed seeing how exercising in a group with others in a like position can benefit individuals and have found it very interesting seeing peer support in action as well as the benefits of the physical activity.*”
- “*I have found the sessions very interesting and expanded their own understanding and experience. The warm up part of sessions really educated them.*”
- “*It was lovely to see them all encourage each other*”

### Improvements

Following the first wave of activities, volunteers noted that some weeks had been better than others due in part to the trainer learning as the weeks went by what has worked for that group of people. Volunteers also highlighted issues regarding the sustainability of the project in terms of both resources and the need for co-ordinators to help to encourage and motivate people. Some concerns were also expressed regarding the potential social isolation of participants when sessions ended.

Following the second review point a number of the volunteers highlighted that they had continued to learn as the sessions had progressed in terms of what worked well with the groups and how to motivate and encourage people. One area which was highlighted as a potential area for improvement, most notably in Central Lancs, was regarding the exercises which volunteers felt



would benefit from being more straightforward and functional in nature so that they could be practiced outside of the sessions.

Finally, one of the Grimsby volunteers felt that the second wave of activities was more enjoyable as the group had bonded more effectively resulting in greater participating in team games and mutual encouragement.

### **Supporting participants to become more active**

All volunteers highlighted many examples of how participants were becoming more active, including:

- “[One participant] gave up completely at approximately half way through. We encouraged him to continue to attend and he came back and completed the course.”
- “[One participant] walking further and completing lamppost training and another completed the Couch to 5K”
- “One service user is walking his dog further”
- “One participant was willing to give everything a go. Her confidence grew and she was exercising at home with the housework.”
- “Inspired members to start a sport they used to enjoy before their stroke.”
- “Range of motion had improved – many members had to use dominant arm to support other limbs when exercising but now not needing to / as frequently.”
- “People are now more confident and join in more socially than earlier in the block of sessions.”
- “Changes are harder to see when the individual doesn’t have as many obvious physical effects of their stroke.”

The importance of providing 1:1 support was felt to be particularly important by volunteers after the second wave of activities in order to provide specific encouragement and tailored support when required.

- “He [the volunteer] found that this was really beneficial for the members and meant that they were able to feel confident and assured that there were people around to help”
- “He [the volunteer] found it enjoyable working with different members within the group on a more 1:1 level. He found this enabled him to know their needs better which enabled him to tailor how he worked in order to provide the support”

Volunteers generally felt they had supported participants to become more active, in one case with benefits to their own confidence:

- “I have supported people to get active as a whole group”.
- “By the end if the sessions I felt we had all achieved.”
- “I have really got to know all of the individuals in the group. Encouraged and praised them. Become a lot more confident in myself.”

Finally, volunteers comments also reinforced the benefits of the sessions on everyday activities on their own health and wellbeing that were also highlighted by group members:



- “for example, members were no longer using their hands to do the sit to stand exercise because they had gained confidence in their movements”
- “has improved her posture, she was very hunched over when she first started the sessions and is now walking a lot more upright”
- “He has lost nearly a stone in weight and is exercising nearly every day. He has increased his walking distances and frequency and is very motivated to keep active. He has joined the gym”

## Training and development

Volunteers had had the opportunity to undertake training on GDPR, CAT, and the induction process itself. Some noted that the training had refreshed their knowledge (particularly GDPR and CAT), and that the induction provided really useful background information on the service. One service user commented on the usefulness of the videos included during induction, particularly in terms of understanding aphasia. Another service user valued the informal conversations with the service coordinator as good preparation for being a volunteer.

Following the first wave of activities, one volunteer noted they had completed a suicide awareness course and footcare with carers support service, which will support them in the volunteering role. Volunteers noted their own future training and support needs and four of them highlighted training in facilitating an exercise group.

After the second wave of activities, a small number of volunteers suggested that they would like to understand more about dealing with people aphasia as they felt this was challenging for them and that they would benefit from improving their skills in this area. Many felt that the volunteer role had given them a much better appreciation of the wide range of stroke effects that people have and that they had become more skilled in working with people as a result of the experience. Volunteers in Grimsby also attended Activity Alliance training, provided by a charity dedicated to supporting disabled people to become more active.

Some of the volunteers stated that they would like to continue in buddying or motivational roles in the future as they enjoyed this aspect and they found it helped their confidence as well as keeping them more active.

## Ambitions for the future

Some of the volunteers stated that they would like to continue in buddying or motivational roles in the future as they enjoyed this aspect and they found it helped their confidence as well as keeping them more active. Others offered further ambitions for the future including:

- “Would like to expand my role to be a motivator. I would like to text and engage/encourage service users to continue with their exercise programs to enable them to continue meeting.”
- “Looking to do the Later Life exercise after stroke qualification and would then like to deliver sessions to stroke survivors in future, feel this is a valuable qualification and would like to gain”
- “Doing ambassador and KYBP (Know Your Blood Pressure) training has allowed me to have more voluntary opportunities when I return to Uni”

## Final points of feedback

Each conversation between co-ordinators and volunteers ended with an opportunity for them to share any final points of feedback. This included potential changes to delivery models, the need for coordinator encouragement and the potential for the use of technology:

- “Discussed changes to the models of delivery going forwards and whether they’d consider facilitating exercise. Volunteers feel strongly that any exercise in sessions needs to be functional and progressive in order for individuals to see a benefit to them. Volunteers concerned that in a group sport there is always going to be a high / low level of functioning, which can be challenging to look after in group settings in order to ensure everyone is supported and feels part of it whereas in the circuit style exercises if someone cannot do one part then they can still have a go at other things.”
- “Everyone exchanged phone numbers to stay together and keep active. This has faded to nothing. It needs a coordinator to continue to encourage.”
- “Volunteers suggested using LA grants for Fitbit’s” While other volunteers spoke about “apps which are available to help individuals exercise / increase understanding outside of sessions e.g. videos of exercises and schedules.”
- “.. talked about using tech/app in order to keep up after sessions finish. Can watch videos, connect with others for peer support, link to Apple Health etc.”

Concluding remarks from volunteers were overwhelmingly positive. The below comment was typical of this and neatly summarised the main themes of the volunteer feedback sessions.

- “He [the volunteer] feels that this experience has pushed him out of his comfort zone. He has realised the importance of putting he effort in socially and how this is important to build the relationships with members of the group in order to break down barriers with the result being that they are more engaged and become more active”

