

Stroke Association Stroke Recovery Service Service User Consultation



October 2014

Consultation and report completed by the NIHR Collaboration for
Leadership in Applied Health Research and Care Greater Manchester
(CLAHRC GM)

This document provides an overview of the background to, and findings of, the service user consultation events held on Monday 13th October 2014 by the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester to support development of the new Stroke Association Stroke Recovery Service and corresponding Outcomes Model. The principal audience for this report is, therefore, Stroke Association Directors and Senior Managers involved in the present service redesign activities taking place within the organisation, although the findings may potentially have wider application. It is intended that the findings of the service user consultation will assist the Stroke Association in developing and designing a Stroke Recovery Service and Outcomes Model, which are tailored and responsive to the needs and preferences of current and potential service beneficiaries.

1. Background and context

The Stroke Association is the UK's leading third sector provider of services for people affected by stroke. Their Life after Stroke Services are presently contracted by NHS and Local Authority commissioning organisations across England, Wales and Northern Ireland to provide specialist and holistic support for stroke survivors, their carers and families, helping to address their, often complex, needs and supporting them through the process of adjusting to life after stroke. 'Life after Stroke Services' provides an umbrella term for a number of different services that can be contracted by NHS and Local Authority commissioners to support people after stroke, including Information, Advice and Support, Early Intervention, Communication Support and Post-Stroke Review services (Stroke Association, 2014a). The Stroke Association's latest annual report (2014b) indicates that there are, at present, approximately 350 contracted Life after Stroke Services in operation in the UK, generating an annual contract income of £11.2 million.

The Stroke Association's Life after Stroke Services are currently being reviewed internally by the organisation and are being reconfigured to create a 'Stroke Recovery Service'. This redesign work is being delivered through a number of different workstreams which not only aim to look at what is to be delivered as part of the service, how and to what intensity, but also aim to define the desired outcomes and impact of the service and, critically, how these can be best measured and evidenced. The move towards an outcome- and impact-based performance measurement and management approach represents a significant change of direction for the Stroke Association whose services were previously principally assessed through the use of output measures, client case studies and the

monitoring of goal setting and attainment (Impact4 and Cadence Works, 2014). However, such a move accords with the current drive “to shift the NHS from a focus on process targets to a focus on measuring health outcomes” (Department of Health, 2013a; p.3), an ambition which is also observable in the government’s outcomes frameworks associated with Adult Social Care (Department of Health, 2013b) and Public Health (Department of Health, 2013c).

A number of activities have already been undertaken to support development of the Stroke Recovery Service and corresponding Outcomes Model. This includes a detailed analysis of the pertinent national outcomes frameworks to identify nationally-relevant outcomes for the Stroke Association’s service, and a consultation exercise, conducted by Impact4 and Cadence Works (2014), with health and social care commissioners that currently contract the Stroke Association’s Life after Stroke Services. However, it is recognised that it is fundamentally important to also engage with and involve stroke survivors, carers and family members in the design of the Stroke Recovery Service and Outcomes Model, in order to ensure that the new service, and the way in which its ‘success’ is measured, reflects the needs of current and potential service beneficiaries and the outcomes they consider to make a difference to their lives after stroke. Collectively, these activities will help to ensure that the Stroke Recovery Service and Outcomes Model delivers and evidences, not only the right outcomes for the people who pay for the service, the commissioners, but also the right outcomes for those who ultimately receive the service, the stroke survivors, carers and their families.

To this end, as part of the NIHR CLAHRC Greater Manchester’s existing partnership with the Stroke Association, the Stroke Association asked CLAHRC GM to design and deliver a service user consultation exercise with stroke survivors, carers and their families, to identify what they considered to be meaningful outcomes after stroke and to examine how they thought the Stroke Association’s services had assisted/could assist them in achieving these.

2. Aim and objectives

The aim of the service user consultation was to capture the views, opinions and experiences of stroke survivors, their carers and families to inform development and design of the new Stroke Association Stroke Recovery Service and Outcomes Model. More specifically, the objectives were:

- To examine what stroke survivors, their carers and families consider a good quality of life after stroke to look like.
- To identify how they think the Stroke Association could support, or had supported, them to achieve this*.

**It was originally anticipated that the service user consultation would additionally capture information concerning what format this support would need to take to achieve a good quality of life after stroke (e.g. group or one-to-one input; telephone or face-to-face input), and when and how much support would need to be provided. However, information collected in this regard was limited, as participants found such issues difficult to meaningfully consider and reflect upon, particularly within the time available.*

3. Methods

The consultation exercise involved the members of two stroke groups in the North West England Region which, due to the limited timeframes associated with the consultation, were selected as a matter of convenience. The consultation occurred in place of each of their routine group meetings on Monday 13th October 2014 at the location and time at which the group routinely met, with one consultation session occurring in the morning and another the same afternoon. While the groups involved were principally selected by the Stroke Association on the basis of convenience, to help ensure that individuals' experiences were as representative as possible of the existing Life after Stroke Services, and the prospective components of the Stroke Recovery Service, the groups were purposely selected to include one which was run as part of an Information, Advice and Support Service, and another which formed part of a Communication Support Service.

A total of twenty-four individuals (Information, Advice and Support Group, 11; Communication Support Group, 13; 12 male and 12 female) participated in the consultation exercise, including 18 stroke survivors and 6 carers/family members, several of whom were also Stroke Association Volunteers. The participants who had had a stroke were between approximately 10 months to six years post-stroke. At each consultation session, to permit effective group interaction, participants were divided, upon arrival, into two smaller discussion groups of 5-8 participants. Each group was led by an experienced CLAHRC GM facilitator and supported by a scribe who kept a written record of the discussion.

The activities of each discussion group lasted approximately 90 minutes and the discussion progressed as follows:

- (i) The members of each group were welcomed. The facilitator explained the purpose of the consultation exercise and answered any questions participants had at this point. Group members, including the members of the CLAHRC team, then introduced themselves to one another.
- (ii) Using a standard discussion sheet as a visual aid (Appendix A), the facilitator asked participants to reflect upon and discuss what a good quality of life after stroke meant, or looked like, to them. Responses were documented, using Post-its, on the standard discussion sheet and were also recorded by the group scribe. All participants were encouraged and given support to be as specific and realistic as possible, and the participants who were carers were encouraged to consider what a good quality of life after stroke meant *for them*, rather than solely what this may have meant for the person they cared for.



Participants were also prompted to consider elements related to their health, physical, social, emotional and economic wellbeing, with further prompts being derived, as required, from the outcomes documented on the draft theories of change (Appendix B) that had been developed by the Stroke Association Directors, Managers and Operational Staff to support development of the Stroke Recovery Service and Outcomes Model.



- (iii) Using the features of 'a good quality of life after stroke' identified in the previous step, participants were then asked by the facilitator to identify, for each of these, how (if at all) they thought the Stroke Association could help them, or had helped them, to achieve this. For example, where

'having confidence' had been identified as a key feature, participants were asked to think about and discuss how the Stroke Association could help or had helped them to gain confidence. As previously, to avoid any loose linkages between the activities of the Stroke Association and the 'good quality of life' features identified, participants were encouraged and supported to be as specific as possible. All responses were captured both on the standard discussion sheet and in the notes kept by the scribe.

- (iv) The facilitator then provided a summary of the discussion that had taken place, thanked group members for their participation and reminded them how the views and opinions they had provided and the experiences they had discussed would contribute to the development of the new Stroke Recovery Service and Outcomes Model.

4. Findings

The central findings of the consultation exercise are summarised below. Findings from each discussion group have been combined and the table below presents and describes (a) the thirteen key features of 'a good quality of life after stroke' identified through the consultation exercise and (b) the ways in which participants believed the Stroke Association could, or had, helped them to achieve this. Notably, several activities were stated to support stroke survivors in achieving more than one 'good quality of life' feature. Furthermore, all identified features apply to stroke survivors, carers and their family members unless otherwise stated, and are described, as far as possible, using the terminology employed by participants on the day.

| Key feature | Description | How could, or has, the Stroke Association help(ed) you to achieve this? |
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| Doing things that you enjoy and are interested in | <p><i>Being able to get out of the house and do things that you enjoy and are interested in.</i></p> <p><i>This may include getting back to doing the activities you used to do before the stroke or challenging yourself to do new things. It may also include doing routine tasks such as shopping which offer structure to the day/week.</i></p> <p><i>It is important to meet, and spend time in the company of, other people, including family and friends.</i></p> | <ul style="list-style-type: none"> • Providing enjoyable social opportunities which take place in a friendly, non-threatening and accessible environment • Identifying activities that are appropriate for and tailored to your needs and preferences • Signposting you to appropriate and reliable social opportunities and activities provided by other organisations (it is important that this is done by someone you trust) • Providing, or recommending, appropriate transport to and from activities (see: 'Being able to get out of the house'). |
| Being supported and understood | <p><i>Being listened to and supported by someone who is proactive, responsive, stable and trustworthy, understands what you are going through and is able to help.</i></p> | <ul style="list-style-type: none"> • Providing services in a way that takes into account your needs (e.g. appropriate times, accessible locations etc.) • Providing someone who you can always go to, who you have faith in and who will listen, offer assistance and provide advice and support. Also someone who is willing to fight your cause and get your point across. Offering holistic support that deals with wider issues, not just those directly associated with stroke • Signposting you to appropriate and reliable sources of support, including carer support, to provide help and address problems. If these are not initially known, proactively identifying what support is available and letting you know as soon as possible • Providing opportunities for peer support, where you are able to meet others who have experienced the same thing and are in a similar position. This enables you to be yourself and normalise your experience. |

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| <p>Being able to get out of the house</p> | <p><i>Being able to access appropriate, affordable and reliable transport.</i></p> | <ul style="list-style-type: none"> • Providing, or recommending, reliable transport options which are appropriate for your needs • Telling you about, and helping you to apply for, financial help with travel costs • Telling you about, and helping you to apply for, relevant permits (e.g. bus passes, blue badges and scooter licenses) • Offering ‘buddy systems’ to provide support when travelling. This helps you to feel confident about travelling • Providing practical advice and strategies to cope with/address any difficulties you may experience when travelling e.g. remembering the route or paying for things using coins (<i>communication support group only</i>). |
| <p>Having motivation and being resilient</p> | <p><i>Being motivated to adjust to life after a stroke, dealing head on with difficulties and challenges that may arise in order to get on and live a good life. Not giving in.</i></p> | <ul style="list-style-type: none"> • Setting goals that are realistic- helping and encouraging you to do things, not making you • Offering guidance regarding practical tools and techniques to support you in dealing with any difficulties you have • Providing accessible and enjoyable social opportunities, including opportunities to meet other stroke survivors and carers who are in a similar position to you. Being able to do things as a group and motivate one another • Providing someone who is always there to offer guidance, support and encouragement, and to make you feel good about yourself. |
| <p>Being, and feeling, safe at home</p> | <p><i>Being and feeling safe and supported at home.</i></p> | <ul style="list-style-type: none"> • Undertaking home visits to look at what changes may be needed to help you be, and feel, safe at home (not an assessment, but a general look around the home) • Signposting to organisations that can provide any |

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| | | <p>necessary aids and adaptations, both adaptations for the home (e.g. wet rooms), but also other things that are available such as pendant alarms and key safe boxes</p> <ul style="list-style-type: none"> • Helping you to access any relevant grants to assist with the cost of any adaptations. |
| Having confidence | <i>Feeling confident around the home and having the self-esteem and courage to get out and do things, including returning to previous activities and also trying new activities and meeting new people. Feeling good about yourself.</i> | <ul style="list-style-type: none"> • Providing ongoing support and encouragement- helping and encouraging people to do things, not making them • Providing opportunities for peer support, where you can normalise your experience, support one another, and be yourself • Supporting you and providing practical tools and techniques to help you manage any difficulties you may have (e.g. practical communication tools and techniques) • Providing opportunities for you to have a role and do something meaningful (see: 'Making a meaningful contribution') • Helping to ensure that you are, and feel, safe at home (see: 'Being, and feeling, safe at home') • Operating 'buddy systems'. |
| Being able to understand and manage emotions | <i>Being able to recognise, understand, manage and cope with emotions after stroke (e.g. feeling low, anger, frustration)</i> | <ul style="list-style-type: none"> • Providing someone who you can always go to, who you have faith in and who will listen, offer assistance and provide advice and support. Someone to help you understand what is normal after a stroke • Providing opportunities for peer support, where you can normalise your experience, support one another, and be yourself • Signposting you to other services and organisations that can provide additional support. |

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| <p>Being able to support yourself and do things independently (<i>stroke survivors</i>)</p> | <p><i>Being able to do things for yourself.</i></p> <p><i>This includes doing things for yourself around the house, so that you don't always need to rely on being helped, generating a sense of achievement, independence and control. Being able to undertake personal care activities independently helps to maintain your privacy and dignity.</i></p> | <ul style="list-style-type: none"> • Helping you to learn practical tools and techniques to help you to do things on your own • Signposting to organisations that can provide any necessary aids and adaptations for your house (see: 'Being, and feeling, safe at home') • Providing support to improve your confidence (see: 'Having confidence'). |
| <p>Making a meaningful contribution</p> | <p><i>Having a role to play and being able to do something that is meaningful and valued.</i></p> | <ul style="list-style-type: none"> • Providing opportunities for you to support other stroke survivors and carers who are going through the same thing as you • Providing, and signposting you to, volunteering opportunities, including opportunities to become a Stroke Association Volunteer and a Stroke Ambassador • Offering social activities where you are given a job to do e.g. working on a gardening project. |
| <p>Being able to keep yourself healthy and active</p> | <p><i>Being able to look after yourself, keeping healthy and active.</i></p> | <ul style="list-style-type: none"> • Providing exercise-based activities which are tailored to what you can do/ what you are capable of doing. • Offering advice in relation to how to eat healthily and how to keep yourself well, including information about what you can do to help avoid another stroke. |
| <p>Being financially secure</p> | <p><i>Being financially secure, having accessed all available financial support, and having adjusted to any reductions in income.</i></p> | <ul style="list-style-type: none"> • Providing information about what benefits and other 'pots of money' are available, what you are entitled to and how you can access it. It is important that this information is provided by someone who knows how the system works • Offering help to fill in complicated application forms and having someone there to track progress and to chase things up for you when things are going slowly. |

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| Returning to work (<i>stroke survivors who worked prior to stroke only</i>) | <i>Being able to go back to work.</i> | <ul style="list-style-type: none"> • <i>No specific information captured during the consultation exercise.</i> |
| Being able to take some 'time out' from caring (<i>carers</i>) | <i>Being able to take a break and have some time out from caring for your loved one, in the knowledge that they are in a safe, friendly and caring environment.</i> | <ul style="list-style-type: none"> • Signposting to other services which can offer you specific respite support • Providing enjoyable social opportunities which take place in a friendly, non-threatening and accessible environment- these may be attended by both you and the person you care for, but you are able to have a break while you are there. |

5. Concluding remarks

This service user consultation exercise has identified thirteen features of a ‘good quality of life after stroke’ which span the areas of health, physical, social, emotional and economic wellbeing. These are summarised by the diagram below and relate to the outcomes that are meaningful to, and valued by, stroke survivors, their carers and families after stroke. The consultation also identified a wide and diverse array of activities that the Stroke Association can do, or has done, to help and support people to achieve such outcomes, making it clear that service beneficiaries consider the services provided by the Stroke Association to have a valuable and a key role to play in helping them to maximise their quality of life, both in the short- and longer-term, after stroke.

It is important to note that, while this work was undertaken specifically and ‘rapidly’ at the request of the Stroke Association to support development of the new Stroke Recovery Service and Outcomes



Model, the findings of this consultation exercise do not exist in isolation, with several key research studies currently being undertaken in similar areas. This most notably includes the critical research being undertaken by Professor Anne Forster and her research team at Bradford Teaching Hospitals NHS Foundation Trust and the University of Leeds as part of the NIHR-funded LoTS-2-Care programme which commenced, but had not reported its findings, prior to this consultation exercise (UKCRN ID: 15383). The LoTS-2-Care programme has explored the barriers and enablers that influence unmet needs, quality of life and participation after stroke, and is using this evidence to develop and evaluate a care strategy to provide support to stroke survivors and their families in the longer-term after stroke. The robust and rigorous evidence generated will be of invaluable benefit to both the Stroke Association and the wider stroke community, providing a strong picture of what matters to stroke survivors in the long-term after stroke and how high-quality post-stroke care can be achieved.

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Appendix A.



How has (or could) the Stroke Association help me achieve this?

What does a good quality of life after stroke look like to me?

A good quality of life after stroke

Appendix B.





