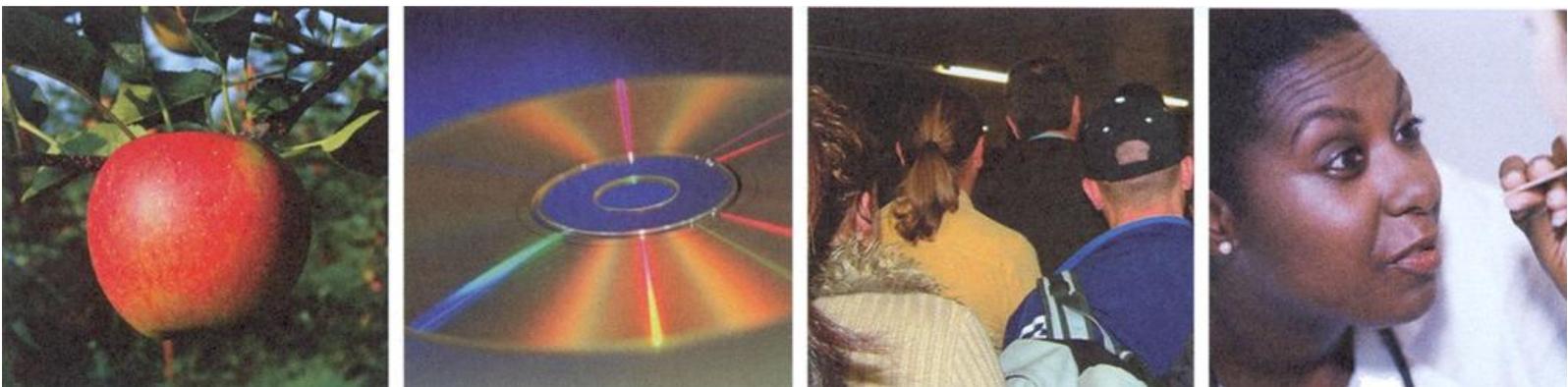


Evaluation of the Stroke Association's Life After Stroke services in Eastern & Coastal Kent



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**Centre for Health Services Studies
University of Kent**

July 2012

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Charlotte Brigden
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Commissioned by:
The Stroke Association
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Executive summary

The Stroke Association commissioned CHSS to evaluate the effectiveness of the Life After Stroke service in Eastern and Coastal Kent in meeting the needs of stroke survivors in the first twelve months after their discharge from hospital care. The evaluation was required to measure the impact of these support services on the lives of stroke survivors and their carers, also to assess the effectiveness of the way the service was being delivered and how well it was working with other agencies.

The evaluation was conducted over a two year period, from May 2010 to April 2012. A mixed methods approach was taken to evaluate the Life After Stroke service. The quantitative approach was based on the views of 98 stroke survivors who completed postal questionnaires and on data from quarterly management reports. The qualitative part of the evaluation was face-to-face interviews and focus groups with stroke survivors, carers, with those providing the Life After Stroke service, and with a small number of wider stakeholders working in NHS acute hospitals and commissioning organisations.

In 2010, the Life After Stroke service in East Kent was run by eight support coordinators with their managers and administrative staff. Information and general advice was provided by three Family and carer support coordinators, and help with speech by another three Communication support coordinators, all working on a patch basis across East Kent. There was also a coordinator providing return to work support and another providing long-term support. By 2012 there had been a significant reduction in the service, with the loss of the last two coordinator posts, most of the administrative staff and some reductions in coordinators' working hours.

Quarterly management statistics showed approximately 160-180 cases were referred to the service generating a similar expected number of initial face-to-face assessment visits to be made by the Family and carer support coordinators. In each quarter there has been a similar number of case closures, and around 40 communication support group sessions have been held. The caseload has remained around 500, but the number of visits to stroke survivors and communication support group meetings fell by over a quarter in 2011 reflecting reductions in staffing.

A series of surveys were used to show the baseline needs of stroke survivors who had been referred to the service, the impact of the service over time and how this differed for users of different parts of the service. Stroke survivors initially reported that their stroke had had a widespread impact on their lives and thought they would benefit from the full range of Life After Stroke services. They also indicated they had a much wider range of problems than the Life After Stroke service could expect to address. After using the services for several months the surveys showed that indeed most had received information and advice and help with communication, and considerable numbers had received stroke prevention, long-term and carer support. This confirmed that the service in East Kent was delivering on a wide front which included many of the services set out in the national model.

Satisfaction with the Life After Stroke service was also rated quite highly, in particular that the Stroke Association had treated stroke survivors fairly and sensitively. For some aspects of the service satisfaction levels among users of the Family and carer support service were significantly higher than those of Communication support users. There are several possible reasons for this. It may be because members of communication groups have greater needs, or because the much higher response rate from these groups led to a wider range of views. It could also be due to the nature of the Communication support service, which has a less clearly defined role, is a more difficult service to deliver, and during the evaluation East Kent had gaps in staffing and geographical coverage.

Finally the surveys indicated that the impact of the Life After Stroke service was rated highly across a whole range of areas. There was little difference between the impact of Family and carer and the impact of Communication services, until it came to the many positive comments from people receiving communication support, who reported that their speech and confidence to cope had been improved. The impact of the local service was similar to the published national Life After Stroke impact figures.

Interviews with stroke survivors and carers reinforced the survey findings that the service was highly regarded and provided the right level of contact at the time it was needed. The key factor for Life After Stroke service users was the personal contact, and even if stroke survivors were not always sure exactly who was offering what service, they were very clear about the support they had received from the Life After Stroke coordinators and administrative staff. Service users felt reassured that someone was there when they needed and had time to listen. They valued coordinators' knowledge and understanding of stroke, and discussions on recovery. There was continuity with the same person and service users were given emotional support.

Stroke survivors and carers also found the information and sign-posting they got from the Life After Stroke service had been useful, and crucially the encouragement they received to face the new situation. Carers valued the fact that communication support group sessions freed them up for an hour or two. Although for carers of stroke survivors not attending these groups an opportunity for some time out or respite care was something they would have liked. There were some negative comments about wanting access to the Life After Stroke service earlier, and disruption to the communication support group sessions when there had been problems due to changes in staffing and meeting times, but overall the people interviewed wanted the Life After Stroke support to continue and did not want to be discharged or completely cut-off from the coordinator.

The interviews and focus groups with service providers and stakeholders highlighted some of the merits of a geographical coverage of the service through the Family and carer coordinators and the Communication support service in dealing with the rather dispersed geography of this part of Kent. For service users, this has meant that there is one coordinator responsible for the locality that they can directly contact and engage with, access is easier and travel times to the venues become more manageable. Organisationally, the arrangement has meant that the service has a degree of flexibility for coordinators to cover in case of absences. It has also mean that stronger links with the acute stroke units could be maintained, although for resource reasons the contact time has decreased over the last few years.

Recent changes in funding have meant that Family and carer support coordinators have had to expand their remit to cover the various aspects of the Life After Stroke model. To some extent this is possible, but more limited resources has inevitably resulted in some service reduction, such as decreasing the time coordinators can spend in the hospital stroke wards and limiting the duration of support with individual stroke survivors. With an increasing workload and fewer resources, team members are realistic that their ways of working need to change.

Case management processes have been improved and become more consistent during the period of the evaluation, capturing more data on patients passing through the acute wards and working with acute hospital staff, although changes to on-line working for record keeping have proved difficult to achieve with the available IT equipment.

Overall though, despite the turmoil of the health and social services landscape and the changes the service had to go through, the service has remained remarkably robust and staff have continued positively in their roles.

All internal and external stakeholders in the evaluation recognised the value of longer term support for the service, and its important role in the stroke pathway. Staff from the acute and community services saw the work of the coordinators as complementary to their own roles, and filling in gaps in provision which they themselves could no longer fulfil. Observers could also see the vulnerabilities of the service with the switch to GP commissioning groups, although Life After Stroke could be in a safe position given the low level of resources needed to run it and the activity statistics that have demonstrated its added value.

Few stroke survivors said that the Stroke Association could improve the service or could have done more to make a difference to their lives. However there were comments about wanting to be able to attend communication support group meetings more frequently, and that there should be more support for carers. External stakeholders also identified the need for more carer support, in the form of flexible respite, more transport and carer support groups, but had the perception that these were being adequately covered. Transport difficulties were raised by both coordinators and service users, and although it was acknowledged that the Stroke Association offered transport to help stroke survivors attend their support groups and other activities, it was seen as being limited.

In general, stroke survivors and carers were not particularly familiar with the 'Life After Stroke' brand, and were unsure of the boundaries of what it did and did not offer. There was a time of uncertainty for potential service users in the early stages following discharge from acute care, when they were sometimes overwhelmed by the situation they were in and the offers of help and support from a range of services. Often they were not quite sure who to turn to for advice at that stage.

The evaluation found that the Life After Stroke service in East Kent has delivered what stroke survivors value, such as the personal qualities of the staff, continuity of staff, having time and being there when needed, being knowledgeable, understanding, providing emotional support, building confidence and enabling recovery. Staff of the Life After Stroke should be complimented on adapting to change and keeping the service going despite working with short-term contracts, uncertainties regarding future commissioning, and recent cut-backs in staffing in the region of 25%. The Life After Stroke is already engaging in a process of developing new ways of working to provide a

sustainable service and ensure that the stroke survivors and their families continue to receive support.

Based on evidence gathered in the evaluation of the Life After Stroke service in East Kent, the following recommendations have been made in the areas of service provision, organisation and funding and development of the service.

Recommendations for the Life After Stroke service provision:

- The survey results and the interviews with stroke survivors and carers demonstrate that the Life After Stroke service overall is highly regarded by service users. As a long-term follow-up it should be maintained to complement the acute hospital provision and community health provision, and to support the needs of approximately 1000 stroke survivors each year in East Kent.
- Stroke survivors and carers have highlighted a number of highly valued characteristics of the service: personal contact with a coordinator, the approach of engaging with clients via visits, phones etc., regular meetings not too far from home and the provision of information. For stroke survivors in particular the service had a positive impact on their lives. NHS colleagues stressed collaborative and complementary working of the service. Any further development of the service should retain and enhance these characteristics of the service.
- A further characteristic of the Life After Stroke support service is its emphasis on social and emotional support, which complements the health-related services. The Life After Stroke should defend the focus on social and psycho-social needs of stroke survivors and their carers alongside long-term health care needs and highlight with commissioners the importance of continued support of this type for stroke survivors and their families.
- The person centred approach to maintaining working with a client is a significant strength of the service. This includes the length of time a stroke survivor and their carer can receive services through the Life After Stroke services, how contact is maintained and when a person can be discharged. The service should retain this flexibility and place emphasis on the individual needs and wishes of the clients.
- At the same time, the service should continue to clarify its function and purpose, for example by being clear about the support it can give, the length of support given and the purpose of meetings and groups run by the Communication support services.

Recommendations for the organisation of the Life After Stroke service in East Kent

- The evaluation highlighted some organisational aspects of the service which are highly valued by stroke survivors, carers and NHS colleagues. These include:
 - The geographical coverage of the service aligned to hospital wards of the Family and carer support coordinators
 - The distribution of the Communication support groups across the East Kent area

- The existing collaborative links with both the acute stroke services (via stroke liaison sisters) and the stroke community nursing team

These organisational principles have worked well, are based on long-standing and well working relationships and should be maintained and where possible, extended.

- The Stroke Association's Life After Stroke service has maintained high visibility of its services in acute stroke wards through various means, including boards in stroke units, leaflets, regular newsletters and other literature and the attendance of the Family and carer support coordinators on acute stroke wards. This personal contact in particular has helped to bridge the collaboration with the acute wards and stroke liaison sisters in hospital. The need to reduce costs for long-term support in stroke needs to be balanced against the importance of enabling good relationships through face-to-face contacts between professionals to maintain trust, understanding and effective collaboration.
- Further work should be done to develop clear demarcation of the Life After Stroke, acute service providers and the community stroke nurses, so boundaries are clear, and a seamless service can be provided collaboratively without duplication and confusion in the delivery of the stroke care pathway.
- While it has been unavoidable in the current public services funding crisis, the current uncertainties about continued funding and short-term extension of contracts are of significant concern. If services to stroke survivors and carers are not to be adversely affected, the funding of longer-term stroke services in East Kent needs addressing as a matter of urgency.

Recommendations for funding and development of the service

- While some services are maintained and spread across the area, some specialist service provisions have been lost due to reduced funding. There should be consideration and discussion with commissioners and funders of services as to how to replace the lost Return to work support and the Long-term support services.
- One of the areas of development is the work with carers. While some carer work is provided through the Family and carer support coordinators and the Communication support group, there is still a great deal of unmet need. This includes various types of respite (including at home respite to enable carers to engage in activities on their own, and residential long-and short term respite). The Life After Stroke service is well placed to explore with carers these needs and should work with others to develop carer services in East Kent further.
- The Life After Stroke service has embarked on a programme of using on-line technology to aid and record activities. While this process should continue and be developed further, equipment used needs to be appropriate and enabling. It should also not be used to substitute for personal contact either with clients or with colleagues.

- The Life After Stroke has also begun to identify suitable outcome data through activity recording. While this is recommendable and will help to enable positive funding decisions by commissioners, care needs to be taken that data are meaningful and accurately reflect the work of the service with stroke survivors and carers.

Introduction

This report describes an evaluation of The Stroke Association's Life After Stroke services in Eastern and Coastal Kent. The Stroke Association commissioned CHSS to evaluate the effectiveness of the Life After Stroke service in meeting the needs of stroke survivors, individually, and in combination with NHS and Social Services providers and to assess the impact on survivors outcomes.

The service to be evaluated consisted of a range of support services modelled on the Stroke Association's Life After Stroke service package, purchased by Eastern and Coastal Kent NHS Primary Care Trust (PCT) and East Kent Social Services (SS). The support services were provided to stroke survivors by service coordinators. East Kent has a population of 730,000 in a predominantly rural area covering 700 square miles.

The evaluation was required to cover the following three elements:

- To measure the impact of services in improving the quality of life of the person affected by stroke and utilise the Stroke Association's Impact Survey, based on data collected at entry to the service, after 3-4 months and after 12 months (or discharge).
- To assess the effectiveness of the Life After Stroke services approach by evaluating service coverage, collaboration between coordinators, case management, drivers and barriers of the service in delivering support.
- To assess whether and how well the Life After Stroke services were working with other agencies through indicators of joint working, indicators of integration of the service into the Stroke care pathway (PCT/SS) , evaluating the added-value for stroke survivors and families, identifying drivers and barriers to the success of the overall approach taken.

The evaluation was conducted over a two year period, from May 2010 to April 2012.

This report describes the context for stroke care in the UK, including key strategy and policy documents and models of care. It then goes on to describe the Life After Stroke service in East Kent and the approach we took to evaluate it using a mix of quantitative and qualitative research methods. Several hundred service users were approached through a survey to ask about their experiences of stroke and their use of the service at three points in time. The evaluation also sought the views of a wider range of service users, carers, service providers (in hospitals and the community), and commissioners using interviews and focus groups. The report concludes by bringing the findings together in a discussion that generates recommendations for the future.

Background to stroke care – policy and practice

A review was made of relevant documents and policies, such as material issued by the Stroke Association about the national Life After Stroke service, and specifications for the local East Kent service. Documents relating to stroke more generally were reviewed, including national strategies, programmes, guidelines, evidence and data. These documents along with the stroke support networks and forums are described here to set the scene for the evaluation.

A national stroke strategy was published in 2007 (Department of Health 2007). This was in response to concerns raised by the National Audit Office in 2005, and came soon after the Healthcare Commission (now Care Quality Commission) highlighted that there was very little help in the community for people who survived a stroke, especially when compared to care received in hospital (CHAI 2006). The national strategy was intended to provide a quality framework to secure improvements to stroke services, it set out how services would change and provided guidance for commissioners of health and social care. It also laid out what patients and their families should expect in terms of high quality care services. This was followed by guidance and funding for local authorities to set up support services for stroke survivors and carers - the funding was for three years from 2008-2011, with Kent and Medway receiving a ring-fenced £255,000 in the latter two years (DH 2009). By 2010 the National Audit Office reported that while care for people with strokes had significantly improved since the appearance of the stroke strategy, this had not been matched by effective post-hospital services and that there was a need for more joint working between health and social care community services (NAO 2010).

A number of gaps in research evidence have been identified relating to the national strategy's vision for post-acute care, for example not knowing the numbers and skills of staff that a community based stroke service would need and how outcomes would be measured (Wolfe et al 2008). There is mixed evidence on how best to provide information and if stroke liaison workers can improve levels of depression, however patients have been found to be more satisfied with support from someone who had really listened to them and when they had repeated opportunities to engage with their support worker and ask questions (Smith 2008, Ellis 2010). Against this background it is not surprising that support for stroke survivors has been found to be poorly coordinated with other services, uneven and inadequate (Commission for Rural Communities 2010). The Care Quality Commission also found significant variation in provision across England and many problems such as services being difficult to access, confusing, not adapted to individual needs, not involving people, and not even organised in a way that will meet needs, and suggested various ways in which the relevant agencies should work and collaborate (Care Quality Commission 2011).

The NHS Stroke Improvement programme website supports the development of stroke networks and provides information, such as a range of quality markers for a stroke support service. Research by the Stroke Association has suggested that Information and Advice Support coordinators are well-placed to carry out the recommended review six months after leaving hospital, and to address the unmet needs the reviews reveal (NIHR CLAHRC 2010). The Stroke Association has also taken a leading role in providing information and resources, for example the Stroke Association's UK Stroke Forum. Support is also available to stroke survivors through a variety of local and national groups

and charities via networks, websites and internet forums. 'East Kent Strokes' is a local support group with a regular newsletter and organised activities.

The Stroke Association's Life After Stroke model

Providing services and information are two of the Stroke Association's strategic objectives, so it is not surprising for the organisation to have developed and promoted a UK-wide Life After Stroke service. The national Life After Stroke model is based on five types of support; Information, advice and support, Stroke prevention, Communication support, Re-enablement and social inclusion, and Carer support. Each of these strands has been expanded to give a range of specific services, for example Re-enablement includes Return to work and Long-term support (see figure in Appendix A). The national Life After Stroke model aims to make these services available to all stroke survivors in order to reach the point when stroke survivors are sufficiently enabled to be discharged from the services or to have some long-term or alternative support in place. When launched the Life After Stroke model required just £1 per day to support a stroke survivor and their family, and offered a range of benefits ranging from improved emotional and economic well-being, to better use of resources and added value (see full list of outcomes in table 1 from the 2009 Life After Stroke pack).

Table 1 Expected outcomes from national Life After Stroke model

Outcomes	Details
Better care and support	
Improved health and emotional well-being	
Improved quality of life (hobbies, activities)	
Making a positive contribution (in community)	
Choice and control (about care and support)	
Freedom from discrimination (inc BME)	
Economic wellbeing	
Personal dignity	
Better use of resources	
Value for money:	Fewer strokes occur
	Faster discharge and fewer readmissions
	Carers provide a lot of health and social care
	Low-cost, self-sustaining support groups/networks
	Support to return to work
Added value:	20% volunteers are stroke survivors
	Life After Stroke staff have professional experience
	Take expert advice and carry out research
	Combine local knowledge with national influence
	Handout Life After Stroke grants
	Track record of working with commissioners
	Include users at all levels

The local service

Each year in East Kent there are around 1000 people who have a stroke and survive, and at the time of this evaluation the local acute hospital's service for stroke sufferers was one of the highest ranked in national performance tables.

The Life After Stroke service in East Kent was commissioned by the local Primary Care Trust to provide support to stroke survivors after they have left the acute hospital setting and are back at home. Life After Stroke is a community-based service, broadly covering the services laid out in the Stroke Association's Life After Stroke model. In Eastern & Coastal Kent there were four distinct contracts for Family and carer support (originally called Information Advice and Support and run in three geographical patches by part-time coordinators), Communication support (also patch-based and run by three coordinators, two of these working part-time), People of Working Age (one coordinator) and Long Term support (one coordinator). Table 2 shows which parts of the national model were provided in East Kent in 2010.

Table 2 Comparison of national Life After Stroke model with East Kent service in 2010

Services in Life After Stroke model	Sub-theme	Provided in E Kent
Information, Advice and Support	Information, Advice and Support Service	Yes
	Emotional support	Yes
	Representation and advocacy	Yes
	Black and Minority Ethnic Service	
	Befriending	
	Economic well-being	Yes
	Information Prescription Service	
Stroke prevention	All clients	Yes
	Stroke Prevention Services	
	Local awareness campaigns	Yes
Communication support	Communication Support Services	Yes
	Carer training	Yes
Re-enablement and social inclusion	Back to Life Services	
	Arts	
	Younger People's Services	Yes
	Return to Work Support Service	Yes
	Long-term support	Yes
	Peer support	
Personal Budget Support Service		
Carer support	Carers' groups	Support, but not in groups
	Carer training	

The coordinators were expected to provide support services for families affected by stroke. In the case of the Family & Carer/Information and Advice service coordinators the job was to intervene as soon as possible after a stroke to give information and emotional support, to enable families to cope and to optimise quality of life for stroke sufferers and their families. Stroke survivors could later be

referred to the Communication support coordinators whose role was to help people with communication difficulties, working with the Speech and Language Therapy service to maximise communication skills. Referrals were also made to the Working Age and the Long-Term support coordinators. The Working Age service aimed to support the needs of younger people affected by stroke, and the Long-Term service was set up to intervene one year after a stroke, at the time when users were likely to be discharged by the other coordinators.

The Life After Stroke services in East Kent were commissioned on a short-term basis with the result that coordinators' contracts were fixed term and not always renewed. The Working Age support contract ended early in the evaluation period (August 2010), and the Long-term support service ceased in December 2010. As a result, this evaluation has only been able to cover the Family and carer and Communication support services; although the views of the Return to Work coordinator were incorporated in the evaluation.

The service was also being run at a time of change to public services, in the shape of NHS re-organisation and looming spending cuts, which are likely to have had an impact on the service and the views of those taking part in the evaluation.

In addition to the Life After Stroke service in East Kent, there were other networks and support groups, some organised under the auspices of the Stroke Association and some self-help groups such as East Kent Strokes. In Kent stroke survivors can generally find such a group within less than 10 miles of their home, with groups offering practical and social support.

Approach to the evaluation

The evaluation ran for 2 years, starting on 1 May 2010 and ending 30 April 2012. Ethical and research governance approval was obtained through the University of Kent research ethics committee in June 2010. This section describes the broad methodological approach that was taken. More details are given in the three results sections that follow. The findings are described separately and have not been triangulated, although common themes are presented in the discussion.

Approach used in the evaluation

A multi-methods approach was followed, combining quantitative and qualitative elements. This was chosen because different methods are appropriate for different questions and different populations. By carefully choosing a mixture of methods, we combined the investigative and interpretive strengths of each, allowing a better understanding of the research question than could have been possible using either of the approaches alone.

The main quantitative approach was a survey to assess the user satisfaction of the service and what impact the service had had on their quality of life. The survey was to be administered to users at specific intervals, in order to track the effectiveness of the services used over time. Again small adaptations were made, this time in order to improve the survey's coverage of service user views. Service users were initially surveyed between August 2010 and January 2011 as they were first contacted by the coordinators, then again after four months, and finally after 12 months or when they stopped receiving the service. Everyone was sent a questionnaire with a free-post envelope allowing them to send their reply in confidence to the evaluation team at the University. The only exclusions were people who were considered too ill to respond or refused to take part. Quantitative information was also available from the local computerised records management system.

The qualitative methods were designed to identify the impact of the services from the perspective of the service users, providers and agencies involved, and to allow for the exploration and discussion of complex issues around the delivery of the services. The proposed methods were individual interviews (with service users and carers) and focus groups (with carers, coordinators, and health professionals). There were minor alterations to the plan, for example interviews were held when it was not possible to convene a focus group, and the timetable for coordinators was extended to get greater coverage of views across a time of changes to the service. Focus groups and interviews of service users, carers, service providers, commissioners and others were spread over two years.

An advisory group was set up to offer advice and guidance to the evaluation. The group which met five times consisted of a service provider (hospital consultant with a special interest in stroke), a stroke survivor, a carer and a Service Improvement project manager on the stroke team in Kent Cardiovascular Network. The role of the group was to comment on research outputs and reports, help review and interpret survey findings, help refine interview and focus group questions, suggest people for interviews and focus groups, and to comment on findings from interviews and focus groups. Regular meetings also took place between the evaluation team and Life After Stroke service managers.

Surveying service users' experiences

Survey methods

The quantitative arm of the evaluation consisted of surveys of people who were referred to the Life After Stroke service. Questionnaires were used as a consistent way to present the same set of questions to a large number of stroke survivors in East Kent. The evaluation team was asked to incorporate a pre-existing questionnaire devised by the Stroke Association to measure the impact of their services, and to ask these questions at several points in time. The existing survey was therefore used (with minor adaptations) as it was seen as a tested and efficient way of assessing the experience of users with the Life After Stroke service, and would minimise the extra burden the evaluation would make on stroke survivors.

The Stroke Association's existing survey was called the Impact and Satisfaction Survey, which ran over 6 pages of questions presented in relatively simple language and a clear format. It was being sent to everyone after 12 months or when they stopped using Life After Stroke services, and there were alternative options of completing it online or via an aphasia-friendly version involving well-recognised images (Widgit symbols). There was also a version of the existing survey aimed at people who acted as carers for stroke survivors.

As service users were the focus for the evaluation, and the online survey option was little used, we decided to base the evaluation on the paper version aimed at stroke survivors, to offer an aphasia-friendly version if requested, and not to carry out any surveys of carers. This decision also helped resolve minor differences between the versions in existence.

The Stroke Association's Impact Survey was adapted for use at three points during the evaluation:- when people were first referred to the service (Baseline), after 4 months from the first contact (Four month), and after 12 months or when users were discharged if that occurred sooner (Discharge/12 month). The baseline survey was to get an idea of the baseline needs of the services users. The later questionnaires would assess the value of the service received over time. Adaptations to meet these objectives were made in discussion with our project Advisory Group, and the local service managers and coordinators. Although an aphasia-friendly version was offered, no-one requested it which was fortunate as preliminary enquiries suggested that it would have been difficult to find the skills and the budget to have developed one.

Changes were made to the covering letter in order to satisfy ethical considerations, by explaining why the information was being collected and the fact that users of the service would be asked at several points in time. The baseline questionnaire was considerably shorter: it simply asked about the impact of the stroke, and which Life After Stroke services people felt they would benefit from. The four month and discharge/12 month surveys were quite similar to each other and the pre-existing questionnaire: they asked which services stroke survivors had used, how satisfied they were with the services received and how much the Stroke Association had helped them deal with a range of typical problems. The problems were based on relevant outcomes for people with stroke, such as improved emotional well-being, choice and control, personal dignity. All responses were to be sent to the evaluators, and the discharge/12 month responses were to be photocopied and sent on to the

Stroke Association to be added to national pool of replies. During the evaluation period the Stroke Association changed its Impact Survey (making it shorter in the hope of increasing the response rate). For those people involved in this evaluation in East Kent it was agreed that we continued with the same set of questions rather than switching to the new ones.

A system was set up by the local Life After Stroke service managers and coordinators to send out questionnaires at the appropriate times, and to keep detailed records of these. If the stroke survivor was discharged from the service during this process, the final questionnaire was sent. Before sending out follow-up surveys a check was made and cases excluded if they had requested not to be sent the survey again, they had moved away, died or were considered too ill to respond. Freepost return envelopes were provided. No reminders were sent, but service coordinators were asked to encourage people to respond.

The baseline survey was to be distributed from August 2010 - December 2010, the four month survey from December 2010 – April 2011, and the final surveys to be sent by the end of 2011. As the number of eligible people was lower than expected (about 30 baseline surveys distributed per month, rather than the anticipated 100), and the response rate was also lower than expected, the mailout periods were extended by two months. It also emerged that stroke survivors receiving support from Communication coordinators were not being picked up at baseline as it was the Family and carer coordinators that provided the initial contact. In an effort to include the views of more service users, and to avoid users getting the baseline survey repeatedly when they were referred on to another coordinator, it was decided to send the 4 month survey to all stroke survivors using the Communication coordinator services (in March-April 2011), following up this new cohort with the Discharge/12month survey as appropriate. In the analysis we have classified replies according to the service and coordinator they were linked to in the Life After Stroke management system at the time the survey was mailed out.

Survey results

The baseline survey was sent out to 125 people, the Four month survey to 170 and the Discharge/12 month survey to 172. These numbers were far lower than the estimated 100 people per month being referred to the service, and the target of 100 taking part in the evaluation. There were 48 responses (38% response rate) to the baseline survey, and these were mainly users of the Family/Carer coordinator service whose main role was to supply information, advice and support. At baseline, there was one response from the Working age, one from the Long-term support service (before these two services came to an end), and no responses from the Communication support service (see table 3).

There were 46 responses to the Four month survey (27% response rate), but this masked the fact that hardly any (8%) of those who had already received a baseline questionnaire replied to the second one. A comment from one respondent indicated that they had not realised they were being asked to reply at several points in time, and this might account for some of the non-response. In contrast 75% of those attending the communication group sessions replied, possibly because it was the first survey they had received, but more likely because it was handed to them at a group session.

On discharge or after 12 months of using the service there were 34 replies, with a 20% response from users of both the Family and carer support and the communication groups.

Table 3 Evaluation surveys distributed and returned

	Baseline			Four month			Discharge/12mth		
	All services	Family and carer	Working age and Long Term	All services	Family and carer	Communication	All services	Family and carer	Communication
Number of responses	48	46	2	46	10	36	34	24	10
Number of surveys sent out	125	119	6	170	118	48	172	120	50
Response rate	38.4%	38.7%	33.3%	27.1%	8.5%	75.0%	19.8%	20.0%	20.0%

A total of 128 survey responses were received from 98 individuals. Four people responded at all time points, 22 people responded at two time points, and the majority (72) responded only once.

Demographics of survey respondents

Overall, the survey replies were fairly evenly split between men and women, although there were more replies from men at baseline: 53% were male, compared to 39% of replies at later stages coming from men (see table 4). At baseline 29% survey respondents were under 65 years old, whereas at four months and discharge the percentage under 65 fell to 20% and 16% respectively. 98% classified themselves as white or white British. The help needed to complete the questionnaire varied, with less than half getting help at baseline (42%), compared to nearly two thirds (64%) getting help to complete the four month questionnaire.

Most said they had help from a relative, friend or neighbour (75%), but those in the communication groups were more likely to get help from a Stroke Association volunteer, probably because those at communication group sessions had help at hand to complete the survey.

Table 4 Demographics of survey respondents

	Baseline	Four month	Discharge/12mth
% male	53.2	38.6	39.4
% female	46.8	61.4	60.6
% under 50	6.3	4.6	6.2
% 50-64	22.9	15.9	9.4
% 65-79	31.3	47.7	43.8
% 80+	39.6	31.8	40.6
% Family and carer support	95.8	21.7	70.6
% Communication support	0.0	78.3	29.4
% Other coordinator (Working age or Long-term)	4.2	0.0	0.0

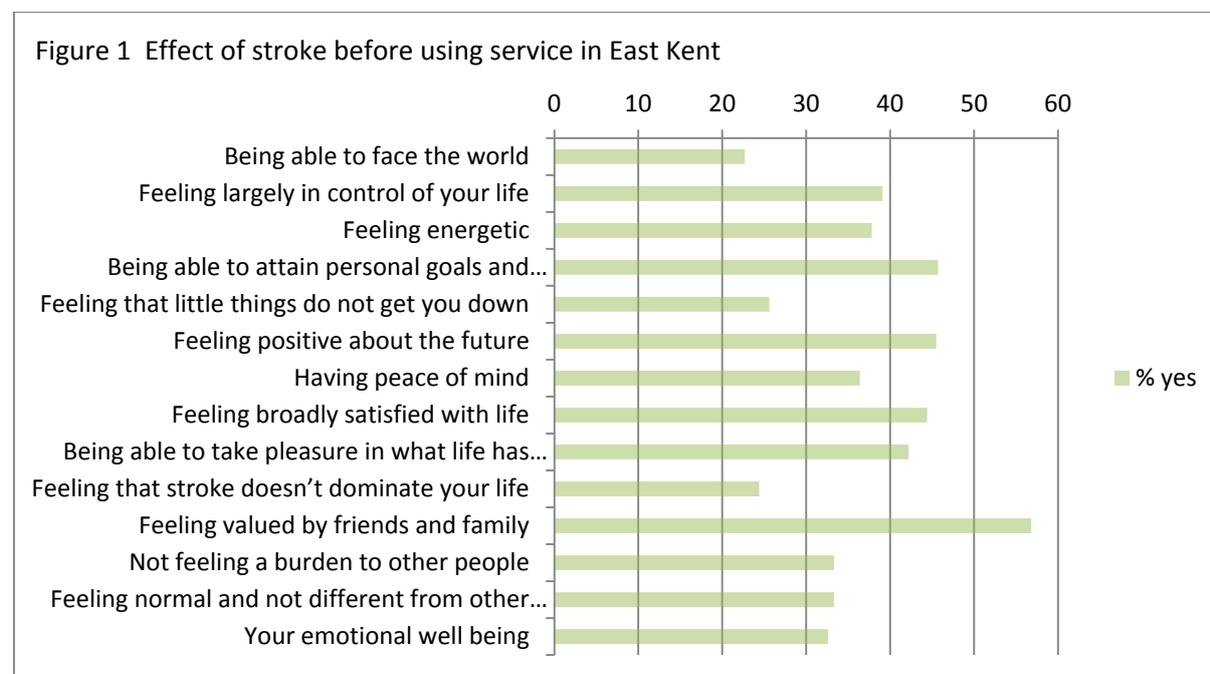
Responses to the survey – baseline needs (N=48)

In the baseline survey we asked which Life After Stroke services people thought they would benefit from and gave a list of six options. Nearly all wanted information and support (90%), with help with stroke prevention (74%) and communication (67%) also high on the wish-list. Over half said they would benefit from long-term support (57%) and carer support (54%), and although only 22% overall wanted help returning to work, this percentage rose to 38% when just looking at those under 65. These figures show that at the point of being referred to the service, there were high levels of need among those responding to the survey (see figure 2).

Of the baseline respondents, over three quarters said they had received an information pack about stroke (76%), 9% were not sure and only 10% said they had not received the pack.

The baseline survey also asked if speech, swallowing, mobility, sight or memory were a problem for stroke survivors. Mobility was the greatest problem (for 76%), followed by memory (for 59%). Speech and sight were problems for over a third (38%) and swallowing for 9%. The survey highlighted that most of these problems were experienced by significant numbers. When asked if there were other problems a longer list emerged, that included balance, confusion, tiredness, frustration, headaches, bathing, incontinence, confidence, anxiety and depression.

When asked about the impact of stroke on their lives, the greatest impact was on feeling valued, being able to attain personal goals, feeling positive about the future, broadly satisfied with life (for 44-57%). The least impact of the stroke seemed to be on being able to face the world, stroke not dominating life, and feeling that little things do not get you down (23-26%). See figure 1.



Services used and satisfaction with these

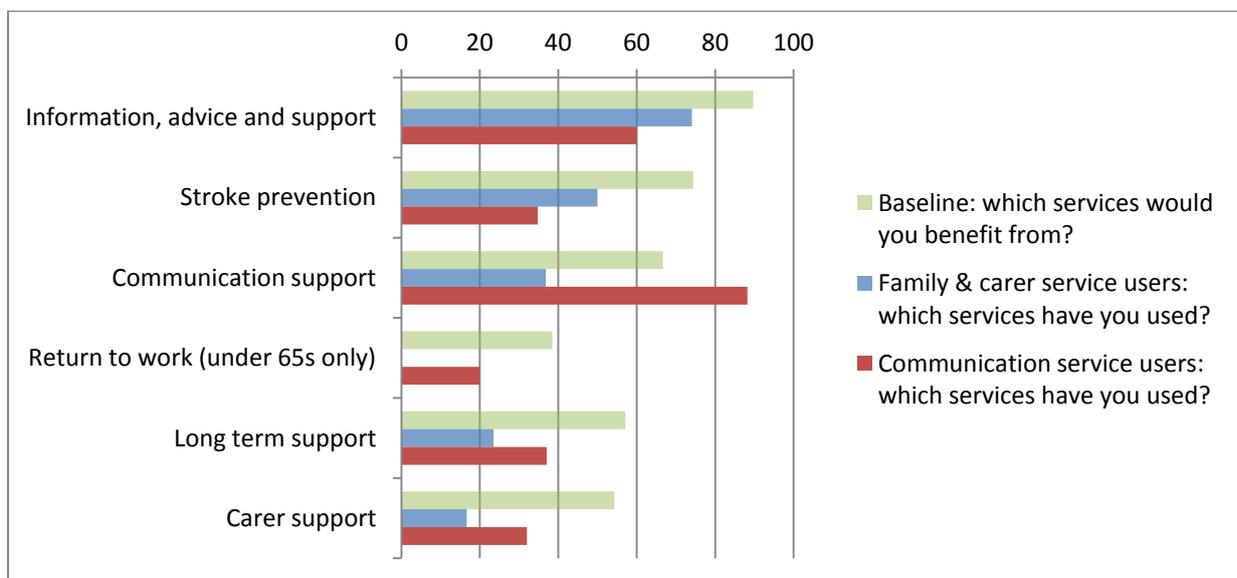
The baseline need for services was compared to the services that were subsequently used, although it should be remembered that the samples being compared are not the same people.

As this evaluation progressed, the differences between the Family and carer and Communication group service became apparent, and it therefore seemed appropriate to separate the views of service users. Because there were lower than expected responses to the follow-up surveys we have also combined Family and carer Four month (6 respondents) and Discharge/12 month (24 respondents) survey results to give a total of 30 Family and carer responders. Similarly for users of the Communication support service the 38 replies are a combination of the Four month (28) and Discharge/12 month (10) surveys.

Nearly three quarters (74%) of users of Family and carer services had received information and advice, quite significant proportions had also received stroke prevention advice and communication support, and about one in five had received long-term or carer support. Users of the Communication support service had also received a range of services with 88% ticking the communication box, followed by 60% saying they had got information and advice. The comparison showed that while actual service use was lower than the perceived need at baseline, quite high proportions of need had been met (see figure 2).

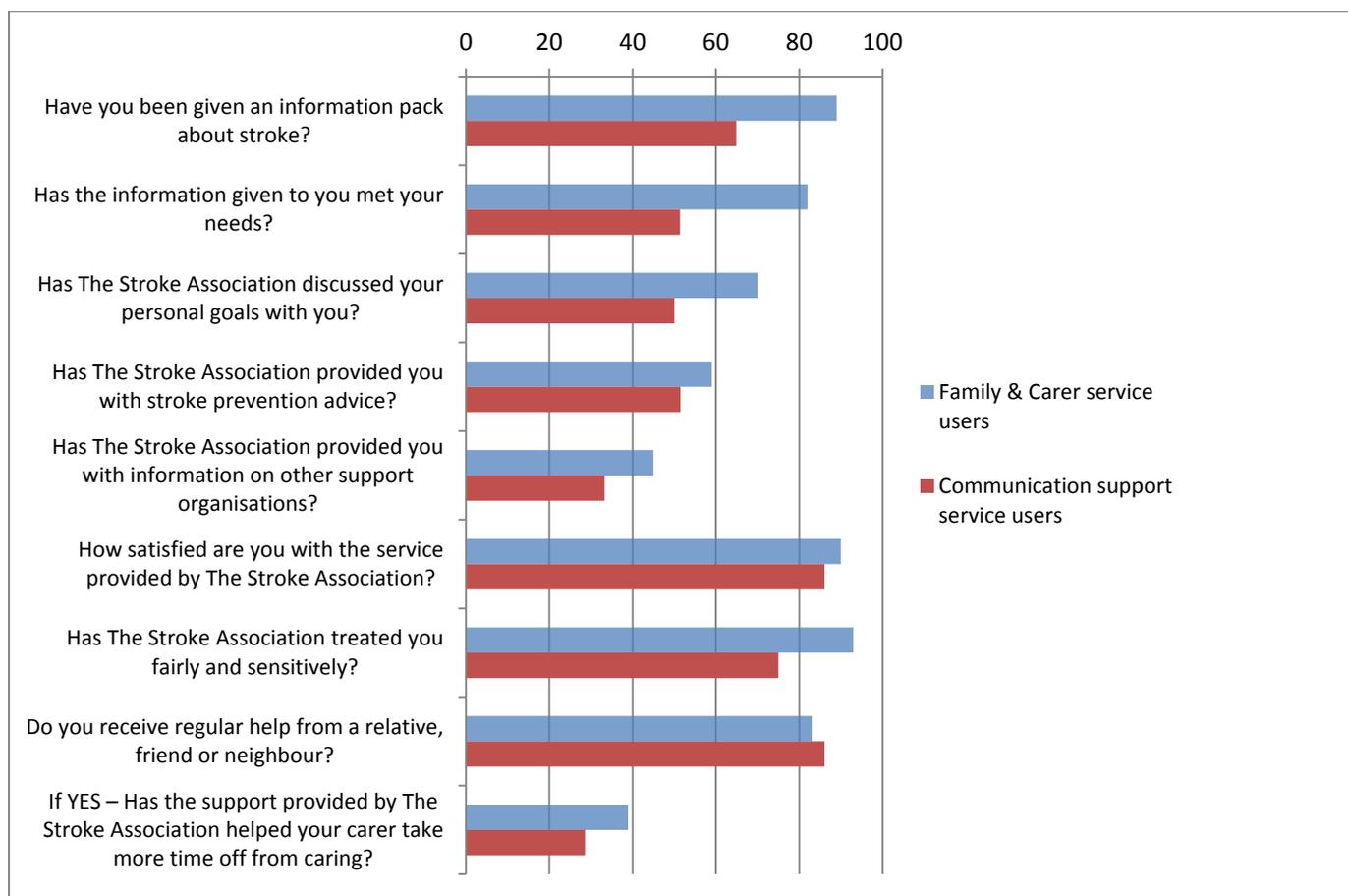
A few survey respondents wrote in comments at this point, several of which showed that although people remembered the person who had contacted them or were familiar with the person coordinating the meetings they attended, they did not necessarily use the label Life After Stroke for these contacts.

Figure 2 Life After Stroke services in East Kent (% responses)



The survey went on to ask about specific services received. There were high levels of satisfaction (80% or more) with the service provided and being treated fairly and sensitively by the Stroke Association (see figure 3). Some of the questions in this section related to information and therefore it was not surprising that users of the information giving services rated them more highly. However levels of satisfaction were generally higher for Family and carer support compared to Communication support, but only significantly different for the following questions: been given an information pack, information given had met needs, Stroke Association had discussed personal goals, and treated fairly and sensitively. Satisfaction levels were lowest for being provided with information on other organisations and whether the Stroke Association support had helped carers take more time off.

Figure 3 Satisfaction with East Kent Life After Stroke services (% responses)



At the end of this section respondents were asked to comment on what difference the service provided by the Stroke Association had made to them and if its services could be improved. Nearly two thirds commented and the great majority were positive. Many comments referred to communication support, saying that getting out to attend meetings and meeting people had made a difference, and that these activities had improved speech, given confidence and provided social contact both to stroke survivors and their families. Comments also referred to help and advice on a range of topics, including benefits, stroke prevention, and getting back to work.

When asked if the Stroke Association could improve the service offered, fewer than one in five people commented. These were mainly asking for more meetings, not to cancel group sessions and to re-instate weekly sessions that had reduced to once a fortnight. The following requests were each made by one person: more information, more support for partners, and help to work on individual goals.

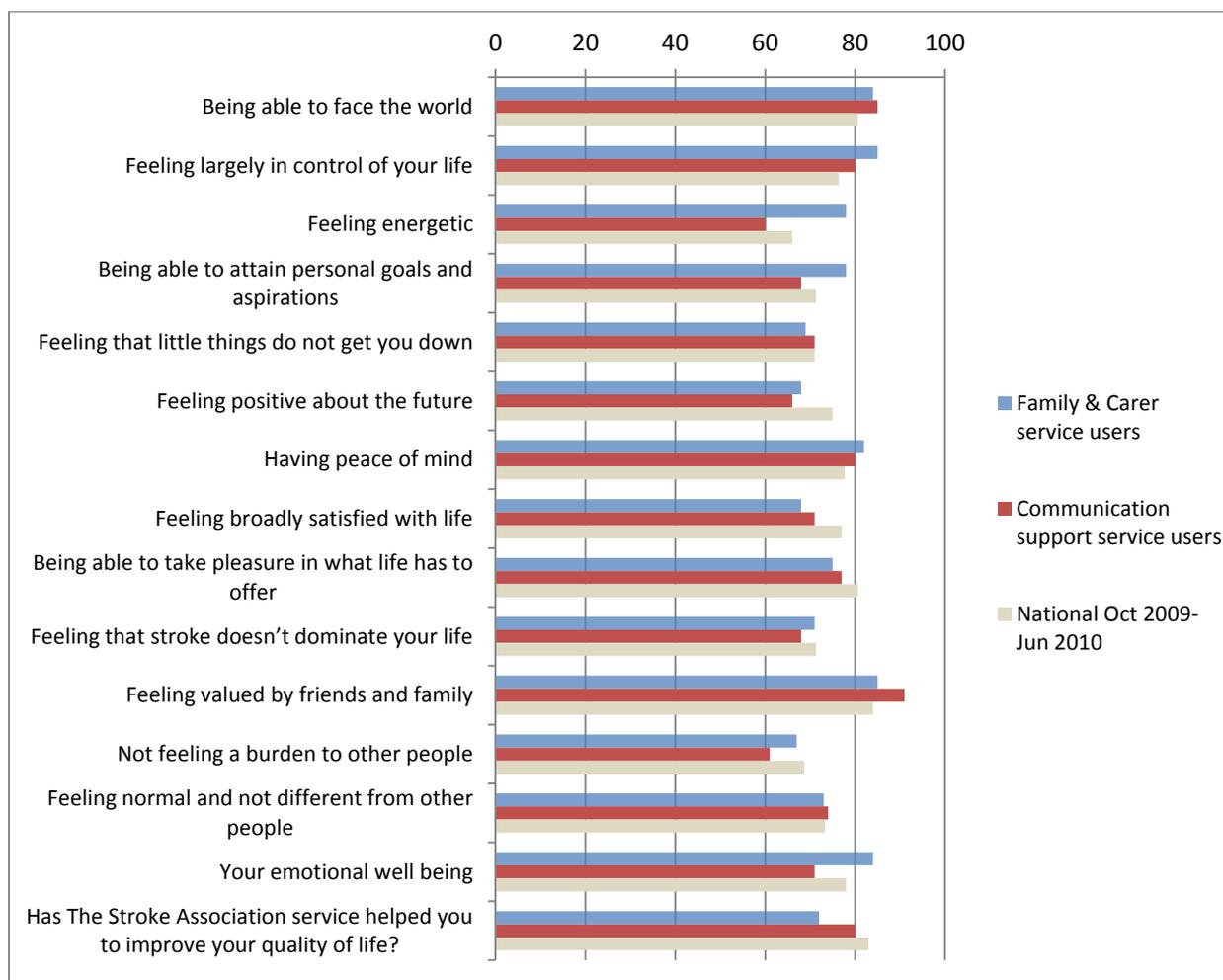
Impact of Life After Stroke service

The impact of the service was measured by the four month and discharge or 12 month surveys. The intention was to track change over time by linking individual responses over the three time-points, but lower than expected user numbers and fluctuating response levels led to some adaptation of the intended analysis. As already mentioned, the views of Family and carer support service users and Communication support group users have been shown separately, so the impact for Family and carer support service users is a combination of Four month and Discharge/12 month survey results, and similarly for users of the Communication support service.

The survey asked if the Stroke Association's services had helped in various ways relating to the stroke survivors' life. The results show the percentage who said 'yes' or 'partly' it had helped (see figure 4).

Impact levels were quite consistent and high, falling between 67-85% for Family and carer services and 61-91% for communication groups. Impact of the Life After Stroke service in East Kent was also quite similar between the two services, although more users of the Family and carer service said the services had helped with 'Feeling energetic' and 'Your emotional well-being'. The highest scores (80% or more) were that the Stroke Association services had helped people with being able to face the world, feeling largely in control of their lives, having peace of mind, and feeling valued by friends and family.

Figure 4 Impact of East Kent Life After Stroke services and national comparisons (% responses)



At this point the survey asked people to comment on whether there was anything more the Stroke Association could have done to make a difference. A small proportion (10%) asked for a range of things including counselling and therapy, more information and more activities. When asked if there was anything more that other organisations could have done the following were mentioned: more physiotherapy occupational therapy, home adaptations, support at home, and quicker response from DVLA on 'fitness to drive'.

East Kent Life After Stroke service statistics for 2010-2011

Quarterly reports from the Life After Stroke service computerised record management system (CRM) were made available to the evaluation. Quarterly reports prepared for NHS commissioners included the number of people referred to the service, various user demographics and other details about the caseload. Some of the management statistics are given here as they show background activity levels at the time of our evaluation

The CRM statistics for the first six months after the evaluation started (July – December 2010), showed 367 new referrals to the Life After Stroke service, with almost three quarters of the referrals

coming directly from the NHS. Over the same period there were many referrals (705 classified as 'discharges') to other services, and 328 case closures. Almost all (95%) of the new referrals were contacted within a week, and 219 information packs were handed out, a number equivalent to 60% of those referred. The caseload during this period was running at 530, there were slightly more men than women (52% compared to 48%), 79% were aged 65 or over, and 99% gave their ethnicity status as white. Between Jul-Dec 2010 the CRM showed there were 431 face-to-face visits and 44 communication support group meetings.

We were told that coordinators made an initial visit to stroke survivors to assess their needs, and that this was followed up by phone calls every 2-4 weeks up to 12 months which was the targeted discharge time. The phone calls were often made by office support staff, and as they were recorded in individual case records, these phone contacts did not appear in management summary statistics. Further visits would be made by Family and carer support coordinators as needed. Coordinators, managers and support staff worked as a team with a culture of trying to maintain support, for example by covering for each other to bridge gaps caused by staff leaving as short-term contracts were coming to an end or for long-term sickness. At the end of our evaluation the support staff had been made redundant and some coordinators' hours had been reduced due to cuts in funding.

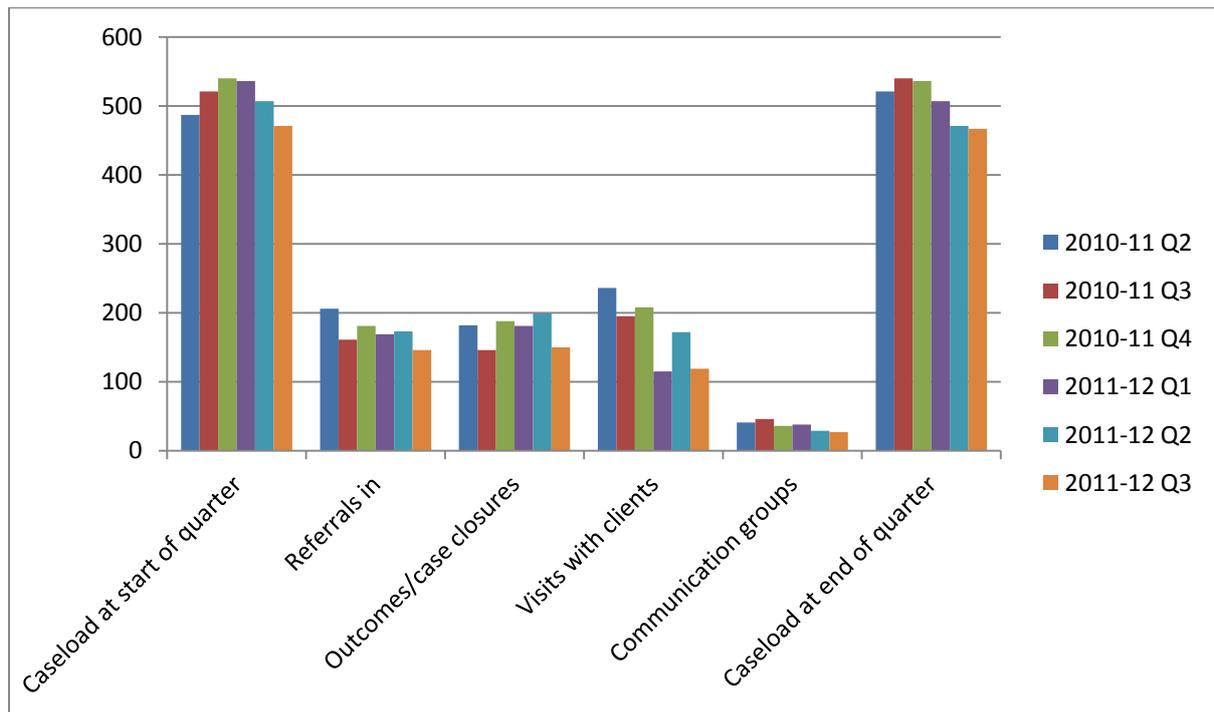
The response rate to the Impact Survey varied between quarterly reporting periods, but on average 27% were returned. See table 5 and figure 5.

To see how the service continued over the rest of the evaluation period, we added up CRM figures for the next four quarters (Jan-Dec 2011). These showed that some patterns of activity such as referrals and even caseloads remained quite similar, whereas the numbers of information packs handed out, visits and communication group meetings all went down between 20-30%. This would, at least in part, be due to reductions in the Life After Stroke service in East Kent after the Working age and Long-term support services ceased (in August 2010 and December 2010 respectively).

Table 5 East Kent Life After Stroke quarterly management reports

	2010-11			2011-12			Quarterly averages		
	Q2	Q3	Q4	Q1	Q2	Q3	Jul-Dec 2010	Jan-Dec 2011	% change
Caseload at start of quarter	487	521	540	536	507	471	504	514	2%
Referrals in	206	161	181	169	173	146	184	167	-9%
Given info pack	131	88	102	65	112	77	109.5	89	-19%
Outcomes/case closures	182	146	188	181	199	150	164	180	9%
Discharges	250	455	438	109	460	445	352.5	363	3%
Impact Survey handed out	62	52	67	65	58	75	57	63	11%
Impact Survey completed	9	19	27	17	11		14	18	31%
Response rate for survey	14.5%	36.5%	40.3%	26.2%	19.0%		24.6%	28.9%	18%
Visits with clients	236	195	208	115	172	119	216	154	-29%
Communication groups	41	46	36	38	29	27	44	33	-25%
Caseload at end of quarter	521	540	536	507	471	467	531	495	-7%

Figure 5 Selected East Kent Life After Stroke quarterly management reports



The overall service figures in East Kent can be compared to the evaluation results to see how representative the people were who completed the impact surveys. While they were demographically quite similar, by gender, age and ethnicity, there were more people in the evaluation who said they had received the information pack (77% compared to 60% in the CRM figures).

National impact survey results

The Stroke Association has published quarterly statistics from using the Life After Stroke impact survey across the UK. The national figures for October 2009 to Jun 2010 are available, and have been averaged in order to compare them with the East Kent Life After Stroke evaluation findings for Family and carer support and Communication support services (see grey bar in figure 4 Impact chart above and table 6 below). Results in East Kent were fairly similar to the national figures and there were no statistical differences between them.

Table 6 Impact of stroke and impact of service in East Kent, and national comparisons

	Baseline: % saying stroke has had this impact on their life	Family and carer service users: % saying LAS has helped with this aspect of their life	Communication support service users: % saying LAS has helped with this aspect of their life	National LAS impact survey results (average of Oct 2009-Jun 2010)
Being able to face the world	22.7	84	85	81
Feeling largely in control of your life	39.1	85	80	76
Feeling energetic	37.8	78	60	66
Being able to attain personal goals and aspirations	45.7	78	68	71
Feeling that little things do not get you down	25.6	69	71	71
Feeling positive about the future	45.5	68	66	75
Having peace of mind	36.4	82	80	78
Feeling broadly satisfied with life	44.4	68	71	77
Being able to take pleasure in what life has to offer	42.2	75	77	81
Feeling that stroke doesn't dominate your life	24.4	71	68	71
Feeling valued by friends and family	56.8	85	91	84
Not feeling a burden to other people	33.3	67	61	69
Feeling normal and not different from other people	33.3	73	74	73
Your emotional well being	32.6	84	71	78
Has The Stroke Association service helped you to improve your quality of life?	-	72	80	83

Summary of survey findings and comparisons with local and national data

This part of the report has described the perspectives of those referred to and using the East Kent Life After Stroke service. Views were obtained from posting and handing out specially adapted versions of the Stroke Association's Impact Survey. The survey findings have been compared to figures from the computerised record management (CRM) system in East Kent and to the Stroke Association's national findings from the Impact Survey.

About one in three of those referred to the service were sent the baseline questionnaires, and these were followed up by further questionnaires at four months and at 12 months or discharge. In order to boost recruitment and include a broader range of service users, we additionally handed out the four month survey to people on the Communication support coordinators' caseloads. Response rates were at an acceptable level for the first questionnaire received, but fell away with subsequent mailings. Due to insufficient numbers of responses, it was not possible to track individuals over time or compare the user experience at four and twelve months. It also became apparent that the Family and carer and Communication support services were quite different, so the analysis was therefore modified to describe baseline needs, and then examine satisfaction with services and impact separately for the two types of service users.

Stroke survivors referred to the service reported widespread **impact of the stroke on their lives** and thought they would benefit from the full range of Life After Stroke services. They also indicated they

had a much wider range of problems than the Life After Stroke service could expect to address. After using the services for several months the survey showed that indeed most had received information and advice and help with communication, and considerable numbers had received stroke prevention, long-term and carer support. This confirmed that the service was delivering on a wide front as set out in the background section of this report (table 2).

Satisfaction with the services was also rated quite highly, in particular that the Stroke Association had treated stroke survivors fairly and sensitively. For some aspects of the service satisfaction levels among users of the Family and carer support service were significantly higher than those of Communication support users. There are several possible reasons for this. It may be because members of communication groups have greater needs, or because the much higher response rate from these groups led to a wider range of views. It could also be due to the nature of the communication support service, which has a less clearly defined role, is a more difficult service to deliver, and during the evaluation in East Kent had gaps in staffing and geographical coverage.

The **impact of the Life After Stroke service** was rated highly in the surveys across a whole range of areas. There was little difference between the impact of Family and carer and the impact of Communication services, until it came to the many positive comments from people receiving communication support, saying that their speech and confidence to cope had been improved. The impact of the local service was similar to the published national figures.

Management reports for East Kent showed that, during the period of the evaluation, the Life After Stroke coordinators' caseload ranged from 470 to 540 in total, with approximately 160-180 referrals in and 160-180 case closures a quarter. The number of face-to-face visits ranged from 119 to 236 and between 27 and 46 communication groups were held each quarter. While referrals in and out and even caseloads remained steady from 2010 to 2012, the number of visits and communication groups held fell by a proportion (25-29%) that was similar in scale to the loss of both the Return to work and Long-term support Life After Stroke services and other reductions in staff funding. We have not been able to evaluate the impact of losing the regular phone contacts made by support staff in the Life After Stroke office.

Interviews with stroke survivors and carers

The qualitative arm of the evaluation included in-depth interviews to complement and enhance the findings from the survey on service user experience. An interview approach enabled further exploration of the process of contact with the Life After Stroke service, what service they have received, their understanding and expectations of the service, whether users have benefited from the service, how helpful it has been, what else could it do to improve, and how the has been used alongside other services/stroke groups. Background information regarding recovery from the stroke was also obtained to put the experience of service use in context.

Stroke survivors and carers of stroke survivors were interviewed to gain different perspectives on their experience of the Life After Stroke service. Initially the perspectives of carers were to be gathered by focus group but it proved difficult realistically to bring a group of carers together on a set date at a location away from home where they were caring for someone (usually their husband or wife) who had had a stroke. The majority of interviews (with stroke survivors and carers) took place in their home.

Interview methods

A topic guide was developed for use by the researchers to capture all the issues identified for further exploration. Similar but separate topic guides were developed for stroke survivors and carers based on the project's aims and objectives (appendix D). Participants for interview were obtained through the Family and carer support coordinators. Coordinators were given project information sheets and letters to give to clients to help explain the purpose of the interviews. The details of names of service users were then given to the university researchers to contact to arrange an interview if they were interested in participating. Informed consent was obtained at the time of interview.

All interviews were tape recorded and transcribed verbatim. The framework approach was used in the analysis of the transcripts (Ritchie & Spencer 1994; Ritchie & Lewis 2003; Srivastava & Thomson 2009; Pope 2000). This involves a process of familiarisation of the transcripts, identifying a thematic framework from the emerging themes, then indexing and charting of data relating to these themes into framework matrices which can then be used to interpret the data. The analysis was conducted using the NVivo 9.2 software.

Demographics of the participants

The university was given 15 names of stroke survivors of which 14 agreed to be interviewed, all 14 were interviewed between October and November 2011. They were fairly evenly split by gender (8 males/6 females) and the majority were of working age (under 65), the rest were over 65. The respondents identified for the interviews were much younger compared to the survey respondents of which 71% were aged 65 or older at baseline. There was a mix in terms of severity and type of stroke (blockage or bleed), and stroke problems (e.g. speech, mobility, eyesight and memory) among the stroke survivors interviewed. The evaluation team was given 12 names of carers and 11 of these agreed to be interviewed between November 2011 and March 2012. A higher number if female

carers were identified, with seven female and four male carers being interviewed. The exact ages of the carers was unknown, but the majority of them were retired (some having to stop work at working age to become full-time carers). See table 7.

The interviewees were selected from all areas of East Kent, with the majority of interest coming from the Thanet area. The majority of stroke survivors interviewed lived with others, rather than lived alone. They tended to live with their spouse who acted as their main carer. For most stroke survivors the stroke had happened over a year ago, and very few had had a stroke within the last 6 months. All the carer interviews involved caring for someone whom had had a stroke over 6 months ago. In some instances the carer needed to be present at the stroke survivor interview and vice versa, and so data has been analysed from both perspectives from both sets of interviews.

Table 7 Demographics of interview participants

		Stroke survivors	Carers
No. of participants		14	11
Gender:	Male	8	3
	Female	6	5
Age:	Under 65	9	unknown
	65+	5	unknown
Area:	Canterbury	2	4
	Dover/Deal	1	2
	Shepway	4	2
	Thanet	7	3
Living arrangements:	Lives alone	4	N/A (<i>All lived with spouse whom caring for</i>)
	Lives with others	10	
Time since stroke:	Under 6 months	2	0
	6 months to a year	5	4
	Over a year	7	7

Background

Setting the scene

The participants described the background to their stroke and the process of recovery. For those having a stroke for the first time it was described by many as unexpected and 'out of the blue', with little recollection of some of the events of the stroke. Some participants had experienced more than

one stroke in the past. Many of the participants had co-morbidities with their stroke, such as diabetes, heart problems, hypertension or high cholesterol. Some stroke survivors now suffered with depression and a lack of confidence as a result of the effect of the stroke on their lives. Stroke affected the participants in varying ways and typically they suffered from problems with mobility, memory, speech, perpetual vision, tiredness and/or difficulty in comprehending information and decision making. Those more severely affected were reliant on the support of their family and friends, and in many cases the husband or wife had to become their full-time carer, often having to give up work to care for them unless they were already in retirement, some had to make adaptations to their home or even move home to more suitable accommodation or to be nearer family. Even so both stroke survivor and carer in many cases had to adapt to a dramatic change in circumstances. Some found it difficult negotiating financial assistance if they found they were not entitled to benefits, and also difficulties in obtaining acceptable care support as it tended to fit around the care provider rather than the person/family in need. For some of the less severely affected stroke survivors it was the frustration of recovering well but still not being able to do some of the activities they used to do, such as returning to their previous job, reading, horse riding and playing the piano/organ. Others were pleased that they could ride their bike again or go on holiday. Participants gave a lot of examples of situations of how the stroke had impacted on their everyday lives. Recovery from stroke was a long process, with many 'hiccups' along the way and this in itself was a particular frustration for many of the participants. Many described the experience of recovering well to a point at which improvement stopped and a new approach had to be explored:

I've been told that there is no shortcuts in stroke um...the Physio told me, and she described it in a perfect way she said; it's like going across a cornfield where you get that path and then that pathway is blocked and then you've got to get another one, you know unblock another path. That's exactly how the brain works with a stroke (Female carer id11c).

Participant's attitude to their stroke and recovery was another recurrent theme in the interviews. Many of the participants described themselves as lucky to have got through it and compared themselves to other stroke survivors, whom perhaps they had observed while they were in hospital that were worse off than they were. Many tried to focus on the positive outcomes in the recovery they had made so far and had positive expectations for the future. Some were interested in supporting the activities of the Stroke Association for example to help other stroke survivors, some were already doing this in the form of hospital mentors, by visiting other stroke survivors while they are in hospital to demonstrate that there is life after stroke. However positivity about recovery and future recovery was not the case for a few of the participants, who didn't feel lucky in their situation. For some it was the outlook of 'why me', as they couldn't identify a reason, such as other health problems, diet, smoking or drinking, as other participants could. Often the future expectations were different for carers; continuing to care for their spouse or partner long term was accepted, but the opportunity for some time out or occasional respite care was welcomed.

Health and social care support

Some participants described their experience in acute hospital as part of the background to their stroke story and recovery. Views were mixed on the care received. Many described their care by the

stroke wards as 'excellent', 'very good', 'marvellous', 'wonderful' and 'amazing'. They were also appreciative of the hospital physiotherapists, particularly the patients whom they helped walk again before discharge from hospital. For those who had experiences of poor care, problems related to initial undiagnosed stroke, not reacting quickly enough, a lack of communication and information provided between patient and staff or between staff, being discharged too early, loss of notes and paper work and patients not liking the hospital ward environment.

Aftercare and rehabilitation services (other than the Life After Stroke service) were mentioned. In particular support was received from physiotherapists, occupational therapists and speech therapists and participant's experience of them was generally positive. It was acknowledged by those participants whose support from these services had stopped that there was only so much the health professionals could do in terms of improvement, but some would have liked to have further treatment. Support by the stroke nurse, community nurse and neuropsychologist and were also mentioned by some participants. Social services assessment and support was also referred to, but sometimes there was a wait to receive the equipment and adaptations provided in the participant's home. In addition to NHS and Social Services, family and friends were mentioned as important in terms of offering support after the stroke.

Process of support from acute to community care

Participant's progression from support in hospital into the community tended to be a smooth process with support from appropriate health professionals in a timely manner following hospital discharge e.g. visits by physiotherapists, stroke nurse, occupational therapists and referrals to counselling and psychiatric services (such as those provided by Westbrook House). However a few participants did not have such a smooth process and didn't have the connection between services. For example notes were lost and so not passed on, or they did not have the visits following discharge. One participant hadn't heard anything from the physiotherapist as expected and others had not had a visit from the stroke nurse after leaving hospital. A recurrent theme for some stroke survivors and their carers was that they felt they were given little information about what to expect from recovery of their stroke or advice on how to manage the care of the stroke survivor when being discharged from hospital in preparation for returning home. This initial gap in information provision came at time of greatest need when both the stroke survivor and carer were beginning to adapt to the change in circumstances the stroke had impacted on their day-to-day lives.

Contact and visits from the Life After Stroke service complemented the other services received (described above) post discharge, and for some the support of the service plugged the gap that participants felt that was missing in terms of providing information and advice soon after discharge from hospital. Participants tended to receive initial contact from the Life After Stroke service in a timely manner, a few days or weeks following discharge. In most cases the Family and carer support coordinators had been informed by the hospital of the need to make contact and the hospital had informed the stroke survivors and their carers about the Life After Stroke service. There were exceptions to this where initial contact with the Life After Stroke service did not happen in a timely manner and the initial connection with the service was missed. In general these participants had received acute hospital care and discharged outside of the East Kent area (e.g. because they had been transferred for treatment to hospitals outside of East Kent, admitted to hospital elsewhere

because they were away on holiday or have since moved to East Kent), or had been admitted into hospital for another reason and had a stroke while in hospital. The movement through the system of these stroke patients and their carers seemed to be stalled due to their different care pathways and as a result initial contact from the Life After Stroke service occurred later (however it was smoother and more timely if the client had moved to East Kent from an area where a Life After Stroke service also existed as they were able to link up).

At this time following acute hospital discharge, when the Life After Stroke service was making initial contact, many participants were also being contacted and visited by other health and community services. For some this was quite overwhelming at a traumatic time, but others welcomed the contact from services and the support and advice they could offer as they had lots of questions they wanted to ask.

Interview findings: the Life After Stroke service

The process of contact with the Life After Stroke service

The majority of participants were first contacted in a timely manner as described above (a few days or weeks following acute hospital discharge). For the majority of participants initial contact with the service was instigated by the Family and carer support coordinators rather than by the stroke survivors or carers themselves. The majority of participants were contacted by a coordinator via a telephone call at home; few participants first had contact on the hospital ward before they were discharged. Many were aware of the service prior to initial contact through the hospital where they had seen or were given the Life After Stroke information packs/leaflets:

I know I've had loads of these [leaflet], yeah, yeah.... I picked these up at the hospital....The hospital gave me them and my husband picked them up as well when I had the stroke. Yeah I've got them (Female stroke survivor id12s).

A minority of participants hadn't seen or received the leaflets in the information pack before they were discharged from hospital, hadn't read them, found them difficult to understand or were not aware of the Life After Stroke service at that time. A few were not sure if they had received the leaflets or not as they had been given so many other things to read. If they had received the leaflet and were aware of the service understandably participants had a lot to deal with after discharge and hadn't felt in a position to think about making contact with the service themselves at that point in time:

There's packs laying around all about the Stroke Association but....To be honest with you, I had other things to think about. I didn't give it much thought at that time...I got a phone call and she.....I can't remember.....I am useless at names but she asked if she could come and see to me and that's how it all started (Male stroke survivor id11s).

At the time really I picked up the leaflets there but with everything that was going on it doesn't really sink in and it wasn't until sometime afterwards and they phoned up and asked me whether [coordinator name] could come and visit so I said yeah fine (Female carer id7c).

Some participants didn't use the information pack to contact the Life After Stroke but did find the contents of the leaflets very helpful:

we had a package from the hospital from the Stroke Association and we found that really useful for what we did.....there was a whole folder full of things and it told us all about claiming for things um.....it gave you little leaflets to send round to your friends as well because they suggested that as friends don't know what's happening to [stroke survivor], it's very confusing to them I sent them round to the friends and family and they read them which helped (Female carer id14s).

After the initial phone call all participants had a visit at home. Many of the interviewees then had, and wanted, subsequent visits at regular intervals (e.g. every six weeks/every couple of months) and continued to do so:

Yeah she's been out...she's been out about three times but she's um....discharged us now because it's been a year and she said unless we need any more help then they'll be....she was very, very useful (Female carer id11c)

Others felt after some support from the service to put them on the right track further home visits were not necessary, and they received follow up phone calls instead from their coordinator to see how they were getting on and whether they would like another visit. All participants were left the telephone number to call their coordinator if they should feel they need to make contact:

I think I'd asked her all the questions in about the first five minutes you know then funnily enough she rung up the other day and she said "do you want me to come round?"..and I said "well not being funny but there is no need for you to". I said "at the moment we're sort of plodding along you know". I said "ok we do have a few little hiccups but you sort of learn to sort it out and get over it you know". We've got her number haven't we so that if we do need her help with anything you know we can ring her up and she said she would come round (Female stroke survivor id4c).

I've had telephone calls but I can have a visit if I wish and they make it perfectly clear to you that if you should need anything or want someone to come and talk to you, which people that are on their own, possibly that's where I think it's a lifeline for them (Female carer id14s)

Services received from the Life After Stroke service

Participants found the Family and carer support coordinators to be a useful source of information and advice about stroke and stroke related issues. Some examples given include information and advice on stroke recovery, practical advice, help with travel insurance, financial advice, benefits you

can claim, diet and exercise, and suggestions to help with mobility. Notably information, advice and discussions around returning to work (part of the service remit) were rarely mentioned by participants, although this was not relevant for some.

Family and carer support coordinators also helped with the form filling to apply for welfare benefits such as disability allowance. The forms were seen to be quite lengthy and complicated by some, and advice was sought on the appropriate wording to include on the forms for example:

She advised about the disability living allowance and the motability living allowance and she did come out and help me fill the forms in which was a grand help (Female carer id6c).

On a more practical level, she has helped me so much with benefits and stuff like that because being horribly brutal, times have got very tough for us..on benefits immediately, no redundancy, no pay offs, no nothing, just terminated through sickness and [coordinator name] advised, helped and got me various levels of benefit which have just been a life saver and it just pays the bills and stuff like that (Male stroke survivor id6s).

Much of the information and advice came from discussions with the Family and carer support coordinators when they made a visit or phone call, but the Stroke Association leaflets, regular magazine and website were also highlighted as useful sources of information and advice:

And we'd sit here and have a coffee and a biscuit and chat, she would come up with little gems of advice, you know, oh that's nice I'd take that on you know, and you'd make a phone call and that would be sorted and so on and so on (Male carer id1s).

I think I got a Stroke Association newsletter. I get that as well and read up on various things. I'm always on the Stroke Association's website. I go on TalkStroke Forum which I found extremely useful. They're very helpful, yeah she's been wonderful, [coordinator name], I can't fault her actually for her support (Female carer id11c).

Discussions relating to stroke recovery (e.g. its management and what you should expect and what is normal) were a particularly prominent part of the visits from the Family and carer support coordinators. Some of the participants felt that these were discussions they were unable to have with other services and health professionals:

Any information you get, if you don't get it from your doctor who just tells you to get on with taking the medicine and others around you who just want to see you moving and walking, they don't tell you that it's possible to have a life afterwards....Being told that yes you're gonna be tired for 6 months, but in that 6 months you'll be within a few months of it, you're gonna be doing things again, You'll not be thinking life's over. Life was over until she [coordinator name] came along (Male stroke survivor id3s).

I've asked her loads of questions and if I see something like in the paper that refers to stroke..., it's when you see something that's happened to you or a letter from somebody that you can associate with and say oh yeah that's exactly what happened to me you know, I'll bring that up or maybe new forms of treatment or, that you see, probably the medical people hate people doing that you know, and on the web you know getting the stuff off, you know I think oh I've got that, you know...I mean did see something, well specifically I cut it out before [coordinator name]... (Male stroke survivor Id2s)

Emotional support and listening

In addition to the more advisory part of the role of the coordinator, participants acknowledged that another part of their role was to check on them to see how they are. Some participants highlighted that the coordinators have provided emotional support for stroke survivors and their carers when they have been feeling down or feeling depressed as a result of their situation following the stroke. For these participants this support has been 'greatly valued' (Male stroke survivor id6s):

Well the thing was it was my support that.... he started to get very depressed and I wasn't quite sure how to handle things..and I thought I was going to ring, not for him but for myself because I needed that extra support, and it just happened to be that I was out and I bumped into [coordinator name] because I knew her from before, and I said "I was going to ring you a couple of days ago because I was sort of starting to get a bit desperate" and she said "well I've got [stroke survivor] down for an appointment", and I think she came the following week (Female carer id1c).

For many others the visits from the coordinators were appreciated because more generally it offered them someone else to talk to who they felt listened to them about their problems or things they wanted to discuss. For some it was a useful opportunity to have that discussion with someone else outside of their family, e.g. other than just between the stroke survivor the carer, or with other family members. Some participants lived alone and had no one immediate to discuss issues with and others did not wish to discuss issues with their family at all and so the Family and carer support coordinator gave them the opportunity to talk:

[Coordinator name] and she is good because she listens and she talks and helps you get through things. If you have a bad day then she knows (Female stroke survivor id12s).

It was nice to talk to somebody on a level and for them to fully understand where I was and to be able to talk openly about any problems such as getting up six times in the night, six or seven times (Female carer id3c).

When he was first home this time, you were really low and I did feel that I could call on [coordinator name] to come round which was very good because sometimes although you are supportive as with all things family, it needs to go out because it escalates...If there are tensions and that, it can escalate if it's worked on in the family, it's better to go outside. You do need that somebody to sound off (Female carer id4s).

Signposting to other service providers

The coordinators have also been able to signpost to relevant services and groups to help with Particular issues or needs of the service user. For example they have referred services users to other parts of the Life after Stroke service, e.g. the communications groups. The coordinator has been able to make arrangements to book them into the group nearest to their home that meets regularly to help them if they have problems with their speech following their stroke. Of the few participants interviewed who were attending a communications group they seemed to enjoy it and it actually provided a bit of respite time for their carer to go and do their shopping for example:

I don't go. I take [stroke survivor], I leave him there um...which I think is good for him to be somewhere without me um...but you seem to enjoy it don't you?...because I know when I go to pick him up....I mean one day they were...they had some Roman artifacts and they'd been talking about Roman Britain um....so you talk about all sorts of things which is good for them and you know it's basically to help you talk about....to talk isn't it?...Because I drop him there and I leave you for a couple of hours and I go off up to the farmers market (Female carer id6c).

They do [enjoy it] and they have board games and read papers to each other and get the conversation going...Well I leave [stroke survivor] there and then I go and do banking and shopping which in the early days I couldn't do at all because I couldn't leave [stroke survivor name] even for a few minutes so that helped out (Female carer id14s).

If support is required that is not provided by the Life After Stroke service, Family and carer support coordinators have referred service users to other local services and support groups in their local area. These services included NHS mental health services for older people in the community, such as Westbrook House in Thanet and Coleman House in Dover:

Since the stroke it's left me really emotional um because a lot of stroke people are really depressed but it's left me really tearful and emotional and when [coordinator name] kept coming round I was sort of breaking down in tears wasn't I?... and she said "have you had any counselling at all?" and we said "no" and she said "I think you need to see someone" and she said "I'll sort something out" and the next thing you know she said "there's a group starting at Westbrook House, I think you definitely need to go" (Male stroke survivor id15s)

A few of the carer interview participants were signposted by the Stroke Association/their Family and carer support coordinator to carer support services (Crossroads and Volcare) which offer respite care. When carers were asked of any other support that would be helpful to them it was clear that many other carers would like to have some form of occasional respite support, but they were not aware of any services available to them. In general this issue was not something that these carers identified as having discussed with their Family and carer support coordinator when they came to visit or made a phone call.

It was often mentioned by participants that the coordinators signposted them to the activities of East Kent Strokes, which proved to be very popular among the participants who had taken part in their activities. Activities mentioned by participants put on by the East Kent Strokes were regular lunches, boat trips, a train ride, golfing, gliding, cruises and other trips. These acted as a means to bring stroke survivors and their carers together and gave them the opportunity and ability to be able to go out and do things again, and meet other people in similar circumstances to talk about their experiences and exchange ideas and information:

They have these lunches and sort of, I think they're.....are they every....they're every week but they are in different areas so we only go to the ones that are sort of local but we don't go to many. I go to a few and you just sort of make your face known and talk to the other people...it's good to talk to the other people and they also in turn, even though they're more experienced than us, you learn from each others' experiences and what you've found out to be helpful (Female stroke survivor id9c).

You meet up once a month at a pub and have lunch and a chat and you can get information...and they do huge trips like they do gliding at one time and a trip on the Medway on an especially adapted boat. It's amazing....It's allowed us to meet other people....They show you that....they are going gliding for goodness sake, why shouldn't you? So it's telling you there is a life after stroke and don't let it get you down and you need peoples' optimism like that I think because stroke is a depressing disability isn't it? (Female carer id14s).

Although access to groups signposted through service proved to be worthwhile and enjoyable for many, some participants decided not to become involved with organisations and stroke groups as they felt it was something they did not wish to do. However in a few cases although they had their own preconceptions of what such groups would be like and had reservations about attending they did decide to go along and were pleasantly surprised with the experience:

No, I am not great with groups...it is a combination of one, it's a personal choice and two, I don't feel that perhaps I or the group would benefit from it. I am quite strong willed. I don't really take kindly to being shepherded (Male stroke survivor id6s).

I don't want to be reminded all the time if you like. I mean I don't mind doing this sort of thing but I'm not sure that I want to sit in a circle and talk about and hear other people. I've got my own problems thank you... it's not me anyway. I've never been that sort of person so...(Female stroke survivor id7s).

I was sort of dubious about going. I thought it's probably going to be all old people who probably won't be able to talk or.... I don't know it's sort of....I didn't know what to expect ... and went there, and met the people and after a couple of weeks it was as though you had known them for sort of forever and it was like really good friends and no one was scared to talk about their experience and how they actually feel and how their partners actually feel (Male stroke survivor id15s).

The Family and carer support coordinators were also able to organise, signpost and link up with service providers and provide practical help and support to the stroke survivors and their carers to help solve problems in their home and improve their day to day lives. For example they were able to link up with relevant services to install lifeline panic button systems, replace household items that had broken such as cookers and washing machines, offer support to solve damp problems, and making useful suggestions to make the lives of carers easier like getting a motor installed on the back of a wheelchair to help push it, and use of a convene to help with toileting.

Positive user experience of the service

The service user experience of the Life After Stroke service was mainly positive. General comments were that the service was 'very good', 'brilliant' and 'excellent', 'marvellous', and 'happy with what they are doing'. It was seen as a reliable service (i.e. they turn up for visits or ring up when they say they will). A recurrent theme was that the service offered service users the reassurance of being somewhere to turn to if and when they are need e.g. that someone was there to talk to about any issues or problems or at the end of the phone if they needed to call. This was something they felt they couldn't get from other NHS services. There was acknowledgment by the few participants who had experienced stroke previously in the past that service provision had increased in their recent experience of stroke which they were appreciative of. There was also acknowledgement by some that service provision was being offered in increasingly difficult financial times and so a squeeze on resources was anticipated for a service they thought was worthwhile:

She's a possible contact rather than having to contact somebody at the hospital which can be long winded. You can't do a direct....you can only make enquiries and you can only wait for them to come back to you but at least with [coordinator name] and her colleagues in and around the area, they would obviously....they are all there for somebody to...you know as a lifeline if you wish. You know if you've got a problem you can always, as I say you just leave a message and she'll come back to you (Male carer id8c).

I think that that's a very good service you know, because you, myself I wouldn't actually like to be cut off completely, you know without any contact with the stroke people...You're talking to people that understand, that actually understand the subject, you know I mean they obviously specialise in it and it's that you don't feel alone or you don't feel well you've been forgotten, you know I mean it's quite serious things that happen...it's the scary things that happen...and that, they're in the background, or a phone call away is, is quite reassuring (Male stroke survivor id2s).

My memories of the Stroke Association are all very good. When they say they are going to come round, they do....Yes, I think they do what it says on the tin or the box. It's probably cheaper a box these days....Their role is to make your life easier (Male stroke survivor id10s)

Resources are wasted in a lot of places, I don't think they're wasted on that service. And I'm surprised that it had to be, which I thought, a charity rather than, now I see there's some NHS funding for it...if they need more, it should be an open cheque book because people can recover, people go back into work, people go back to doing things but not from what they're told by the GP or the stroke ward (Male stroke survivor id3s)

Pivotal to the user experience of the service were the coordinators themselves. They were the faces of the service and often that individual person resonated with the participant's view and understanding of the Life After Stroke service. The coordinators were seen as being helpful, nice and supportive by their service users as well as experienced and knowledgeable. One participant described their coordinator as 'a good comfort blanket' (female stroke survivor id5s) and another described their coordinator as 'a walking encyclopedia' (female carer id7c). Some of the participants classed the coordinators as being like a friend to them who they could trust, they felt comfortable talking to them and/or felt they could discuss anything with them:

With [coordinator name] she does more than just comes in. She obviously knows her subject well but the way she puts you at ease that's where her strength is I think and you don't know until she's gone "you go oh yes she said that". She answers your questions but you are sort of.....you know she's done it but the subjects wonder off into the realms of...which is brilliant but yes she does put you at ease and she does pass information on and we get on with it (male carer id7s).

I can honestly say... I would count [coordinator name] as one of my closest friends. I trust her implicitly. She brings practicality to the table and she has been of great help to me. [coordinator name] is by far and away the most important. She is a lifeline because the one thing that [coordinator name] does, is [coordinator name] makes you forget you have had a stroke, which is nice because there is nothing worse than being perpetually reminded that you've had a stroke (male stroke survivor id6s).

Negative user experience of the service

Some negative views on service experience were also described. Some participants would have liked to receive support from the Life After Stroke service earlier, either whilst the patient was still in hospital before discharge or earlier after discharge if the first contact from the service had been delayed. Some reasons for delay in accessing the service were due to problems with the information filtering through the NHS system (as described above):

It did take a while because when you first have a stroke you don't know where you turn to and nobody comes up and tells you so...I do wish it was sooner but as she said she was busy and she got....which was fair enough but I honestly think it needs to be sooner than it was. I don't think so I just think it needs to be earlier. Once they were involved that was it, it just all came into place. It took quite a while to get....it was six months before we had anybody (Female carer id15s)

Had the lady who came to visit me come to the bedside I would have been, I think recovered a lot sooner..Had it been sooner it would have been helpful (male stroke survivor id3s)

Given that the vast majority of first contacts were coordinator initiated rather than patient initiated the message about the service on offer and what support it can provide doesn't appear to be reaching all that need it at the time they need it in some cases. Some participants were not aware that the service existed before first contact from the coordinator and others were aware of a number to call but were too caught up in trying to cope and deal with what had happened to them to consider ringing and/or they were not sure what support the service could provide. One participant commented that they were aware of the Stroke Association office in the hospital ward but there was uncertainty about whether they should knock on the door for help and support:

When it first happened and [stroke survivor] was in the hospital, he was in a stroke ward um, a dedicated stroke ward should I say and in the corridor of the ward there was a door and it said Stroke Association. Now I never saw that door open and I think it would have been um, because I was in a state I didn't think that that was anything to do with us because I wasn't sure um, it would have been a nice thing if the Stroke Association personnel, if they came out and introduced themselves saying "well we're from here if you need to talk, if you need anything, if we can advise you we're here". If somebody had said that to me I think that would have been a great help because I felt so alone. I didn't know where to turn (Female carer id6c).

A few participants felt that support received from the Life After Stroke service had its limitations and they felt that it didn't offer very much for them personally other than a check up to see that they were doing okay and/or signposting to other groups like the East Kent Strokes. For example they felt that they wanted support that was more practical, an active 'doing' service rather than a passive 'asking' service. This was closely linked with some participants feeling unsure about the boundaries of the service and what they could ask for, and so generally felt they would have liked more information on what the service could offer them.

The participants who felt the service was limited for them also tended to feel generally more able to cope without outside support than others, found it hard to accept help, or had very good support networks around them e.g. from family, friends and carers or from other agencies. These other agencies were charities that would not be open to all stroke survivors and their carers, including Citizens Rights for Older People (CROP), Age UK (previously Age Concern), The Royal British Legion, Soldiers, Sailors, Airmen and Families Association (SSAFA), Headway (the brain injury association) and the In Touch Charity (Home Improvement Agency for older and disabled people). However some

of these participants with access to this extra support did not feel that the support from the Life After Stroke service was unnecessary or redundant, they felt that the support was complimentary and were grateful for it:

Just keeping an eye on things. I can't say that anybody came in and offered practical help or.....I think they realised I was trying to get on with it and left me to it...I think they could be a little bit more practical but perhaps they are leaving that to the Social Services I don't know. They could ask people what they would like but then they can't offer the practical help that Social Services do with gadgets because they don't, do they?..I think people would like to have more advice in a way as to what they can do but everybody is limited (Female stroke survivor id13s).

There are a lot of the services that I don't really need because I've got really good family and friends support and I do still go out you know so..... I'm not like sort of sitting at home on my own and waiting for help, but you can see that the sort of services they offer are quite essential to a lot of people but not for me at the moment. I don't seem to need it yet (Female stroke survivor id9c).

Well I know it sounds horrible but I don't think they have helped me apart from getting me to the groups thing. I don't think the association itself has done anything. That's it really, it sounds ungrateful but it's.....No, she comes and sees me..and she is coming next week just to make sure I'm alright. To be honest with you out of all the services [charity name] were the best but I think she sort of didn't ask me, she just went ahead and organised everything (Male Stroke Survivor id11s).

I like the fact that there is somebody there that I could ask and I can ask at [charity name] as well but [coordinator name] has a different background so she would be more of the physical, emotional support whereas they would probably in the clerical part, they would be able to advise me about like if he has to go into respite that sort of thing (Female carer id3c).

It was noted by the few participants who attended the Life After Stroke communications support groups that although they found them helpful the change in the staffing and timing of the groups had been a disruption to their group. However there was also acknowledgement that this changing in staff was being dealt with and improvements were being made to the way the groups were being set up by the new coordinator in post:

They've made some arrangements to keep it going up until December and then I don't know what...they won't stop doing it but I think you got the impression that; "oh no not again, we've got to start from scratch again" because obviously they are volunteers and they're then having to get used to another new person and start from scratch; what type of things they are going to be doing and so and so and so. I would have thought it would affect morale if you've got too many changes all the time of the coordinator (Female carer id14s).

We haven't met this new lady yet but apparently she is very good and she has changed things around and they don't sit at tables now, they sit in a group, one big group so they're talking together as opposed to little units of tables so (Female carer id6c).

User understanding of the Life After Stroke service

It was highlighted above that some participants lacked understanding of the boundaries of service provision and it was difficult to comprehend and proactively look and find out about service provision immediately after the stroke. In addition participants were quite unfamiliar with Life After Stroke being the name of the service they were receiving. It was unusual for participants to refer freely to the service as the Life After Stroke service in open conversation during the interviews. Most often participants would describe the service they were receiving as the 'Stroke Association' or by the name of the coordinator they had contact with. When participants were asked initial questions about the Life After Stroke service (i.e. their understanding of it and the support they had received from it) often they would refer to other services e.g. other NHS/social services, other Stroke Association services or groups such as East Kent Strokes. In some instances participants replied that they had no understanding of or support from the Life After Stroke service. It was only through further probing by the interviewer that they realised that the visits or contact from the Stroke Association or from that particular named individual (coordinator) was the Life After Stroke service.

The following quotes highlight some of these responses to the initial question about whether they knew very much about the Life After Stroke service:

Not really but everyone has been really quite good. One lot.....Stroke Association was it....had got me that cooker, always on the scrounge and my cooker had broken so ask them if they could do anything (Male stroke survivor id10s).

I don't really know what the service does. I know that [coordinator name]...because ..there isn't much work here at all so we've got to stay here and I've toiled with....I've spoke to [coordinator name] about this (Female stroke survivor id12s).

I know as much as [coordinator name] does, but I'm not involved with it personally...No, she explained it all to me...Because at the beginning [interviewer name], I couldn't understand a lot of what people were saying. It was like double-dutch to me (Female stroke survivor id5s)

Well I think most help has come with respect to um...support from the Stroke Association which is a lady called [coordinator name] locally. She's sort of affiliated to the NHS um.... ...I wonder in my position where her responsibility stops or starts because she's always been very very open with plenty of advice and as I say, I'm not sure whether her responsibility is chasing up Social Services (Male carer id8c).

Perceptions of who the service was for was also highlighted in the interviews. If the stroke survivor had a carer (e.g. their husband or wife) they tended to sit in on visits from the coordinator together and discuss issues together getting both points of view:

She came into talk and ask if everything is ok with [stroke survivor name]; "he's ok?". Yes and asking me if I can generally cope by myself with time for myself (Female carer id2c).

We were both actually because although [stroke survivor name] had the stroke, they tend to forget that there is two sides to the coin and this side tends to get forgotten but this side makes a noise so....I can't help it that's me but having somebody there that you can talk to, she [coordinator] can suggest things and we can take them on board and move on (Male carer id7s)

There was the perception from some carers that the service was more aimed at the stroke survivor rather than for them. One carer preferred not to be involved so much despite encouragement from the coordinator and used the visit as an opportunity for the stroke survivor to talk things over with someone else, taking the onus off of them as their carer. Another carer felt that they themselves were the clear recipient of the service and the stroke survivor was less directly involved:

I don't think I've really used it to be honest...Well there was only the one occasion and I suppose it was more about what sort of support that....I suppose it was a jointly offered thing but it was more directed at you [stroke survivor name] wasn't it? (Male carer id9c).

When [coordinator name] comes I sometimes, although she always says; 'come in' I try to stay out for quarter of an hour and let him have quarter of an hour on his own and I think also gives them a little bit to express their feelings you know rather than to consider what they are putting on their carer (Female carer id1c).

Expectations of the service

Views on what to expect from the Life After Stoke service were mixed. Some commented that they didn't really have any expectations as the experience of stroke and access to services were new to them. For others their expectations were low based on their experience of other service providers so far and so their expectations were generally exceeded when the Life After Stroke service became involved:

Why should we have had any expectation not having had experience of this kind of thing in the past you know...I must be honest, if you're asking me, I have to say that my expectations were pretty low with everybody... I don't know what I expected... it never occurs to you that you're gonna be in this position (Male carer id1s).

Then [coordinator name] came out to visit and that's really when things changed... Well I was expecting the same kind of information I'd had from everyone, virtually nil and not really helpful, and she came in and sat down and said 'right oh you're doing ok', You're the first person to say it. 'Oh you'll make a complete recovery, if not complete it'll be 99%, and the positive attitude was like well get on with it, you've done it, it's over, carry on and you just have to take some medicine and that will stop it happening again, and the difference was like the lights being turned on (Male stroke survivor id3s).

The future expectations of participants predominately were that they wanted to remain in contact with the service in some form, they did not wish to be completely cut off from their coordinator should they need to contact them. Most of those still receiving regular visits hoped strongly that those visits would continue. Others liked the reassurance that their coordinator was only a phone call away should they have any problems or concerns.

Meeting the needs of service users

As described above the needs of service users were met in many ways. For most it was the reassurance that the service and/or their coordinator was there to contact directly should they need something, or need someone to talk to when they came to visit. The Life After Stroke service also met the needs of service users on a practical level as well as an emotional level. This was achieved through the information provided, such as information on recovery, what you can and can't do, financial state benefits they could receive, which contributed to helping service users believe that they can have a life after stroke. For some it changed their attitude to stroke and gave them the knowledge and understanding that you can survive a stroke. They also helped some stroke survivors out with day to day life in the home, e.g. by helping to replace broken kitchen appliances and helping install the lifeline 'panic button' system which made a difference to their wellbeing and quality of life:

She's at the end of the phone for me when, whenever I want her... For me personally it's the sort of, I like to speak to people face to face or on the phone, but I don't like having to communicate with people via somebody else and blah, blah, blah, and pass the message on. I know [coordinator name] would come and talk to me face to face.. That's, I like that, and if I know I could ask her anything. (Female stroke survivor id5s)

I do remember when I came home I was a bit apprehensive going to bed, I didn't really want to go to bed, you know 'cause that's when it happened. I thought oh, you know I stayed up as long as possible you know and I thought god. Anyway what I did do is get one of these panic buttons, you know [coordinator name] set that up for me or gave me the address, you know that, 'cause I live on my own and if it did happen again, I mean I've got one of these you know... if I take that into my bedroom that will work in my bedroom. I mean here's the speaker or whatever, but just for reassurance I got one of those, these alarms (Male stroke survivor id2s).

For those few interviewees attending the Life After Stroke communication support groups a number of needs were met. As well as helping with the speech of the stroke survivor it was offering them a social outlet which was time away from the home and time to engage with others with similar experiences who offered encouragement and new ideas. It also offered their carer a form of respite, some time out whilst the group session was running.

Unmet needs of service users

There were also some unmet needs identified. For some participants the pitfall of the service was the starting point of delivery. These participants either wanted the support to start while they were still in hospital or to start earlier after discharge from hospital, as a few did not receive initial contact until weeks or months after discharge, and hadn't received support from other services in the mean time. They felt there was an information gap between the point of leaving hospital and the first visit from the coordinator, and there was a delay in finding out the answers to questions that were important to them. This included questions around recovery, possible signs of another stroke, advice on what to eat and drink, and how much exercise you can do. One stroke survivor and their carer suggested that an information booklet outlining information on these issues should be provided to stroke survivors and their carers when they are discharged from hospital:

Well like I said I think if we'd been given bits of information when it first happened instead of having to wait months for it...like I said these little bits, like about cranberry etc....These are all little things that would have helped. You know because we could have looked out for them, you know what I mean... See, that's another thing that they didn't say, they said exercise but they don't say how much exercise, or how far (Male carer id8s).

I mean I do appreciate I could have phoned people and asked them but I would have liked to have known not so much now but "oh I've got a headache, have I got another stroke coming". My arm feels strange today, is that another....that type of thing (female stroke survivor id7s).

There was a feeling by the younger and/or well recovered, less severely affected stroke survivors that there was less information and support available for them from services in general. However this went hand in hand with some participants in this group feeling that they needed less support than older, frailer and/or more severely affected stroke survivors. They described feeling like a 'fraud' or a 'cheat' for having recovered with little effect when others whom they observed in hospital were clearly in a much worse position than they were from the effects of their stroke. Some stroke survivors and carers also felt they had each other for support to get through it and the support of their families.

Other unmet needs of participants did not relate directly to the Life after Stroke service itself, but in some instances they were things that the current service may be able to influence or to perhaps adapt service provision to accommodate in the future. Other unmet needs mentioned in particular related to access to other service providers. For example access to more physiotherapy was particularly mentioned as an unmet need by some participants. Some mentioned they would benefit from having more physiotherapy sessions than they had currently. One participant wanted to see a

specialist physiotherapist and another had not received any physiotherapy at all since being discharged from hospital. Other service providers mentioned were stroke nurses and district nurses (because they hadn't visited them at home or been in contact at all) and social services (because they didn't see a person's needs as a priority or there were delays in receiving the help required):

One thing that I thought was particularly bad and that was the physiotherapy which I've not had at all. All I was given was a pot of putty to use by myself but I haven't had a physiotherapist come out and say you want....I was told that I would be seen by a physiotherapist but I have never ever seen a physiotherapist so...I mean to say obviously I would have thought they would have been able to help me with clothing and stuff like that (Male Stroke Survivor id11s)

Respite care was also described as an unmet need for many of the carers interviewed. Many of the carers in the study felt this was not something offered to them and it would be beneficial to have an opportunity to have some time out and a break from being a carer, to have time for themselves. Carer training (shown as part of the Life After Stroke model but not offered in East Kent) attendance at a carer group, and more trips out for the stroke survivor (so they had some separate time away from the home and carer) were also mentioned by some carers as something that would be useful:

Really, the only thing I would say really was if, [survivor name] keeps saying to "have some time of your own, do something". You know I like fishing, I don't often go but I like sea fishing...I haven't been out on the boat at all this year. I only went out in it once last year in it but I am scared to go out now. I don't want to leave [stroke survivor] on her own and it would be nice if someone could come round and sit for half a day or something like and I know she's in safe hands while I want to go and do what I want to do (Male carer id4c).

Another unmet need highlighted by some was having contact with others in a similar position to them. For example attendance at carers group (as mentioned above) to share ideas and learn from experiences of others, or for stroke survivors to be able to be put touch with other stroke survivors who have had similar experiences and problems to themselves. An example of this was a stroke survivor who wanted to make contact with another pianist who had a stroke and wondered if a liaison service could be developed to enable this:

I do think there should be a support network for people that have had stroke where they can actually communicate with each other and this is the ideal world and I think there should be a support group also for carers because it is a great burden on some people.....Yeah two different groups really because I feel that somebody that's.... is almost housebound really um....could be housebound with this and it must be absolutely traumatising and it's not just the older age group because strokes can happen anywhereit's almost debilitating, it doesn't just effect.....it's the whole picture. It's a life changing experience for some people (female carer id1c).

It was acknowledged by other participants that exchanging of knowledge and experiences by meeting other stroke survivors and carers was a by-product of the Stroke Association East Kent

Strokes activities signposted to by the Life After Stroke service. However a few participants mentioned that access to these activities was hindered due to transport and financial difficulties (as these activities required a small charge to take part). It was acknowledged by some participants that the Stroke Association does provide transport to their groups and activities which was commended, however for some participants access to wheel chair accessible transport was limited. Female carers in particular found it difficult to take out their husband who had a stroke (e.g. due to the time it takes to get ready and do everyday tasks, getting in and out the car, pushing round the wheelchair in certain situations). Generally going out took a lot of time and planning for many carers:

They've got a vehicle which is accessible for wheelchairs. That was extremely useful... We've had days out with that and um....but it's a pain because you've got to go all the way to Pluckley to pick the vehicle up and then you've got to come all the way back again and then you've got to take it all the way back... Yeah it's not literally on your doorstep so more accessible vehicles would be an advantage because the taxis we've used; they are a nightmare... There is not enough wheelchair taxis around I feel, not only for people with stroke, anyone with disabilities. You need a knack where you can just wheel them straight in, click them in. (Female carer id11c)

You know if you're going out, you've got an appointment, you know it's going to take him about 10 minutes to get down the pathway and get into the car. It takes quarter of an hour for him to get his jacket and coat on so half an hour before you're due to go out you say "you better make sure you're comfortable and we must get you ready" so the day is very short because they are caught up with just doing the mundane things. I find that quite hard at times (Female carers id3c).

Carers reported the general difficulties of coping with the everyday life or maintaining a life after stroke dependent on them. For some receiving in-home help from outside carers had not been satisfactory as it put more pressure on them to get the stroke survivor up and ready for when they arrived or they had to plan their day around the time the carer would arrive.

Other examples of need for better access and provision of practical everyday things to help stroke survivors and carers were also mentioned. For example one participant found the use of the standard wheelchair provided by the hospital difficult to use and had to apply later to receive an alternative that better suited their needs. Another participant was unhappy with the initial support received in aiding them to wash and bathe the stroke survivor they were caring for, which wasn't seen as an immediate priority by social services.

To summarise the findings from the stroke survivor and carer service interviews showed the service to be a highly valued service by its users. It initially filled a gap following hospital discharge for some respondents and then filled another gap of continuing support after other services stopped later on. However there were some unmet needs around the start of service provision, support from other services, and respite for carers. The required need of the Life After Stroke service was dependent on the severity of the stroke and on other support networks and services around individual users. However in general the service offered a sense of reassurance for all types of users. Some benefitted from the regular contact through home visits where they could seek advice and information and

others were reassured that there was someone they knew (the coordinator) at the end of the phone if they needed them. The fact they had continuity with the same person helped to build a trusted relationship with that coordinator and the service, even if they were unsure of the boundaries of the service more broadly.

Interview and focus group discussions with stakeholders

In addition to the service user survey and interviews with stroke survivors and carers, the evaluation conducted a number of individual interviews and focus group/group discussions with team members of the Life After Stroke service and also with external stakeholders. Members of the Life After Stroke team were interviewed through *a small number of individual interviews and through three focus groups* at three time points in the project. A total of five (two individual interviews and three focus groups) were held with Life After Stroke service providers. The focus group discussions took advantage of regular team meetings, because it was an opportunity to meet with the team and capture their views. The focus group discussions were repeated in order to attempt to capture the changing landscape of services during 2010/11 and 2012.

A small number of external stakeholders were also interviewed, including representatives of the community and acute hospital setting, a NHS commissioner of the service and a representative of the Kent Stroke Network. Data collection used individual and group interviews to accommodate preferences of the participants. A total of seven external stakeholders participated. The interview schedule for both is similar and attached in the appendices. Throughout this section we have made every effort not to identify individuals.

Perceptions of the Life After Stroke team

One of the purposes of the Life After Stroke model is to provide comprehensive services under the Life After Stroke model. In this section the perceptions of the staff and manager of the team about the service are discussed.

Geographical coverage of service across East

As there were aspects of the services already in operation in East Kent when the Life After Stroke model was introduced, bringing services together in the new service model was a way of joining up longer-term services for stroke in East Kent. In turn, the model itself was to provide a focus on care needs and services beyond the acute and rehabilitation phase. The service manager highlighted geographical coverage of the service as one of the achievements of the service:

We have had services within the area for in excess of ten years; we've had communication support and family support. If everybody had everything, then there would be an information and advice support coordinator. Now within Eastern and Coastal Kent they are still called family and carer support coordinators because that's what's in the contract ..., but really the information advice and support coordinator is the family and carer support role with a title that more defines what they do because they give information advice and support to whoever this person may be, rather than to a family. .. Wherever you are in E&CK PCT you have an information advice and support coordinator, albeit called by another name. (Service manager)

The Family and carer and the Communication support coordinator also saw the benefits of geographical coverage:

... It's population-wide and needs-based so we've arranged it that way and sometimes we will cross boundaries depending on the reason. I've got a client who used to live in [name of town] who lives in [name of another town.] now. But I've kept her A) because [other coordinator's name] has been quite busy and B) because she [client's name] wants to move back to [name of town] so it seems silly to swap her for that reason but those are the sorts of things. A little bit flexible. Not rigid. (Family and carer support coordinator 2, Focus Group 2)

The main advantages highlighted were that there was a clear point of contact to the stroke service, a limited number of referrals points (mainly coordinators and the communication support service), and a mechanism to provide support at local level.

Another important factor highlighted by respondents was the flexibility in adapting to changes in service contracts and requirements. Aspects of the service agreements were originally with Kent County Council; they have now been taken over the by NHS Eastern and Coastal Kent in the transition phase to Clinical Commissioning Groups. The Stroke Association has been able to retain the core services in the form of the Family and carer and Communications support coordinators. That has to be a major achievement at a time when funding for voluntary organisations is becoming more difficult. It has meant that the geographical coverage of Life After Stroke function in its core could be preserved, at least for the time being. The current position is that contracts will run until 2013, by which time commissioning groups may be in place and operating.

The core services commented on by the managers and team were as follows:

Family and carer support coordinators

The coordinators' role provides the one-to-one support to clients and carers through individual contact, regular phone calls and referral to other services, amalgamating a number of the model's function within the role. The Family and carer support coordinators have a key worker function; clients are registered with them for individual support. One of the Family and carer coordinators described their role as follows:

I visit patients in the hospital, go to the MDT meetings and visit patients on the ward and meet the families; not everybody but meet some of them there and then I do follow up visits when they go home and for some people it might be just a phone call, sometimes it's a visit or maybe regular visits or one every few months or so according to the person. (Family and carer support coordinator 3, Focus Group 1)

Until well into the second year of the evaluation, the localities had administrative support available that covered a locality part-time. Often, they were the first point of contact for people calling the Life After Stroke service during office hours. While this support staff took on administrative duties and clerking responsibilities, they also responded to inquiries, discussed initial needs with clients and

offered a phone contact point. During the second year of the evaluation, less administrative support became available and family and carer support workers now have to manage their own administrative loads.

Communication support coordinators

Another core service is the communication support groups which run across the three East Kent localities. They have dedicated communication support input from the Communication support coordinator, who coordinates and leads communication support groups and oversees the volunteer supported one-to-one sessions. The various groups cover the East Kent geographical area, so participants have easier access to the group nearest to them and participate on a regular basis. Carer training is also a function of this service. Some of the groups have been established for a long time. A more focused programme 'Communications Plus' is aimed at more intensive support sessions for a limited period of time. During the period of the evaluation, the communication services had experienced some problems with developing further groups and taking the communication support work forward because of long-term illness and turn-over of staff:

I can see how valuable the Communication Plus is. And you notice how great the progress in terms of people's speech and social communication can be. But actually, I see it as one of my tasks to deliver it in a more consistent manner over time across all groups. We also need to make provision for new clients who need a level of support. That these areas need work is not surprising given that there have been so many changes. (Communication support coordinator, Focus group 3)

Return to work support coordinator

Until summer 2010 a dedicated Return to work coordinator was in post. However as this post was based on short-term funding, which run out in the summer of 2010, the post was amalgamated with the Family and carer support coordinator function. The role was specifically to work with working age stroke survivors and provide a specific access point for their needs and, where possible, support pathways back into work. Some of the aspects of the work were similar to that of the Family and carer support coordinators, particularly in relation to the initial contact period:

I phone up first to make a contact with the patient – the client – and see if they want a visit first of all because a lot of people do tend to want to ... people do things on their own, especially at working age because they're used to being independent. They're not used to relying on people. And generally, I'll call back in a couple of weeks and they'll say, 'Oh yeah, could you just come and give me some advice on this' and it starts from there, so ... and it can be anything from advice about benefits, which is usually quite a common one and then maybe we'll go into other aspects of their life from there, so ... and see what else to look at. (Return to work coordinator)

One of the characteristics of the Return to work coordinator role was that much of the work was developmental and longer-term and was initiated some time after the stroke event itself. For example, it involved dealing with the longer-term aspects of stroke after survivors returned to work,

or the need to problem solve specific aspects or working – age stroke related disability, such as the management of fatigue in a work context. The return to work coordinator described this aspect of the work as follows:

Some people come out of the hospital and feel fine in themselves and then don't realise what's going to happen later on and how it's going to affect their work and things like that and it's tiredness and things like that that may have to be looked at...

I'd work quite intensively with them over a couple of weeks, so maybe two ... well over a month, sort of thing, and see them maybe two or three times over that month, so I will get everything sorted and try and help them out and give them information that they need so it's getting ... and finding that information as well.

In one case, the work involved in support career change and achieving a different work-life balance:

He (the client) wanted a less-pressured job where he felt he'd just fit in in the local area because of obviously having a stroke, driving and things like that, so we wrote a CV together to apply to [company name]

The role also included development work into building a resource database to take the return to work agenda forward and map other agencies and contacts that could be drawn upon. These included the potential (local) employers, collating the names of agencies and named staff which could be used as a resource to improve the ability of the Life After Stroke service to sign-post clients to other agencies. At the time of interview (which was just before the post holder left the post) this work was still in its early stages. Subsequently, the work could not be carried forward. It seems that such a tool could be of significant help in re-enabling younger stroke survivors in supporting them back into work.

Other aspects of the service

Working through the Life After Stroke service, the broader Stroke Association initiatives and campaigns were also seen to contribute to the various aspects of the service:

Stroke prevention is part of the pathway. Everybody does get stroke prevention advice whether it's from the information advice and support service or the Communication support service; everybody as a matter of course would have that reinforced as they go along. (Service manager)

Events even, like 'know your blood pressure' events. 'Step up for Stroke' which has been quite highly taken up and goes out through the communication support groups, which is around exercise, so we're able to pass down what we are campaigning about as an organisation as a whole. (Service manager)

Family and carer support coordinators also told us that they made stroke survivors and families aware of any initiative the Stroke Association organised. As stroke survivors were on the mailing and

contact lists, they also received information about special outings and initiatives they could participate in.

One of the services not covered directly in East Kent is support for stroke survivors and their carers from ethnic minority groups and non- English speaking communities. Seven to nine per cent of the population in East Kent come from a British Minority Ethnic group. The service commissioner interviewed for the evaluation pointed out that in one part of the area, there is a substantial community of Nepalese speakers. Some of the literature on long-term conditions, including Stroke Association material for Stroke, had been translated into Nepalese as part of a public health campaign to reach out to various ethnic groups.

The team also highlighted some differences in the way the service was organised. In one locality the Stroke Association currently has a small office right next to the stroke unit (although there is an anticipated move in the new financial year 2012/2013, and the office will no longer be available to the Stroke Association). In other localities, coordinators work from office space outside the acute hospital. Team members reported that the team worked together by using phone and email to stay in regular contact, and by using a database and on-line resources. Meetings were conducted when appropriate. However, regular contact when in the field can be difficult. The Stroke Association has taken the steps to minimise impact by introducing on-line systems and enabling distance working. A new system to help to support the team is the on-line data system. At the time of the 2nd focus group updated technology, which was to enable the progress, had not bedded in and was causing some difficulties for the team. Six months later, at the time of the final focus group, this had begun to settle down and although problems persist, coordinators could see its potential:

Our recording system was updated last year. This is great and should help so that we can do our admin on-line while we are visiting. But the system has become so big, that at the moment some of the equipment we have does not support the system; I have to wait 20 minutes for my system to load up. But I guess we are getting there, but the last few weeks have been a bit frustrating. (Family and carer support coordinator 2, Focus group 3).

During the last focus group, the coordinators in the Life After Stroke team indicated that the service had started to make arrangement for the new contract in April 2012. Working patterns were being rearranged: for example now all sites no longer attend Multi-disciplinary team meetings. While for some sites, this pattern has been well established, for a third site this will involve a considerable adjustment process.

Overall, from the perspective of the team members and the service manager, the services provided in East Kent were regarded as comprehensive. The emphasis of the service lies in the Family and carer support coordinators and the Communication support service. There was consensus that the work on a locality basis, covering all of the East Kent area, was an organising principle which worked well. The team experienced a contraction of the service during the evaluation period, because of the non-renewal of short term contracts (Return to work coordinator), staffing issues (Communication support service) and withdrawal of resources (support services, overall hours of the service). However measures were put in place to minimise the impact of the service. Anxiety

remained among front-line staff on whether with the more limited resources the work could continue.

Case management

This section discusses the perceptions of the team members of the Life After Stroke service about the way stroke survivors and their families are contacted about the service, the way they receive the service and how they leave.

The process of referrals

Stroke survivors and their families were generally referred to the Life After Stroke service through either the acute hospitals or through rehabilitation services (especially for Communication support groups). Acute liaison sisters in the stroke units had most frequent contact with the Family and carer support coordinators, with whom they had established well developed links based on the way the various hospital sites were working. This included face-to-face exchanges on a regular basis but also systems of sharing discharge information with coordinators and alerting each other when a potential problem was identified:

I'm always the only one that refers to our family support worker. Occasionally the therapist will but the nursing staff in general don't ... [name of the community support worker] no longer attends our MDMs on a weekly basis. She usually tries to make one once a month and then the other three weeks I meet with her on a Thursday and just update her with anyone, so I maintain quite a close link with her. If I have any concerns in between times, because quite often they're out of hours, I can email her and she will contact....so I have quite a good working relationship and it works very well. (Stroke liaison sister, Acute hospital 1)

The Life After Stroke service strives to capture all stroke survivors going through the hospital system. Because of the various contact points (direct links with stroke liaison sister, use of discharge information etc.), the system was regarded as comprehensive by the Life After Stroke Family and carer support coordinators:

As all patients are now going through the stroke unit, we're actually getting more referrals that way. Whereas before you'd get some of the filtering to other wards, you wouldn't necessarily pick them up. Now they're all going to the stroke unit but they're going through quick. (Family and carer support coordinator 3, Focus group 1)

Nevertheless, they conceded that some stroke survivors may not be picked up, because wards could not be covered at all times and cover can be affected by holidays and other absences:

Interviewer: So you will capture all stroke survivors through this one way or another?

Family and carer coordinator: We don't. I mean I don't we could honestly have that answer that we do catch them all. We catch as many as we can because we go to the wards and work with the teams but a week's holiday; there's no cover when I'm off so they come in and go out and there's no record (Family and carer support coordinator 1, Focus group 3)

Stroke liaison nurses in the hospitals and also community stroke staff however thought the Life After Stroke service picked up stroke survivors by one method or another and more importantly those survivors deemed most in need were highlighted through informal contacts:

If I have any concerns in between times, because quite often they're out of hours, I can email her and she will contact....so I have quite a good working relationship and it works very well. (Acute stroke liaison nurse, Acute Hospital 1)

She comes and picks a referral from the unit here but she doesn't necessarily come to the meeting to listen or hear about the discussion about the patient so she just comes to the table with the admin there and then gets the names and takes it... (Community stroke nurse 1, Community stroke nursing team focus group)

Contacting and working with clients

From the perspective of the Life After Stroke coordinators, frequency and type of contact with the Life After Stroke service is determined by a number of factors, including the perceived need of the stroke survivors and carers, and their wishes. It is also influenced by the views of health professionals (acute and community nursing staff) who highlight patients or families they feel need early contact.

So they [staff on acute stroke wards] give me all the information and always highlight who needs immediate contact and I do phone people to explain the service over the phone or book an appointment. I go to see them. It's a very individual thing; some families just need information and guidance, some more vulnerable ones will need me to arrange referrals and... and to speak to... to others like speech and language therapists and GPs so it varies. Yes. (Family and carer support coordinator 1, Focus group 1)

I tend to highlight with her [Family and carer support coordinator] the more complex onesusually families more than patients at that stage so if I feel that we have a wife that isn't coping particularly well, I'll highlight it and she will contact them at home (Acute Stroke liaison sister, Acute hospital 2)

When we're discussing the patients, we might say; can you [Family and carer support worker] go and see you know can you make her a priority or whatever. I mean she picks up most of them but sometimes you specifically want her to go and see a patient. (Community Stroke Nurse 2, Community stroke focus group)

The team members of the Life After Stroke service thought that this system of drawing in information from various sources to inform their approach to working with individual clients worked well. Again, need was perceived to be individual and specific to the circumstances of the stroke survivor and their family. Stroke survivors and their families often indicated themselves whether or not they required a service and at what point. The Return to Work Coordinator expressed this as follows:

After surviving their stroke, [they] may come out and not feel that they need anything but it may come down the line. It's whether they actually go out to find it because I think some people come out of the hospital and are ... and feel fine in themselves and then don't realise what's going to happen later on and how it's going to affect their work and things like that and it's tiredness and things like that that may have to be looked at.

Discharge

While the Life After Stroke service is supposed to discharge clients a year after first contact with the service, this rule is applied somewhat flexibly, depending on the needs and perceptions of the stroke survivor.

Again, they're all different and a couple of people I've actually said to... yeah, about coming up to discharge and people have [gasps] 'Please don't discharge me,' because then suddenly they feel like they're being left again so it... for some people it's sort of left open – people can phone me or whatever. Some people, I think you just reach that point where really you can't give them any more. They're sort of ticking along nicely, they know where everything is, they... they feel ready. (Family and carer support coordinator 2, Focus group 1)

The participants in the focus group reported that they try to keep a door for contact open, so that stroke survivors and families are not left without support. On occasions, the service offers the opportunity to renew contact through follow-up phone calls

But we don't totally discharge; if they have a problem they can phone at any time and I will just give them a call when they've not been visited for about 3 months just to check up on them, make sure they're OK and if they have any other problems and 9 times out of 10 they'll say no but we still have contact details so they know that they're not just dropped straight away. (Family and carer support coordinator, Focus group 1)

The Life After Stroke coordinators also reported that it can be clients themselves who initiate discharge, because they feel that they are now ready to cope on their own.

I had... He discharged me! He did. It was so funny because I got my diary out and he said, 'Is that to make another visit?' and I said, 'If you want one?' He said, 'No I don't think I need any more now, I think I'm fine. But I've got your number and I'll ring you if I need you. But thank you very much for your help,' and I just stood there and I thought 'Well!' And it was lovely, but it was just interesting. There's a natural point. (Family and support coordinator 3, Focus group 1)

The idea of a period of useful contact between the Life After Stroke service and its clients which is based around the need of the stroke survivor and the family, was also highlighted by the service manager

I think we've got to learn to discharge people at the end of the block of interactions that we're having, and still saying, if you need us, give us a ring we are here and we can help you (Service manager)

External perspectives of the service

This section describes the perspectives of a small number of external stakeholders of the Life After Stroke service.

Acute and community health services

We asked stroke nurses from acute and community services about the Life After Stroke model and how they thought how the service fitted into the landscape of stroke service provision. They described the role of the Life After Stroke services as mainly dealing with the quite different aspects of stroke, engaging in the main with the 'social', 'emotional' or with 'quality of life' issues rather than the 'medical' or 'health' consequences of stroke. They identified aspects of the service such as benefits advice, emotional support, carer support and being a conversation partner as characteristic working areas of the service:

I guess that my understanding is that they visit each and every stroke patient that goes through the unit and they pick up on any sort of social and general problems that they're having. It is social, it's looking at benefits, and it's all that sort of things, trying to find respite you know assistance for carers and so on. (Stroke liaison nurse, Acute Hospital 2)

[What] she can do better than me are the local support groups, the other supporting networks around the areas, voluntary services or any advice, say for example benefits, CAB. She knows where to point the person in the right direction. ... I know there are lots of clubs, the networks and peer supports it's easier for people to access that through the Stroke Association. (Community stroke nurse 3, community stroke nurse focus groups)

I think it very much has a place, I think there is a huge feeling of abandonment after stroke. As soon as people leave hospital they feel cut loose and nowhere to turn to. We talk with families about the fact that the Stroke Association is there and that we will refer on, and that they will get a visit from this person and you can see them visibly think... "a lifeline". (Stroke liaison sister, Acute Hospital 2)

Both acute and community stroke nurses perceived that the Life After Stroke work was complementary to their own roles, bridging an important gap between the limited availability of acute and community health services and the broader concerns stroke survivors and their families had to face in the aftermath of a stroke event in the family. In particular they identified 'time to listen', 'responding to emotional turmoil' after hospital discharge, and the significance of having a contact point as important qualities of the service. Community stroke nurses 2 and 3 summarised this as follows:

When the patient gets discharged and then they have come out of the hospital and they are the responsibility of the carers, they are a bit panicky but if [name of one of the coordinators] phones or somebody phones you to say; we are from the Stroke Association would you like to chat. As much we like to go and sit down and kind of listen to them because listening also makes them feel better we haven't got that kind of time to do it. (Community stroke nurse 3, Community stroke nurses focus group)

I think between us we cover most aspects that the patient might need as far as support goes. We're concentrating more on the medical nursing side, they are doing the social side, carer information side as well and between us we cover it
(Community stroke nurse 2, Community stroke nurses focus group)

Being able to spend time with stroke survivors was a further aspect of the service which the nursing staff felt was an important element of the support provided and, which incidentally, neither acute stroke liaison sisters nor the community stroke nurses felt they could provide themselves (any longer).

I think that the family support worker has more time and that's the really key part of their job that we don't have, and I'm not saying that they are not pushed by any means but their job is about having that time. (Community stroke nurse 2, Community Stroke nurse focus group)

What works well I think is also that they have the time to build up relationships with the carers to give the support. I think that definitely does work well so you know people that I go back to do a review will say "oh [name] has been coming in and it's been really helpful" and that kind of thing, so from that point of view I think that works well. (Community stroke nurse 1, Community stroke nurse focus group)

One of the acute stroke nurses saw the continuity of information giving as a vital part of the Family and carer support coordinators role. Opportunities to engage in this process adequately in hospital were declining because of the decreasing length of stay and earlier discharge from acute care.

I think from an acute setting, I think we do as much as we can that is appropriate at that time. I think because we are discharging so much earlier that you know if people are here for three months then potentially we can prepare them but if they are only staying in for three weeks and actually there is so much to take on board emotionally. Their life has changed from possibly being completely independent to very dependent. I think the emotion gets in the way of the information given so I think because we are discharging earlier I would like to see more immediate post discharge in some form; how that form would be I don't you know....whether that was a stroke team that followed up. The two week discharge calls that I did were useful but actually seeing someone would be a thousand times more useful. (Stroke liaison sister, Acute hospital 1)

Service boundaries were an issue for the community stroke nurses. Both service specifications had been discussed and newly defined in the summer of 2011. This clarified the differences in the service further, particularly with regards to the role of the Family and carer support coordinator and resulted in clearer areas of expertise and responsibility. Acute and community stroke nurses felt that the Life After Stroke services was complementary to their own service and led into some coverage of post-discharge longer – term provision:

I think between us we cover you know most aspects that the patient might need as far as support goes we're concentrating more on the medical nursing side, they are doing the social carer information side as well
(Community Stroke nurse 2, focus group with community nurses)

One of the acute stroke liaison sisters identified the provision for support for carers as a specific focus for the Life After Stroke service:

I think the carer support side of it....it's very hard a lot of families want to step up to the mark, they want to care for their families, we can't offer you help from the hospital um...it's over to people like the Stroke Association really when they're out there to pick up on the fact that they're struggling (Stroke liaison sister, Acute hospital 2)

While the role of the Family and carer support coordinators was quite well known by both nursing groups, nurses had fewer contacts with the Communication support service, the Return to Work initiative and other services, because it fell outside their own areas of work. One of the acute stroke sisters commented that on occasion a referral was made to the Communication support groups of the Life After Stroke service, but as this was often related to specific rehabilitation services, these other services were not particularly well known.

Service commissioner and Kent Stroke Network views

The perspectives of the service commissioner and the Stroke Network representative focussed on service providing longer term support for stroke survivors and the value it brought to the stroke care pathway in East Kent. The commissioner highlighted the contribution of the Family and carer support coordinators and the Communication support groups in this.

I mean I think that you know essentially the whole thing is about giving people back a bit of power and giving people back a bit of confidence and if that means peoples skills being redeveloped or rekindled or actually strategies being developed and cope better in different situations, ultimately it's empowerment and confidence. (Stroke service commissioner)

The Stroke Network representative had a more strategic viewpoint on the service landscape. He stressed the need for the longer-term comprehensive post-stroke support as part of the stroke pathway :

I'm very clear that there needs to be a review around secondary prevention whether that be of a kind of pharmacological type or relating to lifestyle: benefits, economic support, carer support. I'm very clear that there needs to be some recognition of carer strain and those sorts of things, vocational rehabilitation. I know that the Stroke Association does some good work in our part of the world around communication support and you know family support and carer support. ... (Stroke Network representative)

Both interviewees highlighted the importance of carer support as an important extension of stroke support, not the least because carer support was something the health service itself could only cover inadequately:

Interviewer: What about carers? Is there some....

Commissioner I mean we get activity that's specific about the carers but ultimately I see it as the same....it's part and parcel of the same service but obviously people have got different needs, the stroke survivor will likely have different needs. ... well may well need some other support services or some convincing that they might need some other services to help support them, and so that family carer support service I see as helping the carer as much as the stroke survivor. (Commissioner)

Both interviewees highlighted the need to prepare the service for the commencement of the commissioning groups and the likely changes in the funding landscape by being ready to provide information and data about their service. They thought that in order to position itself for the challenges of future funding negotiations, the Life After Stroke service needed to be able to demonstrate its contribution to the stroke pathways in Kent and to substantiate the value of the service through good data and information about activities and impact.

The service commissioner highlighted the need to identify the specific characteristics of the service and to differentiate them from other services and iron out 'overlap':

I need information....rather than being necessarily performance measures I think it is all activity related. It gives me and I'm predominantly the person that ever sees it, it gives me an understanding of how many people are coming through the services by locality. It gives me an understanding of where those referrals have come from, whether direct from the patient themselves or from the hospital or from the primary care, or from a carer - from which ever source, or from neuropsychology. It will give me some dates, some demographic data about the postcodes that people come from. It will also give me information about how long the people were in the service for and which aspects of the service were accessed. It will give me positive comments, compliments, it will give me any negative comments that people have made. Now all of that is absolutely reliant of course on people giving me the whole picture but that's the nature in it all isn't it? (Commissioner)

The Care Commissioning Groups are now saying; "well we want to kind of look at everything, you know what are we paying for", which, you know, is reasonable so from that point of view we really need to kind of bundle everything up (Stroke Network representative)

In summary, both stakeholder groups were aware of, and supported the work of, the Life After Stroke service. The acute stroke liaison sisters and the community stroke nurses perceived the role of Life After Stroke as an extension of health-related stroke services, and the work of Life After Stroke as complementary to their own service provision. The commissioner and the representative of the Stroke Network took a broader view and regarded the Life After Stroke service in the overall context of the Stroke care pathway, as the provision of long-term support of stroke. They also highlighted the challenges to the Life After Stroke service in having to prove its value if it is to be successful under the new commissioning structures.

Areas of development and the future of the service

Much of the evaluation period was overlaid by the evolving developments in NHS restructuring and the impact of the public services cuts. These impacted on the Life After Stroke services as follows: a prolonged and still continuing period of uncertainty for the service in the form of short-term contracts, a reduction in funding, and the need to prepare for the restructuring of NHS (greater demand on services, perceptions of increased competition, the advent of GP commissioning). Not surprisingly much of the discussion about the development of services touched on this as well and influenced the way internal and external stakeholders thought about future development. There was a consensus among all groups that the Life After Stroke service, as other services, would have to further adapt and work differently.

Operational changes for 2012/2013

Some of the changes expected for the 2012 financial year were already being scoped and planned for towards the end 2011. Thus, the plan for April 2012 is to share discharge information even more systematically with family and carer support workers in all three sites. The agreement had been negotiated in order to streamline the referral process in all three hospitals, but is also to plan for staff changes and reduction in the contracted hours of the service. However, some of the working practices will remain different in the three localities, due to different cultures and staffing in hospitals.

One of the three acute hospital sites will be undergoing considerable changes in the way they relate to the Life After Stroke service due to staff changes in Life After Stroke but also in relation to changes within in the Stroke Unit.

She was there two days a week and so we had quite a close relationship and the coordinator attended all our multidisciplinary team meetings. She picked up every single stroke patient that went through the unit, we didn't necessarily do a written referral to her.. We are now running a different system whereby we print off a separate copy of the discharge notification and that's collected each week by [name of another coordinator] (Stroke liaison sister, Acute hospital 2)

There is a degree of uncertainty in how these new arrangements will work. While accepting this as part of the overall financial constraints both in the hospital and for the service, the stroke liaison sister was concerned about the impact of the new working patterns between the service and the hospital:

I think we will miss the direct contact it meant that we had a good working relationship. It also helped because we got feedback on some of our patients, otherwise we never know what happens to them really when they leave us. A lot of them we don't really get to have any sort of follow up news on them (Stroke liaison sister, Acute Hospital 2).

Less specifically, but nevertheless noteworthy, coordinators also discussed whether or not criteria for contacting and working with stroke survivors and their families would need to be introduced in order to provide a more focussed service. What the detail of such criteria might look like, was not further discussed. However, the third focus group highlighted that coordinators were concerned about managing the increasing numbers of referrals, and also the constraints on the time they had for contacting and visiting clients following the reduction in the contract hours of the service. Informally, as discussed above, coordinators were already alerted by their nursing colleagues when there were concerns about a specific patients or a difficult situation. However, the discussion of criteria for the service is a step on from that. Coordinators stressed that this was not something that had been operationally addressed but clearly formed part of a wider debate around making the service go further.

Discharge

In informal conversations with members of the Life After Stroke team, and the service manager in particular, the idea of a more focussed discharge process had also been mentioned at times, however it had not been particularly highlighted as an area of change during most of interviews and focus groups in the evaluation process. However, by the time the third focus group of Life After Stroke team members, participants reflected on the need for clear criteria for discharge:

Yes we need clearer criteria, because if your resources are going down we need to target our resources more carefully. That may mean that we need to look for ways to decide on who we can provide with telephone support, who needs visits, who may only need an initial phone call. It is different from what we can do and it is not necessarily how we would like to work, but it needs to happen (Family and carer support coordinator 1, Focus group 3).

Clearly, the need for service restructuring has had some impact on the way the service had been running and initiated reflections of the service and its operation by its staff. This is undoubtedly a painful and difficult process. It can also be seen as an indicator of the professionalism of the Life After Stroke team in preserving the longer-term interests of post-stroke support for stroke survivors and carers, and of their productive engagement with the continued process of change and adjustment of the service landscape.

Other service developments

The interview guides asked about other areas for development of the service. The Life after Stroke team highlighted the need for further develop the befriending and peer support service, although with the appointment of a new Communication support coordinator, this work was beginning to be addressed through the Communication and long-term support groups.

Stroke coordinators also saw the need to work with clients on personal budgets:

Personal budget support services. Stroke Association does have personal budget support services but not in the area, so that's where people are using a social service personal budget to buy different things. And really that's very much around an information advice and support while people select but that isn't in this area.(Return to work coordinator)

Access to transport for stroke survivors and carers was seen as a remaining difficulty in the East Kent geography. While there is some provision and the Stroke Association also provides transport opportunities, coordinators did feel that the difficulties of transport particularly in the remoter rural areas impacted on stroke survivors' recovery and limited their ability for social interaction:

The transport is an issue as well, especially, I know we cover the Romney Marsh which the transport links are, you know aren't that brilliant, but even, there's a lot of rural villages around our area, and just people getting to where there is something happening, it's difficult especially if they were the driver and are no longer able to, or they can't afford the taxis to get there. (Family and support coordinator 2, Focus group 2)

For the respondents from acute and community stroke nursing groups, the development needs focussed on improving the integration with the Life After Stroke service. For example, one of the community stroke nurses highlighted the benefits of co-location of the services as a way of integrating both the services more and improving communication:

I think it would be nice if we were based together because we could liaise more about whose seeing who when, because it's a case of updating each other when we see each other and a team kind of approach. (Community Stroke nurse 1, Community stroke nurse focus group)

For one of the hospital based stroke liaison sisters, the lack of continuity of support on personalised secondary prevention was a frustrating gap in the service. This did not directly relate to the Life After Stroke service provision but involved the work with patients which started in hospital but could not be continued because there was no specialist NHS service for this:

I would like to see the NHS taking more responsibility um ...I've been in touch with the Expert Patient Programme, there's nothing specialist within this area and having looked at their programme I would love to have a specialist programme like that for us that may be and we've spoken about it but we just can't facilitate it. I would really like to look at personalised secondary prevention measures, and again I'm not convinced that people take that information away with them (Acute stroke liaison sister, Acute hospital 1)

The commissioner and the representative of the Stroke Network focussed attention on the comprehensiveness of the service from the perspective of the stroke pathway. The network representative highlighted the need for a service that looked, from the perspective of the patient, seamless:

I mean I think that's a reasonable model that encompasses but a service that can deliver all these rather than five different services that patients are going to have to navigate ... (Stroke Network representative).

A question for the commissioner was on how best to align the different perspectives of clinical definitions of need with those of service users. She was well aware that this may be a tension between future service provision and expectations of stroke survivors and carers. While an earlier initiative on carer support had shed some light on this, she thought this would be a future area of work:

The carer service pilot did at least get us the opportunity to test how long is long term because actually in an ideal world you would want the flexibility for people to be able to re contact services but of course what clinically somebody might think is a need and what a patient and/or a carer may think is their need maybe different things (Commissioner)

A specific area of development for the Life After Stroke service organisationally is the recording of individual outcome measures, which have been introduced by the service and will become part of the feedback to the service:

This is what is being developed at the moment. While it was on spread sheets it is now part of the on-line system. This is quite difficult to get your head around – at least for me. But it has to be done, as it is what the commissioners, along with discharge summaries. (Family and carer support coordinator 1, Focus group 3)

While this evolving work on outcomes and documenting activity is not without its problems, the usefulness of the information it provides has been recognised. Both the commissioners and the representative of the Stroke Network provided positive comments on the data they had seen:

I was quite impressed by you know the breakdown of the work and I think it said X percentage of patients have expressed the need for this or that, so it was quite interesting for me in terms of developing what the makeup of the service might be like. I was kind of quite glad to some degree that it was provided by an outside agency. They are very, very good at providing us with data from those services. They are a lot better than our NHS providers are you know... (Representative of Stroke Network)

Both also stressed that from a commissioning perspective, understanding the needs of the clients will be helpful for Care Commissioning groups in their reviewing and planning services.

To summarise, while service cuts and the imminent restructuring of commissioning are contributing to the uncertainty about the long-term future of the service, all stakeholders agree that the need for longer-term support is important for the overall provision of stroke services. All groups of professionals also saw opportunities for further development from their own perspectives. That in itself can be regarded as a resource for planning the future of the service. In the meantime, the Life After Stroke team is adapting the service to ensure that longer-term support to stroke survivors and carers can be provided even in a climate of reduced resources and short-termism.

Discussion of findings and recommendations

The evaluation took place after the national stroke strategy had been published and following a period of dramatic change in acute hospital care for people with stroke. Despite the improvements in acute hospitals to treat stroke patients, there were significant gaps between national policies and aspirations for the kinds of care available to support stroke survivors once they returned home.

Acute services in East Kent for people with stroke have been rated highly in national performance tables, and are in line with the national stroke strategy (DH 2007). The East Kent community support service we have evaluated has been running for over 10 years and pre-dates the Stroke Association's Life After Stroke model which emerged in 2009. Nevertheless, the East Kent service covered a broad range (but not all) of the services in the national Life After Stroke model, with eight coordinators covering Family and carer support (3 patch-based coordinators), Communication support (3 patch-based coordinators), Return to work support and Long-term support. Coordinators worked on fixed term contracts, five out of the eight were working part-time and they were supported by a team of managers and part-time administrative and office staff. The evaluation took place over a period of major NHS upheaval, during which time the East Kent Life After Stroke service lost both the Return to work and Long-term support coordinator posts and, by the end of the evaluation, the administrative staff posts were no longer funded. The evaluation team found that service providers had adopted a professional and flexible approach of covering for each other in order to provide an even and continuous service during times of staff sickness, job uncertainty, staff turnover, and cut-backs in funding.

Management statistics over the evaluation period showed little change in the number of stroke survivors being referred to and being discharged from the service, and that the overall caseload numbers were maintained, but in the second year of the evaluation there were significant decreases in contact with coordinators both in the number of face-to-face visits and the number of Communication support group meetings. The management figures confirmed that new referrals were being contacted in a timely fashion (within a week). They showed that the survey respondents were representative of all users in terms of age and gender. In contrast, stroke survivors taking part in interviews were mainly of working age, so were younger and less representative of the total caseload. There was a very low percentage of people from minority ethnic groups in both the management records and the survey, which may require further investigation into the accessibility of the service for these groups.

The impact of stroke

Before using the Life After Stroke service, our baseline evaluation surveys showed the extensive impact that stroke has on lives, and that stroke survivors could envisage benefiting from a wide range of the Life After Stroke services offered. For each of the fourteen areas of impact we asked about, between a quarter and a half replied that their stroke had affected them, with the highest impact being on feeling valued by friends and family. Mobility and memory were problems for the majority of stroke survivors, and significant numbers had problems with their speech and sight. With these levels of need it was not surprising that nearly all could see themselves benefiting from

information and support, and between a half and three quarters from help with stroke prevention, communication, long-term and carer support. Although there were smaller numbers of stroke survivors of working age, there was a demonstrable need for a 'Return to work' support service.

Service use and satisfaction

Subsequently the Four month and discharge/12month evaluation surveys found that a wide range of services had actually been used, that levels of satisfaction with these were generally high, and that the Life After Stroke service had had a positive impact on many aspects of stroke survivors' lives. Family and carer support service users reported high levels of use of the Life After Stroke information, advice and stroke prevention services. This group also scored highly on receiving information to suit their needs and being able to discuss their personal goals. Members of the Communication support groups had not only received help with speech, but had also had much of their need for return to work, long-term and carer support met. Both groups recorded high satisfaction levels for the service provided by the Stroke Association and (particularly for users of Family and carer support services) felt that they had been treated fairly and sensitively by the Stroke Association. Members of Communication support groups also added comments to say how much they valued the opportunity to go to meetings, gain confidence and improve their speech. Others praised the help they had received with claiming benefits and getting back to work. These findings are echoed in the interviews with stroke survivors and carers, who cited many examples how the Life After Stroke service had supported them and also signposted to other services. Informants were particularly appreciative of the flexible nature of this support in the form of phone calls.

There was a resonance in findings between the survey and in-depth- interviews with stroke survivors and carers regarding the type of support services received from Family and carer support coordinators. Their support was received positively and there was a high level of satisfaction. Similar results were found in relation to the Communication support groups which helped with stroke survivor speech problems but also helped to provide a social outlet for them away from the home and to intersect with others.

There were also parallels between the perceptions of the coordinators themselves and the service users. Both described the service as having a quasi open door policy, whereby even when visits and other contact had stopped the coordinator was still there to call if they should need, and so service users would not be left unsupported, which was reassuring for them.

Impact of the Life After Stroke service

The impact of the Life After Stroke service was consistently highly rated across all areas. Between 60-90% said the service had had an impact on a wide range of aspects of their lives, with the highest for feeling valued by friends and family which had been established as the greatest impact of stroke in the first place. These impact ratings are especially high when compared to levels of need at baseline. Results were similar for stroke survivors receiving either Family and carer or Communication support, and the East Kent service impact was similar to national figures. The only difference in the ratings between the Family and carer and Communication support services in East Kent was that a higher proportion of those receiving Family and carer support said that it had helped their energy levels and their emotional well-being.

The role of the Life After Stroke service in the early stages following discharge from hospital were highlighted by coordinators and services users alike. Both described the thought of stroke survivor and carer abandonment initially following acute hospital discharge, with the Life After Stroke service then coming in offering a lifeline of support thereafter.

Experience of stroke survivors and carers

In-depth interviews further explored the experiences of service users and how the Life After Stroke service had been used alongside other services/stroke groups. There was clear support from the fourteen stroke survivors and eleven carers who were interviewed, which reinforced the survey findings that the service was highly regarded. All were positive about the service and liked it, saying they got visits when they needed or were happy with the level of contact by telephone. Most were positive about the transition from acute care to Life After Stroke support being provided in a timely manner, although some would have liked the support to start earlier (whilst still in acute care or sooner after discharge).

The key factor for Life After Stroke service users was the personal contact. Even if stroke survivors were not always sure exactly who was offering what service, they were very clear about the people providing the Life After Stroke service, and saw them as trusted and reliable friends. Service users felt reassured that someone was there when they needed and had time to listen. They valued coordinators' knowledge and understanding of stroke, and discussions on recovery. There was continuity with the same person and service users were given emotional support.

Stroke survivors and carers had found the information and sign-posting they received from the Life After Stroke service had been useful, for example making them aware of and getting involved in activities, and crucially giving encouragement to face the new situation. Service users particularly valued the verbal information they received from the Life After Stroke service, although other sources such as leaflets had also been helpful. Some mentioned practical help that had been arranged through their coordinator. Overall, people had been pleasantly surprised at both the Life After Stroke services and the other services that the coordinators had pointed them to. Carers valued the fact that Communication support group sessions freed them up for an hour or two to get to the bank or a shop, although for some service users who did not have speech problems and therefore did not have use of these groups, respite for the carer was recognised as an unmet need. It was felt more generally by some that the Life After Stroke service was not really designed for carers.

There were some negative comments about disruption to the Communication support group sessions when there had been problems due to changes in staffing and meeting times. People wanted the Life After Stroke support to continue and did not want to be discharged or completely cut-off from the coordinator. These criticisms are likely to have been the result of a period of uncertainty and staff turn-over in the communications support team. The situation, according to the coordinators themselves has since been stabilised with the appointment of a new communication support coordinator.

Areas for development

When asked, relatively few respondents said that the Stroke Association could improve the service or could have done more to make a difference to the stroke survivors' lives. Some of these comments were about regular meetings, with a consensus saying that they would like to attend more frequently and that meetings should not be cancelled. Low satisfaction with carer support (regarding help to take time off e.g. through respite care) was identified in both the survey and interview results. A desire for more help from outside services was also identified e.g. for support in the home or physiotherapy.

Probing further in the interviews with stroke survivors and carers, informants highlighted some areas for development. This is not unexpected given that the interviews allowed for space to reflect further on experiences. In the interviews with carers, focussed and practical carer support was a theme that was highlighted as a specific need, for example in the form of flexible respite, more transport and carer groups. While carer informants were not always sure whether this was within the remit of the Life After Stroke service, they were clear about the need to address this as something that would be of benefit for their own health and well-being. The carer burden after stroke is considerable and some interviewees found that all responsibility for maintaining a life after stroke depended on them. Interviews with health professionals and coordinators also highlighted this as a possible further development area for the service.

There was some disparity between the external stakeholder view of what the Life After Stroke Service provision was covering for carers and what was perceived by carers themselves in the interviews. Outside stakeholders felt that the Life After Stroke service was offering support to carers, e.g. access to support for respite care, however many of the carers interviewed had not been offered or received support to access respite care which they identified as an unmet need for some valuable time out from being a carer (as described above).

Transport difficulties were also raised by both coordinators and service users. Although it was acknowledged that the Stroke Association offered transport to help stroke survivors attend their support groups and other activities, this was limited and there were unresolved difficulties for some service users.

Branding of the service

There was also the lack of understanding present in both the survey and interview participants regarding the 'Life After Stroke' label. Their understanding of the service was very much the individual person (the coordinator) who came to visit or ran their Communication support group, whom they built up a relationship with. Some criticised the service for not being clearer about what it did and did not offer, but those who felt it was limited tended to be well supported in other ways, for example by their carers, family and other organisations. A particular time of uncertainty was the early stages following discharge from acute care, when they were sometimes overwhelmed by the situation they were in and the offers of help and support from a range of services. Often they were not quite sure who to turn to for advice at that stage.

The perspective of Life After Stroke team members and external stakeholders

The interviews and focus groups with stakeholders highlighted some of the merits of a geographical coverage of the service through the Family and carer coordinators and the Communication support service in dealing with the rather dispersed geography of this part of Kent. For service users, this has meant that there is one coordinator responsible for the locality that they can directly contact and engage with. The interviews with stroke survivors and carers confirmed the importance they attach to continuity of the link and to the opportunity to develop a personal rapport with the coordinators. For the Communication support services, the commitment to run meetings and courses in specific localities across East Kent means that access is easier and travel times to the venues become more manageable. Organisationally, the arrangement has meant that the service has a degree of flexibility for coordinators to cover in case of absences. It has also meant that stronger links with the acute stroke units could be maintained, although for resource reasons the contact time has decreased over the last few years.

Within this arrangement, many of the service aspects of the Life After Stroke model have been embedded in the role of the Family and carer support coordinator. This has meant that Family and carer support coordinators had to enlarge their support remit. The evaluation could not shed light on how the work the various aspects of the Life After Stroke model were covered and whether coordinators could cover all aspects of this. The one aspect highlighted externally as not covered by the current set-up is the specialist support for ethnic minority groups. There is no reason to think that the Family and carer support coordinators in individual situations would not have addressed this specific aspect of the model with their clients where appropriate. However, the example of the Return to work support coordinator showed that the more detailed, focussed and time consuming work he carried out with a small number of younger stroke survivors could not be sustained. Nor could the work on making links with local employment advice organisations and employers be continued. Clearly the more limited resources available had to result in some service reduction somewhere. Overall though, despite the turmoil of the health and social services landscape and the changes the service had to go through, the service has remained remarkably robust and staff have continued positively in their roles.

The case management of the service underwent significant change during the period of the evaluation. While at the beginning, significantly different approaches to accessing patients were in evidence across the three localities, over the course of the evaluation, the processes became more uniform in that the Family and carer support coordinators were collating discharge information of patients passing through the acute stroke units and less time was spent on the unit itself. This was then supplemented in two sites by briefing meetings with the acute stroke liaison sister. A further impact of resource reduction meant that at least in one site the attendance of multi-disciplinary team meetings could not be continued.

Other organisational changes included the development of on-line working for record keeping by coordinators. Coordinators found this a challenging process. While they could see the advantages of using on-line data system, the equipment at their disposal had not always worked well. While some of these problems had been addressed towards the end of the evaluation process and the system overall worked more smoothly, the difficulties experienced show that such technology adaption needs careful consideration and adequate equipment investment for front-line services.

The team members also reported that the work with clients is undergoing a change. While the commitment of the service is to provide longer-term support for up to a year, the experience is that there is a range of need for support and its length can vary. Towards the end of the evaluation, team members spoke about the need to focus resources on providing the support for most need, which may mean that contact time for some clients may be reduced and shorter periods of formal contact would be maintained. While there was some regret at this seeming reduction in the service, team members were realistic that with an increasing workload and fewer resources things needed to change. There seemed to be a consensus building around the notion of regarding a discharge as a success of the service, if discharge was because the client had become more independent and confident in living with stroke.

The final aspect considered in the evaluation was that of the role of the service in the stroke pathway. All internal and external stakeholders we spoke to recognised the value of the longer term support for the service. The stroke nurses from the acute and community services saw the work of the coordinators as complementary to their own roles, but also in filling in gaps in provision which they themselves could (no longer) fulfil. The two external stakeholders also saw the value of the service; although the wider perspective was taken by them they also saw the vulnerabilities of the service. For them, the question was on whether the Life After Stroke service could continue beyond the first phase of the introduction of the GP commissioning changes. Being comparably small could be either a safety net or could become an Achilles heel in restructuring. It could be a safer position to be in because of the limited resources it may not be scrutinised as heavily as the expensive services. However, long-term support could also be attached to an existing health service, for example. Then longer-term care could become a non- or under resourced appendage to health services and be delivered from within health specific contracts. To mitigate against these threats, the Life After Stroke service has done a lot of work to demonstrate the added value of their service. As a result activity data are being collated and attempts at constructing meaningful outcome data are continuing. These were received favourably by the external stakeholders, although they insisted that they were interested in a range of evidence, including the testimony and feedback of stroke survivors and carers. As the restructuring of NHS commissioning continues and needs to settle down and the social care landscape is also restructured due to service cuts, the situation is likely to remain uncertain for some time, until the system settles down and the new lines of accountability and new strategies are in place. Like many of the other third sector services, it is likely that the Life After Stroke service will look at a period of short-term funding, which in the context of the high need of support for stroke survivors and their families is regrettable.

Strengths and limitations of evaluation methods

The strengths of the survey part of the evaluation were that it gathered the views of a large number of people, it was based on a nationally recognised questionnaire designed to assess the impact of the Life After Stroke service, the age/gender profile of respondents suggested they were representative of service users, and response rates were better than experienced in the national survey (although when people were sent a second or third survey the evaluation response fell closer to national rates). The survey content was limited by the need to maintain national service monitoring, and by the fact that to introduce an additional questionnaire would lead to an

unacceptably poor or unrepresentative response. It was also limited by numbers as, during the available time for the survey, only a fraction of the expected number of baseline surveys were sent out (125 compared to an estimated 300) which, coupled with a steeper than expected fall in response rates over time, led to insufficient numbers to make comparisons for individuals over time. The analysis therefore compared baseline need with the services received, and compared experiences with the two services in place, where numbers were sufficient to identify some statistically significant differences.

The strength of the qualitative part of the evaluation was to get a deeper understanding of the views of stroke survivors, carers and a wider range of people connected with stroke services in East Kent through interviews and focus groups. This complemented and reinforced the quantitative findings. Life After Stroke coordinators and managers were asked to provide names of survivors and carers that would be representative of all services users, and suggest the names of other service providers, commissioners and stakeholders. Clearly the evaluation was limited by the choice of people and their willingness to take part.

As mentioned above, the evaluation could not explore in detail the current provision for black and ethnic minority groups. From the interview with the commissioner and also informal feedback there is some work on-going, for example in translating information about stroke to the Nepalese community. However the evaluation could not determine, for example, stroke survivors' and carers' perspectives on this.

Recommendations

The service delivers what stroke survivors value, such as the personal qualities of the staff, continuity of staff, having time and being there when needed, being knowledgeable, understanding, providing emotional support, building confidence and enabling recovery.

Staff of the Life After Stroke should be complimented on adapting to change and keeping the service going despite working with short-term contracts, uncertainties regarding future commissioning, and recent cut-backs in staffing in the region of 25%. The Life After Stroke is already engaging in a process of developing new ways of working to provide a sustainable service and ensure that the stroke survivors and their families continue to receive support. From the evaluation we would recommend the following:

Recommendations for the Life After Stroke service provision:

- The survey results and the interviews with stroke survivors and carers demonstrate that the Life After Stroke service overall is highly regarded by service users. As a long-term follow-up it should be maintained to complement the acute hospital provision and community health provision, and to support the needs of approximately 1000 stroke survivors each year in East Kent.

- Stroke survivors and carers have highlighted a number of highly valued characteristics of the service: personal contact with a coordinator, the approach of engaging with clients via visits, phones etc., regular meetings not too far from home and the provision of information. For stroke survivors in particular the service had a positive impact on their lives. NHS colleagues stressed collaborative and complementary working of the service. Any further development of the service should retain and enhance these characteristics of the service.
- A further characteristic of the Life After Stroke support service is its emphasis on social and emotional support, which complements the health-related services. The Life After Stroke should defend the focus on social and psycho-social needs of stroke survivors and their carers alongside long-term health care needs and highlight with commissioners the importance of continued support of this type for stroke survivors and their families.
- The person centred approach to maintaining working with a client is a significant strength of the service. This includes the length of time a stroke survivor and their carer can receive services through the Life After Stroke services, how contact is maintained and when a person can be discharged. The service should retain this flexibility and place emphasis on the individual needs and wishes of the clients.
- At the same time, the service should continue to clarify its function and purpose, for example by being clear about the support it can give, the length of support given and the purpose of meetings and groups run by the Communication support services.

Recommendations for the organisation of the Life After Stroke service in East Kent

- The evaluation highlighted some organisational aspects of the service which are highly valued by stroke survivors, carers and NHS colleagues. These include:
 - The geographical coverage of the service aligned to hospital wards of the Family and carer support coordinators
 - The distribution of the Communication support groups across the East Kent area
 - The existing collaborative links with both the acute stroke services (via stroke liaison sisters) and the stroke community nursing team

These organisational principles have worked well, are based on long-standing and well working relationships and should be maintained and where possible, extended.

- The Stroke Association's Life After Stroke service has maintained high visibility of its services in acute stroke wards through various means, including boards in stroke units, leaflets, regular newsletters and other literature and the attendance of the Family and carer support coordinators on acute stroke wards. This personal contact in particular has helped to bridge the collaboration with the acute wards and stroke liaison sisters in hospital. The need to reduce costs for long-term support in stroke needs to be balanced against the importance of enabling good relationships through face-to-face contacts between professionals to maintain trust, understanding and effective collaboration.

- Further work should be done to develop clear demarcation of the Life After Stroke, acute service providers and the community stroke nurses, so boundaries are clear, and a seamless service can be provided collaboratively without duplication and confusion in the delivery of the stroke care pathway.
- While it has been unavoidable in the current public services funding crisis, the current uncertainties about continued funding and short-term extension of contracts are of significant concern. If services to stroke survivors and carers are not to be adversely affected, the funding of longer-term stroke services in East Kent needs addressing as a matter of urgency.

Recommendations for funding and development of the service

- While some services are maintained and spread across the area, some specialist service provisions have been lost due to reduced funding. There should be consideration and discussion with commissioners and funders of services as to how to replace the lost Return to work support and the Long-term support services.
- One of the areas of development is the work with carers. While some carer work is provided through the Family and carer support coordinators and the Communication support group, there is still a great deal of unmet need. This includes various types of respite (including at home respite to enable carers to engage in activities on their own, and residential long-and short term respite). The Life After Stroke service is well placed to explore with carers these needs and should work with others to develop carer services in East Kent further.
- The Life After Stroke service has embarked on a programme of using on-line technology to aid and record activities. While this process should continue and be developed further, equipment used needs to be appropriate and enabling. It should also not be used to substitute for personal contact either with clients or with colleagues.
- The Life After Stroke has also begun to identify suitable outcome data through activity recording. While this is recommendable and will help to enable positive funding decisions by commissioners, care needs to be taken that data are meaningful and accurately reflect the work of the service with stroke survivors and carers.

References

Care Quality Commission (2011). *Supporting life after stroke: a review of services for people who have had a stroke and their carers*.

Commission for Rural Communities (2010). *Insights from stroke survivors and providers of stroke care in rural England: Summary report*.

Department of Health (2007) *The National Stroke Strategy*
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081062

Department of Health (2009) *Demonstrating how to deliver stroke care for adults in the community*. Local Authority circular: 28 April 2009 LAC(DH)(2009)4.
http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH_098601

Ellis G, Mant J, Langhorne P, Dennis M, Winner S *Stroke liaison workers for stroke patients and carers: an individual patient data meta-analysis*. Cochrane Database of Systematic Reviews 2010, Issue 5. Art. No.: CD005066. DOI: 10.1002/14561858.CD005066.pub2

Healthcare Commission (2006) *Survey of patients 2006: caring for people after they have had a stroke*. Commission for Healthcare Audit and Inspection, 2006.
http://www.cqc.org.uk/db/documents/stroke_survey_update.pdf

National Audit Office (2010) *Progress in improving stroke care: a good practice guide*.
<http://www.nao.org.uk/publications/0910/stroke.aspx>

NHS Stroke Improvement Programme. Website accessed 25 April 2012.
www.improvement.nhs.uk/stroke

NHS Stroke Improvement website. *Stroke and TIA Data Wall – quality markers*. Accessed 25 April 2012.
http://www.improvement.nhs.uk/datawall/documents/Stroke_Data_Wall_v8.0.xls?documentid=3849&nodeid=645&hideheader=true&email=true&ModuleType=Forum

NHS Stroke Improvement Programme. Hosted by The Stroke Association. Accessed 25 April 2012.
http://www.ukstrokeforum.org/about_us/coalition_organisations/nhs_s_i_p.html

NIHR Collaboration for Leadership in Applied Health Research and Care (2010). *Post-stroke review pilot project: the evaluation report*. Accessed 25 April 2012. <http://clahrc-gm.nihr.ac.uk/cms/wp-content/uploads/Stroke-review-report-web.pdf>

Pope (2000) *Qualitative research in health care: Analysing qualitative data*, BMJ 2000;320:114-116

Ritchie, J and Lewis J (2003) *Qualitative Research Practice* (London: Sage)

Ritchie, J & Spencer, L (1994) "Qualitative data analysis for applied policy research" by Jane Ritchie and Liz Spencer in A. Bryman and R. G. Burgess [eds.] *Analyzing qualitative data*, 1994, pp.173-194. London: Routledge

Smith J, Forster A, House A, Knapp P, Wright JJ, Young J. *Information provision for stroke patients and their caregivers*. Cochrane Database of Systematic Reviews 2008, Issue 2. Art. No.: CD001919. DOI: 10.1002/14561858.CD001919.pub2

Srivastava, A & Thomson, S B (2009) *Framework Analysis: A Qualitative Methodology for Applied Policy Research*. JOAAG, Vol. 4. No. 2

Wolfe C, Rudd A, McKeivitt C, Heuschmann P, Kalra L (2008) *Top ten priorities for Stroke Services Research*. Kings College London.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089773

Appendix A The Stroke Association's Life After Stroke model



Appendix B Baseline user survey



Centre for Health Services Studies **THE STROKE ASSOCIATION SERVICES
IMPACT AND SATISFACTION SURVEY**

Summer / Autumn 2010

Dear Service User / Stroke Survivor

The Stroke Association and the Centre for Health Services Studies at the University of Kent are working in partnership to evaluate the East Kent 'Life after Stroke' Services. We would like to invite you to complete this questionnaire. It will be used as part of the evaluation to tell us whether the Stroke Association are achieving their aim of helping people to improve their lives following a stroke.

During this evaluation all users of the 'Life after Stroke' services will receive a questionnaire at three points in time. This is the first questionnaire and two more will follow in the next few months.

The survey asks you about:

- services you might like to receive from The Stroke Association;
- the impact of having a stroke on your life; and
- yourself, so we can analyse the information we receive.

To keep the evaluation independent, the Stroke Association have asked the Centre for Health Services Studies (CHSS) to carry out the evaluation. They will collect and analyse the information received, report the findings, and make these available to you. The questionnaires are anonymous and confidential, and individuals will not be identified without their consent.

We very much hope that you will be able to support us in this project by completing this questionnaire as much as you can.

PTO

Please return the survey in the freepost envelope provided. Thank you again for helping us.

Linda Jenkins, Annette King and Charlotte Brigden
Centre for Health Services Studies,
George Allen Wing
University of Kent,
Canterbury, CT2 7NF

If you have any questions about this survey or the evaluation, require help to complete the questionnaire, or would like to complete an easy read version instead, please contact:

Centre for Health Services Studies tel: 01227 823878
email: chssenquiries@kent.ac.uk

or

Barbara Sleator at The Stroke Association tel: 01622 351964
email: Barbara.Sleator@stroke.org.uk

SECTION 1 - The Service

Which 'Life after stroke' services **do you think you would benefit from?** (these include one-to-one or group sessions organised by 'Life after Stroke' co-ordinators.)

Information, advice and support	YES	NO	UNSURE
Stroke prevention	YES	NO	UNSURE
Communication support	YES	NO	UNSURE
Return to work	YES	NO	UNSURE
Long term support	YES	NO	UNSURE
Carer support (for your family or carer)	YES	NO	UNSURE

Anything else? Please write in below

Have you been given an **information pack about stroke**?

YES NO UNSURE

Do you receive **regular help** from a relative, friend or neighbour?

YES NO

Which of the following do **you have a problem** with because of your stroke?

Speech YES NO UNSURE

Swallowing YES NO UNSURE

Mobility YES NO UNSURE

Sight YES NO UNSURE

Memory YES NO UNSURE

Anything else? Please write in below

--

SECTION 2- IMPACT

Has your stroke had an **impact on your life** in any of the following ways?

Being able to face the world

YES PARTLY NO UNSURE

Feeling largely in control of your life

YES PARTLY NO UNSURE

Feeling energetic

YES PARTLY NO UNSURE

Being able to attain personal goals and aspirations

YES PARTLY NO UNSURE

Feeling that little things do not get you down

YES PARTLY NO UNSURE

Feeling positive about the future

YES PARTLY NO UNSURE

Having peace of mind

YES PARTLY NO UNSURE

Feeling broadly satisfied with life

YES PARTLY NO UNSURE

Being able to take pleasure in what life has to offer

YES PARTLY NO UNSURE

Feeling that stroke doesn't dominate your life

YES PARTLY NO UNSURE

Feeling valued by friends and family

YES PARTLY NO UNSURE

Not feeling a burden to other people

YES PARTLY NO UNSURE

Feeling normal and not different from other people

YES PARTLY NO UNSURE

Your emotional well being

YES PARTLY NO UNSURE

SECTION 3 - ABOUT YOU:

Gender

- Male
- Female

Your age group

- 18 years or under
- 19-34 years old
- 35-49 years old
- 50-64 years old
- 65-79 years old
- 80 years old or over

And to which ethnic group do you belong?

- White British
- Pakistani
- Irish
- Bangladeshi
- Other white
- Other Asian
- Mixed white and Black Caribbean
- Black Caribbean
- Mixed white and Black African
- Black African
- Mixed white and Asian
- Other Black
- Other mixed
- Chinese
- Indian
- Other
- Prefer not to say

Appendix C Discharge/12month user survey



Centre for Health Services Studies



THE STROKE ASSOCIATION SERVICES IMPACT AND SATISFACTION SURVEY

Dear Service User/ Stroke Survivor

The Stroke Association and the Centre for Health Services Studies (CHSS) at the University of Kent are working in partnership to evaluate the East Kent 'Life after Stroke' Services. We would like to thank you for completing the questionnaire. Now you have been using the service for a while we would like to invite you to complete one more questionnaire. It will be used as part of the evaluation to tell us whether the Stroke Association are achieving their aim of helping people to improve their lives following a stroke. This is the final survey you will receive as part of this evaluation with us at CHSS.

The survey asks you about:

- services you have received from The Stroke Association;
- the impact of the service you have received from The Stroke Association; and
- yourself, so we can analyse the information we receive.

To keep the evaluation independent, the Stroke Association have asked the Centre for Health Services Studies (CHSS) to carry out the evaluation. They will collect and analyse the information received, report the findings and make these available to you. The questionnaires are anonymous and confidential, and individuals will not be identified without their consent

We very much hope that you will be able to support us in this project by completing this questionnaire as much as you can.

PTO

Enter code when prompted:	
----------------------------------	--

Please return the survey in the freepost envelope provided. Thank you again for helping us.

Linda Jenkins, Annette King and Charlotte Brigden
Centre for Health Services Studies,
George Allen Wing
University of Kent,
Canterbury, CT2 7NF

If you have any questions about this survey or the evaluation, require help to complete the questionnaire, or would like to complete an easy read version instead, please contact:

Centre for Health Services Studies tel: 01227 823878
email: chssenquiries@kent.ac.uk,

or

Barbara Sleator at The Stroke Association tel: 01622 351964
email: Barbara.Sleator@stroke.org.uk

SECTION 1 - THE SERVICE

Which 'Life after stroke' services **have you used?** (these include one-to-one or group sessions organised by 'Life after Stroke' co-ordinators).

Information, advice and support	YES	NO	UNSURE
Stroke prevention	YES	NO	UNSURE
Communication support	YES	NO	UNSURE
Return to work	YES	NO	UNSURE
Long term support	YES	NO	UNSURE
Carer support (for your family or carer)	YES	NO	UNSURE

Anything else? Please write in below

SECTION 1 - THE SERVICE (contd)

Have you been given an **information pack about stroke**?

YES NO UNSURE

Has the **information** given to you **met your needs**?

YES NO UNSURE

Has The Stroke Association **discussed your personal goals** with you?

YES NO UNSURE

Has The Stroke Association **provided** you with **stroke prevention advice**?

YES NO UNSURE

Has The Stroke Association **provided** you with **information on other support organisations**?

YES NO NOT NEEDED UNSURE

How **satisfied** are you with the **service provided** by The Stroke Association?

SATISFIED PARTLY NOT SATISFIED UNSURE

Has The Stroke Association treated you **fairly** and **sensitively**?

YES NO UNSURE

Do you receive **regular help** from a relative, friend or neighbour?

YES NO

If **YES** – Has the support provided by The Stroke Association helped your carer take more time off from caring?

YES NO

What **differences (good or bad)** has the **service** provided by The Stroke Association made to you? Please write in below

Could The Stroke Association **improve** the **service** we offer to you?

YES NO UNSURE

If **YES** – Please describe the improvement we could make below

Is there any **other support** you would like from The Stroke Association?

YES NO UNSURE

If **YES** – Please tell us what other support you would like below

SECTION 2- IMPACT

Has the **support** provided by The Stroke Association **helped you** in any of the following ways?

Being able to face the world

YES PARTLY NO UNSURE

Feeling largely in control of your life

YES PARTLY NO UNSURE

Feeling energetic

YES PARTLY NO UNSURE

Being able to attain personal goals and aspirations

YES PARTLY NO UNSURE

Feeling that little things do not get you down

YES PARTLY NO UNSURE

Feeling positive about the future

YES PARTLY NO UNSURE

Having peace of mind

YES PARTLY NO UNSURE

Feeling broadly satisfied with life

YES PARTLY NO UNSURE

Being able to take pleasure in what life has to offer

YES PARTLY NO UNSURE

Feeling that stroke doesn't dominate your life

YES PARTLY NO UNSURE

Feeling valued by friends and family

YES PARTLY NO UNSURE

Not feeling a burden to other people

YES PARTLY NO UNSURE

Feeling normal and not different from other people

YES PARTLY NO UNSURE

Your emotional well being

YES PARTLY NO UNSURE

Has **The Stroke Association** service helped you to **improve** your **quality of life**?

YES PARTLY NO UNSURE

If you answered **NO** to any of these questions – please tell us if there is **anything The Stroke Association could have done** that would have made a difference to you. Please write in below

If you answered **NO** to any of these questions – please tell us if there is **anything that someone else could have done e.g. The NHS** that would have made a difference to you. Please write in below

Section 3 - About You:

Gender

- Male
- Female

Your age group

- 18 years or under
- 19-34 years old
- 35-49 years old
- 50-64 years old
- 65-79 years old
- 80 years old or over

How long is it since you first started receiving The Stroke Association's support or services?

- 3-6 months
- Over 6 months – 1 year
- Over 1 year – 2 years
- Over 2 years
- Unsure

Survey 12mth or discharge

(delete as applicable)

Client No:

Service codes:

Appendix D Qualitative research interview and focus group schedules

D1 Stroke survivor interviews

Explain about the life after stroke evaluation and that we want to enhance our information from the survey, which provides more information.

The extent of the contact is not as important as what the experience was like .

Sign consent form

1. Background information
 - When stroke
 - What difficulties
 - Recovery
 - Carers

2. Contact with service
 - What do you know about the LAS?
 - What happened since you left hospital ? (Support received from LAS; other services?)
 - Which part of the service have you been in touch with? (see LAS chart?)
 - How did you find out about the service?
 - When did you start having contact?
 - What happened?
 - What did you hope the service could do for you ?
 - Have your expectation changes?/ What do you want now from the service?

3. Experience of service
 - How did LAS help you?
 - Do you think you/ your carer have benefitted from the service?
 - What was good/what was not so good about the LAS service you received and still receive?
 - Were there disappointments?
 - What else would have been helpful?
 - What else would now be helpful to you ?
 - Are there any other services that you use?

4. Overall evaluation
 - What do you know about what the life after stroke service does?
 - What does the service do well?
 - What could be improved?
 - What else could/should the service do?

Summing up :

What are your plans for the future? (personally, but also in line with the service)

5. Would you like to add anything else to our discussion?

Have we forgotten anything?

Do you have any questions>

Thank you for participating.

D2 Carers interviews

Explain about the life after stroke evaluation and that we want to enhance our information from the survey, which provides more information.

The extent of the contact is not as important as what the experience was like as a carer.

Sign consent form

1. Background information

- When stroke
- What difficulties
- Recovery
- Carers

2. Contact with service

- Do you know about Life After Stroke?
- What do you know about the Life After Stroke?
- What happened since x left hospital ? (Support received from LAS; other services?)
- Which part of the service have you been in touch with? (see LAS chart?)
- How did you find out about the service?
- When did you start having contact?
- What happened?
- What did you hope the service could do for x ?
- What did you hope the service could do for you as a carer?
- Have your expectation changed?/ What do you want now from the service?

3. Experience of service

- Did Life After Stroke help you as a carer ?
- Do you think x [stroke survivor] has benefitted from the service? How
- What was good/what was not so good about the Life After Stroke service you?
- Were there disappointments?
- What else would have been helpful?
- What else would now be helpful to you as a carer?
- Are there any other services that you use?

4. Overall evaluation

- What does the service do well?
- What could be improved?
- What else could/should the service do?

Summing up :

What are your plans for the future? (personally, but also in line with the service)

5. Would you like to add anything else to our discussion?
 - Have we forgotten anything?
 - Do you have any questions>

Thank you for participating.

D3 Interviews with coordinators and members of the Life After Stroke service

The interviews will use a semi-structured interview guide, which covers a number of themes. The topic guide will be used as guidance only to keep the interview conversation flexible and allow for exploration of additional themes.

These are what we would like to cover in the interview: We are interested in your understanding of what the life after stroke service does; how it fits into the landscape of services you provide/commission, what you understand and think about the aims of the Life After Stroke service and what you think how it is delivered; evaluated the contribution of the service from your perspective; what it does well; where you would like to see further improvements.

We may ask for specific examples to help us understand some issues.

1. Some background information about the role of the interviewee
 - Responsibilities of the post in relation to the commissioning/provider areas
 - Current state of working relationship (in commissioned: what is commissioned)
 - Any performance measured used

2. Perspective of the aims and objectives of service component/role and how it relates to the overall service.
 - a. What is the purpose of the Life After Stroke service
 - b. What specific role does it have and how does it relate to other services that are offered.
 - c. What areas are covered
 - d. To what extent are the national Life After Stroke components relevant

3. Contribution of the service
 - a. What specific contribution does it make
 - b. Where does it add value to stroke services, if at all
 - c. How does it fit in with others
 - d. What works well, what needs improvement

- e. Where are there areas of development/change that you see
- f. Is this the only service you are considering

Overall evaluation

- a. Do you think the Life After Stroke service has a place in stroke provision
 - b. Does it have a future long-term?
 - c. What other areas of work are there that need to be developed from your perspective.
 - d. What else could the service deliver.
4. Personal global assessment of the Life after Stroke service
- What works well and what needs developing
 - Linkage to the national aims of the Life after Stroke service

D4 Interviews with external stakeholder of the Life After Stroke service

The interviews will use a semi-structured interview guide, which covers a number of themes. The topic guide will be used as guidance only to keep the interview conversation flexible and allow for exploration of additional themes.

These are what we would like to cover in the interview: We are interested in your understanding of what the Life After Stroke service does; how it fits into the landscape of services you provide/commission, what you understand and think about the aims of the Life After Stroke service and what you think how it is delivered; evaluated the contribution of the service from your perspective; what it does well; where you would like to see further improvements.

We may ask for specific examples to help us understand some issues.

1. Some background information about the role of the interviewee
 - Responsibilities of the post in relation to the commissioning/provider areas
 - Current state of working relationship (in commissioned: what is commissioned)
 - Any performance measured used
2. Perspective of the aims and objectives of service component/role and how it relates to the overall service.
 - a. What is the purpose of the Life After Stroke service
 - b. What specific role does it have and how does it relate to other services that are offered.
 - c. What areas are covered
 - d. To what extent are the national Life After Stroke components relevant
3. Contribution of the service
 - a. What specific contribution does it make
 - b. Where does it add value to stroke services, if at all
 - c. How does it fit in with others

- d. What works well, what needs improvement
- e. Where are there areas of development/change that you see
- f. Is this the only service you are considering

Overall evaluation

- a. Do you think the Life After Stroke service has a place in stroke provision
 - b. Does it have a future long-term?
 - c. What other areas of work are there that need to be developed from your perspective
 - d. What else could the service deliver.
4. Personal global assessment of the Life After Stroke service
- What works well and what needs developing
 - Linkage to the national aims of the Life After Stroke service