

Report to: **Cabinet**  
Date: **26 June 2018**  
By: **Director of Adult Social Care and Health**  
Title of Report: **Stroke Recovery Service**  
Purpose of Report: **To consider proposals for the Stroke Recovery Service.**

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## **RECOMMENDATIONS**

### **Cabinet is recommended to:**

- 1. agree to give notice to vary the agreement, withdrawing the Adult Social Care funding but maintaining the contract with Clinical Commissioning Group funding; and**
  - 2. delegate to the Director of Adult Social Care and Health authority to take all necessary actions to give effect to the implementation of the above recommendations**
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## **1. Background**

1.1 A stroke service has been jointly commissioned by East Sussex County Council (ESCC) and the Clinical Commissioning Groups since 2009 and during this time has always been delivered by The Stroke Association, initially through the commissioning grants prospectus and now through a contract.

1.2 The service is commissioned to support stroke survivors and their carers to manage the effects of a stroke, including improved or maintained physical, economic and social outcomes and emotional wellbeing. In the last year the service supported 1488 individual beneficiaries and 780 carers. This equates to a cost of £35 per person taking just the ESCC element of the funding into account.

1.3 The service supports stroke survivors and their carers who live in East Sussex or who are registered with a GP in East Sussex

## **2. Supporting Information**

2.1 The total three year gross budget for the Stroke Recovery Service (April 2017 to 31 March 2020) is £476,727 (£158,909 per year); details are set out in Appendix 1. The service is part funded by the three CCGs in East Sussex. The gross Council budget to fund the service is £238,363.50 (£79,454.50 per year).

2.2 The contract is held by the County Council with funding from the CCGs. The contract commenced in April 2017 and is for three years with a possible two year, as the contract allows the commissioners to alter the level of funding.

2.3 De-commissioning of the Adult Social Care element of the Stroke Recovery Service will realise a full year saving in 2018-2019 of £33,106.04<sup>1</sup> and £79,454.50 in 2019-2020.

2.4 The service provides a number of recognised essential components of stroke support, including:

- delivery of personalised and specialised stroke specific information for stroke survivors and carers) which is provided on a face to face, basis normally in the individual's home
- 1:1 communication support

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<sup>1</sup> The year-end saving figure for 2018/19 is an estimated amount as it is not possible to discuss with the Stroke Association timescales unless the proposed saving has been agreed.

- a structured exercise and education programme in a range of community venues across the county
- 6-monthly stroke reviews based on the Greater Manchester Stroke Assessment Tool
- information sessions including training and guest speaker sessions

Appendix 2 sets out the Profile of Services. The service also provides practical and virtual support to nine stroke support groups across the county to ensure that these peer-run groups are sustainable in the longer term.

2.5 The service works closely with the Stroke Rehabilitation teams at East Sussex Healthcare Trust (ESHT) and Sussex Community Foundation Trust (SCFT) to ensure long term stroke recovery support for stroke survivors and their carers.

### 3. Consultation Summary

3.1 In the ten week consultation period from 15<sup>th</sup> February to 25<sup>th</sup> April 2018 three public consultation meetings took place on the Stroke Recovery Service proposals. These were held in each CCG area. In addition, views were sought from a range of stakeholders by letter, telephone and email. Appendix 3 provides more information about the consultation feedback and all of the responses received during the public consultation are in the Members' and Cabinet Room for Members consideration.

3.2 Key themes from the consultation feedback included:

- If the proposals went ahead, stroke survivors are concerned that it would leave them or people like them isolated
- People are concerned that if the proposal went ahead it would affect people's ability to recovery from a stroke
- The information and advice element of the service made a significant difference to over half of the respondents
- The exercise course and communication support made a significant difference to over a third of the respondents
- Generalised exercise programmes are less likely to be effective than stroke-specific courses

### 4. Impact of delivering the savings proposal

4.1 In considering the proposals in this report, Cabinet Members are required to have 'due regard' to the duties set out in Section 149 of the Equality Act 2010 (the Public Sector Equality Duty). Equality Impact Assessments (EqIAs) are carried out to identify any adverse impacts that may arise as a result of the proposals for those with protected characteristics and to identify appropriate mitigations. A summary of the key impacts from the EqIA are attached at Appendix 4. The full version of relevant completed EqIAs have been placed in the Members' and Cabinet Room and are available on the [Cabinet](#) pages of the County Council's website. They can be inspected upon request at County Hall. Members must read the full EqIAs and take their findings into consideration when determining these proposals.

4.2 The following groups are identified as at particular risk of experiencing a negative impact:

- **Age**

People are most likely to have a stroke after the age of 55, and by the age of 75, 1 in 5 women and 1 in 6 men will have a stroke. 76% of Stroke Association cases are aged 65+. Strokes suffered by people of working age may have significant impacts to their capacity to work, affecting their income.

- **Disability**

Stroke is the leading cause of disability in the UK. Stroke can affect walking, talking, speech, balance, co-ordination, vision, spatial awareness, swallowing, bladder control bowel control

and mental health. Stroke survivors may not have access to support with their communication needs, and a reduction to specific exercise classes will mean less opportunity for social engagement and physical activity.

- **Carers**

Carers have to adjust to the physical, emotional, economic and social strains of caring duties. A reduction to the service may impact their mental and physical health, and access to peer support- increasing feelings of isolation. Carers may also be negatively impacted by reductions to other services.

- **Rurality**

People in rural areas may no longer receive support in their home, meaning an additional barrier to accessing support for themselves and their carers, potentially increasing isolation.

4.3 In the short to longer term it is likely that these proposals will also mean an increased demand on adult social care assessment teams and the stroke community rehabilitation teams at ESHT and SCFT.

## **5. Alternative Service Provision**

5.1 On 17<sup>th</sup> May 2018 the project lead, provider and representatives from the CCG met to discuss what the service model could look like with 50% of the funding. The provider agreed to undertake further work on two different service delivery models for the CCGs to comment on. It was agreed by all parties that a service could continue to be delivered with the reduction in funding, but that it would have a significant impact on the type and level of service that could be provided. It was agreed that any new service delivery model would require the provider to introduce a triage process as the new model would not be able to deliver to the same number of clients as it currently does.

5.2 All parties agreed that a preferred model would be approved by them prior to the ESCC Cabinet meeting on the 26<sup>th</sup> June so if the proposal to make the savings goes ahead, the provider and project lead can immediately commence work on implementing the reduction.

5.3 All parties also agreed that if the proposal is agreed on the 26<sup>th</sup> June, the project lead, with the provider, will work closely with the stroke rehabilitation teams from SCFT and ESHT to develop a triage process.

5.4 Whilst a service could continue to be delivered to some stroke survivors and their carers there will be a decrease in capacity against demand. The following therefore explores the possible alternative provision for the different elements of the service for those stroke survivors and carers who may no longer be able to access the service.

### **5.5 Specialist stroke specific information and advice**

#### The Stroke Association website and national helpline:

Stroke survivors and their carers would be able to access this free of charge. However, there will be accessibility issues for those with communication issues and those who do not use or access the internet. Stroke survivors have also indicated through the consultation the importance of having face to face support in their own home.

Access to specialist stroke specific information and advice via the Stroke Association website and national helpline may only be an alternative service provision for a small minority of stroke survivors and their carers. This provision is also unlikely to be able to provide any effective emotional support for stroke survivors and their carers which has been identified in the EQIA and consultation feedback.

Stroke Community Rehabilitation teams at East Sussex Healthcare Trust (ESHT) and Sussex Community Foundation Trust (SCFT):

These teams can provide stroke specific support but this will only be available for those who meet the access criteria for the service. Support and information also tends to be focused on their areas of specialism (e.g. physiotherapy, occupational therapy and speech and language therapy). As identified in the EQIA, recovery from a stroke is very long term (if not lifetime) and the rehabilitation teams input for those who are able to access it, is time limited and very short term.

Access to specialist stroke specific information and advice via the community rehabilitation teams is not seen as a viable alternative service provision.

Avanti and Headway:

These are both specialist building based centres supporting people with Acquired Brain Injury (ABI). Both of these are accessible to people who have had a stroke but will be paid for on a private basis or through being eligible for social care and using personal budgets. However, we know from the stroke consultation events that stroke survivors and their carers have not talked about the importance of having access to building based day services as many of the clients access the community Stroke Association groups which better meet their needs.

Access to specialist stroke specific information and advice via Avanti and Headway is not seen as a viable alternative service provision.

## 5.6 **6-month reviews**

Stroke Community Rehabilitation teams at East Sussex Healthcare Trust (ESHT) and Sussex Community Foundation Trust (SCFT):

ESHT and SCFT Stroke Rehabilitation Teams could deliver 6 month reviews. However, their specialisms and expertise lie in stroke therapeutic interventions whereas 6 month reviews look at the wider holistic health and wellbeing needs of stroke survivors and their carers. Also it is likely that 6 month reviews would only be carried out with those on the team's caseload which would mean that individuals who do not meet the criteria for the service would not have access to a review. It is also likely that the teams would be unable to deliver this service unless they reduced their therapeutic interventions or received additional resources from the CCG to carry out this function.

Delivering 6 months reviews via ESHT and SCFT will be explored with the CCGs through the re-modelling process but it is unlikely that this will be seen as a viable alternative solution due to the need to identify additional resources to enable it to be commissioned.

## 5.7 **1:1 Communication support**

Stroke Community Rehabilitation teams at East Sussex Healthcare Trust and Sussex Community Foundation Trust:

ESHT and SCFT Stroke Rehabilitation Teams currently deliver speech and language therapy support to stroke survivors who meet the criteria for the service. However, this is time limited and short term. The Stroke Association provide communication support to both those who have accessed this service (to help support with maintenance of goals and progression) and also those who do not meet the criteria but still need support with their communication.

Delivering additional communication support would be outside of and in addition to the current remit of the Stroke Community Rehabilitation Teams. This is not therefore seen as a viable alternative service option.

#### Stroke communication groups:

There are two specific stroke communication groups that run in East Sussex (Eastbourne and Seaford) on a peer-led basis. These will probably be inaccessible for those who do not live in close proximity to them. The current Stroke Recovery Service team provide 'virtual' (and some practical) support to these groups in order to maintain their presence and sustainability as they were de-commissioned as part of the new contract which commenced in April 2017. Therefore their longer term sustainability may be under threat with any reduction in service/team members.

Access to communication support via these groups is only a viable alternative option to a small minority of stroke survivors. The groups are not a viable option in the provision of access to 1:1 specialist communication support.

### **5.8 Exercise and education programme**

#### Other leisure providers and private individual fitness trainers:

It may be possible to explore with other fitness providers the provision of stroke specific exercise classes or long term condition exercise classes that stroke survivors could access. However, any provider delivering these sorts of groups would need to have undertaken the Exercise and Fitness Training after Stroke (EfS) course, delivered by Later Life Training. In addition, to make this a viable option for the provider they would need to charge for the classes and this may make it unaffordable to many stroke survivors (please see 'People on low incomes' section of EQIA).

Access to exercise via the delivery of stroke specific or long term condition exercise classes may be a limited alternative option for some stroke survivors if providers are able to expand into this area.

Mainstream exercise is not a viable alternative option for many stroke survivors due to the nature of their disabilities and needing to build up their confidence and fitness in a safe and structured environment before they are able to access mainstream exercise.

### **5.9 Group information sessions**

#### Stroke peer support groups:

These groups will be able to provide peer support to stroke survivors and their carers and may be able to organise guest speakers. However, they will not be a position to provide training courses. Also the Stroke Recovery Service team provide virtual support to these groups in order to maintain their presence and sustainability. Their longer term sustainability may be under threat with any reduction to the service.

Peer support groups will offer some alternative service provision to guest speaking sessions and group information sessions but this will be limited.

Peer support groups will not be able provide training courses and there is no other alternative service provision for this element of the service.

### **5.10 Carers support**

There may be limited support available to carers if the other proposed adult social care savings go ahead. In addition, apart from the Stroke Association's website and helpline there is no alternative stroke specific carer support available.

## **6. Conclusion and Reason for Recommendations**

6.1 The Stroke Recovery Service is held in high regard by people who use the service, their families, carers and professionals in other rehabilitation services. It is seen as a successful and effective intervention for stroke survivors and their carers in supporting their longer term recovery after a stroke.

6.2 Stroke survivors and carers have expressed concern over the loss of the adult social care funding, have recognised the impact that this will have on the wider system (particularly healthcare) and have identified limited opportunities to access stroke specific support elsewhere. It has also been highlighted, via the consultation, that the proportion of adult social care funding and the total value does not seem proportionate to other proposed savings proposals.

6.3 The consultation and EQIA have identified limited alternatives to service provision. This will have an impact on those stroke survivors and carers who will no longer be able to access the service due to the triage process that will need to be put in place to manage demand over capacity.

6.4 The project lead, CCG's and service provider have held constructive discussions about service model options based on a 50% reduction in funding. The impact of this savings proposal is recognised and the wider health and wellbeing benefits of the services are understood. However, the overall level of savings requirement means that the Adult Social Care needs to make significant funding reductions and is no longer in a position to fund condition specific services.

### **KEITH HINKLEY**

#### **Director of Adult Social Care and Health**

Contact Officer: Emma Jupp, Project Manager  
Lead Member: Councillor Maynard  
Local Member: Countywide service

#### **BACKGROUND PAPERS:**

Appendix 1: Financial Breakdown  
Appendix 2: Profile of services  
Appendix 3: Consultation report  
Appendix 4: Equality Impact Assessment summary report

**APPENDIX 1****FINANCIAL BREAKDOWN**

<b>SAVING/INVESTMENT LEVELS</b>	<b>2018/19</b>	<b>2019/20</b>
<b>CCG funding</b>	£79,454.50	£79,454.50
<b>ASC funding</b>	£79,454.50	£79,454.50
<b>Original Funding Available</b>	£158,909.00	£158,909.00
<b>Less ASC saving</b>	£33,106.04 (currently estimated from Nov18 – Mar19)	£79,454.50
<b>TOTAL FUNDING FOR SERVICE</b>	<b>£125,802.96</b>	<b>£79,454.50</b>

## APPENDIX 2

### PROFILE OF SERVICES

<b>Stroke Recovery Service</b>	
<b>2017-2018 gross budget £158,909 Savings proposal (full year) £79,454.50</b>	
<b>Stroke Recovery Service profile</b>	<ul style="list-style-type: none"><li>▪ A total of 1488 individual beneficiaries and 780 carers were supported in 2017/18. At the end of quarter 4 (in year 1) there were 675 stroke survivors with an open caseload.</li><li>▪ 120 people accessed the Exercise and Education programme.</li><li>▪ The service is countywide with an Information and Advice and 6 month review Co-ordinator based in each Clinical Commissioning Group area. The client split per CCG is:<ul style="list-style-type: none"><li>▪ HWLH CCG 27%</li><li>▪ H&amp;R CCG 42%</li><li>▪ EHS CCG 31%</li></ul></li><li>▪ In last quarter January – March 2018 the service supported the following age groups:<ul style="list-style-type: none"><li>▪ 19-34 1%</li><li>▪ 35-49 4%</li><li>▪ 50-64 15%</li><li>▪ 65-79 37%</li><li>▪ 80+ 38%</li><li>▪ (5% did not respond)</li></ul></li><li>▪ 95% of those who responded said they are satisfied with the service they receive</li></ul>

APPENDIX 3

# ASC savings consultation 2018 Stroke Recovery Service



**Date:** June 2018

## Document summary

Results from the ASC savings consultation carried out between February and April 2018, focusing on the Stroke Recovery Service

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## About this document:

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<p><b>Accessibility help</b> Zoom in or out by holding down the Control key and turning the mouse wheel. CTRL and click on the table of contents to navigate. Press CTRL and Home key to return to the top of the document Press Alt –left arrow to return to your previous location.</p>	

## Background

The Council agreed its budget for 2018/19 at its meeting on 6 February. It will see the Council make savings of £17 million. This includes a budget reduction for Adult Social Care and Health of nearly £10 million.

We used the consultation to ask for people's views on how we are proposing to make the savings. Shortly before the consultation launched, the Government announced some extra funding for social care provision. No decisions have been made yet on how the Council will spend the £1.6 million it will receive.

This report is about savings proposal for the Stroke Recovery Service. The service is paid for by the Council and the NHS, with the Council paying half of the costs. We are proposing to stop our funding for the service.

The Council's Cabinet will consider recommendations, the consultation results and Equality Impact Assessments at its meeting on 26 June. All responses received in the consultation will be presented in Members Papers.

## Summary

This section provides a summary of the key themes and activity from the consultation. You can find the full results in the appendices.

We consulted on our savings proposals for the Stroke Recovery Service between 15 February and 25 April 2018.

## Activity and events

Event type	Details	Attendees
Consultation event for people who use services	Monday 26 March 1.30pm – 3.30pm Bexhill Health Centre	28
Consultation event for people who use services	Thursday 5 April 1.30pm – 3.30pm Telscombe Civic Centre	18
Consultation event for people who use services	Thursday 12 April 11am – 1pm Saint Luke's Church Centre, Pevensey	20

### Respondent numbers and response methods

The table below shows the different ways that respondents shared their views. Some people may have taken part more than once.

Method	Volume
Survey for people who use services (Paper and online)	207
General survey about the savings (Paper and online)	28
Other feedback (Email, letter, call, video, feedback form)	Indiv: 8 Org or group: 3
Event or meeting	66
<b>Total responses</b>	<b>312</b>

## Key messages

These key messages reflect the feedback received from organisations, groups and individuals across meetings, surveys and other feedback such as emails and letters.

- Organisations and people said that the service is a valuable resource for stroke survivors and that people would struggle to rebuild their lives without it.
- People are concerned about how the proposals would affect the health of people who are recovering from a stroke or have one in future.
- If the proposals went ahead, stroke survivors are concerned that it would leave them or people like them isolated.
- Organisations and people said it would be more expensive in the long term as people would still need support with their recovery.
- Reductions in the service are likely to put pressure on NHS hospital and community services to fill the gaps and lead to longer stays in hospital.
- People praised the service and the team of staff which provide it.
- They said that carers and families also value and benefit from the support of the service too.
- The information and advice element of the service made a big difference to over half of the respondents, while the exercise course and communication support made a big difference to over a third.
- Organisations said that generalised exercise programmes are less likely to be effective for stroke survivors than stroke –specific courses.
- People value the peer support that is offered through the service.
- Organisations are concerned that it would be harder for people to reach their full potential without the support of the service.
- People who've used the service say they have achieved things they didn't expect, like being able to walk, drive and get back to work.
- People don't know where they would have gone if the service wasn't available, although many said they would have tried their GP instead.
- People think the Council should look for savings from other departments instead.
- People commented on the recent allowance raise for Councillors and said savings should be made there.

## Summary of themes by response method

### Client and family survey

*How much difference the services made:* Information and advice made a big difference to over half of the respondents, while the exercise course and communication support made a big difference to over a third of respondents.

Top themes from the comments about the difference the services made:

- Information and advice: How helpful the service was.
- Group information sessions: The value of peer support.
- Communication support: How it helped with their speech and thought processes.
- Exercise course: How it improved their mobility:
- Six-month review: It showed them how they are recovering.

*Top theme for where they would have gone if this service didn't exist:* The top answer for all service areas was that people said they didn't know and that they would have tried their GP.

*Other services:* People named various services and local groups they have found helpful, with the Stroke Association and local groups or clubs being mentioned most often.

*How they would be affected:* People said that if the proposal went ahead it would make them and people like them isolated and affect their ability to recover from a stroke.

### General survey

Views on the proposal

- It would be more expensive in the long term as people would still need support with their recovery.
- The most vulnerable would be affected.

The impact of the proposal

- People are concerned about how the proposals would impact on the health of people who've had a stroke.
- It would leave people isolated.
- This is a vital service and reducing or cutting it would affect people's ability to recover after a stroke.

Suggestions

- People commented on the recent allowance raise for Councillors and said savings should be made there.
- The Council should look for savings from other departments instead.
- Cut management and support staff posts.

### Other feedback via letter, email etc

#### Organisation and group feedback

Views on the proposal

- The service is a valuable resource for stroke survivors and they would struggle to rebuild their lives without it.
- Specialist exercise courses are needed for stroke survivors in order to ensure they are appropriate and effective.
- Communication support is invaluable in offering rehabilitation in a social setting.

- Reductions in funding would make it much more difficult for people to access structured exercise courses.
- If the information provision and six-month review are lost, then stroke survivors would have reduced knowledge and access to rehabilitation when they need it.

#### The impact of the proposal

- Any cuts to the service would impact on people's ability to recover from a stroke.
- Cuts to the service would impact on NHS acute and community teams, with the most probable impact being an increase in hospital stays.
- The NHS community services would have to fill in the gaps, particularly in terms of communication support and cardiovascular exercise.
- It would be harder to access exercise classes and people would find it harder to reach their full potential without this support.

#### Individual feedback

##### Views on the proposal

- People disagree with the proposal and say that this service offers important community –based assistance with recovery.
- The impact this would have on people who need support in the future.

##### The impact of the proposal

- It would have a negative impact on people's recovery and affect their carers/family.
- There would be more pressure and need for support from NHS services.

### Events feedback

##### Views on the proposal

- People value the service and the amount of help it can offer. If the service funding was cut, then stroke survivors would feel like the Council is giving up on them.
- Cutting the service would be a false economy and just increase the pressure on other NHS and Council services.
- This is an integrated service that gets people back on their feet and back into work and driving etc. Why would you cut something that is working?
- Carers and families value and benefit from the support of the service too.
- It's not just older people who have strokes and it's important to remember that.
- People particularly value the caring and knowledgeable staff who support them and the peer support and social aspects of the service.
- People are concerned about whether the NHS will continue to fund its part of the service.
- They are worried about what support would be available to people in future. Would they just be left to manage?

##### The impact of the proposal

- Reducing or stopping the service would affect people's ability to have the best recovery possible and affect their ongoing quality of life.
- It would increase the pressure on NHS acute and community services.
- People would find it harder to return to work and driving.
- Carers and family members of stroke survivors would be at risk of breakdown without this support service.

### Sample quotes

These comments are a small selection of the comments we received during the

consultation. They have been chosen as they either reflect the key themes or offer a specific suggestion.

### **Organisation comments**

“[The service] is an essential resource within this locality. A decrease in the services provided locally would leave those who have suffered a stroke with significantly less support available to them. It will also have a detrimental effect on our team as we would need to fill the gaps left, particularly for communication support and cardiovascular exercise.”

“Last year, the service received 701 referrals and actively supported 1094 stroke survivors. It employs 6 coordinators to deliver the service. The service in question has been acknowledged as highly effective in delivering essential support to stroke survivors.”

“[The service] helps support ... with daily activities, physical activity, return to work, leisure activities and one to one basic help with aspects such as form filling, benefits etc. These are services which are often not provided by traditional services due to constraints on budgets. Cuts in funding will significantly impact on their rehabilitation and recovery, with the potential to lead to increased dependency on acute NHS services and Social Care Organisations.”

“Many of our clients access the exercise groups provided by the Stroke Association, where they are able to maintain the progress they have made in their physical recovery. Exercising with others is important psychologically and socially, and enables people to access the community via the local leisure facilities.”

### **Individual comments including clients, carers, staff and the public**

“It was really useful that they came to my home... I attended the stroke exercise group which was terrific. I didn't think I'd cycle again. You lose your confidence. If the stroke service was not available I wouldn't know who to ask for help. I can't speak more highly of them. I want other people to have what I've had.”

“Husband was made to fight back and given all kinds of support to work at his own recovery. Wonderfully skilled team of therapists.” (Information and advice)

“These groups have given a lot of help and advice and a better understanding of the effects a Stroke can have.” (Group information sessions)

“Dad has just said: "really good it was" ... without this support he may not have been able to comment at all.” (Communication support)

“A huge improvement in mobility and cognition as well as coordination was provided by the exercise course.” (Exercise course)

“Its a bench mark, open and honest, and sets out the next goals.” (Six-month review)

“In the last 11 months, our lives have been transformed because he now has access to experts who know what they are talking about... It is a vital lifeline, without it we would all struggle, we would disappear. Emotionally and personally, we need to fight for this service.”

“The Stroke Association is the only body which offers any help to stroke survivors when they have been ejected from hospital and they continue their support in the years after... Share the funds more fairly, please, or we will become not stroke survivors, but we will become stroke sufferers.”

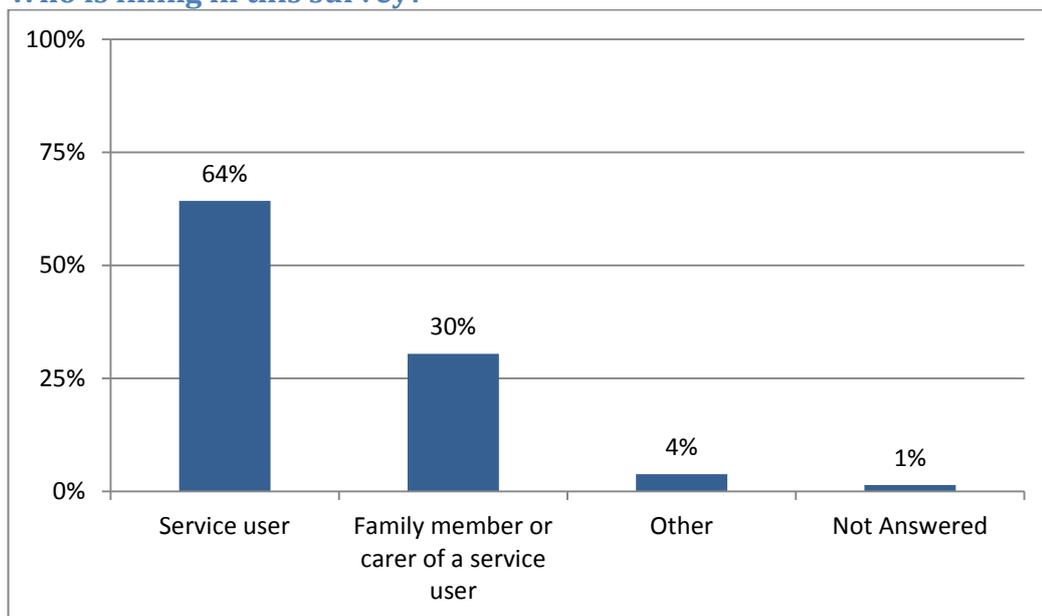
“[W]e are trained in the medical profession, but the Stroke Association is a non –medical

environment. They can be holistic and they can be supportive in ways that we can't."

"That is understated, the benefits of that [the social aspect]. People aren't isolated, able to get out. Being in those four walls is huge because it leads to other problems."

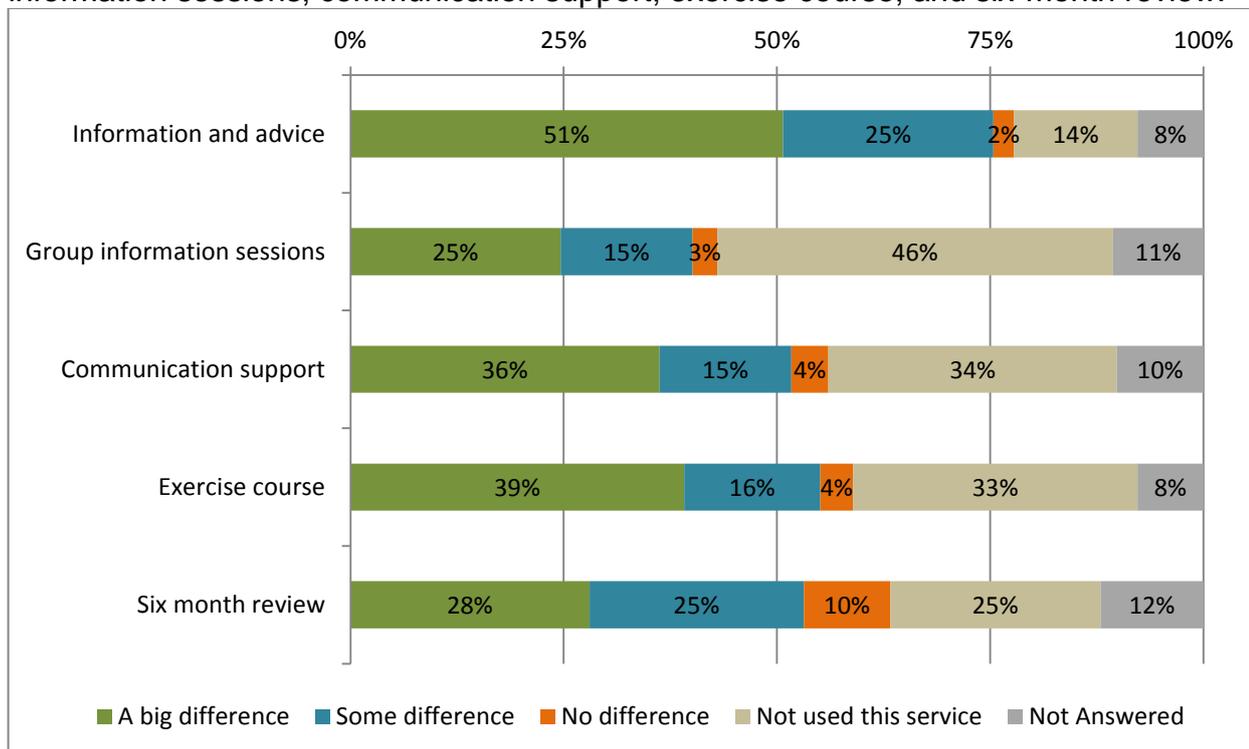
## Appendix 1: Client and family survey

### Who is filling in this survey?



### How much difference has the [... service name] made to your recovery and maintaining independence?

There was a question for each area of the service: 1 –2 –1 information and advice; group information sessions; communication support; exercise course; and six-month review.



### If you have any comments about what difference the (service name) made to you, please explain below:

1 –2 –1 information and advice:	<b>Top theme:</b> People talked generally about how helpful the service was to them.
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	<p>Other key themes:</p> <ul style="list-style-type: none"> <li>• The service gave them confidence.</li> <li>• They valued the information it provided.</li> <li>• The service was a practical support.</li> <li>• It had a positive role in their recovery.</li> <li>• It helped them to understand about strokes and what they could do to aid their recovery.</li> </ul>
Group information sessions:	<p><b>Top theme:</b> People valued the peer support that the group information sessions offered them.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• They said they didn't use the service or didn't use it much.</li> <li>• The sessions were a useful source of encouragement and helped them to regain their confidence.</li> <li>• The sessions provided help and advice.</li> </ul>
Communication support:	<p><b>Top theme:</b> People talked about how it helped with their speech and thought processes.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• The service increased their confidence.</li> </ul>
Exercise course:	<p><b>Top theme:</b> The service improved their mobility.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• It improved their coordination.</li> <li>• The service and support from staff encouraged and motivated them in their recovery.</li> <li>• The service gave them more confidence.</li> <li>• Some did their own exercise course too.</li> </ul>
Six-month review:	<p><b>Top theme:</b> It showed them how they are recovering.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• They talked generally about how they found the service helpful.</li> <li>• It is important to have contact with someone at this stage in the recovery process.</li> <li>• They benefited from the feedback and help with planning ahead and setting future goals.</li> </ul>

**Without the stroke recovery service, where would you have gone for [...service name] like this?**

1 –2 –1 information and advice:	<p><b>Top themes:</b> Many people said they don't know where they would have gone for a similar service and that they would have tried their GP.</p>
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	<p>Other key themes:</p> <ul style="list-style-type: none"> <li>• They would have looked online.</li> <li>• They would have tried the hospital.</li> </ul>
Group information sessions:	<b>Top theme:</b> People said they don't know where they would have gone and that they would have tried their GP.
Communication support:	<p><b>Top theme:</b> People said they don't know where they would have gone and that they would have tried their GP.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• They would have just done without the service.</li> </ul>
Exercise course:	<p><b>Top theme:</b> People say they don't know where they would have gone instead.</p> <p>Other key themes:</p> <ul style="list-style-type: none"> <li>• They would have gone to the gym instead.</li> <li>• They would have done without the service.</li> <li>• They would have tried their GP.</li> </ul>
Six-month review:	<b>Top theme:</b> People said they don't know where they would have gone and that they would have tried their GP.

**If you have a comment about any other Stroke Recovery Services and the difference they made to you please write them below: (93 answered)**

**Top theme:** People talked about services they had found helpful in their recovery or in the recovery of a family member. The services that were named are mainly provided by other organisations:

- Avanti
- Bexhill Choir
- Meadow Lodge Intermediate Care Unit
- Meet and Eat Lunch
- Rehabilitation Unit Bexhill
- Stepout for Stroke
- STEPS
- Stroke Club, Bexhill Hospital
- Stroke Exercise Group at Brighton University
- VSE by Ladies of Newhaven Stroke Unit

The other key themes were:

- Praise for the Stroke Recovery Service, the team providing the service and individual staff members.
- The value of the practical support it provides and the difference it has made to them.

**Please tell us about any other services you know about which provide stroke –specific information and support: (88 answered)**

People told us about the following services:

- Age Concern
- Avanti (abi)
- BOSS GROUP

- Café Club
- Citizens Advice Bureau
- Different strokes – online and for under 65
- DYSCOVER
- Headway
- Health in Mind
- Irvine Unit home visit
- Joint Community Rehabilitation (ASC)
- Local arts groups
- Local stroke meeting
- Neuro – Gym
- Ore Community Centre lunch club
- Red Cross
- Sing out for stroke
- Speech Therapy
- SS –UK
- Steps
- Stroke Assn. (Seaford)
- Stroke Association
- Stroke Club (Hastings)
- Stroke UK exercise group

**Please tell us in the box below how you and your family would be affected if the proposal went ahead? (130 answered)**

**Top themes:** People said that if the proposal went ahead it would make them and people like them isolated and affect their ability to recover from a stroke.

The other key themes were:

- People said that future stroke victims would be affected and have less support to recover.
- They would lose vital support and advice.
- Their family would be negatively affected if it made their recovery slower and harder.
- People praised the service and how it helped them.
- They wouldn't be affected, as they have finished using the service.
- It would put more pressure on the NHS and mean that no other support would be available to people.
- People said they would be upset and demoralised.
- They commented on their disagreement with public spending policies.

### About you questions

#### Gender

	Respondents		Census
Male	95	46%	48%
Female	96	46%	52%
Prefer not to say	2	1%	N/A
Not answered	14	7%	N/A

#### Transgender

1 person identified as transgender, while 151 (73%) answered 'no' and 7 chose prefer not to say. The rest (48) did not answer the question.

#### Age

	Respondents		Census
under 18	0	0%	19.8%
18 –24	1	0%	7.3%
25 –34	1	0%	9.6%
35 –44	2	1%	12.5%
45 –54	9	4%	14.2%
55 –59	11	5%	6.3%
60 –64	20	10%	7.5%
65 –74	39	19%	11.2%
75+	101	49%	11.6%
Not answered	23	11%	N/A

## Ethnicity

	Respondents		Census
White British	180	87%	98%
White Irish	3	1%	
White Gypsy/Roma	0	0%	
White Irish Traveller	0	0%	
White other	1	0%	
Mixed White and Black Caribbean	1	0.5%	0.5%
Mixed White and Black African	0	0%	
Mixed White and Asian	0	0%	
Mixed other	0	0%	
Asian or Asian British Indian	1	0.5%	0.6%
Asian or Asian British Pakistani	0	0%	
Asian or Asian British Bangladeshi	0	0%	
Asian or Asian British other	0	0%	
Black or Black British Caribbean	0	0%	0.3%
Black or Black British African	0	0%	
Black or Black British other	1	0.5%	
Arab	0	0%	0.3%
Chinese	0	0%	
Other ethnic group	0	0%	
Prefer not to say	1	0.5%	N/A
Not Answered	19	9%	n/a

## Disability

101 (49%) respondents consider themselves to be disabled, while 77 (37%) don't and 6 chose prefer not to say. The rest (23) did not answer the question.

### Impairment type

Please note that this is a multiple choice question.

	Respondents	
Physical impairment	89	43%
Sensory impairment (hearing and sight)	49	24%
Long standing illness or health condition, such as cancer, HIV, heart disease, diabetes or epilepsy	50	24%
Mental health condition	24	12%
Learning disability	8	4%
Other	19	9%
Prefer not to say	3	1%

## Religion

124 (60%) respondents consider themselves to have a religion or belief, while 57 (28%) do not, and 7 chose prefer not to say. The rest (19) did not answer the question.

### Stated religion or belief

	Respondents		Census
Christian	128	62%	60%
Buddhist	0	0%	0.4%
Hindu	1	0.5%	0.3%
Jewish	0	0%	0.2%
Muslim	1	0.5%	0.8%
Sikh	0	0%	0%
Other	2	1%	0.7%
Not answered	75	36%	N/A

## Sexuality

	Respondents	
Bi/Bisexual	3	1%
Heterosexual/Straight	153	74%
Gay woman/Lesbian	0	0%
Gay Man	1	0.5%
Other	1	0.5%
Prefer not to say	12	6%
Not answered	37	18%

## Marriage or civil partnership

119 (57%) respondents are married or in a civil partnership, while 52 (25%) are not and 6 chose prefer not to say. The rest (30) did not answer the question.

## Appendix 2: General survey

All the data in this section shows responses for people who ticked to say that they were providing a comment about this savings area (28 people) and not everyone who filled in the general survey (over 700 people).

### Are you completing the survey as (28 answered)

Please note that this was a multiple choice question.

Answer option	Count
A family member or friend of someone who uses social care services	9
An employee of a health or social care organisation	5
A member of the public	11
A group or forum (providing an official response)	0
An organisation (providing an official response)	2
Other (please explain below)	2
Not Answered	1

### If you are providing an official organisation or group response, please tell us your:

The following organisations and groups provided a response through the survey:

- School of Health Sciences, University of Brighton
- Stroke Association
- Sussex Community Development Association

### What do you think about our savings proposals? (27 answered)

**Top theme:** It would be more expensive in the long term as people would still need support with their recovery.

The other key themes were:

- The most vulnerable would be affected.

### How would people and organisations be affected by the proposals? (26 answered)

**Top theme:** People were concerned about how the proposals would impact on the health of people who've had a stroke.

The other key themes were:

- It would leave people isolated.
- This is a vital service and reducing or cutting it would affect people's ability to recover after a stroke.

### Do you have any suggestions for alternative ways of making the savings? (23 answered)

**Top theme:** People commented on the recent allowance raise for Councillors and said savings should be made there.

The other key themes were:

- The Council should look for savings from other departments instead.
- Cut management and support staff posts.

### Do you have any other comments about the proposals?

21 people ticked 'No', while 6 ticked 'Yes'. There weren't any key themes.

## About you questions

### Gender

	Respondents		Census
Male	9	32%	48%
Female	19	68%	52%
Prefer not to say	0	0%	N/A
Not answered	0	0%	N/A

### Transgender

One person identified as transgender, while 26 (93%) answered 'no' and 1 chose prefer not to say.

### Age

	Respondents		Census
under 18	0	0%	19.8%
18 –24	0	0%	7.3%
25 –34	4	14%	9.6%
35 –44	3	11%	12.5%
45 –54	6	21%	14.2%
55 –59	4	14%	6.3%
60 –64	4	14%	7.5%
65 –74	5	18%	11.2%
75+	0	0%	11.6%
Not answered	2	7%	N/A

## Ethnicity

	Respondents		Census
White British	26	93%	98%
White Irish	0	0%	
White Gypsy/Roma	0	0%	
White Irish Traveller	0	0%	
White other	1	4%	
Mixed White and Black Caribbean	0	0%	0.5%
Mixed White and Black African	0	0%	
Mixed White and Asian	0	0%	
Mixed other	0	0%	
Asian or Asian British Indian Pakistani	0	0%	0.6%
Asian or Asian British Bangladeshi	0	0%	
Asian or Asian British other	0	0%	
Black or Black British Caribbean	0	0%	
Black or Black British African	0	0%	0.3%
Black or Black British other	0	0%	
Arab	0	0%	
Chinese	0	0%	0.3%
Other ethnic group	0	0%	
Prefer not to say	1	4%	N/A
Not Answered	0	0%	n/a

### Disability

4 respondents consider themselves to be disabled, while 23 (82%) don't and 1 chose prefer not to say.

### Impairment type

Please note that this is a multiple choice question.

	Respondents	
Physical impairment	3	11%
Sensory impairment (hearing and sight)	1	4%
Long standing illness or health condition, such as cancer, HIV, heart disease, diabetes or epilepsy	1	4%
Mental health condition	2	7%
Learning disability	0	0%
Other	0	0%
Prefer not to say	0	0%

### Religion

9 (32%) respondents consider themselves to have a religion or belief, while 16 (57%) do not, and 3 chose prefer not to say.

### Stated religion or belief

	Respondents		Census
Christian	8	29%	60%
Buddhist	0	0%	0.4%
Hindu	0	0%	0.3%
Jewish	0	0%	0.2%
Muslim	0	0%	0.8%
Sikh	0	0%	0%
Other	1	4%	0.7%
Not answered	19	68%	N/A

## Sexuality

	Respondents	
Bi/Bisexual	1	4%
Heterosexual/Straight	22	79%
Gay woman/Lesbian	1	4%
Gay Man	0	0%
Other	0	0%
Prefer not to say	3	11%
Not answered	1	4%

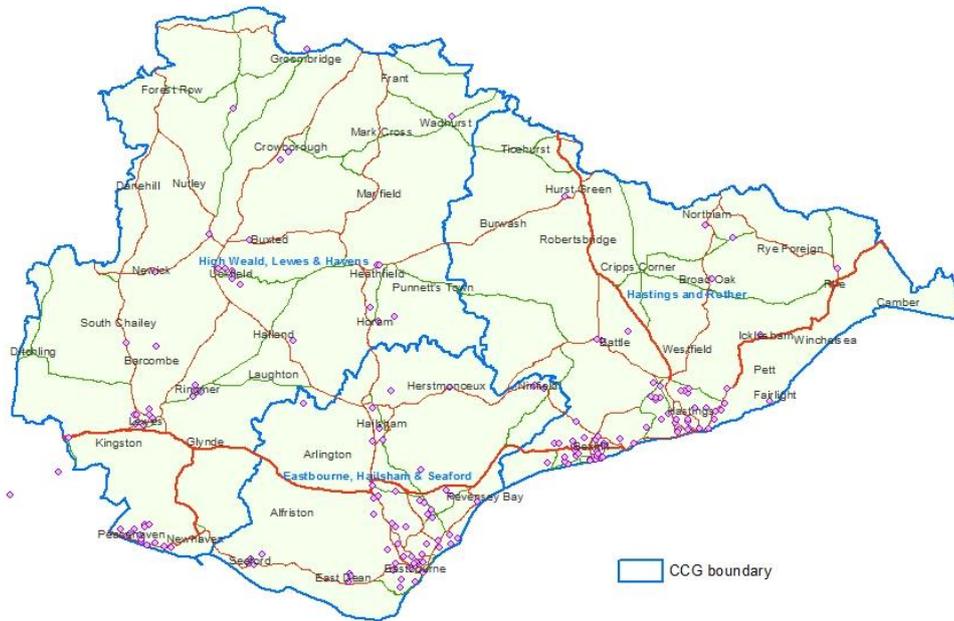
## Marriage or civil partnership

14 (50%) respondents are married or in a civil partnership, while 7 (25%) are not and 6 chose prefer not to say. The rest (1) did not answer the question.

### Appendix 3: Location of respondents

The map shows the location of respondents who provided their post code on one of the surveys (client/family and general). Of the 204 people who shared their views about these proposals and provided their post code, a total of 182 were mappable.

#### Stroke



30/05/2018

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Note: points may represent multiple addresses at the same postcode

## Appendix 4: Other feedback

### Organisation and group feedback

The following organisations provided feedback about the proposal:

- 1) Hastings and District TUC
- 2) Sussex Community NHS Foundation Trust
- 3) Stroke Association

### Key themes

The overall themes were:

- The service is a valuable resource for stroke survivors and they would struggle to rebuild their lives without it.
- Specialist exercise courses are needed for stroke survivors in order to ensure they are appropriate and effective.
- Communication support is invaluable in offering rehabilitation in a social setting.

The key concerns were:

- Reductions in funding would make it much more difficult for people to access structured exercise courses.
- If the information provision and six-month review are lost, then stroke survivors would have reduced knowledge and access to rehabilitation when they need it.

The key impacts were:

- Any cuts to the service would impact on people's ability to recover from a stroke.
- Cuts to the service would impact on NHS acute and community teams, with the most probable impact being an increase in hospital stays.
- The NHS community services would have to fill in the gaps, particularly in terms of communication support and cardiovascular exercise.
- It would be harder to access exercise classes and people would find it harder to reach their full potential without this support.

### Responses

Please note that the summaries cover all topics that the organisations have provided feedback on and not just the ones directly relevant to this report.

Code: Org0004	February	Letter	Sussex Community NHS Foundation Trust
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)
			Stroke Recovery Service
<b>Summary</b>			
<ul style="list-style-type: none"> <li>• The Stroke Recovery Service is a valuable resource for those who've had a stroke. They have witnessed directly the positive impact that their service has on their patients.</li> <li>• Any cut to the service would have a negative impact on local stroke survivors, which could impact on their overall recovery from their stroke.</li> <li>• Any change to service provision would likely impact on them too, with the most probable impact being an increase in length of stay due to reduced</li> </ul>			

specialist tertiary services through which patients can continue with the next stage of their rehabilitation.

- They would also need to fill the gaps left, particularly for communication support and cardiovascular exercise.
- Without specific stroke exercise groups it would be much more difficult for their patients to access structured cardiovascular exercise in the community. This would influence the long –term uptake in cardiovascular exercise as well as preventing patients from reaching their full potential due to a lack of continued support to exercise.
- Whilst there are other generic exercise programmes available in the community, these are often aimed at the elderly population which many of our patients are not. They are also unspecific to their condition and likely to be less effective. Those with more significant impairments struggle to access generic classes as they are unable to complete the exercises unless adapted for them.
- The communication support is an invaluable way for patients to continue implementing what they have learnt through rehabilitation in a social setting but where the principles of supported conversation can still be reinforced.
- If this information provision and the six-month review are lost stroke survivors, particularly those who have not received rehabilitation, would have reduced knowledge of local services and access to rehabilitation when they need it.
- Feedback from their patients about the peer support group in the area has been positive in helping them to meet others and take their first steps in integrating back into the community. Many of their past patients had expressed a need for a local support group, and this had been identified as a gap locally.
- The £300 grant service allows people to purchase items which make their life easier following a stroke. If this service was no longer available it would adversely affect rehabilitation as we would not have access to purchase small items of equipment that can be crucial to independence for those that have no other means of affording these.

Code: Org0005	Before consultation started	Letter	Stroke Association
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)
			<input checked="" type="checkbox"/>
			Stroke Recovery Service

### Summary

- The respondent has provided vital support for stroke survivors and carers affected by stroke through its Stroke Recovery Service in the East Sussex area for the last eight years.
- In the absence of this service stroke survivors would feel abandoned and struggle to rebuild their lives to return to work and driving after stroke.
- Last year, the service received 701 referrals and actively supported 1094 stroke survivors.
- Over the past 12 months the service has actively worked on 743 needs and achieved a range of outcomes including reduced isolation, reduced carer

stress, improved wellbeing, improved understanding of stroke and prevention of stroke, increased ability to communicate and increased confidence with activities.

- The impact of the loss of this service would be devastating to the East Sussex community and those affected by stroke.

Code: Org0024	April	Email	Hastings and District TUC
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV support service	Carers support	DESSS	Intermediate care and day services (Milton and Firwood)
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Overall	Older people's day centres	Supporting people (accommodation)	Supporting People (Community)
			LD dps & residential
			Stroke Recovery Service

### Summary

- They do not accept the rationale for cuts and are disappointed at the half – hearted Stand up for East Sussex campaign.
- They are concerned that staff in Adult Social Care are taking the brunt of the cuts, which would lead to inevitable delays in services for those members of the community who are least able to cope with it.
- The decimation of local services would remove well –established safety nets from already disadvantaged people (they name STEPS, Home Works, the Stroke Recovery Service, carers support, and the HIV Support Service).
- The lack of an Equality Impact Assessment in the consultation is telling.
- The staffing cuts would be false economy as people would have to wait much longer to access services and would inevitably end up on hospital wards.
- The abandonment of the preventative agenda would have the same effect.
- They urge councillors to consider using unallocated reserves to limit the impact and mitigate the proposals with the additional government funding.
- They are opposing the cuts and urge the Council to oppose national funding decisions.

## Individual feedback

About the feedback	
<b>Number of respondents:</b>	8
<b>When it was received:</b>	Before the consultation: 1 February: 1 March: 2 April: 4
<b>How it was received:</b>	Email: 3 Letter: 5
<b>Who it was from:</b>	Client: 6 Employee: 1 Member of the public: 1

### Key themes

The overall themes were:

- People disagree with the proposal to cut funding for the service.
- Once someone no longer needs clinical support, this service offers important assistance and motivation to help people progress.
- They praised the service and shared their experience of how it has helped them after a stroke.

The key concerns were:

- The complete cutting of funding compared to other services which are seeing reductions.
- How others who need help in the future would be affected if this service isn't available.
- What would happen to them if they had another stroke and needed this sort of support again.

The key impacts were:

- The negative impact on people's ability to recover in the community and on their carers and family.
- It would affect a group who finds it harder to make themselves heard.
- More pressure on an already strained NHS.

## Appendix 5: Events feedback

### Key themes

The overall themes were:

- People talked in detail about their personal experiences and the struggles they had gone through. Many of them said how much they valued the support of the service and said they don't know what they would have done without it.

- People value the amount of help the service can offer and how it steps in at a point when the medical emergency has passed, but you still need help with recovery.
- Cutting the service would be a false economy, particularly due to the risk of people having another stroke.
- Stroke survivors would feel like the Council is giving up on them if this service goes.
- The service is clearly making a difference to people and enabling them to get their life back, such as returning to driving and work, so why would you cut it?
- The amount spent on the service is relatively small and compared to other savings it's not fair to remove all the Council's funding for a service which is demonstrably making a difference to people.
- The service saves the Council and the NHS money and gets people back on their feet and taking steps back to normal life. Part of the value of the service is that it is integrated with health.
- The service plays a valuable role in helping people to return work and, if that isn't possible, to be able to contribute towards society in other ways.
- People value the role the service plays in supporting the carers and families of stroke survivors and making life easier for them.
- It's important to remember that it's not just older people who have a stroke.
- The peer support and social aspects are really valued by people, who feel this really helps them to recover and re-integrate with the community.
- Having support from caring staff with understanding of the condition and good knowledge of the support and services available makes a big difference to people.

The key concerns were:

- About whether the NHS CCGs would continue to fund the service if the Council stops its funding?
- What support would be available if the service was reduced or stopped? There is nothing else like this, so would people just be left to manage. What would happen then?
- If the Council is contributing towards funding the service it would lose its entitlement to input into the service agenda.
- People who have strokes in the future won't get the help and support they need to make the best recovery possible.

The key impacts were:

- There would be an impact on already stretched NHS services, both in terms of people staying in hospital for longer and with people needing more support from rehabilitation services.
- It would affect people's ability to recover from a stroke and their ongoing quality of life.
- People would find it harder to return to work or would struggle more when they do.
- It would be harder to return to driving without the support and confidence building of the service and its ambassadors.
- Carers and family members of stroke survivors would be at risk of breakdown without this support service.

Suggestions:

- Get rid of the police and crime commissioner and use the funding on services.

## 26 March, Bexhill Health Centre

The meeting was opened and everyone was welcomed. It started with a presentation on the Council's savings proposals and consultation opportunities, followed by a presentation on the services offered by the Stroke Association.

There was then a Q&A and attendees were given post –it notes to write down their views.

### Q & A

**Question: Attendees were asked what they had found to be the most important part of 'life after stroke'?**

*Attendee comments: Responses included 'the exercise group helped to make me more mobile and throw away my stick. I stopped using my stick after the 10 week class', 'I have continued to go to the gym' and 'having visits'.*

**Q: An attendee asked whether the NHS Clinical Commissioning Groups (CCGs) could make up the shortfall in Council funding?**

Answer: The financial position for the NHS is as challenged, if not more so, as that of the local authority. The Stroke Recovery Service is funded 50% by ESCC and 50% by the CCGs. So far as we are aware, there are no plans to cut the CCG funding. There is always a discussion with the CCGs when proposals are drawn up and the option is investigated, but unfortunately they are not in a position to replace the ESCC funding. We know that stroke has an effect on health services.

**Q: There was a lot of information included in the opening presentation – is it possible to have a copy for further consideration?**

A: Yes, we will share the presentation. Please let us know if you have a preferred method of receiving this.

**Q: Are you open about this or have you already made a decision, like Brexit? [Are the decisions about cuts already being made or are they open to changes?]**

A: Potential areas for savings have been identified, which are set out in the consultation, but no final decisions have been made. It will be necessary to balance the books and make the stated level of savings overall, so if it is decided that the proposed savings will not be made from this service, they will need to come from somewhere else.

The Stroke Recovery Service was included in proposed savings a few years ago, but this was changed following the consultation.

**Q: How are you going to decide on the cuts – will it be numerical, based on number of people who respond to the issues?**

*Attendee comment: There needs to be a clear scientific method for making the final decision.*

A: There is no weighting given to the number of people who respond and the decision will not be made based on numbers. This is because some smaller services may not have the same level of response as larger ones, but this does not mean that the smaller service is less important or has less impact. All key messages or themes will be presented at the end of the consultation. So, for example, if lots of respondents overwhelmingly say that one area is important, this would be highlighted.

*Attendee comment: A lot of people attend the Stroke Association groups, however there are also stroke survivors who cannot come to an event because they are at work. Often, the Stroke Recovery Service will have helped them get back into work.*

A: It is possible for people to respond to the consultation online, and by email, post or telephone. If there is anything more that you think should be done to promote the consultation, please do let us know.

**Q: Is it worth writing to MPs about funding from central government? Have you exhausted all support from central government? Should we petition central government?**

A: I cannot be political as an officer. There is a lot of engagement already going on – for example, Stephen Lloyd MP has organised petitions and demonstrations around savings, and ESCC leader Councillor Keith Glazier has had regular meetings with Jeremy Hunt.

A Green Paper is expected to be issued later in the year, before Parliamentary summer recess, which is likely to discuss health and social care integration as a way to ensure that social care can be sustainable in future, and the possible cap on social care costs. There are significant pockets of deprivation across East Sussex and it is not true that all money comes to the south east! We are constantly lobbying parliament.

*Attendee comment: I am concerned that the cuts are false economies. The Community Stroke Rehab Team service could not run without the Stroke Association, as people need somewhere to go to be supported back into everyday life. Back into life groups, like the exercise groups are priceless. The cuts need to be looked at as stroke is a lifelong condition and people will come back to the rehab team and won't have that valuable stepping stone back to normal life. Whatever is being done is going to be false economy because of the risk of having another stroke.*

A: We do know that savings around some of these services that support independence and active life, social and emotional support will be creating bigger problems further down the line. There is academic research that supports that. Unfortunately, the Council are faced with having to look for savings in areas that have not been looked at before, even where changes will create demand and cost down the line. There is no logic anymore.

*Attendee comment: One of the major problems is that the impact will be felt on someone else's budget.*

A: The Council has a wide range of funding responsibilities. We are also making savings proposals to a number of other areas, such as libraries and grass cutting. Even if we closed all of the libraries, it would not cover the savings. The Council has a duty to provide services, however, what this looks like can be determined.

Some money (£400k) has been transferred from verge cutting into social care, which has protected some packages of care. However, broadly as a community, verge cutting and potholes are important to people. Councillors have to listen to comments from their community when balancing local priorities.

*Attendee comment: How much did they spend on the library in Hastings?*

**Q: I learned about the Care Act on a recent course. My interpretation is that the Local Authority are obligated to meet terms in providing care and support, particularly in relation to Sections 1,3, 4 and 8 – if the Stroke Recovery Service funding is cut, how will the Council meet the obligations?**

A: Part 1 of the Care Act talks about wellbeing, information, care and advice. The Act does provide flexibility on how that is provided. As an organisation, the Council have to challenge ourselves to meet our statutory responsibilities. We have to go through all legislation and ensure that we are meeting statutory responsibilities. In terms of information and advice, we don't have to fund this, but we have to make sure that it is available. We may have to pull back from some support that has previously been provided. The starting point for consideration will always be statutory duties, including safeguarding vulnerable adults. The Care Act has hundreds of 'to dos', some are statutory, and some are guidelines as to what 'may' be provided.

Directors of Adult Social Care from across the country are making representations to central government about how realistic it is to meet statutory duties on the current level of funding. If anyone has concerns that the responsibilities are not being met, it is important that they say so.

**Q: The Stroke Recovery Service in East Sussex has always been joint funded by ESCC and the CCGs and has a commissioner who knows about stroke and cares about the**

**services, users and carers. It does not make sense in terms of the Five Year Forward View and working together in the future. It seems mad to take a step backwards.**

A: I would suggest that that is one of the unique selling points that needs to be communicated in the consultation, if you do get more value.

*Attendee comment: I think, overall, the service does save the Council money and helps to get people back on their feet. I think it is efficient and relatively cheap.*

*If you take something away it causes more problems down the line.*

**Q: Can people doing community service cut the grass instead? You might have to pay supervision.**

A: It is not my area but I'm sure all options are considered. There are, for example, voluntary groups, who offer to do it. It is important to find different ways to do things.

*Attendee comment: Get rid of the Police Commissioner – they take a big whack of the money.*

**Q: How come they can find the money for that but not for stroke victims?**

A: The funding comes from money for local policing and the model is supposed to be much cheaper than the old model.

*Attendee comment: We need to prove why we think we should keep our money and be forceful about that. We've just got to show the impact. MPs are there to represent you.*

*Attendee comment: The switch from shared funding to just NHS funding is important, as it means that the Council could lose their entitlement to input into the agenda. The NHS recognise that the Stroke Association plug a gap in what the NHS provides. £79k seems like a small sum to pay for what you get.*

**Q: Who gives the support to the next person who has a stroke?**

**Q: If the council funding stops and NHS funding continues, then will the level of service significantly reduce?**

A: There are questions for the Stroke Association about what is viable with the funding available. The service will probably be a different offer in the future. Some providers in the past have continued to deliver services on less money. We are having conversations on the impact and level of service.

**Q: How do you decide on what we keep?**

A: We need to understand whether other services meet the needs.

**Q: What services will be provided if the Stroke Association service will not be there?**

A: The Council will be completing an Equality Impact Assessment (EIA), which looks at the impact of changes and assesses any alternative provision that might be available to meet the needs. If there is no alternative, we have to say that and then Councillors will need to consider this and what the risk involved will be.

**Q: When will the work be done to look at other services? If there are none, how can we get community help?**

A: This work is going on now. The EIA looks at the impact on individuals against a range of personal features and at the impact on meeting needs. It is running as a parallel process to the consultation. The EIA is not required by law, but the Council feels that it is very important.

**Q: Is this the end of the Stroke Association?**

A: No.

**Q: What are the next steps? What happens to the consultation feedback?**

A: We receive thousands of responses to a consultation. The Council officers will pull out key themes and highlight these to Councillors to make very clear the impacts of any changes. A report and every bit of evidence will be provided to the Council, and I can assure you that they do read the responses.

I can assure you that where councils end up in court it is because they have not undertaken proper consultation or not shared everything with councillors transparently.

**Q: Is there anything else we can do with our local councillors?**

A: You can lobby councillors and MPs – that is your right as citizens. Councillors will often write to the Director of Adult Social Care to share views. Some MPs and organisations have also started petitions for Firwood House and Milton Grange.

**Q: Do you consult with GPs about the effect on their patients?**

A: The Council consults with all partners and stakeholders and from a commissioning point of view, we are in constant dialogue with health colleagues.

**Q: How would people be signposted to other organisations if there are no coordinators, as provided by the current service? It would be very difficult for people to access services themselves.**

A: The Council will be looking at how people would need to access services, for example, via a website or leaflets. GPs may also have a list of services. We cannot say that this will be a like –for –like service, but will look at the risk associated with this.

*Attendee comment: After you have had a stroke, you do not know where to go for help. The Stroke Association come to you and point you in the right direction.*

*Attendee comment: I come from a rehab background and worked with the coordinators for 5 years. I know that they provide reliable long-term care.*

A: It is important to look at continuity in the community, and it may be that some alternative support is not available in all areas. If there are concerns about this, it is important to raise them in the consultation.

#### **Post-it note comments and other feedback**

“Without the Stroke Association we wouldn’t have been able to cope. They offer such a range of help from practical to building self –esteem and enabling a person to get their life back.”

“Don’t try to mend it if it’s not broke. It is great as it is.” (Stroke Survivor)

“Day very interesting. Didn’t know what was for.”

“If someone became severely depressed as they had not had this help, this would result in a far greater cost to the NHS and the local authority. The singing group really does give back their voice!”

“What will happen if the NHS can no longer provide ½ of the funding?”

“If funding stops future stroke survivors won’t get the same support. The Coordinator helped us and my wife (who is semi –invalid). She helped us get Attendance Allowance and it really helped. After my cancer diagnosis I received no help. The Stroke Association have done us proud. They’ve helped me and my wife. It was really useful that they came to my home. The worker also got in touch after my second stroke. I attended the stroke exercise group which was terrific. I didn’t think I’d cycle again. You lose your confidence. If the stroke service was not available I wouldn’t know who to ask for help. I can’t speak more highly of them. I want other people to have what I’ve had.”

## 5 April, Telscombe Civic Centre

The meeting was opened and everyone was welcomed. It started with a presentation on the Council's savings proposals and consultation opportunities, followed by a presentation on the services offered by the Stroke Association and a short video about the Stroke Recovery Service.

There was then a Q&A and attendees were given post-it notes to write down their views.

### Q & A

**Question: With regard to funding cuts, is it an all or nothing scenario? Will it be the whole amount or none, or could it be half?**

Answer: Yes, from a specific area, if you re-worked and said it was £35k instead of £79k, that's possible but the rest would need to come from somewhere else. We could rework the offer but would still have to find the money from elsewhere.

**Q: We have got to make cuts and been doing it for ten years – where does it stop? We cannot keep cutting back, there is only so much meat on the bones. On 31 December 2016, if you told me I was going to have a stroke, I'd tell you you were talking out of your backside – 1 January, I had a stroke. I cannot believe the amount of help that we have had – endless information, help, support, nurses or physios have visited to help me get back into a life routine and we go to the group. I am lucky it has only affected me in my walking and [strength in my arms/speech?]. I am still working, through necessity, that wouldn't have happened.**

**All we have done all our working life is put money in, but I don't see why these people should suffer and why we should suffer, how can that be justified? We have already seen one lady go because of restructure. You can only keep cutting so much meat off the bone.**

A: Personally I would agree, I cannot be political. I came into social care to ensure that as many people as possible can live independent lives regardless of their condition. I understand exactly where you are coming from. The answer is very complicated. It is a national decision of the national government about the direction to take health and social care. They have promised a green paper in autumn this year which will outline how they propose to make health and social care services sustainable, including alternative funding sources.

There is always a way to improve services to help as many people as possible, but at the end of the day no matter how smart we are there is a limit to how much we can stretch out the tape. We have come to that point now.

*Attendee comment: It's not fair on you guys – you've got to say to layers below that we have to lay people off.*

A: It is a very hard decision and clearly does impact on people's lives. And it has reached that stage. Make sure your voice is heard and that you individually or collectively approach those who are elected to make decisions. It doesn't matter the colour of your politics, it is important in a democracy to make sure your view is expressed.

Irrespective of the green paper it is not going to be solved quickly – even if the government injected the full deficit, we still need to manage more older people. This is a great success but there are more long-term conditions, disabilities, learning disabilities – it is a major achievement but enormous pressure on the health and social care system. We must make sure that voices are heard in the right place.

The system that we work in was designed in 1948 to alleviate pressures of the 1930s. The war stopped and it came together after that. We cannot continue to work with the 1948 system. Dialogue about change will require changes for all of us, including things that will need to be paid for by us. We need to determine a system that works with as many people as possible. The consultation is an opportunity to get your views in the system. It is not me who will take the final decision.

*Attendee comment: I would like to apologise for my wife, who was a stroke victim two years ago – She would have liked to have been here today and wants me to convey how appreciative she is for work by the Stroke Association. I am the husband trying to fill in the gap. From the work that I have seen the support given to us has been particular invaluable, in the one sense, my wife having two strokes two years ago, the other since my own condition which is progressive ataxia, I rely on her to help me and she relies a great deal on me to fill in the gaps which she is least able to do with short term memory and speech problems. May I convey that very strongly because she does feel that it has been an experience to us both which we could have not wished for better.*

*If there has been any critical period involved in her receiving the treatment, it has been the actual stroke diagnosis period which has been the greatest problem, when prescriptions did not suit her and we lost a lot of time getting that diagnosis agreed between doctors and consultants, who often disagreed on treatment. Eventually we got a balance. We do appreciate that one prescription might not be suitable for all. The actual follow up of that stroke mechanism has helped us both tremendously. Please convey that to the hospital and all people involved with the stroke.*

*Attendee comment: Looking at the East Sussex discussion and resolution in June – who is going to fight our corner to preserve as much of the stroke support mechanism that we have? I did write to our MP Maria Caulfield. I requested that she should personally attend the County Council meeting which was first discussing the cuts. She did attend, she did not speak, I would like to think that she took a more active part in supporting the good work that you have done. I think that it is going to be possible to deliver a small part of the service which has in the past meant so much to our ageing population. I cannot thank your Stroke Association more.*

A: The Stroke Association do all the hard work. You make some really good points – you answered your own question about making sure that elected members receive the message. In terms of making elected members aware, so that they convey at a national level the messages. There are limitations to local members as they will have to find this cut at a local level.

*Attendee comment: There was very little dialogue possible at the County Council meeting between members of the public and councillors which seems a shame as we were unable to express how important it was. Many of us may have looked at last night's Southern TV broadcast – it was declared, the amount of backing which the Stroke Association gave. It was opportune for today's meeting.*

**Q: If this service is removed because of lack of funds and inability to keep it running, what will be put in its place? I am 54 year old woman with plenty of working life left, I was coming home from work in London and had a haemorrhage and stroke. I was very fortunate due to being introduced to the Stroke Association, 6 weeks down the road, I could not understand where they had got my information – I was having support through NHS physios and OTs, who were amazing. I found out from more questions that they work with the Stroke Association so they can pass you on. Four months down the road they have helped me to progress so that I can return to work. I am a maternity nurse, so I can give a lot. Without the help of the Stroke Association I would not be where I am today. This is four months to the day. I had open brain surgery, I have not met many people who had, I am able to drive and am looking at returning to work and it has been amazing. I would not be in this situation now had it not been for the support of the Stroke Association.**

A: It is those kind of stories that have the most impact and congratulations on your story.

*Attendee comment: You don't need them but I have all the details of the operation and I have photographs of the surgery, so it is pretty real. I have got there in only 4 months. Thank you to everyone. It is continuing to help. The measures that were put into place are ongoing. I feel*

*blessed to live in a county where there is so much help. I didn't know before. I am living proof that it does work...*

*Attendee comment: I came in and said that I wanted to get back to work because of my pension, about driving – through the Stroke Association they guided us into –*

*(Person 2) You had a driving assessment. He wasn't happy to go back driving without a proper assessment with a piece of paper to say he was safe –*

*(Person 1) Through the Stroke Association we found out about the assessment.*

*Attendee comment: Someone at Stone Cross gave a talk, went through that. My issue was only confidence.*

*Attendee comment: That was one of our stroke ambassadors, who gave the talk about returning to driving. This is the value of ambassadors.*

*He helped a lot.*

*It is great to have our ambassadors. He spoke to a lot of people. He has an adapted car.*

*Attendee comment: I would have gone to the doctor after a month and he would have said 'yes, you can go back to driving', but I wanted the reassurance. But the fact that a professional... I was reasonably confident but not 100 per cent. I went for 2 hours verbal test – it's quite an intensive assessment. The real value was it helped me to realise where I was going wrong – I didn't realise that I was drifting. If it hadn't been for that, I would have been driving in the middle of the road. Your perception changes. It is through the help of the Stroke Association that can put you in the right direction to make sure that you have the confidence and ability.*

A: You need to portray these points. It is difficult if you haven't experienced it. At the end of the day, we do not want to see any of these cuts, we have had many go over the years.

*Attendee comment: I cannot reiterate how important it is. One day it was hunky dory, then the next day gaga. I've got a wonderful wife and support team. If we didn't have the team, it would all fall back on [wife]'s shoulders. I am not being disrespectful, but you are just one person. I will be writing.*

**Q: How do you think the impact of these cuts will affect an already stretched NHS service? If people do not have support, many people will be going to GPs and other NHS services. All you are doing is moving the burden to an already struggling and burdened NHS.**

A: I have been working in East Sussex for four years. All direction has been towards working in partnership with our NHS colleagues. We know the value of prevention.

*Attendee comment: This is what the success is and now were being told that because it is successful, it is being cut and it will be going back to the beginning again.*

A: I don't know what the answer is. The difficulty is system wide – if you look at the way the service runs – quite a lot is acute sector and hospital dependent. This is the sign of the age old system. We are aware that if you mention closing a hospital, there is public outcry, whereas some answers lie less in hospital beds and more community services.

*Attendee comment: Now they are taking that away.*

A: The problem is that many services are not a statutory requirement and that is where some of the conflicts run.

*Attendee comment: The Prime Minister recently said that she would like to run a nation on volunteers – we have a lot of volunteers who run... now you're saying we cannot have this because they're taking funding away, and cannot have reliance on hospitals or NHS.*

A: It is about where they spend the money – as tax payers you vote for the party of your choice. My job is to ensure that I implement their policies on a practical level. There are some solutions – it is about how services are run. Ultimately, it still comes down to the issue of funding. The issue I'm guessing for the government is about how much money we have to spend on an ageing population with long –term conditions and few children to care for

parents. Ultimately it will depend on what the government intends to do in green paper. That is what we are legally required to do. We will do what we can with partners such as the Stroke Association, we can only do that with the envelope at any given time. I take on board comments, I am supportive of what service does. I do not need a spreadsheet full of data, I can just listen to what you are saying. I do not make decisions, I try to make them work a bit better. Politicians are not responsible for making these things work. People like myself and Stroke Association come up with programmes which have a significant impact. In many ways I can say, yes, this does not make sense to me either.

*Attendee comment: I think it is understanding that stroke is such a long term...it is not a quick fix – if you take away the ability to monitor that over the long term, then problems will only get greater.*

A: I agree. We have spent a lot of time doing preventative services. We know that they take a long time to bed in and are not always successful first go – I am sure that the Stroke Association will say not everything works, but you learn, change and move on.

We know the value...you can see the value, the issue is how we fund as many people as there are to receive those services. There are always problems – mental health, learning disability, they each have their unique set of circumstances, and their unique set of responses that work. The question is how do we move money away from acute to community? There are some very sick people, it is that balancing act. It is a complex debate at a national and local level.

**Q: Has anyone taken on the task of comparing the cost of the home visits compared with the cost of the hospital visits to achieve the same thing – this is a saving perhaps, if the home visits were increased?**

A: There have been a number of attempts – it is never an exact science – it is called cost avoidance, that is what services would be avoided, and there is a lot of academia around it. It is quite a task because individual care pathways are so individual – you have to make judgements. It is a tool – we know from work at local level and we know the value of those services – we do know that even if you avoid hospital admission, you instantly save money. For many survivors of strokes they will know that the amount of time in hospital, is variable but the interventions are getting quicker and quicker but it doesn't go away as it is a long recovery period, it is about maintenance. It is fair to say even with that knowledge we are developing programmes of work that will tell us that information. Nationally, no one has achieved it. There are some good guestimates. We know the value and I think society does. The scale of the problem – people are living longer with more complex conditions and that requires different interventions. The whole health and social care economy knows that it is better to move closer to people. The trouble is how do we get there? You need to keep both going for some time. It can take five years to see results. That is part of the issue, how do you fund it when we haven't got enough money, not knocking people by raising taxes so much – all of those issues are in the pot. Members are very conscious of those things.

**Q: Shouldn't the Stroke Association be arguing that a good recovery is saving money – we won't be going back to work. Good recovery is money saving and that is what the argument should be.**

A: I don't know what submission the Stroke Association make will be – most people's submissions are around the value of preventative work and services in the community. That is what we are encouraging people to do.

These are very good case studies and those are important because they mean more than tables of how much you have saved. In a sense, I am realising the value. You won't find any managers in social care who say that this makes sense because we know how much they save the system.

Some of the savings are not quantifiable – quality of life, increase in confidence. I suspect in some levels irreplaceable.

*Attendee comment: We both have contributed to society for many years, it doesn't matter what your age is, you've got to get back to living your life – they are just patching the holes, at the end of the day it is all about money. Everyone is entitled to a good service. One of the people had a nephew who had a stroke at 14 – if you're taking away those services you're not getting the quality of life – it really bugs me because it just seems so unfair.*

A: There is online a video of what the changes are. In it, we raise the fact that the kind of savings we make equates to 10,000 potholes. I have seen people get really passionate about those things. For me in social care, I say if I have to put up with a few more potholes, that is my choice. I have to respect other people's opinions that things are important. What is fascinating is that every consultation event is different but there are fundamental themes and the ones that you are talking about are really important – you don't even have to think about this, it saves a system under pressure. You cannot put a price on quality of life. It is a broad terms – wellbeing – what makes it up? People are happier when they have a home, relationships etc. The chances of survival and mental health are better. You'll find no argument about that happening. That doesn't take away from elected members who are still having a difficult time.

*Attendee comment: About the consultation period – the reason that you hear a lot about them is that people who can talk and can come to meetings – we see hundreds of people who cannot get out of the house, or fill in a form. I know that a lot of those people, the support we give is important. Some people have not seen anyone from NHS teams because they do not have physical problems, they have hidden effects. We can go out and help them with, just little things. They say thank you, 'no one has told me these things'. We hear all the time that the wards are good, but they don't have time to listen to them. I feel passionate that they do not have a voice. It is very good that other people can come out, but for every one person who can, we have hundreds who are vulnerable people, who the consultation period is not hearing about.*

A: I hope you will submit all that information. We have recorded it, but you cannot say it enough.

*Attendee comment: I am meeting these people, I have been doing it four and a half years. I think it is very important.*

*Attendee comment: You are right because we know how many people can attend, if the community transport bus turns up. Otherwise, they cannot get out. It really is a big problem. Not your fault that £10m is being cut, but we have all contributed, I cannot get around the fact that people like us deserve good support that we are getting – is it that they are so successful at doing the job that it is being cut? If you are spreading the £10m about, they really need to keep the qualified staff. They are all passionate about the job. It is such a hard thing to get across to superiors. No one appears to listen to the public. I really think it is a hard problem. Is it going to happen next year and the year after?*

A: It could do. I do hear – the staff in my division commissioned this service, we didn't do it because it was fun, we know that it is necessary. I do not take any pride in services being decommissioned. If services do not work, that would be different.

What it is, is a bit brutal at times. I stand up in front of other groups who also tell me genuinely positive things. You cannot measure the different impacts – you can't measure like for like. You have to take a punt – if my head tells me... How do we come to sensible decisions? The Q&A was stopped to allow everyone an opportunity to speak on a 1:1 basis, if they wished to do so.

## 12 April, Saint Luke's Church Centre

The meeting was opened and everyone was welcomed. It started with a presentation on the Council's savings proposals and consultation opportunities, followed by a presentation on the services offered by the Stroke Association and a short video about the Stroke Recovery Service.

There was then a Q&A and attendees were given post-it notes to write down their views. There were also group discussions at this meeting.

### Q & A

*Attendee comment: I just wanted to make this statement that for 12 years my husband suffered strokes and we weren't allowed access to any of this. In the last 11 months, our lives have been transformed because he now has access to experts who know what they are talking about. We felt very denied and totally isolated, we don't feel that now. We have strong support and I'm sure everyone would agree. It is a vital lifeline, without it we would all struggle, we would disappear. Emotionally and personally, we need to fight for this service. We have all benefited. I had no idea that this was available – I was attached to the medical professional world, that counted against me, no support whatsoever. Now if you look at the amount £79k, to my household that is a lot of money, in the bigger picture it is relatively small, so please fight to hold on to that. That money does not just help the people in this room. There are people who could not make it, they may not be well. Please fight for that relatively small amount.*

*Attendee comment: I have a statement which includes some questions – I am a hemiplegic stroke survivor. I have experienced the benefits of what the Stroke Association can offer. I am appalled of how social care funds have been allocated. Why in 2017 –18 Stroke Association had the lowest funding and yet has funding slashed by greatest 50%. It cannot be right and it's not fair. The largest reduction is something called Discretionary East Sussex Support scheme that even with this enormous reduction they still enjoy twice as much funding as Stroke Association. Surely it cannot be as important as the established organisation which is giving such an important service to the stroke community and in turn saving the authorities money. The Stroke Association is the only body which offers any help to stroke survivors when they have been ejected from hospital and they continue their support in the years after. They are also active in educating people in how to avoid catastrophic life changing condition. When I experienced stroke I was not expected to walk at all, if I survived. Now I'm walking, talking and driving. I am just one person that the Stroke Association has helped to recover some of my life. There are of course countless others, I might add that they are there to support carers as well. By reducing funding, you are reducing a section of community to poorer quality of life, a section of the community, that due to the effects of their stroke, are unable to raise their voice in protest against the unfair funds. Share the funds more fairly, please, or we will become not stroke survivors, but we will become stroke sufferers.*

Answer: Thank you so much because I can see that it is difficult to share your personal experience, but it is hugely powerful. I would encourage you to certainly express all of those issues in your feedback if you decide to submit it in another way.

*Attendee comment: Yes, I have shared a statement.*

A: There is something about the proportion of the savings... also that impact in terms of prevention as well and stroke survival, it is about recognising the reach of the service for the individual, their carers and families as well.

*Attendee comment: I had two strokes over a period of about 5 years and they [Stroke Association] have been a godsend to me. It enables me to help others to support one another when we meet, which we do every two weeks. We have about ten people and all of us have suffered in some way and without the Stroke Association we would not be able to go forwards*

anymore, so they are very very important. It doesn't matter how much money they need, without them we are going to be at a loss and people will suffer. For me and my wife, who is my carer, they have been a real help because she has been able to see how much I have developed over the years and also how much other members of the Stroke Association can help one another by encouraging and by supporting each other when times seemed dark. The Stroke Association is vitally important and to my wife who is my carer.

Attendee comment: My husband was a vicar so he is very used to going on! I would like to say myself that when he was discharged from hospital after 3 weeks, my world had come to an end. I thought I could not cope. The Stroke Association really helped us and without it I do not know what we would have done. When we left the Irvine Unit, who did an incredible job, he could not speak, he couldn't say a word. Then he could say 'two cappuccinos!' When we came home, we were promised everything, speech therapy, physio, but nothing...we did it on our own by playing games and word association. Without the Stroke Association we would have been up the Nile without a paddle, so please keep the money coming because if you don't you won't be making any savings because all the other services will be used more. You will have carers having breakdowns and stroke survivors not surviving. The fall out will be in other departments. Please reconsider.

Attendee comment: The other thing is that as a survivor, we are able to help other people too. I visit another man who had a stroke. He is not so fortunate as me, he cannot walk or talk, but when I go to see him I am able to support him and help him to get mildly better than he is. I use the guide from the Stroke Association to help him to get even more better than he is, so we can do other things just because of the Stroke Association.

Attendee comment: Hello everybody – I am only one of a number – one of, my own success story directly related to the Stroke Association – I am going to try my damndest not to cry – I had a subarachnoid haemorrhage four months ago and nobody can believe where I am standing today, walking and talking and I do most things on my own. Just last week I got back to driving and I was late today because I had a meeting about getting back to work. I had open brain surgery four months ago. I would not be standing here today without the support from the Stroke Association. Words cannot thank you enough. When I first came from hospital, I could not go out. I am in my early 50s and a qualified maternity nurse, I am not ready to be thrown on the scrap heap. If the money is cut, what is put in place so that you are looking at someone like myself, who will be there to help me if I cannot turn to the Stroke Association, who have put in place physios, SALT...just meeting people and getting back to holding conversations.

Attendee comment: I come from a slightly different perspective – I work for the community stroke rehab service, so I am bringing the views of the team on how much value there is working alongside the Stroke Association. We are a rehab service, so we only see people for a time limited period – 12 weeks more or less, that is not very long when thinking about support for stroke survivors. We value being able to hand over clients. We have strong links with the Stroke Association, they attend our meetings on a fortnightly basis. We don't see everybody who has had a stroke, we only see people who have rehab goals. Six-month reviews are done on everyone – this is really important in terms of secondary prevention work – we see people much sooner after stroke and secondary prevention at that point is not always the time, by the review, that can be a better time to do it. We try not to be too medical, see people at home, but we are trained in the medical profession, but Stroke Association is a non – medical environment. They can be holistic and they can be supportive in ways that we can't. We are concerned for ourselves too, it is likely to have an impact on our service and people may need support for longer if clients cannot attend communication support or exercise groups. If they are not supporting people long term, it is possible that people may deteriorate and come back to us – this can impact on other services....[Name removed] is also here from stroke team....

*Attendee comment: I think you've covered everything – length of stay, social getting together, sense of wellbeing, sharing experiences. The social element is really important and giving people a sense of wellbeing.*

*Attendee comment: It is really important sharing with people in similar situations.*

*Attendee comment: That is understated, the benefits of that. People aren't isolated, able to get out. Being in those four walls is huge because it leads to other problems.*

*Attendee comment: If this all disintegrates because of lack of funding, can you imagine the expertise of all these wonderful people that they bring to us. Holistic is the right word – it is important from step one and it is a continuing need. We have had a couple of weeks away from the exercise class and it is noticeable that the person deteriorates, it is continuity which is important. If you start destroying the team and network – they are all important – without it we will not move forward it will just grind to a halt. We all know, we will all be more expensive, it will not just be my husband's needs, it's mine as well.*

**Question: What research has the Council done on the costs if they don't give the grant to the Stroke Association. Have they done any?**

A: There is a lot of research nationally and locally on the effect of reducing services such as this – as many of you have reflected, it means reduced services here, it costs more down the line as people deteriorate and needs increase. What is not costed is the side around mental support and wellbeing, social isolation. The Kings Fund have done some work on that. So yes absolutely, it came up at another session what is the logic behind this, everything points in the opposite direction for us, whether it be prevention, stroke survival, increasing costs if the service or support isn't there. One of the things that I would reflect is CQC came and gave a local area review of East Sussex health and social care, it was focused generally on older people and looking at the hospital experience. One of the things they reflected back was that the level of investment that East Sussex has maintained for early intervention and prevention compared to other areas....we reflected back that we have fought hard to protect investment but now entering phase where we have to broaden the search of where to take savings from. ....here we are in terms of that...there is no logical argument I can provide you for the position we are in today, it is not difficult to find the evidence in terms of early intervention or prevention. Which doesn't answer the question.

*Attendee comment: The cost won't be known until it actually happens. To some extent it seems to be the Council pushing this stuff on the NHS resulting in more costs for the NHS.*

A: That is a view. One of the things that we are hoping for, if it emerges, is the government's green paper, which is expected to provide for health and social care integration...bring it on, I say! If we don't legislate for integration we are going to be in that continued phase of social care at a cost and health care which is free at the point of provision, those tensions, there is a whole other agenda there.

*Attendee comment: I am a neurophysio in Eastbourne, I run the exercise group in the Eastbourne area – one of the services that will be affected – exercise is a great way to deal with isolation and make people feel better – some of the people that I see...exercise is a way to prevent people getting worse, reduce risk of having a stroke because people understand that it is one of the things that Stroke Association is good at, giving the 10 week free session, people who have not exercised before will have a go....I push them into whatever they want to do. If you have had a stroke, your exercise capability is reduced,... people are scared, they need professional input. From my own personal point of view, the exercise groups are crucial.*

*Attendee comment: I had a stroke and bleed in 2014 and spent 6 [months] in hospital, 6 months in rehab. When I came home, my wife left me because she said I was embarrassing. I met various people and they gave me courage to go on, and they helped me get where I am now, I drove, went back to work, they continue to support me, various friends and colleagues got me into a group and I met other people and understood what was going on and what I*

*could do, you can do all those things. If you take all those facilities away, I would have fallen over. I would not have been able to do it... I got back to work, I had messed up my finances, so they sent STEPS in, they sorted that out. ...it gives me an opportunity to say thank you because I appreciate the opportunities given me.*

*Attendee comment: I was 24 when I had my stroke 4 years ago...afterwards I didn't have any reablement or help. I was living in Brighton. I felt abandoned and lost, no idea what was going to happen, instead of getting better, my mental health deteriorated....got bad. I had to move back a year later, I went to the Step Up To Stroke event ...I approached them and asked whether there was anything in the area where I could get help. [Name removed] took me to Bexhill to a young stroke survivors support group. I was so anxious I couldn't leave the house on my own. She helped me feel safe and was there to support me. About a year or two after I had to quit my job because my health deteriorated more. ...I went back to the Stroke Association and said could I do volunteering, but I still suffered with anxiety quiet severely, they came with me for the first couple of meetings and made me feel safe and supported. It is important to have someone there. I can also see how much it affects other people, there are groups which I know will be self –funded and run from now on but it is also the input from the Stroke Association coming along and being there which is really important. Sometimes you need someone there and that is worrying if it going to be taken away. There are also a lot of other areas that are not met – mental health side and stroke fatigue...these are things that are completely ignored, there is nowhere in East Sussex that will support you with fatigue management, that is my biggest impact, why I cannot work, my doctor said that it will get better.....for mental health there is Health in Mind but you have to wait 9 months and they are not trained for brain injury. I know that the stroke rehab team have been asking for a stroke neuropsychologist...it is a massive gap, if people have that support, I have not and I am stuck, I had appointment with the stroke rehab and quote was “you are out of our depth”, when you are told that something is wrong but there is no –one to help you, what to do you do? I have a lot to give but I can't. It feels like we are being given up on. A lot of people who have strokes are older, it almost feels like saying there is not much point helping because they have had their life, but even if you are retired you can give back. I am on benefits – how much is that going to be costing? I have gone back to Health in Mind – how much is that costing? I have gone back to hospital – how much is that costing? If there was facility in place it would stop it.*

Stroke Association comment: In Colchester, I have recently set up an emotional support counselling service. It is something we will be trialling and roll out if we get funding. We want to work together to conquer the psychological effects of stroke.

A: Thank you for that – the impact of the support that is given by professionals or supporters and volunteers – the far reaching nature and longevity of ongoing support has really come out today, as has the fact that people's lives are turned around.

Thank you to those who have told their stories – it has been very touching. We are going to come round to tables, we have some questions to discuss, you don't have to answer them. We want to make sure that everyone has the opportunity to have their say. There are also surveys – we are here to help, there are post-it notes.

## **Table –based discussions**

### **Table 1**

- It was like a shock and then a miracle as she couldn't do anything and then she could walk and talk. I liken it to when you have flu and you feel really unwell and then suddenly you get better. I didn't expect there to be the ongoing problems that there are.
- I went back to work but then I was really struggling. I was bullied at work. By the time I realised that I needed reasonable adjustments it was too late and no reasonable

adjustments were made. I got stressed and went off sick. I went from that job to another job but was bullied by my manager.

- If my daughter had input and she was helped back to work this could have been avoided.
- I attend a young adult group in Bexhill. They understand what it's like but it's still difficult to relate because they're not the same age. I am 28 and the youngest other person is in their 40s.
- I've started volunteering with the Stroke Association and they understand my challenges. If I am having a bad time I go there and get supported myself.
- When the stroke happened I was in shock. A few months later it kicked in. The fatigue has been one of the most difficult things to deal with.
- I know the groups will continue with the service but they will have to do this without support. We are sustainable but the input the team gives is invaluable. I don't want it to become a coffee morning. As a volunteer I can't give advice.
- I want to do more things like outings. If the team aren't around they won't be able to help with this. You need that background support.
- The communication support is good and you can see how people have improved. 1:1 support in the home has been helpful.
- The support from nurses. Physio's OTs is fine but they see everything from a medical point of view.'
- 'When I left Bexhill hospital I was there for 6 weeks. I had to pay for my own private physio as the wait was 19 weeks and I couldn't wait. Luckily I had a bit of money but others can't afford that. Then after that I had stroke support. [The] (Co-ordinator) came in and told me about these groups and that has helped with my speech.
- The communication group gets people to talk and they understand your problems.
- It feels like being condemned. It's not always about lifestyle choices.

## Table 2

- We haven't had strokes for anything that we have done – it is not something we have brought on ourselves. Without the stroke association you are on your own.
- I did have NHS support when I came home. They knew about me and what my needs were. There is nothing in the NHS to put you in touch with others.
- I was in Firwood House – detailed report on what I should do – I've used it so many times. I wish there was a year check-up when I had my stroke. I have had TIAs and have to walk with a stick. Strokes are on the increase, if the service taken away god help the NHS.
- I wanted to know how they knew so much about me. I can't see how the NHS could do six-month reviews.
- I could have been lost in the system.
- You have to drive – I got public transport and walked around with a stick. I could not work out how to get back. I asked a bus driver. A friend said to find out about driveability. The Stroke Association gave me the information. I have been using a manual. I am self-employed so financially it is difficult. Got a new automatic.
- We take it for granted.
- I like the time that they can take to escort people to groups. Sometimes you need somebody by your side.
- You wake up in the morning and it is a long time until night time if you don't see anyone. You know you are going to see someone with the Stroke Association.
- I was very emotional but it doesn't matter if I cry in the group.
- They put me in touch with Headway. I had an interview, they are great for signposting. I got in touch for counselling.
- I used to be a workaholic; now I am a bedaholic.
- Social isolation has such an impact on mood.

## Table 3

- Feel supported.
- Access to some amazing people.
- There are so many different types of stroke. It's a privilege to learn from each other.
- Struggled with medical professionals for 11 years. Multiple strokes and change of medication. Told not to call for an ambulance.
- Last year help from the Stroke Association was like SUNSHINE!
- Stroke Association present at Doctor's when I had the flu jab.
- Isolation is worst.
- Quality of life important.
- Fatigue is a real worry – Headway group booklet – understanding what is going on e.g. brain fatigue
- Acquired brain injury – response if different from stroke. Feel it's the poor relation.
- We forget it affects all ages.
- What's been useful: Information, 1:1 contact, groups. Exercise.
- Without the service: Tied to home; Isolation; Imprisonment; No friends; No confidence; No support to navigate problems; Laughter and fun – priceless and invaluable.

## Table 4

- Can you remember what it was like when you first had your stroke: Bewildering, devastating, frightening, fearful, life changing. Not knowing what is happening/going on.
- Can you tell us if life was different after you received support from the Stroke Association? Gave me confidence and reassurance; Helpful, guidance; Getting together with others who have had a stroke – learning from them; Making you and your life feel valued; Not feeling alone and isolated.
- Do you think the input from the Stroke Association contributed to lifestyle changes? For example, changes in diet, exercise, etc: Exercise through the Stroke Association exercise classes; General awareness; Confidence to engage in exercise groups, make changes.

**APPENDIX 4**  
**EQUALITY IMPACT ASSESSMENT SUMMARY REPORT**