Central Sussex Stroke Review

# Responses to feedback received

**15 February 2017**

This document sets out the responses from local clinicians to the feedback and questions received from patients, carers and the public through the recent engagement about stroke services. A list of contributors is at the end of the document. Full details of the engagement process and feedback received are set out in the February 2017 stroke engagement report.

## Concerns about the proposed change

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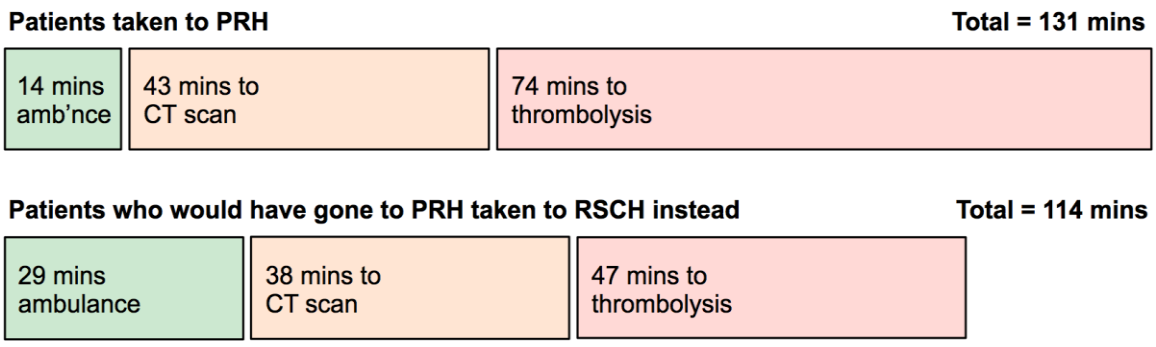
| The main concern raised was about the impact of longer ambulance journey times. | We understand this concern. However, clinicians are confident that any increase in the length of journey is offset by the prompt and enhanced care available at Royal Sussex County Hospital (RSCH).<br><br>The ambulance alerts the hospital en-route and the specialist stroke team are able to meet the ambulance at the door of the RSCH A&E so there is no delay in triage.<br><br>Stroke patients have been temporarily diverted to RSCH from Princess Royal Hospital (PRH) since February 2016, due to a shortage of specialist staff at PRH. Figures confirm that, since then, the increased travel times have been offset by quicker treatment times.<br><br>The chart below shows that the average ambulance journey time for patients taken to PRH was 14 minutes and for patients who would previously have gone to PRH who are now taken to RSCH it is 29 minutes. However, average times for patients to receive a CT scan and then for appropriate patients to receive thrombolysis are significantly shorter at RSCH. The total average time to thrombolysis, including the ambulance journey was 131 minutes at PRH. For those patients who would previously have gone PRH but are now taken to RSCH the total average time is just 114 minutes.<br><br>Importantly, following treatment, the larger integrated stroke team at RSCH are also better able to offer more care more quickly to begin the patient's rehabilitation. |



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| A concern has also been raised that the journey time does not take into account the wait for the ambulance to arrive. | South East Cast Ambulance (SECAmb) respond to suspected strokes with the same top priority as other life threatening conditions, including heart attacks. The response target is 8 minutes in 75% of cases.<br><br>All ambulance services face a challenge in ensuring that a prompt response can be achieved in some rural areas. SECAmb continues to work to maintain its performance and is increasing the number of community first responders in rural areas to enable assessment and treatment where possible to begin before the ambulance arrives.<br><br>Anecdotal feedback from BSUH stroke team staff is that since the temporary divert from PRH to RSCH, the majority of patients and families have been pleased with the speed of the ambulance response. |
| Concerns were raised about how much more difficult it will be for some families and carers to visit patients at RSCH than PRH. | We appreciate that visiting patients at RSCH will be less straightforward for some people. However, we believe that any drawbacks over the time the patient is in the stroke unit (usually 11-12 days) are far outweighed by the longer-term benefits of improved outcomes and reduced disability and dependency.<br><br>On admission, patients from outside of Brighton are identified so that the stroke team are aware of the distances involved for families and carers and work with the family to reduce the impact of travel, if possible. Unit visiting times will be as flexible as possible to reduce the burden.<br><br>Follow up appointments will still be held at the patient's nearest hospital (either RSCH or PRH). |
| Assurances were sought that the changes would not impact on other hospital services and took into account expected population growth. | Stroke patients have been temporarily diverted to RSCH from PRH since February 2016, due to a lack of specialist staff at PRH. During this time there has been minimal impact on other services and patients at RSCH.<br><br>Mapping and shaping services to meet current and future demand has been an important part of the whole stroke review process. |
| Brighton and Sussex University Hospitals (BSUH currently being in special measures was mentioned as a concern. | When it comes to stroke services, the Care Quality Commission (CQC) singled out the stroke services at RSCH as being outstanding. BSUH is working hard to make the necessary improvements to other services and address the issues raised by the CQC. |

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| Reassurances were sought that the changes would not have any negative impact on the inpatient stroke rehabilitation offered by the Sussex Rehabilitation Centre at PRH. | The Sussex Rehabilitation Centre will continue to be based at PRH and will continue to provide complex rehabilitation services for stroke patients from both the PRH and Brighton areas. |
| Concerns were raised about the transfer of medical records to the right hospital. | Both PRH and RSCH are part of BSUH and share the same patient record systems. Letters and discharge summaries are stored digitally and can be accessed by clinicians at both sites as appropriate. |
| It was queried whether the change took into account stroke services at other hospitals and any potential changes to these other services. | The stroke review has worked closely with neighbouring stroke services to ensure that the recommendation has considered the impact on other services. The clinically-led central Sussex stroke programme board have agreed that, regardless of any wider changes considered elsewhere, the best location for patients (delivering the highest quality of care and best outcomes) is at RSCH. The CCGs continue to be involved in decisions about the location of stroke services in surrounding areas. |

## Suggestions to minimise potential consequences

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| The majority of suggestions that were made focused on making things easier for visitors to RSCH, including further improving parking facilities, reducing parking costs (and keeping appointments to time to minimise parking costs) and improving bus services. | The RSCH car park is now exclusively for the use of patients and relatives, increasing the number of spaces available for these visitors.<br><br>Building work is already underway to completely modernise the RSCH site and includes new underground car parks which will offer 390 more spaces for patients and visitors that there are now.<br><br>There are good public transport links to RSCH, the 40X bus runs between PRH and RSCH, there are regular mainline train services into Brighton from Haywards Heath and elsewhere, with regular bus services stopping directly outside the hospital. |
| It was suggested that more support might be available from the voluntary sector to help people with travel to RSCH. | We have identified a number of voluntary organisations that provide support for people who need help with transport for hospital appointments or visiting relatives in hospital. BSUH will include details of these organisations in the carers pack that they are preparing. |

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| Several people wanted to see improvements to make it easier for people with mobility problems to access and navigate the RSCH site and problems with the lifts were mentioned several times. | Building work is already underway to completely modernise the RSCH site, which will address many of these issues. There will be direct access by lift from the car park to the reception of the building which will contain the new stroke unit, due to open in 2020, then a lift from the reception to the floor housing the new stroke unit.<br><br>In the meantime, the stroke unit has improved signage and is easily accessed on the third floor of the Barry Building. The building is accessed via a short ramp with a direct lift to the third floor, with the stroke unit immediately on the left.<br><br>The recent technical faults with the public lifts in the Barry Building have now been rectified. |
| Several people wanted to see services as local as possible, queried whether some stroke services could be available at other locations, and wanted assurances that patients would be taken to other acute stroke units if they were nearer. | The ambulance will always take the patient to the nearest specialist stroke unit. This could include Eastbourne, Worthing, Redhill and Tunbridge Wells.<br><br>The centralisation of expertise in a larger acute stroke unit is shown to lead to improved outcomes for patients, which is why they cannot be available at every hospital. When 32 stroke units were consolidated into eight in London, fewer people died and more people recovered sooner. (There was a 17% reduction in the number of people who died within one month and a 7% reduction in the amount of time stroke patients needed to stay in hospital before they were well enough to go home.) |
| It was asked whether outpatient follow up appointments could be held at Horsham Hospital if that was more convenient. | BSUH is not currently commissioned to provide outpatients appointments at Horsham Hospital. However, it might be feasible for commissioners to explore this idea, particularly for stroke patients who receive their acute care at East Surrey Hospital in Redhill. |
| One person asked whether paramedics could give clot-busting treatments for stroke patients en-route to hospital. | A CT scan needs to carried out and the results interpreted by a stroke specialist to determine whether thrombolysis is safe for the patient before clot-busting drugs can be administered. It is not possible to do this in the ambulance. |

## Suggestions for improving discharge

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| There were several suggestions that more information could be provided at discharge on what will happen next, who to call in the event of any concerns, and on the support groups available, both for patients and carers. A common theme was that carers should be fully involved and need particular support at the time of discharge, as well as the patient. | All stroke patients are given a patient handbook with useful information about their care and treatment. It includes a specific section that is completed with patients and carers at discharge, which includes specific contact names and telephone numbers. The booklet also lists the contact details for various support groups and other services.<br><br>The BSUH stroke patient support group will be asked to help keep the patient handbook under regular review and are helping to prepare a specific information pack for carers.<br><br>After discharge, patients and carers are also invited to one of the regular patient group meetings with the stroke team. These are an opportunity to ask any questions and offer feedback to help improve services. |
| There were calls for greater coordination with (and availability of) other health and social care services. | The CCGs and local authorities are working very closely to increase support from health and social care services in the community. The availability of social care is a national challenge and locally we continue to work to improve supported discharge, including the provision of social care.<br><br>As we further develop the rehabilitation aspects of the stoke pathway, we will explore the possibility of specific roles in the community team to help coordinate care for patients as they prepare for discharge. |
| One respondent said assessments for support needs should be carried out in-house, prior to discharge. | An assessment for support needs is completed in-house, but this can be further enhanced with the higher number of allied health professionals on hand with a centralised team. Home visits - either access visits with families or home visits to patients and families - are undertaken where appropriate.<br><br>As part of the work to develop the rehabilitation pathway, we will consider the potential for in-reach into stroke units from the community stroke rehabilitation team. |
| The point was raised that not all people recover from a stroke and palliative care should be part of the service. | We agree. The BSUH stroke team work closely with specialist palliative care colleagues in BSUH, Sussex Community NHS Foundation Trust and hospices. |

## Suggestions for improving rehabilitation

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| There was a common desire to see more and better rehabilitation, with therapy starting as soon as possible. | The speed with which therapy starts is one of the key standards against which stroke services are measured. Centralising the stroke service at RSCH means that there will be a larger team of therapists on hand, and the changes mean that BSUH will be able to recruit additional therapists, so patients will get more therapy more quickly.<br><br>Once patients are discharged, a detailed assessment takes place with the patient and their carer, building on the discharge information from the hospital, to ensure a patient-centred rehabilitation programme commences as soon as possible.<br><br>We will explore the possibility of rotation for therapists across the community and acute teams to support more joined-up services and greater continuity of rehabilitation for patients. |
| It was asked whether enough specialist rehabilitation staff, especially speech and language therapists, were available to deliver the improvements that were hoped for. | It is correct that there is a national shortage of speech and language therapists. We believe from our experience at BSUH, and from the findings of the stroke review in London, that these posts will be more attractive centralised into a one larger service at RSCH, which will increase our chances of recruiting to them all. |
| People wanted to see a focus on community therapies to help people to live well after a stroke. | We are developing early supported discharge teams to deliver therapy in patient's homes, along with social care support as required. The aim is to promote patient reablement and independence after stroke.<br><br>A key component of existing community stroke rehabilitation teams is the focus on prevention of future strokes, so advice regarding lifestyle, weight, smoking and drinking is offered to all patients. |
| It was stressed by several that rehabilitation should continue for as long as it is needed, not just what is delivered as part of early supported discharge. | The latest Royal College of Physicians stroke guidance also supports rehabilitation for as long as it is needed. As such we are working with our stroke rehabilitation service to provide this.<br><br>Rehabilitation is provided for as long as required within the community stroke rehabilitation service. However, at present, the joint community rehabilitation team covering High Weald and stroke interventions are time limited. This is being reviewed with a view to extending provision across the locality and ensuring it is based on need, rather than a fixed period of time. |

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| Some thought it important that patients know how much therapy they should expect. They queried whether access to therapy was equitable and whether all patients are aware of what they are entitled to. | All patients have different therapy and rehabilitation needs. The national guidance for stroke recommends 45 minutes of appropriate therapy per day for as long as it provides benefit. We work with our stroke care services to ensure all patients are aware of the rehabilitation options available. Therapy is tailored by the rehabilitation team to the individual patient's needs in discussion with the patient and their family/carers and takes into account medical conditions and stability at the time and ability to tolerate therapy, which includes fatigue and mood. This is then reviewed at regular intervals and adjustments are made when required based on patient need regarding both the frequency and intensity of therapy input. |
| It was suggested that stroke rehabilitation should have the same emphasis as other illnesses, for example the services provided by Macmillan nurses. The cardiac rehabilitation service was also cited as a good example. | High quality rehabilitation is fundamental to improving wellbeing after stroke. By centralising care at RSCH we hope to improve patients' access to specialist therapists in the early stages after their stroke. In addition, we are working on improving access to home-based rehabilitation with our early supported discharge teams. We are also working with our specialist inpatient rehabilitation teams to ensure they can continue to provide high quality rehabilitation.<br><br>The BSUH stroke team have learnt a lot from the cardiac rehabilitation team and are using this learning to strengthen stroke services. |
| It was thought that regular reviews, involving family or carers, were needed. | Stroke patients normally receive an initial outpatient follow up appointment within 4-8 weeks of discharge and we encourage family/carers to attend these appointments with them. Six-month follow up appointments for BSUH patients are also made by the stroke rehabilitation team.<br><br>In East Sussex, six-month reviews are currently carried out by the Stroke Association. Crawley, Horsham and Mid Sussex and Brighton and Hove CCGs are planning to commission six-month reviews as part of their work on supported discharge in collaboration with Sussex Community NHS Foundation Trust and the Stroke Association.<br><br>All CCGs, therefore, recognise the importance of assessing the longer-term impact of a stroke. |

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| It was asked whether patients receive mental health screening and it was suggested that counselling should be offered to both patients and carers. | All stroke patients are screened for cognition and depression and anxiety during their inpatient stay.<br><br>Clinical psychology services are currently available at the Sussex Rehabilitation Centre and a variety of counselling services are available in the community. For example, the Time to Talk service offers good access to psychological services across the area, including for people with long-term conditions like stroke.<br><br>We will explore what further support might be made available from other services or commissioned from the voluntary and community sector. |
| One respondent thought that inpatient stroke rehabilitation should be provided on a dedicated ward. | Evidence shows that the majority of stroke patients have the best outcomes when they receive rehabilitation in their own home. However, some stroke patients will have complex disabilities after stroke and they will receive what is called 'level 2' rehabilitation in the dedicated inpatient stroke rehabilitation unit in the Sussex Rehabilitation Centre at PRH. Other patients will not have complex needs, but will require further hospital care before they are well enough to return home. They will continue to be receive inpatient rehabilitation in local community beds, for example at Crawley Hospital, delivered by appropriately trained nurses, supported by specialist stroke therapists from our community responsive service team. |

## Suggestions for improving prevention

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| Many people mentioned the 'FAST' campaign. It was well received and many thought it should be continued and promoted as widely as possible. | Public Health England resumed the FAST campaign on 2 February 2016. The CCGs locally are supporting the campaign and using the opportunity to deliver key prevention and awareness messages through a range of channels. |
| Several people also mentioned greater promotion of prevention messages in primary care. | Health promotion campaigns such as 'FAST' are supported through primary care. In addition, the CCGs all have projects underway to support the early identification of patients at risk of developing stroke, ensuring they receive information about preventing stroke and are on the right preventative medication where appropriate. |

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| Public services could set a better example, for example through their staff and the food and drink they sell on their premises, and by making school gym facilities available for the wider public to use. Schools could also play a greater role in promoting stroke prevention messages to children. | As recognised by many respondents, improving public health requires a joined-up approach across all agencies and public services. CCGs work very closely with local authority public health teams to improve the health and wellbeing of their local populations.<br><br>In Brighton and Hove, for example, Sugar Smart is a joint initiative that looks at what we can all do at home, in schools, shops, restaurants and cafes to tackle excess sugar in our diet in order to reduce diabetes – a key risk factor for stroke.<br><br>Reducing childhood obesity is a priority, and public health teams commission a number of initiatives for this, such as Family Shape Up. The Active for Life initiative also offers a variety of programmes and sports development opportunities for people of all ages and abilities and health trainers can offer 1:1 support and advice. |
| Patients could be better supported to make a choice about which atrial fibrillation medication is preferable for them. | All the CCGs take the management of atrial fibrillation very seriously. Projects to both identify patients with AF, and to ensure correct medication use, are part of our GP contracts. In addition we have carried out specific work to support GPs to help patients make an informed choice.<br><br>Brighton and Hove CCG have commissioned a number of community schemes such as hypertension and atrial fibrillation clinics. These are run by specialist pharmacists who invite patients to discuss the options for preventing stroke related to atrial fibrillation and offer a patient-centred approach to decision making. |

## Contributors

The following have contributed to the responses in this document:

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