

Report to: **East Sussex Health Overview and Scrutiny Committee (HOSC)**

Date: **19th March 2009**

By: **Chairman of the Review Board**

Title of report: **Review of Stroke Care in East Sussex – Final Report**

Purpose of report: **To present the final report of the Review Board and request the committee's support for the recommendations**

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## **RECOMMENDATIONS**

### **HOSC is recommended:**

- 1. To welcome and endorse the report of the Review Board on Stroke Care in East Sussex.**
  - 2. To agree that responses to the recommendations should be requested from the organisations named in the report, for consideration at the HOSC meeting in July 2009.**
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## **1. Background**

1.1 In June 2008 HOSC established a Review Board to examine stroke care for East Sussex residents. This topic had been identified as a priority for review by the committee at a work planning seminar.

1.2 Councillors Davies, Healy, Martin and Rogers were nominated to form the Review Board. The Board subsequently agreed to invite co-opted representatives from the County Council's Adult Social Care Scrutiny Committee and the East Sussex Primary Care Trusts' (PCTs) non-executive directors to join the Board. It was felt that these perspectives would add to the review process and help ensure that these groups would gain increased awareness of stroke care issues and the developments required. Councillor Forster from the Adult Social Care Scrutiny Committee and John Barnes, Chairman of East Sussex Downs and Weald PCT therefore completed the Board's membership.

## **2. Objectives and scope of the review**

2.1 The objective of the review was to assess and make recommendations on the stroke care provided to East Sussex residents, with particular focus on awareness and prevention, provision of acute services and the integrated provision of rehabilitation and long-term support.

2.2 To achieve this the review intended to:

- Research public and professional awareness of stroke prevention and care;
- Seek the views of patients, carers and professionals in relation to current stroke services and their views on how services can be improved;
- Examine how stroke services in East Sussex compare to regional and national best practice and;
- Research stroke prevalence and outcomes data for East Sussex, with particular reference to identifying areas of health inequality.

2.3 The Review Board met seven times between August 2008 and February 2009 and interviewed a wide variety of witnesses from health, social care and voluntary sector organisations

at these meetings. In addition, the Board visited stroke units at hospitals in Eastbourne, Hastings and Brighton and a rehabilitation unit at Bexhill Hospital.

2.4 In order to obtain views from patients and carers the Board held a patient and carer workshop (jointly with the PCTs) and publicised the review widely, prompting 35 people to contact the Board with their experiences. In order to research the public's awareness of stroke the Board undertook a survey of 1159 members of the public via the County Council's residents' panel.

### **3. Findings and recommendations**

3.1 The Review Board's findings and recommendations are outlined in the report attached at appendix 1.

3.2 Overall, the Review Board is encouraged by recent progress in stroke care. However, the Board has heard directly from patients and carers that their experiences of care are inconsistent, and there are gaps in services and services that are stretched to capacity. Rehabilitation, in particular, requires priority attention to ensure a consistent county-wide approach, offering a range of options to cater for the widely varying needs of stroke patients.

3.3 The elderly profile of the East Sussex population demands that stroke care is treated as a priority and that the county should be at the forefront of best practice. The Board is concerned that previous reviews of stroke care have not produced sufficient change, but encouraged that there is now momentum, both nationally and locally.

COUNCILLOR ANGHARAD DAVIES  
Chairman of the Review Board

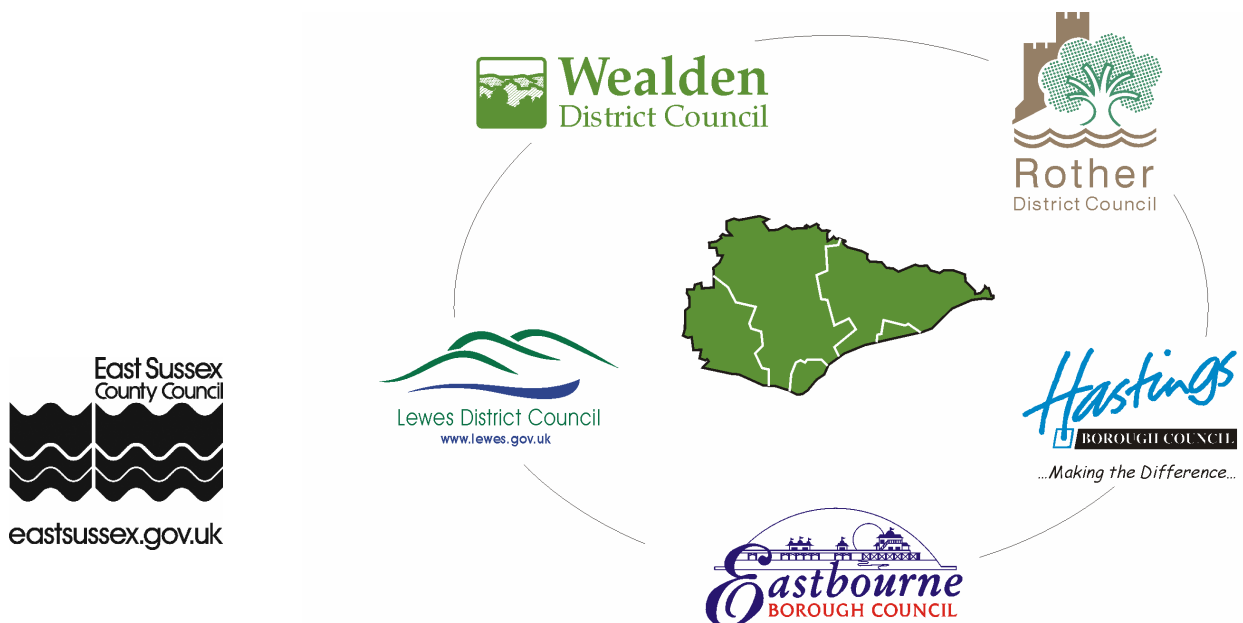
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# East Sussex Health Overview and Scrutiny Committee



## Review of Stroke Care in East Sussex

March 2009



## Preface

Stroke has been a 'Cinderella' specialty for too long, a somewhat overlooked and misunderstood condition, but there are now treatments and strategies which can bring about real improvements for patients. Reduction in the incidence and impact of stroke can be achieved through creating widespread awareness and promoting changes in lifestyle which can prevent stroke.



The Health Overview and Scrutiny Committee's role, as a group of councillors representing local people, is to examine the care available from the viewpoint of patients and carers, whilst appreciating the problems faced by health and social care professionals. We have investigated, from a lay perspective, people's experiences of stroke care, the services currently available, and questioned how these can be improved.

In our report we make recommendations on what the evidence suggests are the most important areas for development. We will submit these to health and social care bodies, ask for their response and monitor progress.

We have a very high proportion of elderly people in East Sussex compared to other counties. Stroke is a common problem and there are many people who can be helped. East Sussex is emerging as a leader in stroke care and the Board has seen examples of innovative practice which should be built upon and extended.

We want to convey our thanks to the many patients and carers who shared their personal experience with us, the 1159 members of the public who completed our survey on stroke awareness, and the numerous health, social care and voluntary sector professionals who discussed the services they provide.

I am grateful to the members of the Review Board who devoted a great deal of time to interviewing witnesses, visiting local hospitals and preparing this report.

We are pleased that the profile of stroke care is being raised, with new treatments being made available, and trust that the commissioners will act on our recommendations to bridge the gaps in care.

A handwritten signature in black ink, appearing to read 'Angharad Davies', written over a light blue horizontal line.

### **Councillor Angharad Davies**

Health Overview and Scrutiny Committee (HOSC)

### **Review Board**

Councillor Angharad Davies (Chairman)

Councillor Beryl Healy

Councillor Eve Martin

Councillor David Rogers

Councillor Martyn Forster (co-optee – Adult Social Care Scrutiny Committee)

John Barnes (co-optee, East Sussex Primary Care Trusts' Non-Executive Directors)

The report of the Health Overview and Scrutiny Committee (HOSC) Review of Stroke Care

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# Executive Summary

## 1. Introduction

A stroke is caused by an interruption to the normal blood supply to the brain. This can occur because a clot blocks a blood vessel, or because a vessel in the brain bursts. Because it destroys brain cells, a stroke can leave lasting damage, affecting mobility, cognition, sight or communication.

Nationally, stroke is the third most common cause of death and the single largest cause of adult disability. In East Sussex, in 2006/7, 1370 people were admitted to hospital as a result of a stroke and GP practice data showed that 11,088 people in East Sussex were registered as having had a stroke or TIA at some time and therefore living with the after-effects.

In 2007, the Department of Health published a National Stroke Strategy which set out a framework of 20 quality markers for raising the quality of stroke prevention, treatment, care and support over the next decade. This strategy has given stroke national priority and it is supported by a public awareness campaign which began in February 2009. Local NHS organisations are expected to work towards implementing these quality markers in the context of local strategies and services.

## 2. Objective of this review

The objective of this review was to assess and make recommendations on the stroke care provided to East Sussex residents, with particular focus on awareness and prevention, provision of acute services and the integrated provision of rehabilitation and long-term support.

The review was undertaken in parallel with the development of a local stroke strategy by East Sussex Primary Care Trusts (PCTs). The HOSC Review Board considered the strategy recommendations prior to their agreement (in January 2009) to ensure they were in line with the review findings to date. The HOSC review aims to influence the action plan and the prioritisation of recommendations arising from this strategy.

## 3. Review Findings

### ***a) Awareness and prevention of stroke***

A survey of 1159 East Sussex residents showed that there is scope for improving people's awareness of stroke, particularly amongst the oldest age groups, and that people are interested in knowing more about stroke, in terms of reducing their risk, recognising a stroke and taking action. The results also highlight the central role of GPs in prevention as many people prefer to receive information from their local surgery and feel that GPs' advice would be most influential.

Feedback from patients indicates that many did not realise they were having a stroke and they did not always call 999 for an emergency response. Their experiences also demonstrate some variability in response to stroke symptoms by GPs.

The Review Board identified that there remains a need to ensure that all strokes are recognised and treated with the same degree of urgency as, say, heart attacks and that more training and awareness raising amongst front-line health and social care staff is required.

Feedback from patients and carers also highlights a high degree of inconsistency in the follow-up care received by people who have had a stroke. GPs also highlighted that follow-up care for stroke is not as well defined and robust as for other conditions such as heart attack and diabetes. The Board concluded that the maintenance of robust risk registers and a clearly defined pathway for follow up care are essential to effective prevention.

### ***b) Acute care***

The Board found that significant progress has been made recently, notably the establishment of specialist stroke units in each local hospital and the limited introduction of thrombolysis (clot-

busting drugs) treatment, with associated improvements in access to scanning. There is also evidence of the beginnings of a cultural change in relation to stroke care, with increased urgency and increased optimism about patient outcomes.

However, it is apparent to the Board that there is still some way to go to fully implement the National Stroke Strategy quality standards and that the pace of change must speed up. The Board is, in general, impressed by the care which can be offered by local stroke units, but concerned that this level of care is not experienced by all patients on a consistent basis. There are several key issues:

- Differing availability of care within normal working hours compared to 'out of hours'
- Staffing shortages – particularly certain therapy staff
- Capacity in stroke units – which can result in patients being cared for on other wards
- Variable access to community rehabilitation – which can have a knock on effect to the acute stroke units

These, and other, factors mean that one patient can have an excellent experience and another a poor experience within the same hospital, depending on when they arrive and the pressures at the time.

The Review Board is concerned by the *extent* of this inconsistency and believes the aim should be to achieve a 24/7 consistent standard of acute care. The Board believes it is necessary to take a whole pathway approach to developing round the clock stroke services and that effort directed to extending the use of thrombolysis should be proportionate, bearing in mind that it will only be suitable for a small proportion of patients.

The review also highlights the need to expand scanning capacity and the need for hospitals to proactively 'pull' stroke patients into the stroke unit so that they receive specialist help as quickly as possible.

### **c) Rehabilitation and long term care**

#### ***Inpatient rehabilitation***

Specialist community inpatient rehabilitation services are limited, although what is available appears to work well. There are waits to get patients into the available units and difficulty catering for patients requiring lengthy periods of rehabilitation.

The main issue with inpatient rehabilitation is a lack of capacity which has impact on patients in a number of ways, including patients receiving generic (rather than specialist) care and patients with complex needs being transferred earlier to the care of community rehabilitation teams whose caseload becomes unmanageable. The Board has concluded that there are clear gaps in the availability of specialist inpatient rehabilitation for stroke patients, particularly in the Eastbourne area and in the north of the county.

#### ***Community rehabilitation***

The Board is concerned about the inconsistency of community rehabilitation available to stroke patients in different parts of the county. In particular, the absence of a specialist stroke team in the north of the county should be addressed urgently as it represents a real inequity in provision. The differing models of community rehabilitation in different parts of the county also have the potential for inequity or confusion and a consistent approach is needed.

The limited availability of community rehabilitation is having an impact on patients, carers and staff in a number of ways:

- Waiting lists create gaps in care when patients leave hospital which can result in deterioration.
- Teams are not able to provide the intensity of rehabilitation needed for optimum outcomes.
- Some patients receive rehabilitation for too short a time to make any real progress.

Not only does this affect health and quality of life for both patient and carer, investment in rehabilitation would also be cost-effective in the longer-term. It can reduce a patient's

dependence, thus saving on future ongoing care needs and may prevent re-admission to hospital.

The Board noted the complete lack of specialist psychological input to the rehabilitation process, despite the significant emotional impact of stroke described by patients and carers, and the fact that psychological support may be needed for some patients to engage effectively with rehabilitation.

### ***Long term care***

Post-discharge, problems may arise if a patient experiences a deterioration or crisis and needs rapid additional support from community health services and/or social care. Patients and carers are unclear on what to do in this situation and may end up calling 999 or a GP, which can result in readmission to hospital.

Patients and carers face some difficulties in accessing information and support. A contact point of some kind, such as a direct line to a specialist stroke nurse for patients and carers with specific concerns, could help prevent the escalation of problems and could be a lifeline.

The support provided through the voluntary sector is welcome, particularly once patients have completed the period of formal rehabilitation care. However, the PCTs and Adult Social Care should work together to ensure that these services, or any future variation on them, are commissioned on a county wide basis to ensure equity.

For stroke survivors with significant ongoing impairment, the process of organising or co-ordinating support can often fall heavily on carers. This means there is a risk that people without a carer may lose out and a process is needed which ensures that all stroke patients are identified and assisted to access the support available.

### **Conclusions**

The Review Board is encouraged by recent progress in stroke care. However, the Board has heard directly from patients and carers that their experiences of care are inconsistent, and there are gaps in services and services that are stretched to capacity. Rehabilitation, in particular, requires priority attention to ensure a consistent county-wide approach, offering a range of options to cater for the widely varying needs of stroke patients.

The elderly profile of the East Sussex population demands that stroke care is treated as a priority and that the county should be at the forefront of best practice. The Board is concerned that previous reviews of stroke care have not produced sufficient change, but encouraged that there is now momentum, both nationally and locally.



## Recommendations

	Recommendation	To	Page
1	<p><b>The public need to be more aware of:</b></p> <ul style="list-style-type: none"> <li><b>a) the causes of stroke and what the public can do to reduce risk.</b></li> <li><b>b) the symptoms of stroke and that calling 999 is the normal action to take on suspecting a stroke.</b></li> </ul> <p><b>The national awareness campaign is welcome but must be complemented by local, targeted work co-ordinated by the PCTs and involving a range of local agencies (e.g. Older People's Partnership Board). The findings from the awareness survey should be used to inform this work.</b></p>	East Sussex Primary Care Trusts (PCTs) and partners	19
2	<p><b>GPs and other front line health and social care professionals need to be more effective at recognising stroke and ensuring an emergency response. It is recommended that the PCTs and Adult Social Care consider ways to increase awareness and training for community and primary care staff and ensure that clear protocols are available and followed.</b></p>	East Sussex PCTs  GPs  Adult Social Care	19
3	<p><b>A robust pathway for follow-up care/secondary prevention should be put in place to ensure that all stroke and TIA patients receive regular checks, information and advice in line with National Stroke Strategy standards. This should include the maintenance of robust and consistent registers of stroke and TIA patients at all GP practices.</b></p>	East Sussex PCTs  GPs	19
4	<p><b>A mechanism should be put in place to identify those at higher risk of stroke on practice based 'at risk' registers to ensure regular health checks and preventative medicine.</b></p>	East Sussex PCTs  GPs	19
5	<p><b>When moving towards 24 hour acute stroke services, progressing the full range of specialist care is essential. This should include, but not be dominated by, 24 hour access to thrombolysis, as thrombolysis will only be appropriate for around 10% of patients.</b></p>	Sussex Stroke Network  East Sussex PCTs  Hospital Trusts	23
6	<p><b>The PCTs should commission for the provision of all diagnostic investigations for stroke patients to National Stroke Strategy standards well ahead of the Strategy's 10 year timescale. Patients (and carers as appropriate) should be informed of the outcomes in a way they can understand.</b></p>	East Sussex PCTs  Hospital Trusts	23
7	<p><b>All stroke patients' discharge from hospital should be managed by the multi-specialist stroke unit team. There should be a protocol in place to ensure this happens even if, in exceptional circumstances, a patient is on another ward prior to discharge, so that they have the same access to community stroke services as patients discharged from the stroke unit.</b></p>	Hospital Trusts	23

8	<b>Rapid access to the specialist stroke team is crucial. Acute Trusts should have strategies in place to proactively ‘pull’ stroke patients into their stroke units. Ideally, there should be a dedicated A&amp;E bay for stroke, a stroke co-ordinator monitoring admissions to ensure they reach the stroke team and all stroke patients should be allocated to a stroke specialist consultant who will oversee their care.</b>	Hospital Trusts	24
9	<b>Urgent action should be taken to remedy all staffing shortages and to bring staffing standards up to National Stroke Strategy guidelines.</b>	East Sussex PCTs Hospital Trusts	24
10	<b>Patients should have access to a phased process of rehabilitation, including availability of inpatient rehabilitation between the acute and community care settings. The PCTs should commission additional and improved community inpatient rehabilitation. This should support consistent access and standards across East Sussex, based on analysis of need.</b>	East Sussex PCTs	27
11	<b>There must be options available for longer-term rehabilitation. A pathway for patients requiring ‘slow-stream’ rehabilitation should be developed, supported by appropriate bed provision based on needs analysis.</b>	East Sussex PCTs	27
12	<b>The Sussex Stroke Network should consider the provision of a Sussex-wide service for young stroke survivors and those needing specialist rehabilitation. Longer travel times may be necessary for such specialist care but the need to travel outside Sussex should be avoided.</b>	Sussex Stroke Network	27
13	<b>The debate on whether stroke or neurological community rehabilitation team models are best practice should be resolved. A consistent patient pathway and model of community rehabilitation for stroke patients should then be introduced across East Sussex. Priority should be given to the north of the county which currently has no specialist service. Additional resources will be required to enable existing teams to meet demand, to expand their remit if appropriate, and to establish a team in the north.</b>	East Sussex PCTs	30
14	<b>Community neuro-psychologist/psychological counsellor roles should be developed to provide rapid response to referrals from community teams and inpatient units.</b>	East Sussex PCTs	30
15	<b>A county-wide approach is needed to cope with deterioration or crises. This should incorporate clear information for patients and carers on what to do and availability of rapid response, short-term, nursing and social care.</b>	East Sussex PCTs Adult Social Care	33

16	<b>On returning home or to residential care, patients and carers should have access to a single contact point (a 'helpline') for questions or concerns about their condition or care. This must be available on an ongoing basis, not just while receiving rehabilitation, and advice should be available from specialist, qualified staff.</b>	East Sussex PCTs	33
17	<b>Support commissioned from the voluntary sector should be on a county-wide basis, and ensure that <i>all</i> stroke patients are identified and assisted to access support if required.</b>	East Sussex PCTs Adult Social Care	33
18	<b>The Health Overview and Scrutiny Committee should develop a plan to ensure the findings of this review are shared widely with key groups in East Sussex.</b>	Health Overview and Scrutiny Committee	34
19	<b>Mechanisms should be established to ensure the ongoing active involvement of patients and carers in the implementation and evaluation of the stroke strategy. The Health Overview and Scrutiny Committee should indicate its willingness to participate in this process.</b>	East Sussex PCTs Health Overview and Scrutiny Committee	34
20	<b>The Health Overview and Scrutiny Committee should monitor progress against the recommendations in this report, and wider aspects of the PCTs' stroke strategy in 6, 12 and 18 months from its publication. The Committee should make use of the South East Coast stroke dashboard as part of this monitoring.</b>	Health Overview and Scrutiny Committee	34

# 1. Introduction

## ***What is a stroke?***

1. A stroke is caused by an interruption to the normal blood supply to the brain. This can occur because a clot blocks a blood vessel, or because a vessel in the brain bursts. Because it destroys brain cells, a stroke can leave lasting damage, affecting mobility, cognition, sight or communication. A transient ischaemic attack (TIA) is defined as stroke symptoms and signs that resolve themselves within 24 hours. Stroke and TIA are potentially preventable and treatable conditions.
2. Strokes can occur at any age but are much more common amongst older age groups. A quarter of strokes occur in people aged under 65. Risk factors for stroke link with lifestyle: poor diet, smoking, physical inactivity, excessive alcohol intake, obesity and high blood pressure. These tend to be found in association with socio-economic deprivation.
3. Strokes usually occur without warning and symptoms commonly include weakness or paralysis of the face or limbs and problems with speech or communication.
4. Rapid emergency treatment of stroke can improve a patient's outcome and individual recovery can be enhanced through specialist rehabilitation and wider social support.

## ***Prevalence of stroke***

5. Nationally, every year, approximately 110,000 people have a stroke and around 150,000 people have a suspected TIA. Of those who have a stroke, a quarter of people will die immediately or within a few days. However, more than half of stroke survivors will have resolution of most or all of their symptoms. Stroke is the third most common cause of death: 11 per cent of all deaths are the result of stroke.
6. Stroke is also the single largest cause of adult disability: there are over 900,000 stroke survivors living in England, and 300,000 people live with moderate to severe disability as a result of stroke.
7. Hospital in-patient data in East Sussex for Stroke and TIA during 2006 – 2007 shows the number of admissions recorded as strokes / TIAs as below. (N.B. this will not include patients who only went to outpatients / Accident & Emergency and were not admitted):

	<b>East Sussex Downs and Weald Primary Care Trust area</b>	<b>Hastings and Rother Primary Care Trust area</b>
Number of Strokes	752	618
Number of TIAs	183	66

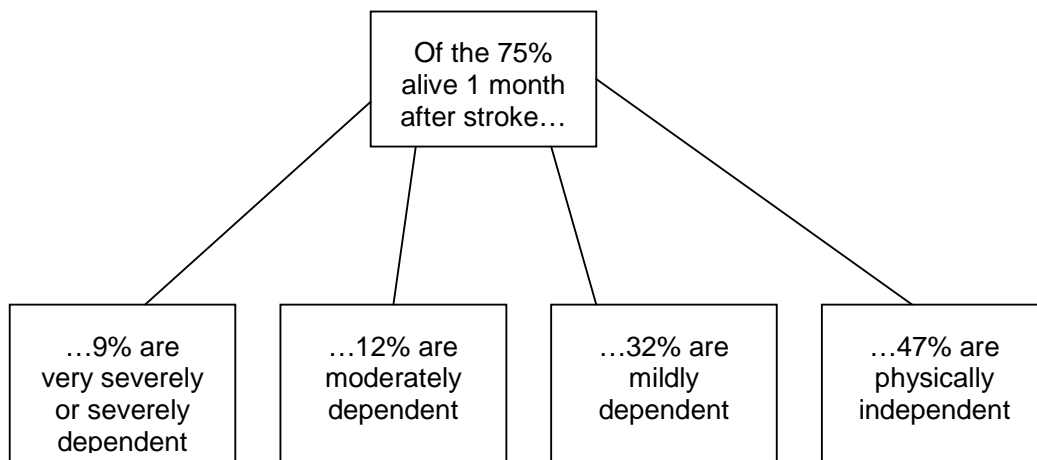
8. GP practice data for 2006/7 shows that in total 11,088 people in East Sussex were registered as having had a stroke or TIA at some time and are therefore living with the after-effects. That equates to 21.3 people per 1000 of population. The rate is noticeably higher in Rother (26.6), and lower in Hastings (16.2) which reflects the relatively older and younger than average populations respectively in these districts. The rate of stroke in East Sussex is higher than the rates for South East Coast area and England, the older than average population in the county being a key factor.
9. When standardised for age, it is noticeable that Hastings exceeds the national mortality rate for stroke in both males and females, whereas other districts are below the national rate.

10. Elderly people make up a significant percentage of the population in East Sussex, with one in four residents being over pensionable age. The county has the highest percentage of very elderly residents of any county in England (over 75s, over 85s and over 90 years old). Population projections show that future population growth will be heavily concentrated among people in older age groups (50+). Given the link between stroke and age, these figures demonstrate the importance of stroke care for East Sussex now and in the future.

11. The number of deaths from stroke appears to have reduced overall in recent years, as treatment has improved. However, the number of strokes occurring is expected to increase as the population ages and the number of expected hospital admissions will increase accordingly. This increase can be mitigated to a certain extent by improved preventative measures.

12. Research on outcomes for stroke patients suggests that there will be varying degrees of dependency amongst patients who survive a stroke as illustrated below:

#### Flowchart of stroke disability in East Sussex



Source: Adapted from 'Older people in East Sussex: an epidemiological needs assessment', NHS Public Health Resource Unit

13. Analysis undertaken by East Sussex PCTs shows that 322 strokes could be prevented each year if four key preventative measures were undertaken (e.g. improved management of blood pressure and prescribing of medication to reduce cholesterol). Further analysis shows that improved outcomes could be achieved if a range of hospital based improvements were made. Measures such as optimum use of stroke units, thrombolysis (clot-busting drugs), TIA clinics and early supported discharge could achieve outcomes such as stroke prevention following TIA, stroke survival or reduced disability for around 150 East Sussex patients each year.

### Stroke Care

14. Stroke care covers a wide spectrum from prevention to long-term care as is illustrated by the diagram below.

## Aspects of a network of stroke care

**Co-ordination: an overarching stroke network**

Prevention	Symptoms	Diagnosis	Treatment	Rehabilitation	Long term care
<p>Lifestyle:</p> <ul style="list-style-type: none"> <li>▪ Diet</li> <li>▪ Exercise</li> <li>▪ Smoking</li> <li>▪ Alcohol</li> </ul> <p>GP risk registers</p> <p>Statins/aspirin prescribing</p> <p>Treating high blood pressure</p> <p>TIA clinics</p> <p>Follow-up care/ secondary prevention</p> <p>Screening (currently available privately)</p>	<p>'FAST' test</p> <p>Public and professional awareness of stroke symptoms</p> <p>Awareness of stroke as an emergency</p> <p>Awareness of TIA symptoms and need for rapid assessment</p> <p>Clear stroke and TIA pathways</p>	<p>Effective diagnosis by health professionals e.g. GPs, Accident &amp; Emergency</p> <p>Ambulance Trust role</p> <p>Access to specialist stroke unit</p> <p>Rapid, 24/7 access to scans</p> <p>Multi-disciplinary assessment</p>	<p>Establishing a consistent 24/7 service</p> <p>Access to thrombolysis</p> <p>Access to specialist stroke unit with specialist stroke-trained staff</p> <p>Access to therapy services</p> <p>Information, advice and support</p> <p>Involvement of patients &amp; carers</p>	<p>Early access to therapy services</p> <p>Multi-disciplinary assessment</p> <p>Discharge planning</p> <p>Access to inpatient and community based specialist rehabilitation services</p> <p>Emotional support</p> <p>Support for carers</p>	<p>Information, advice &amp; support</p> <p>Regular review</p> <p>Links to Adult Social Care</p> <p>End of life care</p> <p>Carers support</p> <p>Supporting participation in community activities &amp; work</p> <p>Prevention of further stroke</p>

## ***Targets and performance indicators***

15. In 2007, the Department of Health published a National Stroke Strategy which set out a framework of 20 quality markers for raising the quality of stroke prevention, treatment, care and support over the next decade. Local NHS organisations are expected to work towards implementing these quality markers in the context of local strategies and services.

16. Other key national guidance which must be taken into account includes the National Service Frameworks (NSFs) for Older People and Long Term Neurological Conditions and clinical guidelines from the National Institute for Health and Clinical Excellence (NICE).

17. Locally, the East Sussex Local Area Agreement includes an 'all age, all cause mortality rate' indicator, with specific targets for reducing the mortality rate for males and females. This target includes mortality from stroke but also a whole range of other conditions.

18. Within East Sussex Primary Care Trusts' (PCTs') commissioning plans, specific targets have been set to reduce cardiovascular disease mortality by 40% in the under 75 age group. In addition, a 'Vital Signs' target requires approximately a 20% reduction from latest figures by 2011 in each PCT.

19. In January 2009 the PCTs agreed an East Sussex Stroke Strategy which outlined a three year plan for improving stroke services in order to deliver the local vision which is:

*"The delivery of world class, co-ordinated, consistent and high quality stroke services across the whole care pathway, which reflect and adhere to the best practice recommendations of the National Stroke Strategy, the NICE stroke and TIA guideline and the National Service Framework for Long Term Conditions."*

20. The strategy is to be taken forward through the development of a detailed action plan specifying key deliverables and timescales. The HOSC Review Board considered the strategy recommendations prior to their agreement (in January 2009) to ensure they were in line with the Review findings to date. The HOSC review aims to influence the action plan and the prioritisation of recommendations arising from this strategy.

## 2. Objectives and scope of the review

21. **The objective of this review was to assess and make recommendations on the stroke care provided to East Sussex residents, with particular focus on awareness and prevention, provision of acute services and the integrated provision of rehabilitation and long-term support.**

22. To achieve this the review intended to:

- Research public and professional awareness of stroke prevention and care;
- Seek the views of patients, carers and professionals in relation to current stroke services and their views on how services can be improved;
- Examine how stroke services in East Sussex compare to regional and national best practice and;
- Research stroke prevalence and outcomes data for East Sussex, with particular reference to identifying areas of health inequality.

23. The Review Board decided to focus primarily on care for people who have experienced a 'full' stroke as opposed to a TIA. This was because significant work had already been undertaken, or is in progress, on improving care for TIA patients and a new clinic model was being introduced imminently at East Sussex Hospitals Trust at the time the review started. It was important to allow time for these developments to become established and evaluated before their effectiveness could be evaluated.

24. During the course of the review the Board visited the acute hospitals in Brighton, Eastbourne and Hastings and an inpatient rehabilitation ward at the Irvine Unit in Bexhill. Meetings were also held with representatives of community rehabilitation teams covering Lewes and the Havens and Hastings and Rother. The Board is therefore able to make specific references in this report to examples within these services, but the visits and meetings also highlighted more general issues which may affect all patients, not just those using these particular services.



### 3. Review findings

25. This section of the report is divided into the three main topics considered by the Board.

**a) Awareness and prevention of stroke**

**b) Acute care**

**c) Rehabilitation and long-term care**

26. Each section gives a brief overview of the current situation in East Sussex and goes on to outline key findings from the review. Finally, in each section, recommendations are made on key issues.

#### ***a) Awareness and Prevention of stroke***

##### **Overview**

27. The National Stroke Strategy highlights the need to improve awareness of stroke symptoms amongst both the public and professionals and the need to take appropriate action. It points out that the failure to recognise stroke as a medical emergency can mean that urgent medical treatment for stroke is delayed, thus leading to more damage to the brain and poorer outcomes. The strategy also suggests that people do not know enough about stroke risk, how to reduce that risk, or how to prevent stroke.

**Suspect a Stroke?**  
**Act FAST and call 999.**

**F. A. S. T.**

**FACE      ARM      SPEECH      TIME**  
**weakness weakness problems to call 999**

Source: Department of Health

28. As a result of the national strategy, a nationally funded and organised three year public awareness raising campaign began in February 2009, preceded by a campaign aimed at professionals. The public campaign comprises TV, radio and press adverts, a website, posters and information leaflets. The campaign focuses on using the FAST test to recognise symptoms (see box above) and the need to call 999 for an emergency response.

29. Improving awareness is not just about recognition and emergency action, but awareness of the causes of stroke and adapting lifestyles to reduce risk. National strategy states that promoting healthy living is very important in preventing stroke, particularly in disadvantaged areas and groups, and those with specific risk factors. For those who have already had a stroke or TIA, prevention is even more important, and advice about modifying lifestyle is vital to reduce risk of further stroke.

30. East Sussex PCTs have launched an initiative called 'Investing in Life' which aims to reduce health inequalities and raise life expectancy by tackling vascular disease (including stroke), by:

- reducing smoking rates
- improving stroke services
- improving diet and exercise
- increasing prescribing of statins (drugs that reduce blood cholesterol)
- implementing cardiovascular disease risk registers

31. The 'Investing in Life' initiative will be introduced across all areas of East Sussex but with additional emphasis on increased services in those wards with lowest life expectancy. (Source: East Sussex Stroke Strategy.)

32. The system for performance management and payment of GPs in the NHS, known as the Quality and Outcomes Framework or QOF, contains a number of indicators related to stroke care, particularly for people who have already had a stroke or TIA. These indicators include the following: patients with stroke or TIA referred for further investigation, having blood pressure and cholesterol checks, and taking appropriate medication.

33. The PCTs' East Sussex Stroke Strategy estimates that, across East Sussex, 322 strokes per year could be prevented if preventative measures such as effective management of blood pressure, preventative medications and smoking cessation were routinely implemented for all appropriate patients with specific risk factors. This is a sizeable proportion of current stroke statistics.

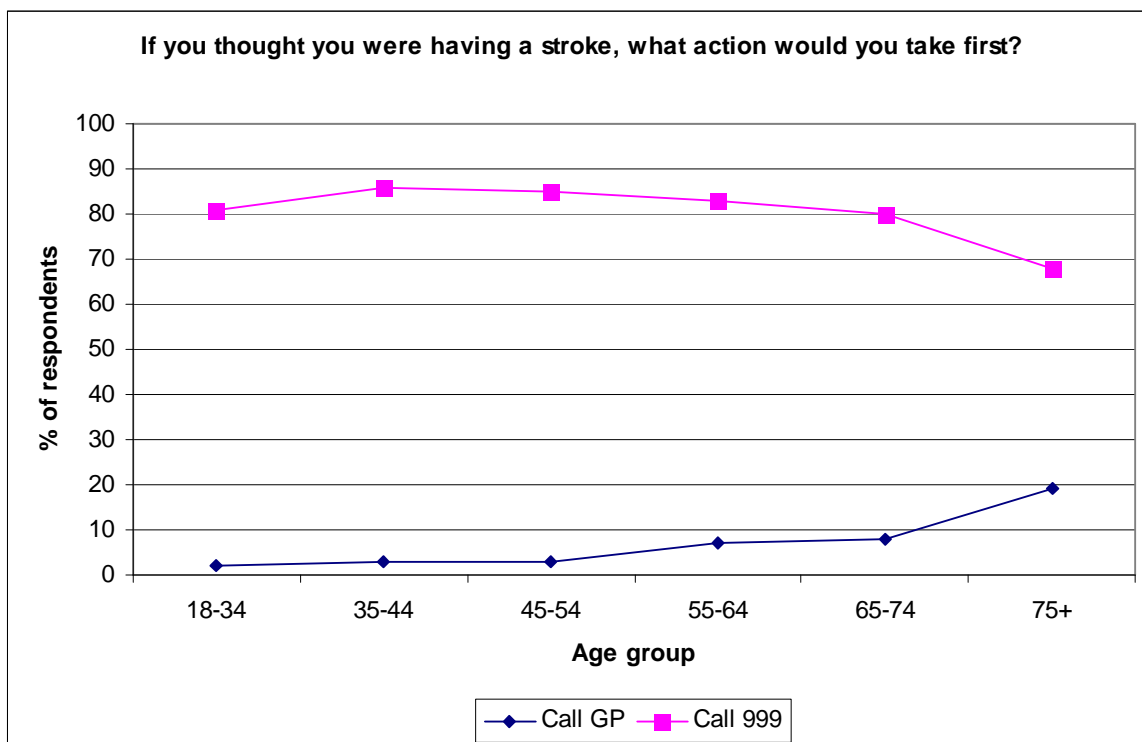
### Key findings

34. Although national polls have been commissioned to examine the public's awareness of stroke, no detailed research had been done at local level. To investigate this, the Review Board commissioned a survey of 1900 local people through the County Council's residents' panel (a group of local residents who have agreed to complete regular surveys about local issues). There was an excellent response, with 1159 (61%) completing the questionnaire.

35. Overall, the survey showed a relatively high level of awareness of stroke, particularly when compared to national polls. However, the Board is conscious that the sample is a self-selected group, likely to be more interested and proactive than the general population, and so likely to over-represent awareness.

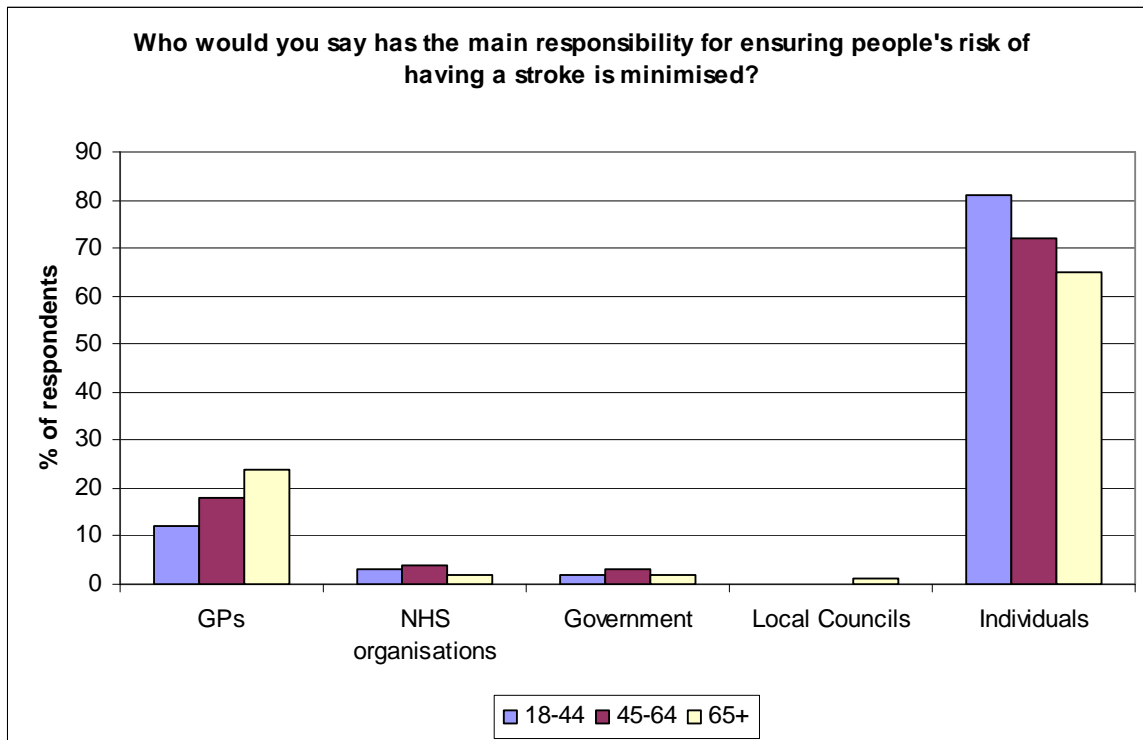
36. Despite the fairly high level of awareness, around a quarter of respondents could not name any symptoms of stroke, rising to a third of those with no experience of stroke through family or friends. The over 75 age group appears least likely to be aware of symptoms.

37. Likewise, when asked what they would do on identifying a stroke, although 80% know to call 999, 20% would do something else, most commonly call their GP. This is particularly notable in older age groups, as shown in the chart below.



38. The survey shows that people are interested in knowing more about stroke, in terms of reducing their risk, recognising a stroke and taking action. Different groups prefer different methods of receiving this information, for example older people strongly favour information from GP or practice nurse, whereas younger people are more likely to favour the internet. Men are likely to be less receptive to information than women. These results show the importance of targeted communication using different methods to target different groups.

39. In terms of prevention, there is a generally good awareness of some of the key risk factors e.g. high blood pressure, but still only 55% picked out poor diet as a risk factor and 61% being inactive. The over 65 age group were even less likely to identify these two factors. Most respondents (71%) felt that it was the individual's own responsibility to minimise their risk of having a stroke but this differs by age as the chart below shows:



40. In general, the survey suggests that older people (particularly over 75s) are more likely than younger age groups to depend on, or prefer, their GP for information and advice. When asked about possible ways to help prevent stroke, people most strongly favoured GPs identifying and advising people who are at increased risk, in preference to targeted information campaigns or general publicity. The results highlight the central role of GPs in prevention.

41. Overall, the survey indicates that, although there is an encouraging amount of awareness amongst the residents' panel respondents, there is certainly scope for increasing awareness in East Sussex as recommended by the national stroke strategy.

42. The Board received 35 letters, emails and telephone calls from stroke sufferers and carers, as well as meeting several individuals to discuss their experiences in detail. Their stories indicate that many did not realise they or their loved one were having a stroke and they did not always call 999 for an emergency response. Some patients contact GPs in the morning, having experienced symptoms the night before or over the weekend. Where first contact was with GPs, the Board noted several instances where patients were not sent to hospital for immediate assessment and treatment. In some cases a stroke was not diagnosed and in some cases the ambulance response was delayed.

*Mr A knew he was having a stroke – the symptoms were ‘unmistakable’. However, his friend did not realise and assumed he had fallen over. Mr A was unable to communicate verbally but was able to convey with one arm to his friend to call 999. (Participant at patient/carer workshop)*

*Three years ago Mr B woke up in the morning to find he had no use of his side. He went to his GP who diagnosed a stroke. The GP raised the level of the hypertension drug he was already taking and sent him home. The next day his condition worsened and the GP was called again. The GP arrived at midday and the ambulance called but this did not arrive until 9pm. (Participant at patient/carer workshop)*

*Mr C felt a pain in his arm and was numb-faced. He fell over as he tried to get out of bed. He had no idea that he might be suffering from a stroke. (Participant at patient/carer workshop)*

*“My father died of a stroke. If I had known what to have done the outcome could have been different. I think this survey is very important” (Comment from member of public on questionnaire)*

43. The NHS is clear that stroke should be treated as a medical emergency and the preferred response is to call 999 for an ambulance. South East Coast Ambulance Service (SECAMB) has changed procedures to ensure stroke is categorised with a higher degree of urgency and developed protocols with local hospitals designed to ensure appropriate response. However, not everyone will call 999 or know they are having a stroke and may approach other health professionals first. Work has been undertaken recently to raise awareness of stroke amongst health professionals, to improve diagnosis and to highlight the importance of treating stroke as an emergency. For example, a presentation has been given to a GP Forum, and South East Coast Ambulance Service has worked with East Sussex Hospitals Trust to test a new training programme for health professionals. However, the Review Board is concerned that feedback from patients and carers demonstrates inconsistency of response and that there is a need to ensure that all strokes are recognised and treated with the same degree of urgency as, say, heart attacks.

44. Given the older age profile of stroke sufferers, it is likely that a proportion will be in receipt of social care services or be in residential care of some kind. It is therefore important that staff in these environments are also aware of stroke symptoms and appropriate response. Staff training should be encouraged through service specifications drawn up by health and social care commissioners in the future.

45. Feedback from patients and carers highlights inconsistency in follow-up care received by people who have had a stroke. Many had received little or no contact with their GP and some were not aware of what they should be doing to minimise the risk of further stroke, whereas others had received good follow-up:

*“I keep having to remind folk that, as I had a bleed stroke, aspirin is not for me, although I think it is now sorted on my medical record.” (Letter from patient)*

*Mr D says that his GP is ‘non-existent’ and there has been no follow up on his partner. (Phone call from carer)*

*Mr E’s medication was changed to reflect his stroke and he has regular medical reviews and blood tests every two months through his GP. (Participant at patient/carer workshop)*

46. GPs interviewed by the Board reported that hospital doctors tend not to be as directive and proactive in specifying follow up care for stroke patients compared to, say, cardiac patients and that they would welcome more challenge in this respect. GPs also highlighted that follow-up care for stroke is not as well defined and robust as for other conditions such as heart attack and diabetes, although recent changes to the QOF are designed to help this. There is potential for innovative models of follow-up and secondary prevention involving pharmacists or the voluntary sector.

47. A key prerequisite for improving stroke care is the maintenance of registers by GPs, both of patients who have had a stroke/TIA and of those who have certain risk factors which could lead to stroke. Once a patient has had a stroke the register should be used to ensure supervision and regular testing. GPs are expected to keep registers of patients who have had a stroke/TIA under the QOF. However, the Board noted that the quality and consistency of data is variable which makes comparison difficult and therefore hinders the identification and sharing of good practice. As a first step, the sharing of data and procedures for coding and identification of stroke patients should be facilitated with a view to improving the quality of information. Maintaining additional 'at risk' registers which identify those with specific risk factors who have not yet had a stroke would enable better primary prevention as they can be targeted with specific interventions.

## **Recommendations**

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### **Recommendation 1**

**The public need to be more aware of:**

- c) the causes of stroke and what the public can do to reduce risk.**
- d) the symptoms of stroke and that calling 999 is the normal action to take on suspecting a stroke.**

**The national awareness campaign is welcome but must be complemented by local, targeted work co-ordinated by the PCTs and involving a range of local agencies (e.g. Older People's Partnership Board). The findings from the awareness survey should be used to inform this work.**

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### **Recommendation 2**

**GPs and other front line health and social care professionals need to be more effective at recognising stroke and ensuring an emergency response. It is recommended that the PCTs and Adult Social Care consider ways to increase awareness and training for community and primary care staff and ensure that clear protocols are available and followed.**

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### **Recommendation 3**

**A robust pathway for follow-up care/secondary prevention should be put in place to ensure that all stroke and TIA patients receive regular checks, information and advice in line with National Stroke Strategy standards. This should include the maintenance of robust and consistent registers of stroke and TIA patients at all GP practices.**

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### **Recommendation 4**

**A mechanism should be put in place to identify those at higher risk of stroke on practice based 'at risk' registers to ensure regular health checks and preventative medicine.**

## **b) Acute care**

### **Overview**

48. Acute care normally refers to care provided in a major hospital. Acute stroke services for East Sussex residents are primarily provided by East Sussex Hospitals Trust (Eastbourne and Conquest (Hastings) Hospitals), with some residents in the west and north using Brighton and Sussex University Hospitals Trust (Royal Sussex County Hospital in Brighton and Princess Royal Hospital in Haywards Heath) and Maidstone and Tunbridge Wells NHS Trust. All these hospitals now have specialist stroke units which consist of designated stroke beds with specialist stroke teams.



49. Specialist neurological care for unusual and complex stroke cases is available at Hurstwood Park, Haywards Heath.

50. Although specialist stroke units are in place, patients may spend time on other wards before or after admission to a stroke unit, and some patients may spend their whole stay on other wards.

51. Best practice for acute stroke care is clearly defined in national guidance. Key features include rapid access to scans which determine the type of stroke and enable appropriate treatment, availability of thrombolysis (clot-busting drugs) for suitable patients, direct admission to a specialist stroke unit and rehabilitation starting as quickly as possible. Care should be overseen by a specialist stroke consultant with a trained multi-disciplinary team and with the involvement of patients and carers.

### **Key findings**

52. The Board found that significant progress has been made recently, notably the establishment of specialist stroke units in each local hospital and the limited introduction of thrombolysis treatment, with associated improvements in access to scanning. There is also evidence of the beginnings of a cultural change in relation to stroke care, with increased urgency and increased optimism about patient outcomes, probably linked to the introduction of thrombolysis and better evidence about appropriate rehabilitation strategies.

53. However, it is apparent to the Board that there is still some way to go to fully implement the National Stroke Strategy quality standards and that the pace of change must speed up. Professionals are well aware of the ongoing challenges and there is little, if any complacency. Although the national strategy has a 10 year timeframe, the desire to move more quickly than this in East Sussex was frequently mentioned. Commissioners have reflected this prioritisation of stroke in local strategic commissioning plans and this is welcomed by the Review Board.

54. The Board is, in general, impressed by the care which can be offered by local stroke units, but concerned that this level of care is not experienced by all patients on a consistent basis. Feedback from patients demonstrates a wide variety of experiences, even amongst patients treated at the same hospital. There appear to be a number of issues:

- **'In hours' vs 'out of hours' care** – at all hospitals there is a substantial difference between the level of care offered in normal working hours (i.e. 9am-5pm, Monday to Friday) and that offered overnight and at the weekends. For example, specialist stroke staff work largely normal working hours meaning that assessment and treatment of patients by the specialist team is only available during these times. Thrombolysis is currently offered only 'in-hours' and, at many hospitals, access to scanning is significantly reduced out of hours.

- **Staffing shortages** – there are serious gaps in staffing at some hospitals. For example, there has been no specialist speech and language therapist at Eastbourne’s stroke unit for some time, requiring some patients to pay for private therapists. The Conquest Hospital’s unit has a shortage of specialist occupational therapists. Therapy staffing is especially affected by recruitment difficulties, particularly when experienced, specialist staff are required. There are also differing levels of input from the lead stroke consultant at different hospitals, for example, a recent Sentinel Audit showed that specialist medical input at the Conquest and Eastbourne hospitals is lower than guidance demands. The Board were also concerned that levels of nurse staffing were below recommended standards at some hospitals visited and, given the demanding caseload, this is not acceptable. There is also a lack of clinical psychologist input in acute units.
- **Capacity in stroke unit** – due to demand on beds, some stroke patients experience delay in reaching the stroke unit and may spend significant time on other wards, e.g. medical assessment units and general medical wards, thereby not always accessing specialist stroke care immediately. Patients may be moved two or three times during their hospital stay and if this occurs at the end of their stay, this can cause problems with their discharge. Teams on other wards may not ensure the links to specialist stroke community services are made in the same way as they would be by the stroke unit team. The Board regretted that acute bays on some stroke units were mixed-sex, which is unacceptable and measures should be taken to prevent this.
- **Variable access to community rehabilitation** – The capacity issues are compounded in parts of the county with little access to community inpatient rehabilitation. Patients may have to wait in the acute unit until a bed in a community facility becomes available, or may have to spend longer receiving rehabilitation within the acute ward. This then creates unacceptable pressures on beds and can result in patients being moved to other wards.

55. These, and other, factors mean that one patient can have an excellent experience and another a poor experience within the same hospital, depending on when they arrive and the pressures at the time:

### **Good experiences**

*On-call doctor came straight away in the evening. Called ambulance and taken to Sussex County Hospital. Scan taken straight away followed by assessment including a swallow test. Mrs F now undergoing therapy and Mr F is very impressed with the service and quality of staff. (Phone call from carer)*

*“My brother’s treatment at the Conquest Hospital was very good - they have their own stroke department. The staff knew exactly how to treat the patients and the care was excellent. The severity of my brother’s stroke was explained in detail with the treatment being given also explained.” (Letter from carer)*

*“My husband had a major stroke at was not expected to live – he was admitted to the Stroke Unit at Eastbourne DGH. My son and I were treated with total consideration and had everything explained to us. It was clear from the outset that the staff were amazing.” (Letter from carer)*

### **Poor experiences**

*Mr G's wife spent five hours in A&E waiting for a bed, then taken to Medical Assessment Unit, then onto another ward and eventually to stroke unit where she stayed for 14 days. Had a scan two days after admittance. Asked sister about the scan and was told the information was confidential. No information offered during the two weeks his wife was in hospital.*

*(Phone call from carer)*

*Did not know there was a stroke unit and was told that ward x (stroke ward) 'is the old people's ward'. Did not see a stroke specialist of any kind or receive any therapy.*

*(Younger participant at patient/carer workshop)*

*Ms H's father suffered a stroke early evening on a Sunday and was taken by ambulance to A&E. Arrived 6.30pm but not seen by a doctor until 11.00pm. Admitted to stroke unit by 1am but little was done until early morning and a scan could not be done until Thursday. Ms H was particularly concerned that her father did not receive a scan soon after being admitted.*

*(Phone call from carer)*

*No-one told Mr A the results of the scan. He was 'most curious' about the result and anxious that maybe they did not tell him because it may be bad news - 'you fear the worst'.*

*(Participant at patient/carer workshop)*

56. The Board is concerned by the extent of this inconsistency and believes the aim should be to achieve a 24/7 consistent standard of acute care, whilst addressing some of the blockages elsewhere in the system which cause additional pressures, such as the availability of community rehabilitation (see later section). There may be a need for additional designated stroke beds, for example to address mixed sex bays and to cater for the expected increase in strokes from an ageing population. Commissioners should use modelling of future trends in stroke prevalence to determine the need.

57. Much attention is being given, across the Sussex Stroke Network, to ways to develop thrombolysis into a 24/7 service. Whilst this is important, and the Board understands that the introduction of thrombolysis can act as a catalyst for other improvements such as rapid access to scanning, attention must equally be given to good acute stroke care for patients not eligible for the technique. Only a small proportion of patients will fit the criteria for thrombolysis (under 80 years of age and within 3 hours of having the stroke, approximately 10% of patients). For the great majority, a prompt scan, specialist assessment and treatment and access to therapy will be more important. The Board believes it is necessary to take a whole pathway approach to developing round the clock stroke services and that effort directed to extending thrombolysis should be proportionate.

58. Scanning services at most hospitals are currently unable to provide sufficient capacity to meet National Stroke Strategy and NICE guidance on appropriate timescales (urgent brain scans in the next available slot within working hours and within 60 minutes out of hours, and other scans within 24 hours). The evidence suggests that a significant proportion of patients are not receiving scans within 24 hours at the Conquest and Eastbourne Hospitals and that it can be significantly longer at the weekend. Although potential thrombolysis patients are prioritised and can receive urgent scans, a step change is required in the scanning capacity commissioned and the way it is provided in order to ensure 100% of stroke patients can be scanned within in National Stroke Strategy standards. Options such as telemedicine for the interpretation of scans could be considered to help make this achievable.

59. The Board was concerned to hear that some strokes may be classified as 'routine strokes' or 'partial strokes' which may not require urgency. The Board's view is that there is no such thing as a 'routine stroke' and that all stroke patients require a prompt scan to enable effective diagnosis and treatment. Scans should also be available on an outpatient basis through TIA clinics if required in certain circumstances. Evidence suggests that GPs are admitting some patients purely in order to access a scan more quickly.



60. Direct emergency admission to the stroke unit should be routine. For example, much work has been done in Brighton to raise awareness of stroke across the hospital and to pull patients into the stroke unit from A&E, the medical assessment unit and other wards as soon as possible. Specific initiatives include a dedicated stroke bay in A&E and the designation of a member of the team as stroke co-ordinator. These approaches should be shared with other Trusts.

61. The teams at all the hospitals visited by the Board confirmed that patients and carers are involved in care decisions and discharge planning. Information in various formats is provided for patients to take away and patients and carers can be put in touch with voluntary sector workers where available. Experiences from patients and carers were mixed, with some feeling they had very good information and involvement and others very little.

*Mr and Mrs B would have liked to have spoken to a doctor or a consultant. Mrs B said that the nurses were not sure about individual cases and the consultant was never around. She and her husband still do not know what caused the stroke. (Participant at patient/carer workshop)*

*“What I think needs to be improved more than anything is keeping the patients’ relatives informed. There are serious failures of communication.... Nobody told me for ages that my brother had some brain damage and there was a problem with his mobility.... When I found things out – often by chance – I was able to help my brother much more.” (letter from carer)*

*There was a lot of information when Mrs I was on the stroke unit – hard to take it all in. (Participant at patient/carer workshop)*

## Recommendations

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### Recommendation 5

**When moving towards 24 hour acute stroke services, progressing the full range of specialist care is essential. This should include, but not be dominated by, 24 hour access to thrombolysis, as thrombolysis will only be appropriate for around 10% of patients.**

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### Recommendation 6

**The PCTs should commission for the provision of all diagnostic investigations for stroke patients to National Stroke Strategy standards well ahead of the Strategy’s 10 year timescale. Patients (and carers as appropriate) should be informed of the outcomes in a way they can understand.**

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### Recommendation 7

**All stroke patients’ discharge from hospital should be managed by the multi-specialist stroke unit team. There should be a protocol in place to ensure this happens even if, in exceptional circumstances, a patient is on another ward prior to discharge, so that they have the same access to community stroke services as patients discharged from the stroke unit.**

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**Recommendation 8**

**Rapid access to the specialist stroke team is crucial. Acute Trusts should have strategies in place to proactively 'pull' stroke patients into their stroke units. Ideally, there should be a dedicated A&E bay for stroke, a stroke co-ordinator monitoring admissions to ensure they reach the stroke team and all stroke patients should be allocated to a stroke specialist consultant who will oversee their care.**

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**Recommendation 9**

**Urgent action should be taken to remedy all staffing shortages and to bring staffing standards up to National Stroke Strategy guidelines.**

### ***c) Rehabilitation and long-term care***

62. This section is divided into three areas:

- Community inpatient rehabilitation
- Community rehabilitation
- Long-term support

#### ***Community inpatient rehabilitation***

##### **Overview**

63. Best practice dictates that rehabilitation should start as soon as possible after someone has a stroke. For most patients, this means that rehabilitation should start during their stay in an acute hospital stroke unit. Some patients with very significant needs may require an extended stay in an acute unit for rehabilitation but, for most, rehabilitation can continue elsewhere.



64. After a stay in an acute hospital, some patients, although medically fit to be discharged, will not be independent enough to return home and will require an additional period of rehabilitation as an inpatient in a community hospital or rehabilitation centre. For stroke patients, best practice is for rehabilitation to be overseen by specialists with expertise in neurological conditions, as opposed to by generic rehabilitation teams.

65. Inpatient rehabilitation is currently provided as follows:

- In the Hastings and Rother area inpatient rehabilitation for stroke patients is provided within the 54-bedded Irvine Unit at Bexhill Hospital which, although not a dedicated stroke/neurological unit, has specialist input from the community stroke rehabilitation team staff who are based at the Unit. In addition, there are 19 generic rehabilitation beds at Rye Memorial Hospital which also have input from the community team
- In the Eastbourne area the only community inpatient rehabilitation facility with specialist input for stroke is Firwood House (a joint health and social care unit). As this is an intermediate care centre it takes patients with less complex needs and stroke patients are in the minority. However, specialist input for these patients is available from the community stroke rehabilitation team who are based there. Non-specialist rehabilitation is available within Social Care units at Gilda Crescent and St Anthony's. Currently, much of the inpatient rehabilitation takes place within Eastbourne Hospital which has very good facilities. However, if patients require longer term rehabilitation, the lack of community based options can create pressure on the stroke unit.
- In the west of the county, patients may move from acute care to the Sussex Rehabilitation Centre (previously at Southlands Hospital in Shoreham but recently moved to Princess Royal Hospital in Haywards Heath) which specialises in neurological conditions. Beds are also available at Newhaven Rehabilitation Centre but these are currently mainly being used by Brighton and Hove Primary Care Trust, with some beds available for East Sussex residents. Specialist input is available from the community team based here. Patients may also receive rehabilitation at non-specialist units within the Lewes Victoria Hospital, Uckfield Community Hospital and Crowborough Community Hospital.

66. The differing availability and standard of community inpatient rehabilitation units in different areas has an impact on the length of time stroke patients stay in acute hospitals. Eastbourne DGH has a longer average length of stay (25 days) compared to patients at hospitals in Hastings, Haywards Heath and Brighton (19, 16 and 9 days respectively) where there are more community inpatient rehabilitation beds available.

67. Patients tend to stay around 3-6 weeks in inpatient rehabilitation units before being discharged to home or to residential care, although this can vary depending on individual cases.

68. Patients requiring very specialist rehabilitation e.g. younger stroke patients, may receive care some distance away at highly specialist units e.g. Salisbury.

## Key findings

69. The specialist community inpatient rehabilitation which is available appears to work well. For example, the Irvine Unit in Bexhill is well equipped and has good specialist input from the community stroke rehabilitation team based there. Patients and staff generally give positive feedback about the services available at Firwood House and Sussex Rehabilitation Centre. However, the services are stretched, with waits to get patients into the Irvine Unit and Firwood House and difficulty catering for patients requiring lengthy periods of rehabilitation.

70. The main issue with inpatient rehabilitation is a lack of capacity, which is having an impact on patients and staff in a number of ways:

- Patients may stay longer in an acute hospital setting when they could be moved to a less intensive setting if it were available. This then creates additional pressure on space in the acute units.
- Some patients are transferred from acute care to a generic community rehabilitation unit which is not able to provide the specialist care required for stroke.
- There is very little provision for patients requiring lengthy rehabilitation – the expectation is of a 4-6 week period when for some patients several months may be more appropriate.
- Patients are being discharged to community rehabilitation teams when still quite heavily dependent, thus creating pressures on the community teams who have an increased caseload of patients requiring longer periods of support. In some cases this had led to lengthy waiting lists.
- Some patients requiring more specialist rehabilitation, particularly younger patients, are being transferred long distances with subsequent impact for visiting families.

71. A further issue is the range of professional support available in the existing units. Feedback from patients and carers highlighted the emotional impact of having a stroke, which is usually a sudden, unexpected event, demanding emotional support. There is no provision for professional psychological support in existing inpatient units or in the community and no consistent way to ensure that depression is addressed.

*“The whole experience was devastating.... The stroke meant that I lost my husband (as I had always known him).... A stroke is almost certainly a bereavement without the death” (letter from carer)*

*Mrs J was getting depressed and was going to get some ‘happy pills’ but the depression is on and off. Her mood has definitely changed since the stroke’. (Participant at patient/carer workshop)*

72. The Board has concluded that there are clear gaps in the availability of inpatient rehabilitation for stroke patients, particularly in the Eastbourne area and in the north of the county. In Hastings and Rother, the Irvine Unit is providing this service but is not being used to its full potential, given the space, facilities and expertise available. This Unit is best placed to develop as a specialist stroke rehabilitation centre. In the west, there is potential for better use of the Newhaven Rehabilitation Centre and the provision of neurological input to one or more of the community hospitals to provide appropriate rehabilitation for stroke patients. In the Eastbourne area, the potential to expand the well-regarded service at Firwood House should be considered. It was suggested to the Board that 8-10 dedicated stroke rehabilitation beds here would be appropriate. The designation of appropriate capacity for longer-term inpatient rehabilitation at Eastbourne Hospital should also be considered so that there is no undue pressure on the acute stroke unit.

73. Very specialist rehabilitation, by its nature, must be concentrated in fewer centres but the distances some patients are having to travel are substantial. Consideration could be given to establishing specialist rehabilitation for younger patients on a Sussex-wide basis in order to improve accessibility for families.

## **Recommendations**

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### **Recommendation 10**

**Patients should have access to a phased process of rehabilitation, including availability of inpatient rehabilitation between the acute and community care settings. The PCTs should commission additional and improved community inpatient rehabilitation. This should support consistent access and standards across East Sussex, based on analysis of need.**

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### **Recommendation 11**

**There must be options available for longer-term rehabilitation. A pathway for patients requiring 'slow-stream' rehabilitation should be developed, supported by appropriate bed provision based on needs analysis.**

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### **Recommendation 12**

**The Sussex Stroke Network should consider the provision of a Sussex-wide service for young stroke survivors and those needing specialist rehabilitation. Longer travel times may be necessary for such specialist care but the need to travel outside Sussex should be avoided.**

## **Community rehabilitation**

### **Overview**

74. When stroke patients are discharged home or into residential care, many will require ongoing rehabilitation and will be referred to community based teams. Best practice is for these to be teams with specialist expertise in stroke as opposed to generic rehabilitation teams. Such teams should include a variety of disciplines including physiotherapy, occupational therapy, speech and language therapy, with support from psychologist and social worker.

75. In the Hastings and Rother area, this service is provided by a community stroke rehabilitation team (CSRT) based at Bexhill Hospital. This team provides support to stroke patients in their own homes, and in residential homes. A similar, but smaller, team covers the Eastbourne area, based at Firwood House.

76. In the west of the county, Lewes and the Havens area is covered by a community neurological rehabilitation team which has a wider remit encompassing patients with long-term neurological conditions as well as those with stroke or acquired brain injuries. The Crowborough and Uckfield area has no specialist community rehabilitation team for stroke, these patients instead being treated by the generic community rehabilitation team for that area.

### **Key findings**

77. The Board is concerned about the inconsistency of community rehabilitation available to stroke patients in different parts of the county. In particular, the absence of a specialist stroke team in the north of the county should be addressed urgently as it represents a real inequity in provision. The differing models of community rehabilitation in different parts of the county also have the potential for inequity or confusion and a consistent approach is needed. The Board noted the benefits from the neurological team model in Lewes and Havens which enables staff to gain broader experience and for stroke to be treated as a long-term condition if appropriate. This model may be the way forward, although its mixed caseload creates challenges (see below).

78. Where specialist teams are established, they are providing a good service within the resources available, but are stretched, for a number of reasons:

- Patients are being discharged earlier from acute hospitals than in the past. They are deemed medically fit by doctors but have not necessarily reached the optimum level of rehabilitation to be transferred to community teams. They therefore have more complex needs, requiring more and lengthier support.
- There is a lack of community inpatient rehabilitation beds to take patients who are fit for discharge from acute hospitals but still require intensive rehabilitation.
- In the Lewes and Havens area, the neurological rehabilitation team has struggled to cope with an increased caseload due to the factors above, combined with an increased number of patients with long-term neurological conditions. Waits rose to 8-9 months for the team's services. This has resulted in the team narrowing their remit to stroke, which will improve waits for stroke patients (4-5 months at time of this report and decreasing) but mean a loss of service for other patients and the benefits of a broader neurological remit.
- There are staff vacancies in some areas and some teams do not have adequate staff for the caseload. It can be difficult to recruit senior staff with specialist neurological skills.

79. The limited availability of community rehabilitation is having an impact on patients, carers and staff in a number of ways:

- There may be a waiting list for community rehabilitation which creates a gap in the patient's care on leaving hospital. Staff are concerned about the impact of such gaps on patient outcomes and on carers as there is a real risk of rapid deterioration and re-admission to hospital. The possibility of a treatment gap influences acute units' discharge decisions. Some patients are being transferred to inpatient rehabilitation units or kept in the acute unit to ensure they receive ongoing support, when they could return home if community team input was immediately available. It is possible that stroke patients transfer into residential care when they could return home if more support and rehabilitation was available.
- Teams are not always able to offer the intensity of rehabilitation that is ideally required for best possible outcomes. Voluntary organisations are concerned that this is placing additional burden on carers who may have to assist patients with exercises as well as their general care. This can have an impact on the carer's own health and wellbeing. Without sufficient intervention, patients may deteriorate, needing a higher package of care, or re-admission.
- Some patients receive rehabilitation for too short a time to guarantee any success or progress.

80. Not only does this affect health and quality of life for both patient and carer, investment in rehabilitation would be cost-effective in the longer-term. It can reduce a patient's dependence, thus saving on future ongoing care needs and may prevent re-admission to hospital. Savings from increased independence could benefit both the NHS and social care.

81. The Board noted the complete lack of any specialist psychological input to the community teams, despite the significant emotional impact of stroke described by patients and carers, and the fact that psychological support may be needed for some patients to engage effectively with rehabilitation. The Board believes that psychological counselling available on an inpatient and outpatient basis would have benefits for rehabilitation and long term health and wellbeing of patients and carers.

82. Patients and carers also reported difficulties accessing speech and language therapy which many found distressing. This creates practical difficulties with communication of needs. Some are paying privately for speech and other therapies to supplement the limited NHS care available.

*The physiotherapy is quite good but it was of limited length and ended abruptly. Mr B has had private physiotherapy but at £75 a session the cost is prohibitive.*

*(Participant at patient/carer workshop)*

*Mr J said that the hardest thing has been frustration over communication which has been very tiring. Speech therapy was short term but was very good. Mr and Mrs J would have liked more information on speech therapy – not just therapy itself but also if there was anything else available that Mrs J could use. (Participant at patient/carer workshop)*

*"I must have had home physio for around six months before it finished (I was advised it would not be for ever). Now some four years down the line I have gone privately to a physio and a chiro chap as I seemed to have got a lot more movement back and I feel this is something lacking in the system. It may be my fault for not asking." (Letter from patient)*

*Mr K pays for his own physiotherapy - £50 per session. There was some physiotherapy from the state but this was stopped. Mrs K believes that Mr K has shown some physical improvement and Mrs K's main concern is that if treatment had been better at the outset, he would now be in better condition. (Phonecall from carer)*

*My brother's hospital care was very good. Unfortunately this can't be said for the aftercare since being discharged – this is where the system fails the stroke patient. The physiotherapy was very slow getting set up and wasn't in place prior to him leaving hospital. I had to write letters of complaint to get any action. (Letter from carer)*

83. The links between community rehabilitation teams and acute and inpatient units within East Sussex are good, with members of the community teams attending multi-disciplinary team meetings at local hospitals. However, links are less good with hospitals based across the county border, for example in Brighton. Communication takes place but formal involvement in discharge planning is less strong, due to East Sussex residents representing a relatively small proportion of patients at these hospitals, and a lack of capacity in the Lewes and Havens community team. The Board's view is that these links should be strengthened and formalised to avoid inequity in care for residents in the west and north of the county, and that this will require additional resources.

## **Recommendations**

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### **Recommendation 13**

**The debate on whether stroke or neurological community rehabilitation team models are best practice should be resolved. A consistent patient pathway and model of community rehabilitation for stroke patients should then be introduced across East Sussex. Priority should be given to the north of the county which currently has no specialist service. Additional resources will be required to enable existing teams to meet demand, to expand their remit if appropriate, and to establish a team in the north.**

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### **Recommendation 14**

**Community neuro-psychologist/psychological counsellor roles should be developed to provide rapid response to referrals from community teams and inpatient units.**



## **Long-term care**

### **Overview**

84. Once patients have been discharged from community rehabilitation teams, ongoing healthcare will be led by the person's GP with input from community health services such as district nursing.

85. Some stroke patients, left with ongoing impairments, will require support with everyday tasks or full-time support in residential care. Adult Social Care services are based on need rather than a specific medical condition, and stroke patients' care needs are therefore assessed on the same basis as any other person. Assessments should be triggered through hospital discharge planning or through referral from community health services. Social workers work closely with inpatient units and community teams, often attending multi-disciplinary team meetings with health staff at which individual cases are reviewed. Currently, East Sussex Adult Social Care funds those assessed as having 'critical' or 'substantial' needs and the amount people pay is dependent on a financial assessment to ensure charging is on a fair basis. Adult Social Care also funds the community and voluntary sector to provide universal services aimed at those with low to moderate needs.

86. Carers (friends or family members) play a significant role in long-term care and support for stroke patients. This role can have a significant impact on the carer practically, physically and emotionally.

87. The voluntary sector provides ongoing support for stroke patients and carers by offering advice and information, running support groups and providing practical services, many of which are not specific to stroke. Specifically in relation to stroke, East Sussex PCTs commission two Stroke Association Communication Support Workers who cover the former Eastbourne Downs PCT areas, Hastings and Bexhill. They also commission Family and Carer Support Workers for the former Eastbourne Downs area and Hastings and Rother area. The varying areas covered by these services partly relate to previous four PCT boundaries before reorganisation into two PCTs. The PCTs and Adult Social Care part-fund Care for the Carers who provide information support for carers county-wide and a Carers Liaison Worker who covers Eastbourne and Conquest Hospitals. Adult Social Care has recently received around £115,000 funding over three years from the Department of Health specifically for stroke and the intention is for this to be used to fund a voluntary sector support service to stroke patients county-wide, which will include developing community education and exercise groups, peer volunteer services and family and carer support services.

### **Key findings**

88. Discharge planning aims to begin as early as possible, preferably from admission, and this will include social care assessment. The Board found that links between social care and acute units in East Sussex are in place, with social workers working in the units at Eastbourne and Hastings. A social worker also works closely with the Irvine Unit in Bexhill. However, links appear to be less close with hospitals over the county border. An out of area social work team is in place but works less directly with individual hospital units compared to the arrangements for in-county hospitals. This is because smaller number of East Sussex residents use out of county hospitals and they are split across several hospital sites. Hospital staff in Brighton suggested that social care assessments for East Sussex patients are not starting as early as they could and that there is room for improvement in the links to East Sussex Adult Social Care.

89. Post-discharge, problems may arise if a patient experiences a deterioration or crisis and needs rapid additional support from community health services and/or social care. Patients and carers can be unclear on what to do in this situation and may end up calling 999 or a GP, which can result in readmission to hospital. A rapid response nursing team is available in the north of the county which assists GPs in keeping patients at home pending additional longer term support being put in place, but this is not available in other parts of the county. In other areas there is evidence of community rehabilitation teams picking up short term nursing/care needs, which although effective at keeping the patient at home, is not the best use of rehabilitation staff time and expertise.

90. Patients and carers face some difficulties in accessing information and support. As well as knowing who to contact in a crisis, there are ongoing questions and concerns in the home. During an inpatient stay or rehabilitation there is access to specialist stroke staff who can help, but after this, the same level of specialist expertise is unlikely to be available from GPs. Feedback from patients, carers and voluntary groups suggested that this can be a particularly difficult time, as the realisation of coping on an ongoing basis sets in at the same time as the higher level of support from rehabilitation teams comes to an end. A contact point of some kind, such as a direct line to a specialist stroke nurse for patients and carers with specific concerns, could help prevent the escalation of problems and might be a lifeline.

*Advice on strokes has been patchy (e.g. advice on driving) and no information in the GP surgery on strokes. Mr L would have liked to have been referred to a nurse/professional who would talk in general about strokes. Aware of help groups but would prefer to talk to a professional. (Phonecall from patient)*

*Mr and Mrs J felt 'on their own' about 6 months after the stroke, when all the services and therapy had stopped. A 'rehab group' would have been useful. (Participant at patient/carer workshop)*

91. The support provided through the voluntary sector is welcome, particularly once patients have completed the period of formal rehabilitation care. Voluntary sector services are especially valued in terms of the emotional and social support they provide, for both patients and carers. However, the PCTs and Social Care should work together to ensure that these services, or any future variation on them, are commissioned on a county wide basis to ensure equity. The range of support services available can be overwhelming and confusing and practical support in negotiating and accessing these is needed, as opposed to only signposting. The navigator role piloted under the Partnership for Older People Programme offers a model which could provide such practical support.

92. There are other national voluntary organisations which provide support for stroke patients e.g. Different Strokes (for younger stroke survivors) and Connect (on communication issues) but some of these do not have a local presence in East Sussex, despite having branches in Brighton or West Sussex. Local support groups are available in some parts of the county but the PCTs and Adult Social Care should encourage more peer support. Voluntary organisations are well placed to provide longer-term support to help stroke survivors back into work or leisure pursuits, needs which cannot be met by the inevitably time-bound rehabilitation teams. However, voluntary (or other) organisations would require commissioning in order to do this.

*“There needs to be local clubs where both the patient and family can go to talk and share their problems/experiences and get any help or assistance they need, for example benefit claims, completing forms etc.” (Letter from carer)*

*Many of the services and groups were in Hastings or Eastbourne. None were local in Bexhill and I couldn't drive. (Participant at patient/carer workshop)*

*Mr A would like to help others through volunteering e.g. a buddying scheme or hospital visiting. He thinks this could help others as it helped a man he spent time talking to in hospital. (Participant at patient/carer workshop)*

93. For stroke survivors with significant ongoing impairment, the process of organising or co-ordinating support can often fall heavily on carers, who may have to press hard to gain access to services. This means there is a risk that people without a carer may lose out and a process is needed which ensures that all stroke patients are identified and assisted to access the support available. Patients without a carer can be particularly isolated and may need psychological counselling and help.

## **Recommendations**

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### **Recommendation 15**

**A county-wide approach is needed to cope with deterioration or crises. This should incorporate clear information for patients and carers on what to do and availability of rapid response, short-term, nursing and social care.**

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### **Recommendation 16**

**On returning home or to residential care, patients and carers should have access to a single contact point (a 'helpline') for questions or concerns about their condition or care. This must be available on an ongoing basis, not just while receiving rehabilitation, and advice should be available from specialist, qualified staff.**

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### **Recommendation 17**

**Support commissioned from the voluntary sector should be on a county-wide basis, and ensure that *all* stroke patients are identified and assisted to access support if required.**

## Conclusions

94. The Board is encouraged by recent progress in stroke care. The development of an East Sussex stroke strategy and establishment of a Sussex Stroke Network are welcome indicators that progress will continue. The development of a 'dashboard' of indicators for stroke care across South East Coast area is also welcome and will assist greatly in monitoring patient outcomes over time.

95. The Review Board has heard directly from patients and carers that their experiences of care are inconsistent, and there are gaps in services and services that are stretched to capacity. There is clearly some way to go in meeting the National Stroke Strategy standards and ensuring high quality care for all patients. Rehabilitation, in particular, requires priority attention to ensure a consistent county-wide approach, offering a range of options to cater for the widely varying needs of stroke patients.

96. The elderly profile of the East Sussex population demands that stroke care is treated as a priority and that the county should be at the forefront of best practice. There is a desire amongst patients and professionals for the pace of development to be in advance of that required by the national ten year strategy. The Board is concerned that previous reviews of stroke care have not produced sufficient change, but encouraged that there is momentum, both nationally and locally.

97. The Board would like to ensure that this report, and the evidence gathered to inform it, is shared widely with key groups and organisations in East Sussex. The report should be used to inform the development of detailed implementation plans for the East Sussex Stroke Strategy. The experiences gathered from patients and carers are especially valuable in highlighting how stroke care should develop.

98. It is important that PCTs ensure ongoing patient and carer involvement in the implementation of their strategy. The Health Overview and Scrutiny Committee should be involved in that process.

## Recommendations

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### Recommendation 18

**The Health Overview and Scrutiny Committee should develop a plan to ensure the findings of this review are shared widely with key groups in East Sussex.**

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### Recommendation 19

**Mechanisms should be established to ensure the ongoing active involvement of patients and carers in the implementation and evaluation of the stroke strategy. The Health Overview and Scrutiny Committee should indicate its willingness to participate in this process.**

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### Recommendation 20

**The Health Overview and Scrutiny Committee should monitor progress against the recommendations in this report, and wider aspects of the PCTs' stroke strategy in 6, 12 and 18 months from its publication. The Committee should make use of the South East Coast stroke dashboard as part of this monitoring.**

## **Appendix 1: Review Methodology**

### **Board Membership and project support**

Review Board Members: Councillor Angharad Davies (Chairman), Councillor Beryl Healy, Councillor Eve Martin, Councillor David Rogers from the Health Overview and Scrutiny Committee. Councillor Martyn Forster, co-optee from the Adult Social Care Scrutiny Committee and John Barnes, Chairman, East Sussex Downs and Weald Primary Care Trust (PCT), co-optee representative of East Sussex PCTs' Non-Executive Directors.

The project manager was Claire Lee, Scrutiny Lead Officer and project support was provided by Sam White, Scrutiny Support Officer.

### **Review methodology**

The Review Board undertook a variety of activities to gather evidence which would inform the review. Firstly, the Board reviewed key documentation, both national and local (listed below). Secondly the Board invited key professionals from health, social care and voluntary sector organisations to attend Review Board meetings to be interviewed about stroke care (listed below). Thirdly the Board visited local hospitals and a rehabilitation unit to see care being provided, the facilities available and to talk to front-line staff and patients. Finally, the Board gathered views from the public, patients and carers by holding a half-day workshop (jointly with the PCTs) for several patients and carers who had recently used services to talk in detail about their experience, and by publicising the review and inviting people to share experiences. The Board also commissioned a survey of 1900 local people on stroke awareness through the County Council's residents' panel, to which 1159 people responded.

### **Review Board meeting dates**

Tuesday 5<sup>th</sup> August 2008

Thursday 4<sup>th</sup> September 2008

Friday 17<sup>th</sup> October 2008

Thursday 20<sup>th</sup> November 2008

Monday 8<sup>th</sup> December 2008

Tuesday 27<sup>th</sup> January 2009

Tuesday 17<sup>th</sup> February 2009

### **Visits as part of the evidence gathering programme**

Friday 17<sup>th</sup> October 2008 - Irvine Unit, Bexhill Hospital, Bexhill on Sea

Tuesday 4<sup>th</sup> November 2008 – Egerton Stroke Unit, Conquest Hospital

Thursday 18<sup>th</sup> December 2008 – Wilmington Stroke Unit, Eastbourne DGH

Thursday 20<sup>th</sup> November 2008 - Soloman and Donald Hall wards, Royal Sussex County Hospital, Brighton

### **Stroke workshop**

Monday 10<sup>th</sup> November 2008 - Stroke workshop with patients and carers, Eastbourne

### **Witnesses providing evidence**

The Review Board would like to thank the many people who contributed to the evidence gathering phase of this review. This included 35 members of the public who responded to the call for their experiences of stroke services. These, often detailed and revealing responses,

gave graphic illustrations of individual's experience and added considerably to the Review Board's knowledge of the situation for stroke patients and their carers in East Sussex. It also included 7 stroke patients and carers who attended a workshop to discuss in detail their experiences of stroke services. The Review Board are extremely grateful for all their input and time. We have not named them individually here in order to protect their confidentiality.

The Review Board would also like to thank the 1,159 members of the East Sussex Residents Panel who took the trouble to complete the stroke awareness survey. The results of the survey highlighted several key messages and formed a robust body of evidence which helped inform the Review Board.

The work surrounding this review spanned several months and the Review Board is indebted to the many members of staff in stroke services both in statutory and voluntary organisations who gave so generously of their time to attend one of the evidence gathering sessions, help at the workshop or host visits to stroke units.

The people who contributed are listed below.

**Brighton and Sussex University Hospitals NHS Trust - Stroke Unit – Soloman and Donald Hall Wards**

Vicky Brill, Thrombolysis Nurse

Christina Elgie, Stroke Co-ordinator

Dr Nicola Gainsborough, Elderly Medicine Consultant

Mark Holmes, Ward Manager

Julia Smith, TIA and Triage Nurse

**East Sussex County Council**

Sue Buxton, Consultation Officer, Chief Executive's Department

Sophie Clark, Strategic Commissioning Manager, Adult Social Care

Imran Yunus, Strategic Commissioning Manager, Adult Social Care

**East Sussex Primary Care Trusts (PCTs)**

Sally Allen, Improvement Manager for Sussex Stroke Network

Dr Richard Blakey, GP Stroke Lead, East Sussex Downs and Weald PCT

Angela Broomfield, Health Promotion Specialist – Older People, East Sussex PCTs

Michelle Croucher, Stroke Services Commissioning Lead (to Dec 08), East Sussex PCTs

Peter Davey, Cardiac Improvement Manager, Sussex Heart Network

Dr Roger Elias, GP Stroke Lead, Hastings and Rother PCT

Vicky Farakar, Community Rehab Team Manager, Hastings and Rother PCT

Lisa Fairclough, Cardiac Improvement Manager, Sussex Heart Network

Rachel Harrington, Stroke Services Commissioning Lead (from Jan 09), East Sussex PCTs

Ellie Harvey, Project Support Officer, East Sussex Downs and Weald PCT

Jane Moseley, Senior Occupational Therapist, Hastings and Rother PCT.

Kirsten Phillips, Acting Team Leader, Neurological Community Rehabilitation Team, East Sussex Downs and Weald PCT

Murray Seivwright, Acting Professional and Regional Lead, East Sussex Speech and Language Therapy Service for Adults

Pippa Spooner, Service Improvement Lead, Service Redesign and Transformation Team, East Sussex PCTs

Emma Thomas, Team Leader, Neurological Community Rehab Team, Lewes and Havens, East Sussex Downs and Weald PCT

Dr Jane Thomas, Consultant in Public Health, East Sussex PCTs

Sarah Valentine, Director of Commissioning and Primary Care, East Sussex PCTs

Alice Webster, Locality Manager, East Sussex PCTs

Helen Wiggins, Speech and Language Therapist, Neurological Community Rehabilitation Team, East Sussex Downs and Weald PCT

### **East Sussex Hospitals NHS Trust**

Dr Ahmed Abras, Egerton Ward, Conquest Hospital

Dr Conrad Athulathmudali, Stroke Lead Consultant, Eastbourne DGH

Emma Brinklow, Cardiac Specialist Nurse, Conquest Hospital

Deidre Connors, Clinical Matron for Elderly Care, Conquest Hospital

Jim Davey, Director of Operations, East Sussex Hospitals NHS Trust

Jane Gallagher, Stroke Specialist Nurse, Eastbourne DGH

Dr David Hughes, Divisional Director – Clinical and Diagnostic Support, East Sussex Hospitals NHS Trust

Liz King, Senior Sister, Egerton Ward, Conquest Hospital

Jane Morris, Deputy Director – Clinical Strategy and Service Development

Dr Javaid Rahmani, Lead Consultant Stroke Physician, East Sussex Hospitals NHS Trust

Les Saunders, Divisional Senior General Manager – Medicine and Emergency Care, Eastbourne DGH

Sarah Snowball, Specialist Stroke Nurse, Conquest Hospital

Jane Stevens, Clinical Matron for Medicine, Eastbourne DGH

Dr James Wilkinson, Divisional Director – Medicine and Emergency Care, Eastbourne DGH

### **South East Coast Ambulance Service NHS Trust**

David Davis, Paramedic, Stroke Lead / Clinical Pathways Co-ordinator

### **South East Coast Strategic Health Authority**

Dr Quentin Sandifer, Deputy Regional Director of Public Health

## Evidence papers/references

Ref.	Item	Date
1	Act FAST – national stroke campaign materials from <a href="http://www.nhs.uk/actfast">www.nhs.uk/actfast</a>	February 2009
2	Trust helps pioneer stroke care course – press release, East Sussex Hospitals NHS Trust	February 2009
3	East Sussex Stroke Strategy 2009-2012, East Sussex PCTs	January 2009
4	Investing in life ‘adding life to years and years to life’ – Cynthia Lyons, Deputy Director of Public Health, East Sussex PCTs	January 2009
5	Papers on determinants of health and stroke prevalence – Jane Thomas, Consultant in Public Health, East Sussex PCTs	January 2009
6	GP Services in your area are improving – East Sussex Downs and Weald PCT	January 2009
7	Big Little Heart – a play about heart disease and stroke (leaflet) – The Stroke Association	January 2009
8	Leading the fight against brain attacks – The Stroke Association Annual Review 2008	January 2009
9	Women ‘ignorant’ of stroke risk – BBC news channel	November 2008
10	Stroke services update – Sarah Valentine, Director of Commissioning and Primary Care, East Sussex Downs and Weald PCT Board paper	September 2008
11	Clinical performance indicators report – South East Coast Ambulance Service NHS Trust	September 2008
12	More GP hours ‘could cut strokes’ – BBC news channel	September 2008
13	NHS ‘has more to do over stroke’ – BBC news channel	September 2008
14	Stroke Strategy: how are we doing – John Kemm, Health Service Journal	August 2008
15	National Sentinel Stroke Audit – Phase 1 organisational audit 2008 – Clinical Standards – Royal College Of Physicians	August 2008
16	Quick reference guide – stroke – diagnosis and initial management of acute stroke and transient ischaemic attack (TIA) – National Institute for Health and Clinical Excellence	July 2008
17	Early assessment and treatment of people who have had a stroke or transient ischaemic attack (TIA) – National Institute for Health and Clinical Excellence	July 2008
18	National Sentinel Audit of Stroke 2008 – Generic results for the organisation of stroke care	June 2008
19	Conquest introduces a new treatment for stroke patients – press release	June 2008



20	£77m to improve stroke services as UK 'lags behind Western nations' – Times on Line	May 2008
21	Demonstrating how to deliver stroke care for adults in the community – Local Authority Circular – Department of Health	May 2008
22	Thrombolysis management in acute care – guidance notes and associated protocols, East Sussex Hospitals Trust	June 2008
23	National Stroke Strategy – East Sussex Hospitals NHS Trust current position and future plans – Jane Morris and Dr Javaid Rahmani, Lead Consultant Stroke Physician - Draft Board Paper	March 2008
24	Care after stroke or transient ischaemic attack – The Stroke Association and Royal College of Physicians	2008
25	Bridging the quality gap – stroke – Quest for Quality and Improved Performance – The Health Foundation	2008
26	Older people in East Sussex: an epidemiological needs assessment (stroke section), NHS Public Health Resource Unit, 2007	February 2007
27	National Stroke Strategy, Department of Health	December 2007
28	Increasing life expectancy in the twenty wards with the lowest life expectancy in East Sussex	December 2007
29	National Stroke Audit Report - Sarah Valentine, Director of Commissioning and Primary Care, East Sussex Downs and Weald PCT Board paper	December 2007
30	Joint Strategic Needs Assessment, East Sussex PCTs and East Sussex County Council	October 2007
31	National Stroke Audit – report prepared by Dr Quentin Sandifer, Deputy Regional Director of Health, South East Coast Strategic Health Authority	May 2007
32	Improving stroke services: a guide for commissioners – Department of Health	December 2006
33	Mending hearts and brains – clinical case for change – Professor Roger Boyle, National Director for Heart Disease and Stroke	December 2006
34	What's the emergency? – report on the emergency response to stroke – The Stroke Association	October 2005
35	East Sussex Clinical Services Review – Stroke Services, Final Report, East Sussex NHS	2004
36	UK's knowledge of strokes and heart attacks 'patchy' – Ipsos Mori	September 2002

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