

## Central Sussex Stroke Review

# Engagement feedback report

10 February 2017

## Executive summary

As a result of a review of stroke services in Sussex, begun in 2014, clinicians have recommended changes to how and where Brighton and Sussex University Hospitals NHS Trust (BSUH) provides its stroke services.

Before implementing the recommendation, the clinical commissioning groups (CCGs) that plan, buy and monitor services for local people wanted to consider any further feedback from patients and the public. In particular, while the clinical benefits for patients are compelling, some relatives and carers will have further to travel to visit patients. The CCGs and BSUH were keen to understand the impact of this and what could be done to make things easier for relatives and carers.

Patient and public representatives have been part of the team leading this work from the start and there has been extensive and on-going public and patient involvement throughout the whole process. A further targeted engagement process ran from November 2016 until 31 January 2017 to continue the dialogue with patients, the public and interested groups around the development of local stroke services.

A core approach and materials were agreed centrally, but each CCG decided on its own engagement methods over and above this to ensure engagement was appropriately targeted and proportionate for their area.

The engagement carried out in High Weald Lewes Havens was particularly extensive, reflecting the East Sussex Health Overview and Scrutiny Committee (HOSC)'s request for the CCG to carry out further targeted and proportionate engagement. In addition to the survey carried out by all CCGs, a series of public events was arranged and widely promoted through fliers in 31 GP surgeries and at 24 other public locations such as libraries, shops and sheltered accommodation. Members of the stroke review team also offered to present to meetings of stroke groups and other patient and public groups. In addition to the survey respondents, a further 32 people attended events and meetings in High Weald Lewes Havens.

Over half of the survey respondents thought that the change would improve services, be better for them, or have no impact on them. Feedback from the events and meetings showed that attendees agreed with the clinical rationale for the changes.

The main concern raised by survey respondents was around longer ambulance journeys. However, this concern was not evident in the feedback from the events and meetings, where stroke clinicians had been able to explain that any increase in

the length of journey would be offset by the prompt and enhanced care available at Royal Sussex County Hospital (RSCH).

The other main concerns raised were around the difficulties for relatives and carers visiting RSCH. These included public transport and parking at RSCH and the difficulty of accessing and navigating the RSCH site for visitors who have mobility problems.

The majority of respondents did not have anything to add to what is already planned to minimise the consequences of the changes. However, a range of suggestions were made for how things could be made easier for visitors to RSCH, including improving transport options and parking, and improving signage and accessibility.

A common theme in the feedback on discharge was that carers need particular support as well as patients, and a desire to see greater coordination with other health and care services. There were several suggestions that more information could be provided at discharge on what will happen next, who to call in the event of any concerns, and on the support groups available, both for patients and carers.

People were also keen to see more and better rehabilitation, with therapy starting as soon as possible, and a focus on community therapies to help people to live well after a stroke. Several stressed that rehabilitation should go on for as long as it is needed, not just what is delivered as part of early supported discharge.

There is considerable support for all initiatives that could help people to reduce the severity of strokes or avoid them in the first place. The 'FAST' stroke awareness campaign was highly regarded by respondents and many thought it should be continued and promoted as widely as possible. Suggestions were also made for a greater promotion of stroke prevention messages through primary care and in schools.

## **Introduction**

The NHS is making important improvements to the way people who have a stroke are cared for by local hospitals in Brighton and Haywards Heath.

As a result of a review of stroke services in Sussex, begun in 2014, clinicians have recommended changes to how and where Brighton and Sussex University Hospitals NHS Trust (BSUH) provides its stroke services. BSUH currently provides emergency stroke services at the Royal Sussex County Hospital (RSCH) in Brighton and Princess Royal Hospital (PRH) in Haywards Heath.

Clinicians have recommended that BSUH centralise its emergency stroke services in Brighton.

Before implementing the recommendation, the GP-led clinical commissioning groups (CCGs) that plan, buy and monitor services for local people wanted to consider any further feedback from patients and the public. In particular, while the clinical

benefits for patients are compelling, some relatives and carers will have further to travel to visit patients. The CCGs and BSUH were keen to understand the impact of this and what can be done to make things easier for relatives and carers.

In addition, while clinicians have developed a clear plan for bringing acute stroke care up to the standards of the best, they want to continue improving the whole stroke pathway from prevention through to discharge and rehabilitation. Work will be continuing with patients, carers and the public over the coming months to understand what other improvements would make the most difference.

This report details the feedback received during the period of engagement that ran from November 2016 until 31 January 2017.

The CCGs and BSUH would like to thank all those who have taken the time to get involved and give their valuable feedback to help improve stroke services for local people.

## **Background**

In 2014, a team of specialist stroke doctors, nurses, therapists, GPs and other health and care professionals began a review of stroke services in Sussex. They found that services were not meeting all the standards set out by the National Institute for Health and Care Excellence (NICE). For example, too many people were waiting too long to be assessed by a stroke consultant and to have rehabilitation plans put in place.

The review concluded that much more could be done to improve stroke services and outcomes for local people. BSUH were asked to develop options for how they could meet the clinical guidelines and improve services and outcomes. At the same time, local people were asked what they thought about stroke services so that their views could help shape the options for improvement.

A group of the most senior local clinicians in the region, along with national stroke experts, looked at all the information about local stroke services, the feedback from local people and the options from BSUH. They recommended that BSUH centralise its acute stroke services RSCH. This means that acute stroke services will not be provided at PRH, although specialist inpatient stroke rehabilitation will continue to be provided at the Sussex Rehabilitation Centre at PRH for appropriate patients.

## **Extensive engagement throughout the review**

Patient and public representatives have been part of the team leading this work from the outset and there has been extensive and on-going public and patient involvement throughout the whole process.

The review began in 2014 by collecting the views of over 130 patients and carers on their experience of stroke care. A further specific engagement exercise was carried out during 2015, focused particularly on the clinical care of a stroke. Nineteen meetings and focus groups were held across Sussex and feedback received from over 500 people. Nearly three quarters said they would be happy to travel further to get the best treatment for a stroke (48% very happy, 28% somewhat happy, 26% not very happy, 2% don't know). Their main concern was the impact it would have on relatives and carers.

The recommendation has overwhelming clinical support from GPs across the region, regional and national stroke specialists, local hospital doctors, nurses, therapists, the ambulance service and social services.

County council overview and scrutiny committees are responsible for examining the details and implications of decisions about changes to health services and how those decisions were made. The committees in West Sussex and Brighton and Hove are supportive of the recommendation. In September 2016, the committee in East Sussex asked for some further targeted engagement with people with particular knowledge and interest in the issues.

In September 2016, the CCGs wrote to all groups that had previously been engaged in the stroke review. They provided an update on the recommendation and explained that further feedback on the implications of the changes and how to address any issues would be sought before the recommendation was taken forward.

## **Further recent engagement**

A further engagement process was designed from November. Initially due to end on 16 January 2017, it was extended until 31 January 2017 on 9 December after a request from a stroke group that would not meet again until mid-January. Its purpose was:

- To continue the dialogue with interested groups around the on-going development of local stroke services. In particular:
  - a) To ensure that groups with special knowledge and interest in the issues were aware of the plans for change, how they have been developed and the rationale behind them.
  - b) To generate and collect actionable feedback from individuals and groups with special knowledge and interest to help commissioners and providers to:
    - Fully appreciate the impact of the proposal and mitigate any issues arising from the improvements planned to acute services.
    - Consider what improvements could be made to the post-acute stroke pathway, particularly around discharge and rehabilitation.

A consistent approach to engagement and core materials were agreed centrally, but each CCG was able to tailor the materials and decide on its own engagement methods. This enabled CCGs to ensure that the engagement approach was targeted, proportionate and appropriate for their own areas.

### **Core materials and approach**

Across all CCGs, a core engagement document and feedback form were developed (example at Annex A). An online survey was set up and information placed on each CCG’s website, with a link to the engagement document and survey. The document was sent out to all those groups previously engaged in the review and through each CCG’s established patient and public involvement channels and networks.

### **More extensive engagement in High Weald Lewes Havens**

Reflecting the East Sussex HOSC’s request for further targeted and proportionate engagement in High Weald Lewes Havens, a more extensive approach was taken by the CCG. A series of public events were arranged and promoted through fliers in 31 GP surgeries and at 24 other public locations (see full list at Annex B). In addition relevant stroke groups and other patient and public groups were also invited to request for members of the stroke review to attend their meetings to explain the changes, answer any questions and receive feedback. Three such meetings were arranged although one was cancelled by the organisers due to adverse weather on the day.

In Brighton and Hove and Crawley, Horsham and Mid Sussex, extensive and widespread engagement had already been carried out and overview and scrutiny committees had indicated satisfaction with the process and the resulting recommendation. It was decided that the most appropriate and proportionate approach in these areas was to work through established engagement channels and those individuals and groups that had already been involved in the review.

Details of the engagement carried out by each CCG are set out below.

### **High Weald Lewes Havens engagement activities**

16 Nov	<p>Invites to engagement events sent to:</p> <ul style="list-style-type: none"> <li>• GP Practice Participation Group (PPG) forum chairs and secretaries</li> <li>• County and district councils (and cascaded to town and parish councils)</li> <li>• Community and voluntary organisations</li> <li>• MPs</li> <li>• Lay and PPG members and public stakeholders</li> <li>• All stakeholders previously engaged in the stroke review</li> </ul>
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17 Nov	Fliers promoting the public engagement events distributed to 31 GP surgeries and at 24 other public locations such as libraries, shops and sheltered housing
25 Nov	Engagement document live on website with link to online survey
30 Nov	Uckfield public event
9 Dec	Lewes public event
9 Dec	Engagement document distributed to all previously engaged stakeholders
13 Jan	East Sussex Seniors Association (ESSA) Health & Community Care Theme Group - meeting cancelled due to adverse weather but materials circulated to members with invitation to complete surveys or to contact the programme director to discuss
19 Jan	Lewes Havens Patient and Public Forum meeting
26 Jan	High Weald Locality Patient Representative Group meeting

#### **Crawley, Horsham and Mid Sussex engagement activities**

30 Nov	Engagement document live on website with link to online survey
2 Dec	Document distributed to all previously engaged stakeholders
9 Dec	E-mail to notify all document recipients of extended deadline
Jan	Stroke engagement promoted in public newsletter
12 Jan	Reminder sent to all those contacted in December and to patient reference groups

#### **Brighton and Hove High engagement activities**

9 Dec	Engagement document live on website with link to online survey
12 Dec	Document distributed to <ul style="list-style-type: none"> <li>• All stakeholders previously engaged in stroke review</li> <li>• PPG members</li> <li>• Older People's Council</li> <li>• Community and voluntary sector organisations</li> </ul>

## Survey responses

Following the widespread promotion of the survey and the public meetings, a total of 46 survey responses were received. Of these, 41 were from individuals and five on behalf of groups (High Weald Patient Group, Phoenix Stroke Clubs in Horsham and Crawley and two responses from the Cuckfield Stroke Group).

### Location of respondents

Brighton and Hove	8
Crawley	6
Havens	5
High Weald	2
Lewes	7
Horsham and Mid Sussex	12
Other	1 (Worthing)
Not answered	5

### Respondents' experience of stroke

Have experienced a stroke	10
Have cared for someone with stroke	9
No direct experience of stroke	11
Health professional with experience of stroke	5
Other (i.e. experience of suspected stroke, knows someone who has had a stroke)	5
Not answered	6

## Other responses and feedback from meetings

In addition to the survey responses, feedback was also collected from the events and meetings in High Weald Lewes Havens which were attended by a total of 32 people. Furthermore, two e-mails were received from members of the public in Crawley, Horsham and Mid Sussex. These were responded to individually, and the points raised included in the analysis of the feedback where appropriate.

### Note on the analysis of feedback

This additional feedback has been considered alongside the analysis of the survey responses below. Due to the relatively small number of survey responses, the findings represent important qualitative feedback. Along with the other feedback received they clearly indicate the level of support for the proposed changes, the key issues and concerns that have been raised and how these might be addressed, and what other improvements people would like to see across the whole stroke pathway. The survey results cannot be treated as quantitative results as any differences would not be statistically significant.

## Impact of the proposed change

Survey responses to the following question have been categorised to aid analysis, with some responses being noted against more than one category.

***How do you think the changes proposed for BSUH's stroke services will affect you?***

	<b>Total</b>	<b>Location</b>	<b>Experience</b>
The changes will improve services / be better for me	11	3 x Havens 2 x B&H 2 x Lewes 2 x Mid Ssx 1 x H Weald 1 x Crawley	3 x No experience 3 x Carer 2 x Had stroke 2 x Professional 1 x Other
Concern about ambulance journey times / distance	10	5 x Mid Ssx 2 x H Weald 1 x B&H 1 x Crawley 1 x Havens	4 x Carer 3 x No experience 2 x Other 1 x Not answered
The changes won't affect me	9	5 x B&H 2 x Havens 2 x Lewes	3 x Had stroke 2 x No experience 1 x Carer 1 x Professional 2 x Other
Concern about difficulties of travel / parking / accessibility for families and carers	6	3 x Mid Ssx 1 x Lewes 1 x Havens 1 x Crawley	3 x Carer 2 x No experience 1 x Had stroke
Concern related to impact on BSUH	2	1 x Crawley 1 x Mid Ssx	2 x No experience
Not answered	12		

People were asked how they thought the proposed change would affect them. Among those who responded to this question, over half thought that the change would improve services, be better for them, or have no impact on them. Feedback from the meetings in High Weald Lewes Havens was that attendees believed there was a clinically compelling rationale for the recommended change. The improvements seen in other services that have made similar changes were also noted by meeting attendees.

*"I think it will improve my chances of survival quite a lot."*

Lewes survey respondent

*"I think a centre of excellence is vital."*

High Weald survey respondent

*“It is probably a good thing to send all stroke patients to Brighton if they can get the best care. I certainly think it saved my husband’s life by going straight to Brighton.”*

Mid Sussex survey respondent

*“It will improve overall services.”*

Crawley survey respondent

The main concern that people had was about a longer ambulance journey because of the further distance to Brighton from where they lived or because of the traffic in Brighton. Most of these responses came from people in the Mid Sussex area. The concern was not notable in the feedback from the events, where stroke clinicians were able to explain that any increase in the length of journey would be offset by the prompt and enhanced care available at RSCH.

*“I have paroxysmal atrial fibrillation and am concerned about the additional journey time from Lindfield to the County Hospital in Brighton should I have a stroke.”*

Mid Sussex survey respondent

*“Long and potentially life threatening journey time.”*

High Weald survey respondent

*“I would not be happy with the time it takes for the journey to Brighton.”*

Mid Sussex survey respondent

A significant number of people also raised concerns about the difficulties of public transport and parking at RSCH and several people with mobility problems said they found the RSCH site very difficult to access and navigate. It was noted that travelling to visit a loved one in Brighton was particularly difficult for elderly carers who may themselves have health needs.

*“Travel to Brighton and parking are problematical. This is a basic fault in siting any centre of excellence on the extremity of the area served. This was an historical blunder that we have to suffer and it will continue to be detrimental to the health of the county.”*

Lewes survey respondent

*“The biggest problem is parking. It can cost a lot and can take up so much time waiting for a space when visiting.”*

Mid Sussex survey respondent

*“Will be more difficult for the relatives to visit as bus services are unreliable.”*

Mid Sussex survey respondent

Several respondents wanted assurances that the changes would not impact on other hospital services and took into account expected population growth. One mentioned BSUH being in special measures as a concern with regards to its ability to expand the service.

*“I hope that account has been taken of the increased stroke caseload on Brighton in the 3Ts\* development project and the expanding population in the Mid Sussex area.”* [\*3Ts is the development of the Royal Sussex County Hospital site in Brighton]

Mid Sussex survey respondent

*“Brighton & Sussex University Hospitals NHS Trust is [currently] in special measures, so taking over a full service at this time maybe difficult.”*

Crawley survey respondent

Concerns were raised in the response from one stroke group about the transfer of medical records to the right hospital.

Attendees at the High Weald Lewes Havens meetings also sought reassurances that the changes would not have any negative impact on the inpatient stroke rehabilitation offered by the Sussex Rehabilitation Centre at PRH.

Crawley, Horsham and Mid Sussex CCGs received two e-mails from members of the public. One was highly critical of the proposed change. The other was supportive of the change and asked for further information about what was happening to stroke services in neighbouring trusts.

## Minimising any possible consequences

Survey responses to the following question have been categorised to aid analysis, with some responses being noted against more than one category.

***Do you have anything to add to what is already planned to minimise any possible consequences of the change?***

*Already planned: The BSUH stroke team will be reviewing visiting times to offer more flexibility and preparing a carer's pack that will include information about visiting, ward routines, travel and parking. Outpatient follow up appointments will continue to be held at PRH in Haywards Heath if that is nearer for patients. BSUH have also improved parking for visitors by no longer allowing staff to park in the multi-story car park.*

Improve parking at RSCH	6
Improve signage and accessibility at RSCH (i.e. ensure lifts are working and make it easier for people with mobility problems to get around)	3
Reduce parking costs (and keep appointments to time)	2
Improve bus services	1
Improve ambulance response times	1
Paramedics to give thrombolysis	1
Take appropriate patients to Tunbridge Wells	1
Interim assessment for suspected stroke at Uckfield Hospital	1
Keep services local	1
Nothing to add	8
Not answered	21

Most survey respondents did not have anything to add to what was already planned to minimise any possible consequences.

The majority of suggestions that were made focused on making things easier for visitors to RSCH, including further improving parking facilities, reducing parking costs (and keeping appointments to time to minimise parking costs) and improving bus services. Attendees at one meeting suggested that more support might be available from the voluntary sector to help people with travel to RSCH. Several people wanted to see improvements to make it easier for people with mobility problems to access and navigate the site and problems with the lifts were mentioned several times.

*Parking still requires improvement."*

[Brighton and Hove survey respondent](#)

*"Keep parking costs reasonable. Run appointments to time as much as possible so that parking costs are kept down."*

[Havens survey respondent](#)

*“Car parking is much in need of more spaces and bus services could be improved. Wheelchair access is woefully inadequate.”*

Mid Sussex survey respondent

*“Going to the RSCH can be a nightmare when the lifts are out of order as has happened on many occasions to myself and I am on crutches. This is unforgivable and should be addressed.”*

Havens survey respondent

Following on from concerns about ambulance journey times, several survey respondents and meeting attendees wanted to be assured that the ambulance service was able to respond promptly to suspected strokes.

*“The ambulance service consistently fail to meet the 8 minute Red 2 target in this rural area and that must be addressed.”*

High Weald survey respondent

Several people wanted to see services as local as possible, queried whether some stroke services could be available at other locations, whether paramedics could do more for stroke patients en-route to hospital and wanted assurances that patients would be taken to other acute stroke units if they were nearer.

*“Will paramedics be trained to use clot busting drugs where appropriate?”*

Mid Sussex survey respondent

*“Provide interim assessment facilities at Uckfield hospital.”*

High Weald survey respondent

*“Surely these proposals do not discount Tunbridge Wells?”*

High Weald survey respondent

One stroke group queried whether outpatient follow up appointments could be held at Horsham Hospital if that was more convenient for patients.

## Improving discharge

***Do you have anything to add to what we have already heard about what works well and what could be improved about stroke discharge?***

*Through previous engagement we had already heard: Many people reported feeling lost when they were discharged, with a lack of follow up and little information on the support available. Some identified a lack of coordination between hospital, community and social services.*

The majority of survey respondents did not answer this question or had nothing to add to what we said we had already heard. Among those that did respond, and in

the feedback from the events, a common theme was that carers need particular support at the time of discharge, as well as the patient.

There were several suggestions that more information could be provided at discharge on what will happen next, who to call in the event of any concerns, and on the support groups available, both for patients and carers.

*“If all patients and their relatives were given some type of aftercare guide it would be really helpful. After all, from a safe environment we are discharged into lions’ jaws.”*

Havens survey respondent

*“When discharged I was given no advice on the services available. Struggled to make my own way and at times still do!”*

Brighton and Hove survey respondent

Several wanted to see carers more involved from the start of the discharge process.

*“Support for carers earlier.”*

Mid Sussex survey respondent

*“Carers need to be part of the discharge process.”*

Crawley survey respondent

A desire to see a greater coordination with (and availability of) other health and social care services was also expressed by several respondents and meeting attendees.

*“We all know about the extreme problems with funding for social care. This is clearly an essential service if people are to have the confidence to return to life in the community after a stroke. One would like to see some evidence of work done on coordinating services and on funding better provision.”*

Lewes survey respondent

*“Social services were inadequate and non-responsive.”*

Mid Sussex survey respondent

Several respondents commented that their experience of discharge had been very positive.

*“No. The staff were exceptional and explained each and every test etc.”*

Havens survey respondent

*“I was not feeling lost. I had lots of support. My stroke was in 2011 and all the support I got was great. But I don’t think it is as good today.”*

Mid Sussex survey respondent

## Rehabilitation

***Do you have anything to add to what we have already heard about what works well and what could be improved about stroke rehabilitation?***

*Through previous engagement we had already heard: Priorities for life after stroke were information, regular reviews and regaining independence. Therapy – that starts as soon as possible, and continues for as long as it is needed – was important. The emotional and practical impact of stroke needs as much focus as the physical symptoms.*

The majority of survey respondents did not answer this question or had nothing to add to what we said we had already heard. Among those that did respond, and in the feedback from the events, common themes were similar to what was heard through the previous engagement. This included a desire to see more and better rehabilitation, with therapy starting as soon as possible, and a focus on community therapies to help people to live well after a stroke. It was stressed by several that rehabilitation needs to go on for as long as it is needed, not just what is delivered as part of early supported discharge.

*“You need to meet SSNAP Category B consistently at worst but A should be expected of such a specialist unit.”*

High Weald survey respondent

*“We need to ensure there is better specialised rehab for stroke patients.”*

Crawley survey respondent

*“Therapy discontinued too soon.”*

Mid Sussex survey respondent

One stroke group thought it was important that patients should know how much therapy they should expect. They queried whether access to therapy was equitable and whether all patients are aware of what they are entitled to.

Several people raised a concern about whether enough specialist rehabilitation staff, especially speech and language therapists, were available to deliver the improvements that were hoped for.

*“The shortage of SALT and other support professionals is a serious issue.”*

High Weald survey respondent

*“If there is not enough staff for a stroke unit at each hospital, how are you going to [offer the best rehabilitation]?”*

Mid Sussex survey respondent

It was also suggested that it would be good if stroke rehabilitation had the same emphasis as with other illnesses, for example the services provided by Macmillan nurses. The cardiac rehabilitation service was also cited as a good example.

*“Look at the current Cardiac Rehab services. All eligible patients are seen, allocated a nurse specialist whilst in hospital and followed up. Also referred to other hospitals if non local - it works!”*

Brighton and Hove survey respondent

One stroke group said that regular reviews, involving the family or carers, were needed. They also raised the need for mental health screening and felt that that counselling should be offered to both patients and their carers.

One respondent thought that inpatient stroke rehabilitation should be provided on a dedicated ward.

*“Level 2 rehab needs to be local and kept on a separate ward. Mixing stroke patients with others gives poorer outcomes.”*

Crawley survey respondent

## Prevention

***Do you have anything to add to what we have already heard about better promoting stroke prevention messages?***

*Through previous engagement we had already heard: People feel reasonably well informed about stroke, symptoms and what they should do if a stroke is suspected but less knowledgeable about prevention. Changing lifestyles is seen as key to prevention and there is scope for greater public awareness campaigns.*

The majority of survey respondents did not answer this question or had nothing to add to what we said we had already heard. However, the issue was discussed extensively at the public events and meetings where there was a great deal of understanding and support for all and any initiatives that could help people to reduce the severity of strokes or avoid them in the first place.

Among survey respondents, many mentioned the ‘FAST’ campaign. It was well received and many thought it should be continued and promoted as widely as possible, including through social media. Several people also mentioned greater promotion of prevention messages in primary care. Several respondents also thought that schools could play a greater role in promoting stroke prevention messages to children.

*I thought the ‘FAST’ adverts on TV were excellent, but of course are expensive. More posters perhaps in public places like libraries, surgeries etc? Not so effective but cheap!”*

Lewes survey respondent

*"I think the FAST message is the best and stands out in people's minds."*  
Havens survey respondent

*"Primary care needs to highlight the risks."*  
Brighton and Hove survey respondent

There were various suggestions for supporting people to reduce lifestyle-associated risks. These included public services setting a better example through their staff and the food and drink they sell on their premises, and making school gym facilities available for the wider public to use.

*"As one example: stopping sale of fattening products, such as fizzy drinks in NHS and local authority premises (they have a prevention role!!). Convincing NHS staff that obesity does not set a good example."*  
High Weald survey respondent

*"Maybe the usage of local schools that have gym space available would help."*  
Lewes survey respondent

Medication for atrial fibrillation was discussed in several of the meetings and it was suggested that many patients could be better supported to make a choice about which atrial fibrillation medication is preferable for them.

## **Analysis of feedback by CCG area**

### **High Weald Lewes Havens**

The engagement in High Weald Lewes Havens was particularly extensive. Targeted engagement with those groups and individuals with particular knowledge and interest in the issues was supplemented with a broader engagement with the wider public. In addition to the 14 survey responses received, a further 32 people were involved through events and meetings.

The majority of survey respondents from High Weald Lewes Havens did not raise any concerns about the changes. Six of the fourteen thought that the changes would improve services and a further four thought they would have no impact on them personally. Feedback from the events and meetings showed that attendees agreed with the clinical rationale for the changes.

The concerns that were raised by High Weald Lewes Havens respondents mirrored those raised elsewhere, namely a concern about longer ambulance journeys and difficulties for relatives and carers visiting RSCH. Concern about ambulance journeys was not notable in the feedback from the events, where stroke clinicians were able to explain that any increase in the length of journey would be offset by the prompt and enhanced care available at RSCH.

Suggestions for minimising the possible consequences of the changes from High Weald Lewes Havens respondents were consistent with those made by respondents from elsewhere, as was the feedback on improving discharge, rehabilitation and prevention.

### **Crawley, Horsham and Mid Sussex**

A high proportion of the survey responses came from people in the Crawley, Horsham and Mid Sussex area and four responses were received from stroke groups in the area, reflecting the high level of involvement these groups have had throughout the review.

Concerns about longer ambulance journeys and difficulties for relatives and carers visiting RSCH were highest from respondents from this area, which is unsurprising given that PRH is their main local hospital. However, many respondents still acknowledged the clinical benefits of the changes. Many helpful suggestions were made for how the impact of the changes can be mitigated.

Feedback on improving discharge, rehabilitation and prevention was consistent with that received from respondents elsewhere.

### **Brighton and Hove**

Unsurprisingly, given that RSCH is already their local acute stroke unit, half of the respondents from Brighton and Hove felt that the changes would not affect them, while two recognised that the changes would improve services overall. Several respondents did make suggestions for improving parking and accessibility at RSCH.

Feedback on improving discharge, rehabilitation and prevention was consistent with that received from respondents elsewhere.

## **Conclusion**

The views of patients and the public have been central to the stroke review since it began in 2014.

The feedback received through the most recent engagement exercise reiterates the findings of the 2015 engagement which showed that most people who gave their views are supportive of the proposed change. While a significant number of people are concerned about the change, more people are in agreement with the clinical rationale for change or believe that the change will result in improved services and outcomes for local people.

Among the concerns raised, the most frequent is about the impact of longer ambulance journeys. However, it was noted in the events that this concern is reduced when people are reassured by clinicians that the impact of any increased

length of journey would be offset by the prompt and enhanced care available at RSCH.

Concerns also remain about the impact on relatives and carers for whom RSCH is less convenient. Common issues were also raised about parking, transport and accessibility generally for all visitors to the RSCH site. However, the feedback includes various suggestions for mitigating some of these problems that will be further explored by BSUH and the CCGs.

The feedback also includes a range of issues and ideas for stroke services and commissioners to consider as they continue to improve arrangements for stroke discharge, rehabilitation and prevention.

The CCGs and BSUH would like to reiterate their thanks to all those who have taken the time to get involved and give their valuable feedback to help improve stroke services for local people.

## **Annex A**

### **Engagement document and feedback form**

Attached separately. Example also available from:

[www.crawleyccg.nhs.uk/EasySiteWeb/GatewayLink.aspx?alld=443670](http://www.crawleyccg.nhs.uk/EasySiteWeb/GatewayLink.aspx?alld=443670)

## **Annex B**

### **Locations where HWLH events were promoted**

Public engagement events were promoted through fliers distributed to 31 GP practices and 24 other locations:

#### Uckfield

- Sheltered housing, Streatfield House
- Sheltered housing, Baker Court
- Sheltered housing, Margaret's House
- Citizens Advice
- Copperbeech Care Home
- St Thomas a Beckett Church, Framfield
- St Bartholomews Church, Maresfield
- Tesco
- Uckfield Library
- Uckfield Hospital

#### Lewes

- Two pharmacies
- Citizens Advice
- Two charity shops
- Yorkshire Building Society
- Phoenix Community Centre
- Tesco
- Costa
- Lewes Library
- Barons Down Care Home
- Sheltered housing
- Lewes Victoria Hospital

#### Forest Row

- Forest Row Library