

HEALTH SCRUTINY PANEL

22 OCTOBER 2009

**STROKE SERVICES
DRAFT FINAL REPORT**

PURPOSE OF THE REPORT

1. To appraise the Health Scrutiny Panel of the evidence collected so far regarding Stroke Services in Middlesbrough.
2. To introduce representation from Middlesbrough PCT and *Positive Strokes*, in attendance to discuss the evidence collected so far and discuss the DRAFT Conclusions and Recommendations.

RECOMMENDATIONS

3. That the Panel considers the evidence outlined below.
4. That the Panel discuss the evidence outlined below with the PCT and Positive Strokes representation at today's meeting and discusses whether any further evidence is required, before consideration is given to the DRAFT conclusions and recommendations.

CONSIDERATION OF REPORT

5. In advance of receiving detailed information from the local NHS pertaining to local stroke services, the Panel felt it would be useful to receive a briefing on essential Stroke information. This included such as the different sorts of strokes, stroke incidence and risk factors.
6. To receive this briefing, the panel heard from the Regional Manager of the *Stroke Association*.
7. The panel heard that the *Stroke Association's* vision and mission were respectively;

'we want a world where there are fewer strokes and all those touched by stroke get the help they need';

'our mission is to prevent strokes and reduce their effect through providing services, campaigning, education and research;'

8. The Stroke Association has a number of regional centres, one of which is the North East. The main strands of work centred on campaigning for stroke services; encouraging and identifying ways of funding research; and providing information and publicity material examples of which were made available at the meeting.
9. In terms of statistical background, the Panel heard that currently one person every five minutes had a stroke in the UK and that strokes killed 60,000 people per year and quarter of a million people lived with the consequences of a stroke.
10. Strokes are the third major cause of death in the UK with 110,000 new strokes a year and 20,000 TIA's (mini strokes). Twenty five per cent of strokes occurred to those under 65 and 300,000 lived with the effect of stroke along with those who cared for them. It was noted that an increasing number of young people between the ages of 20 – 30 years had strokes.
11. The Panel heard that the overall current costs of strokes were identified as follows: -
 - 11.1 £2.8 billion in direct costs to NHS which was more expenditure than coronary heart disease;
 - 11.2 £1.8 billion costs in lost production and disability;
 - 11.3 £2.4 billion in nursing home and personal care.
12. A stroke was defined as a 'brain attack' when the blood supply to part of the brain was cut off. Blood carried essential nutrients and oxygen to the brain. Without such a blood supply, brain cells could be damaged or destroyed.
13. The two main types of stroke were identified as Ischaemic stroke, which was the most common type, caused by a blood clot in the brain and a Haemorrhagic stroke caused by a bleed in the brain.
14. A Transient Ischaemic Attack (TIA) was also known as a mini stroke and occurred when the brain's blood supply was briefly interrupted.
15. The Panel heard that common problems after a stroke include problems of weakness, clumsiness or paralysis; swallowing; speech and language; understanding; eyesight; recognising objects and knowing how to use them; concentration of paying attention and remembering; and difficulty in controlling emotions.

16. It was said that some of the major risk factors and lifestyle issues in relation to strokes included inactivity, age, family history and ethnicity, high blood pressure, heart disease, diabetes, smoking, obesity, unhealthy living, oral contraception & Hormone Replacement Therapy, previous strokes and TIAs, binge drinking and substance abuse.
17. The Panel was referred to the Department of Health document, National Stroke Strategy, December 2007, which involved the culmination of the work of six project groups and wide consultation exercise and had resulted in a significant number of recommendations.
18. The Panel was briefed on the five parts of the strategy. The first part related to raising awareness the aims of which were to make sure the public and professionals understand what can cause a stroke, the symptoms of a stroke, and what to do if someone has a stroke and to make sure people who have a stroke and their carers are involved in making decisions about treatment and in designing stroke services.
19. Experience had shown that many people including some GPs did not see stroke as an emergency and there was insufficient information for people with stroke or their carers. It was noted that many people from socially deprived areas and BME communities were more likely to have strokes and to have less awareness on the correct course of action.
20. In relation to pathways of care, the strategy aims were reported as assessing people who had a TIA quickly to minimise the chances of them having a full stroke and to treat people with suspected stroke as medical emergencies to maximise their chances of making a good recovery.
21. Current research showed that only a third of people who had a suspected TIA saw the appropriate experts within 7 days and only a few hospitals and ambulance services could deal with strokes quickly and with the right treatments.
22. In terms of life after a stroke the strategy's aims were to help people who have had a stroke, and their family and carers, have a good quality of life and to make sure people who have had a stroke get the support they needed to live as independently as possible.
23. The Panel was told that although improvements had been made since the introduction of the Stroke Strategy it was stated that:
 - 23.1 only about half the people who have had strokes get the rehabilitation they needed to live at home during the first six months after they had left hospital;
 - 23.2 three-quarters of younger people wanted to go back to work after a stroke;
 - 23.3 a third of people who have had a stroke developed depression;

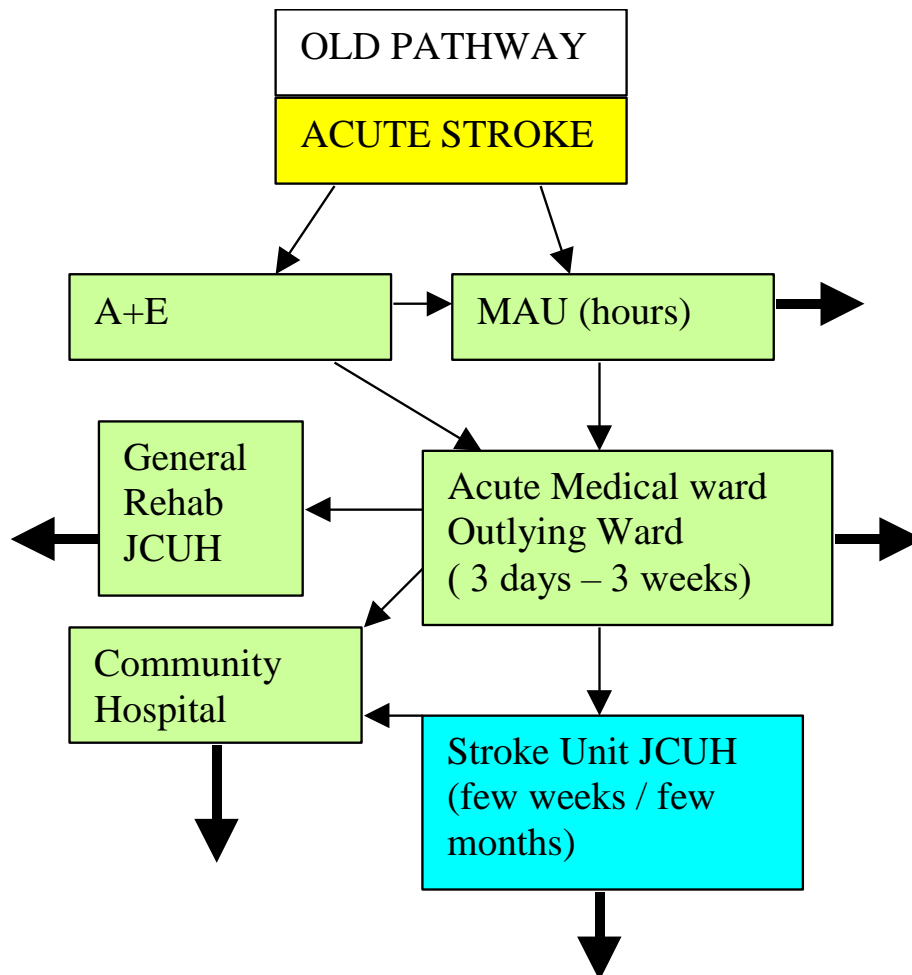
- 23.4 a third of people had problems with speech or understanding;
- 23.5 currently about a third of people died within three months of having a stroke.
- 23.6 Reference was made to the part of the strategy headed 'working together' the aims of which were to make sure services continued to improve and that people who had had a stroke or were at risk of stroke, and their carers got care from people with the right knowledge, skills and experience.
- 23.7 Evidence showed that many stroke units had insufficient staff with the right skills and not everyone got the help with rehabilitation they needed.
- 24. The implementation of the Stroke Strategy had led to five demands from stroke survivors for future services;
 - 24.1 Stroke must be treated as a medical emergency at all times;
 - 24.2 all stroke patients must be taken immediately to and spend the majority of their time in a stroke unit;
 - 24.3 all stroke survivors must receive a smooth transition from hospital to home;
 - 24.4 all stroke survivors must receive all the rehabilitation and long-term support that met their specific needs;
 - 24.5 all transient ischaemic attacks (TIAs/mini strokes) must be treated with the same seriousness as a stroke.
- 25. Reference was made to the incidence of stroke in Middlesbrough of 400 per year admissions to the dedicated stroke unit at James Cook University Hospital and 20 – 30 per week covering the South Tees area going through TIA clinics.
- 26. Reference was made to the commitment of the South Tees Hospitals NHS Trust stroke services, which included: -
 - 26.1 Stroke Co-ordinator in post to ensure appropriate services in place;
 - 26.2 Dedicated Stroke Consultant;
 - 26.3 Dedicated Stroke unit;
 - 26.4 Community based/acute based Therapy teams;
 - 26.5 Community Hospital rehabilitation Beds at Carter Bequest Hospital;
 - 26.6 Dedicated Family Care Support Services provided by Stroke Association, funded by the Primary Care Trust and based at Carter Bequest Hospital;
 - 26.7 Dedicated Communication Support Services;
 - 26.8 Intermediate Care facilities;

- 26.9 24 hour Access to Thrombolysis Treatment – Middlesbrough was ahead of other areas in prescribing such treatment which had to be administered within four hours of stroke;
- 26.10 Multi Agency Rehabilitation review (report and recommendations to be submitted a copy of which would be made available to the Panel).
27. Members sought clarification on the funding attached to the Stroke Strategy. It was confirmed that Middlesbrough's allocation (ring-fenced) was £90,000 per year over a period of three years from April 2008. Such funding had been utilised on employing a Stroke Co-ordinator and a Dedicated Stroke Social Worker; contribution towards Communication Support Services; and for the implementation of stroke training programmes for such people as residential care workers and home care workers to raise awareness to the needs of patients and carers.
28. Reference was made to the significant work undertaken by the Panel as part of its review of Life Expectancy with a particular focus on cardiovascular disease in Middlesbrough an important element of which related to the need to pursue appropriate preventative measures. The similarity of such areas of work between CVD and strokes was acknowledged and therefore the Panel was mindful to give careful consideration to the parameters of the proposed scrutiny investigation of Stroke Services.
29. It was confirmed that Thrombolysis treatment was a drug which had to be administered in hospital after a patient had had a brain scan.
30. The Panel was keen to seek how JCUH compared with others in the North East region in terms of its stroke services. Mr Moore reported that from his perspective JCUH was one of the best in the region but indicated that other areas had dedicated preventative services and some had better rehabilitation facilities. It was noted, however, that the Multi Agency Rehabilitation Review would help to address such issues.
31. Specific reference was made to the current public campaign FAST (facial, arm, speech, time) to raise awareness that a stroke was a medical emergency and needed prompt action and early treatment. It was considered that the response to such a campaign had been good and had resulted in an increased number of people going to hospital and receiving Thrombolysis treatment.

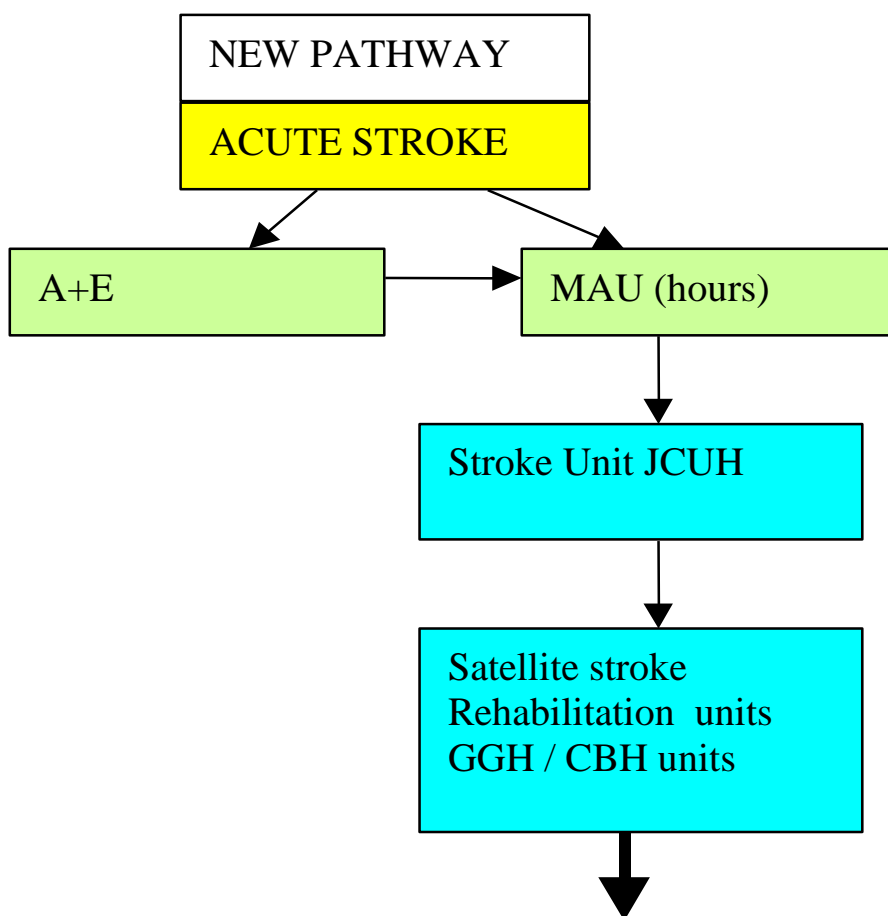
A visit to James cook university hospital

32. Before the Panel engaged in detailed conversations with local health and social care professionals, The Chair and Vice Chair (with a support officer) attended a visit at the Stroke Unit at James Cook University Hospital. The purpose of the visit was for Members to familiarise themselves with the hospital based services for Stroke.

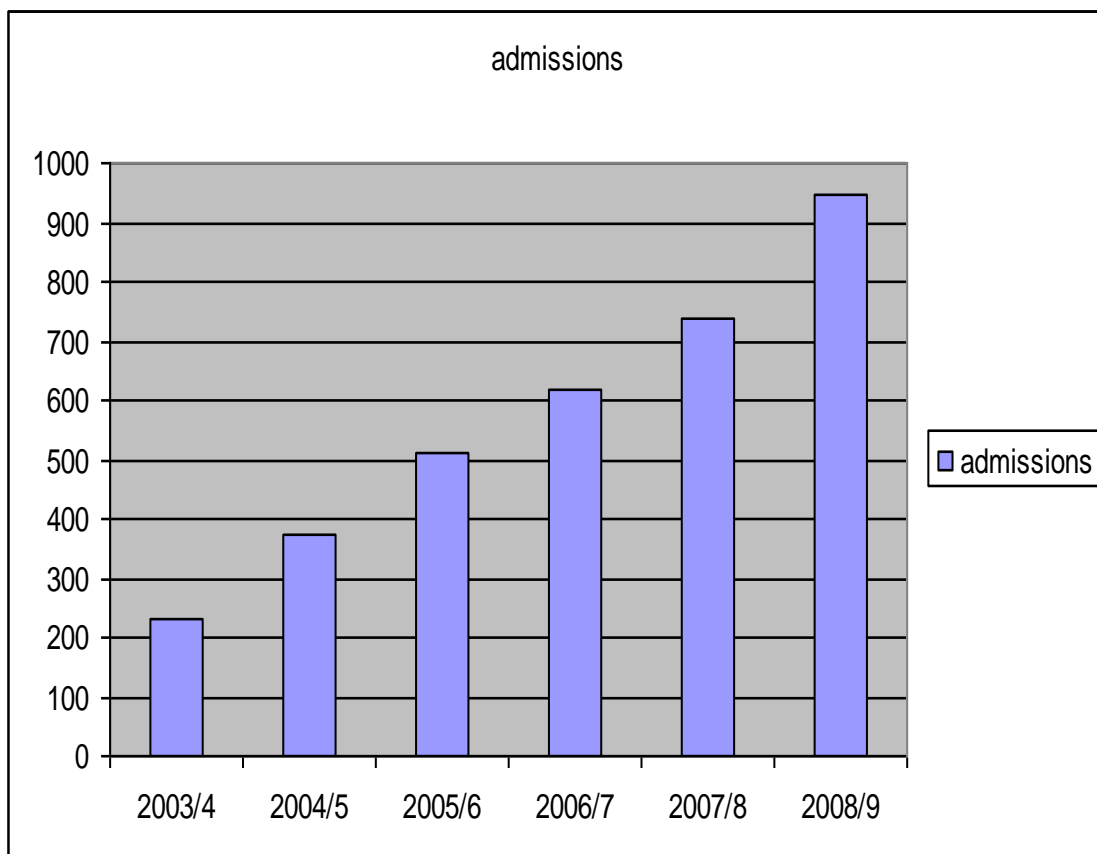
33. Before having a guided tour of Stroke facilities at JCUH, the Chair & Vice Chair of the Panel received a briefing from clinical and non-clinical staff, responsible for the treatment of Stroke and the management of the Stroke Unit.
34. Members were given some initial background as to the origins of Stroke Services across the South of Tees area. It was said that prior to 1994, Stroke patients' were managed on a general medical ward and there was no specialist Stroke Unit. In 1994, a 20 bed Stroke rehabilitation ward opened at South Cleveland Hospital, which is now JCUH.
35. By 2002, the reorganisation of hospital services in Middlesbrough was complete and all acute services were concentrated onto a single site, which is now JCUH. Members were also advised that there are also 4 community hospitals across South of Tees with elderly and GP beds.
36. Outlined overleaf is the former 'Patient Pathway' for Stroke patients, which was taken out of operation in 2004 and the new pathway which replaced it.



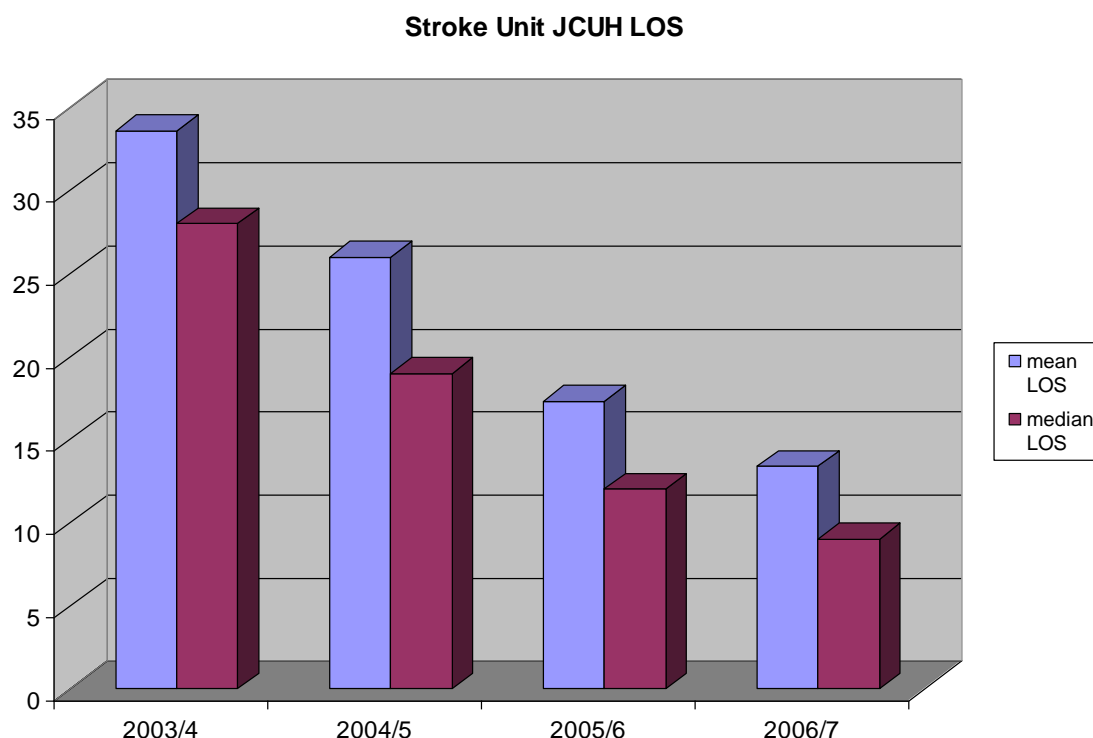
New Pathway Model



37. Members were advised that the National Service Framework (NSF) for Stroke had been a significant catalyst for change in addressing Stroke Services and three major pieces of work informed the development of the service. Those were a major Stroke Stakeholder event, an audit of rehabilitation services for older people and the results of the National Sentinel Stroke Audit.
38. Members heard that fundamental aim behind the changes to the Stroke Pathway, was to ensure an increase in the number of suspected Stroke patients accessing specialist stroke services. It was said that this done by changing the role of the Stroke Unit to acute/early rehabilitation. Further, developing stroke rehabilitation services has been identified as a priority. There has been an increase in therapy input into Carter Bequest Hospital and the use of up to 10 beds for stroke rehabilitation.
39. A number of other positive developments were mentioned including the development of a user and carer group, the appointment of a Stroke co-ordinator, a family support worker and daily TIA clinics. The unit also has consistently good performance in the National Sentinel Stroke Audit, whilst offering Thrombolysis (first patient treated July 2007). It also provides a '24/7' Thrombolysis service, which is one of only 37 units out of 210 nation-wide to offer this.
40. The following graph offers some information on the number of admissions to the Stroke Unit. It should be noted that not all admissions actually have a Stroke has some conditions can mimic the symptoms of a Stroke.



41. The following graph indicates that Stroke Unit's Length of Stay (LOS) and demonstrates the increasingly efficiency of the department. The reducing length of stay also highlights the effectiveness of early and assertive treatment such as Thrombolysis. Reducing LOS also highlights the importance of effective and efficient community rehabilitation services, if more of a patient's rehabilitation will take place in the community.



42. The following graph also highlights the improved percentage of patients reaching the Stroke Unit and the substantially increased percentage of patients receiving most of their care on the Stroke Unit and the reduced the delays in transfer.

	Admitted to stroke unit	> 50% stay on SU
2002	50%	42%
2004	63%	60%
2006	89%	85%
		>90% stay on SU
2009	95% (74% Nat)	85% (58% Nat)

43. Members were keen to speak to professionals at JCUH regarding the challenges that Stroke still posed and where matters could be improved further. It was said that there are a number of areas which could be improved.
44. Awareness of people to the dangers and symptoms of Stroke remains an area of concern. Only 8.3% of Stroke patients at JCUH receive thrombolysis, which is only useful for Stroke if it is administered in the first three hours after a Stroke. Whilst it is true that thrombolysis only works on certain sorts of Strokes, the Panel heard that another reason for such a low rate of thrombolysis was to do with a lack of awareness in people about Stroke and the lack of speed with which people access specialist assistance.
45. The Panel was interested to hear that for patients from areas of affluence, such as parts of North Yorkshire, the rate of thrombolysis was over 10%, whereas in areas of higher deprivation the rate could be as low as 3 or 4%. This, it was said, is largely attributable to people from the more affluent areas having more awareness of Stroke symptoms and the appropriate course of action when a Stroke is suspected.
46. It was said that not enough people were treating Strokes (or suspected Strokes) as a medical emergency and approaching their GP for advice, when a major factor in dealing with a Stroke is accessing appropriate specialist care as soon as possible. It was therefore emphasised to Members that awareness of Stroke in the public consciousness is probably not where it needs to be and requires a great deal more work.
47. Members also heard the views expressed that people in Middlesbrough are quite well served for Stroke services in an emergency sense. It was said, however, that there are a number of deficiencies in how the local health and social care economy deals with the rehabilitation of people with Strokes, particularly around speech therapy, physiotherapy and Occupational Therapy.
48. Whilst there are facilities in Carter Bequest, it was said that community services to help people after having a Stroke.
49. The Chair & Vice Chair were keen to ask professionals about the sorts of things that were considered to be 'goals' for Stroke Services in the future. It was said that a major goal of all involved in the treatment of Strokes should be to increase the awareness of Strokes, the symptoms and the urgency of accessing treatment when a Stroke or TIA has taken place. It was said that a fully functioning and sufficiently resourced hyperacute stroke unit would only really deliver on its potential, if there was a greater awareness of Stroke and those requiring the facilities used them.
50. Members heard that another issue is that not all people entering JCUH with suspected Stroke presently are seen by a Stroke specialist, which is

a result of not having a full rota and it was said that this needs to change. Members heard that greater investment would be necessary for this, which would require a business case to be submitted to the PCT, although it could also be argued that extra clinical posts should be funded under the existing tariff.

51. The view was put forward that a specialised Stroke Unit would be advantageous at JCUH, in a similar vein to a Cardiac centre. A principal feature of Cardiac Units centre of the fact that those entering the hospital via an ambulance with a suspected heart attack would go straight to a cardiac unit, rather than being triaged in Accident & Emergency. A Stroke patient currently goes to Accident & Emergency for triage before arriving at Stroke Unit for appropriate treatment.
52. Members heard that in the view of clinical staff at JCUH, a Stroke Unit would be able to provide a lot of support services to patients, carers and families in addition to the clinical services that would be expected. The Panel has learned that the topic of specialised Stroke Units, where patients would circumvent traditional Accident & Emergency are the subject of some debate and disagreement within those dealing with Strokes, as the Panel explores later in the report.
53. It was emphasised again that Stroke awareness in Middlesbrough is poor and that a lot of people, including some General Practitioners, do not seem to appreciate that Stroke is a medical emergency. It was said that too few people in Middlesbrough present with a Stroke and too many people seemingly dismiss them as 'funny turns', especially when it comes to TIAs. It was stated that a major goal of the service would be to ensure that all high risk suspected TIAs receive an assessment within 24 hours.
54. Members were particularly interested in the BME community and their ability to access Stroke Services, given the BME communities' particular risk factors around such conditions as Diabetes and Hypertension¹.
55. Members heard that, in the view of clinicians, the BME population was significantly under represented in the cases that the unit dealt with, even

¹ It has been well documented that people from the BME communities have a high representation of health conditions such as diabetes and hypertension as compared to their white counterparts. This means that they run a higher risk of suffering from stroke (e.g. south Asians in UK face higher risks of stroke according to Dr. Pankaj Sharma; General practitioner and 'Hypertension: Diagnosis and Management in Ethnic Minorities, Dr. Neil Chapman, and Geriatric Medicine). Another issue that faces BME communities is that stroke occurs at lower age groups (Stroke Association fact sheets '**Stroke in African-Caribbeans**'). Stroke is the third most common cause of death and the largest cause of disability in the UK It is therefore imperative that these facts be brought to the attention of BME communities so that they can be well informed and to take appropriate measures to prevent it from happening and to access the available services once stroke has happened.

Please see

http://afiyatrust.org.uk/index.php?option=com_content&task=view&id=224&Itemid=56

when it is considered that the BME makes up around 7.5% of the 138,400 population², which equates to around 10,300 people. This is an area of concern to Members. It would appear that a significant amount of the population, which has an added susceptibility to Strokes, do not seem to be presenting at the Stroke Unit and accessing the services they require. As such, the Panel can only guess that Strokes are going undiagnosed and people are enduring worse health outcomes than necessary. This is a topic that the Panel expressed an interest in exploring further.

56. Following initial briefings and the visit to JCUH, the panel was keen to hear about regional expectations and standards pertaining to Stroke Services. The panel heard from the regional co-ordinator of the North East Cardiovascular Network (NECVN).
57. The panel heard that the NECVN is not a statutory organisation and therefore is not required to deal with performance management type information or deal with financial commitments. The improvement and development of Stroke Services has been devolved from NHS North East (SHA) to the NECVN. The Panel noted that the performance management of stroke services remains the responsibility on NHS North East. As a network, it is most interested in the quality of services that are provided and the outcomes for patients. It was confirmed that the NECVN has a mandate to work across all relevant services.
58. In advance of the meeting, the Panel supplied a number of questions to the NECVN to consider and they were addressed in a paper submitted to the Panel.
59. The first area that the Panel asked about was the service standards currently demanded of Stroke Services that a patient could expect to receive when they suffer a suspected Stroke. The Panel heard that there are national 'must do' targets in place for Stroke which are considered as Tier 1 under the *Vital Signs* targets. They are:
 - 59.1 Patients who spend at least 90% of their time on a Stroke Unit
 - 59.2 TIA cases with a higher risk of stroke who are treated within 24 hours
 - 59.3 The panel heard that these indicators are considered to be a good proxy for reducing disability and death due to stroke
60. The Panel heard that when the above targets were first established in 2004, it was considered that 56% of people with a stroke spent the majority of their time in a stroke unit and 35% of people with a risk of TIA are treated in 7 days. The panel heard that the expected position by the end of 2010/11 is to ensure that 80% of people with stroke spend at least

² Figure obtained from the Middlesbrough Local Area Agreement 2008-11, 2009 Refresh.

90% of their time on a stroke unit and 60% of higher risk TIA cases are treated within 24 hours.

61. The panel was told that other standards are also in existence such as the national clinical guidelines for Stroke which are produced by the Royal College of Physicians, in existence since 2000 and updated in 2008. The Royal College of Physicians is also responsible for the process to support the national sentinel audit for Stroke. The Panel heard that this audit has been active for the last six years and has demonstrated that care has improved significantly over this period of time.
62. Whilst this was to be welcomed, the Panel heard that there is no room for complacency. Further, the Panel heard that Stroke data has historically been collected using different methodologies and at times not necessarily recorded properly, which is now being corrected, although some historical data is open to question.
63. The Panel heard that the region's stroke services are providing excellent care which is often down to the commitment and quality of staff within hospitals and their different services. The Panel heard that historically, Acute Trusts have not been particularly good at 'looking around' at what other Trusts do and they have concentrated on themselves, which is a mindset which needs to be challenged.
64. The Panel heard that following the publication of the *National Stroke Strategy* in December 2007 the NECVN is planning to improve stroke services even further to provide up to date, best evidence based practice to all patients and their carers in the North East. This strategy is a 10 year plan however the Network plan (covered by NHS North East and the North Yorkshire and York PCT area of NHS West Yorkshire) is to implement the biggest changes within the first 3 years.
65. The Panel heard that two network standards are subject of a great deal of attention presently around the network. They are the network standards for hyperacute³ services and TIA care. It was said that network standards around such areas would assist in driving up standards and also help in ensuring equity of care across the area. It was confirmed that the NECVN would be most interested in focusing attention on quality of care issues as opposed to sticking stringently to services 'hitting targets'.
66. The importance of hyper acute services following a stroke was discussed, including the importance of stroke specialist staff seeing stroke patients. Not for the first time, it was emphasised to the Panel that having this specialist advice available when it is needed most has a huge impact on the outcome for a patient from whether or not they survive the

³ By way of definition, it was explained to the Panel that 'hyperacute' refers to the 72 hours immediately after a Stroke.

stroke up to and including the sort of recovery they can expect to have and the level of disability they may be left with.

67. It was emphasised that the town of Middlesbrough is fortunate to have JCUH on its doorstep, where a '24:7' specialist Stroke service is available, which includes thrombolysis. It was emphasised to the panel that thrombolysis is crucial to counter the early impact of a Stroke as without it parts of the brain can die and be put beyond use. The panel heard that the patient has to receive it within three hours of having a Stroke and the fact that it is available '24:7' in Middlesbrough is very positive for local people. It was said to the panel that a number of other hospitals in the north east only offer it within the hours of nine to five.
68. The Panel was keen to hear the views of the NECVN about whether suspected Stroke patients should go into a specialised Stroke assessment unit, or continue to use Accident & Emergency as their 'first port of call'. The panel had previously heard from staff at JCUH that a Stroke assessment centre should be patients' first port of call, similar to what happens with a suspected heart attack patient, who would go straight to a Cardiac Assessment Unit.
69. The Panel heard that a suspected stroke patient should be taken to A&E initially, in the view of NECVN. The reason for this is that suspected Stroke patients require a CT scan, which are only available in hospitals due to the size of the equipment required. This represents a critical difference between heart attack patients, when an ECG can be performed in an ambulance, so the paramedics are in possession of much more information about a patient when it is a suspected heart attack, rather than a Stroke. The Panel heard, therefore, that from a triage point of view that A&E is better and possible stroke patients going to a stroke unit when they may not have a stroke. As such, the Panel noted that there is something of a disagreement between the Stroke Services staff at JCUH and the NECVN about the possibility/merit of a specialist Stroke assessment unit.
70. The Panel was keen to hear the views of the NECVN representative on the challenges facing Stroke services.

Awareness

71. Consistent with the message that the Chair & Vice Chair heard at JCUH, the NECVN told the Panel that Stroke awareness in Middlesbrough was not particularly good and something in great need of improvement.
72. Again, the Panel heard that the NECVN has particular concerns over the level of Stroke awareness amongst the BME community, who are under represented in the groups accessing services, but also at higher risk of having a Stroke due to reasons outlined on page 11.

73. The Panel was also told that another group to improve awareness about was General Practitioners (GPs). The Panel heard that according to best estimates, around 50% of Stroke patients make the first call to the GP for assistance, rather than contacting emergency medical services. As such, the Panel heard it was crucial that those working in General Practice increased their awareness of Stroke, its symptoms and particularly what to do if someone contacts General practice with such symptoms. Overall, it was considered absolutely crucial that the message be emphasised to General Practice that Stroke is a medical emergency.
74. The Panel noted that a tendency to contact General Practice when feeling ill (though a Stroke) was at odds with an increasing tendency for people to present at A&E with (by comparison) fairly minor complaints. It was therefore ironic that in such a medical emergency as Stroke, a substantial number of people do not utilise the emergency facilities available. It was suggested that perhaps people are not so certain to contact emergency services, as a Stroke does not necessarily cause pain, only something which is often described as a 'funny turn'. Nonetheless, it was described as completely essential that the message be better communicated that people should seek emergency care when a Stroke is suspected.
75. In connection with people seeking emergency services when suffering from a Stroke, mention was made of TIAs. It was said that people having or who have had a TIA should not be admitted into a Stroke unit, although they should certainly have an outpatient appointment. People having undergone a TIA are at greater risk of having a Stroke and should be monitored accordingly.
76. The Panel was interested to hear the views of the NECVN about the BME community and Stroke Services, especially in light of what Members had heard from staff at JCUH.
77. It was confirmed to the Panel that the BME is indeed a high risk group for Strokes, yet is grossly under represented in Stroke Units' case mix. The Panel heard that a big factor in this is a significant lack of awareness in those communities. The Panel was interested to hear about a pilot project in South Tyneside which was conducting a social marketing exercise, to ascertain how best to engage with the BME community on such matters⁴. The Panel will receive copies of that report when

⁴ The Panel has subsequently queried why the number of BME patients with stroke in hospital was low, given that they had higher risk rates. The Panel has been advised that on some further enquiry at the PCT, while this is true, it is offset by the fact that the age profile of our BME community is young, compared to the age profile of the white community. As stroke prevalence increases with age, this has a significant effect:

For 0-64 yrs, prevalence is between 0.4% and 4.7%

For 65+ yrs, prevalence is between 17% and 36% (higher rate for over 75's)

completed. It was felt that local authorities could assist the local NHS greatly in engaging with such communities, given their experience in such matters.

78. The Panel was interested to hear about the NECVN and partners would like to see Stroke Services in the next three to five years. The Panel heard that The National Stroke Strategy is a 10-year plan to improve stroke services. There will be an intensive push to improve services as much as possible until March 2011. £2.4 million has been ear marked for NHS North East to improve stroke services. Additionally Local Authorities have received central allocations to improve stroke services from a social care perspective.
79. It was said that the following list is an example of the NECVN's priorities to have implemented by March 2011.
80. By using these finances and re-evaluating the use of our current finances NECVN anticipates the following improvements by March 2011
 -
 - 80.1 Improved awareness raising of stroke and TIA leading to rapid assessment, diagnosis and treatment.
 - 80.2 Improved rate of thrombolysis for eligible patients.
 - 80.3 Robust 24/7 hyperacute services and rapid admission to a dedicated stroke unit.
 - 80.4 Improved referral of suspected TIA patients to stroke specialists
 - 80.5 Improved access to imaging services
 - 80.6 Reduced waiting times for vascular surgery.
 - 80.7 Timely assessment of stroke and TIA patients for rehabilitation needs
 - 80.8 Access for all stroke and TIA patients to all aspects of rehabilitation they require, as and when they require it.
 - 80.9 Improved integrated links between health and social care services
 - 80.10 Better signposting of stroke and TIA patients and their carer needs for long term care and support
81. The Panel was interested to hear the NECVN's views about which aspects of Stroke Services were in need of development.

19% of our white community are over 65yrs, but by comparison only 5% of our Asian community are over 65yrs and 0% of the black community. There are only approx. 400 Asians over 65 years, so the numbers are comparatively small (although the numbers should grow unless older Asians chose to migrate to other areas of the country).

82. The Panel was told, which concurred with other evidence received, that Middlesbrough was quite well provided for in a hospital based care sense, with a '24:7' Thrombolysis service at JCUH. It was said that improvements were required in community rehabilitation, with specific emphasis on specialist therapeutic input such as speech therapy and psychological support.
83. It was mentioned that a significant number of working age people have strokes every year and many of those people will have financial commitments such as mortgages or young families which necessitate a return to some sort of paid employment. It was felt that an improvement in the services to assist people in doing this was very much needed, with some degree of urgency. This would include services like Physiotherapy and Occupational Therapy. The Panel heard that one could not underestimate the importance of psychological therapies in helping people to come to terms with having a Stroke. It was said that people can offer suffer a sense of bereavement, loss or anger over their 'losing' of their previous life, as they may lose some ability to perform certain types of paid employment or pursue certain interests that they could, before the Stroke.
84. It was also said that it should be easier for people to access such services sometime after having had a stroke. The panel heard that many people are not necessarily ready to access such services immediately after a stroke and would prefer to take stock for some time. It was said that unless you take such services upon discharge, there is a perception that it is very difficult to re-enter the system to access those services in, say, six months or a year.
85. The Panel heard that joint commissioning was an area whereby a lot of these improvements could be made and the local health and social care economy's attentions should be focused on joint gap analysis work and then joint commissioning with the benefit of the intelligence gathered about gaps or weak points in services.

Evidence from NHS Middlesbrough

86. Following the Panel's consideration of evidence from Stroke Association, South Tees Hospitals NHS Foundation Trust and the NECVN, the Panel was keen to seek the views of NHS Middlesbrough as the prime commissioners for health services in Middlesbrough. The Panel spoke with the Stroke Lead for NHS Middlesbrough, who provided a great deal of information and insight on Stroke Services and also provided a great quantity of additional and background information for the Panel.
87. The Panel heard that historically, it was widely accepted that Stroke Services had to improve and the vast majority of efforts were, understandably, put into improving Stroke Services at hospitals, when

the patients needs are at their most acute. It was said that the publication of the National Stroke Strategy and the development of the NECVN had helped considerably in raising standards in acute Stroke Services. Once people arrive into JCUH with a Stroke, they are progressed onto the Stroke Unit very quickly, where high quality staff delivers a specialised service.

88. The Panel heard it was now widely accepted that a similar focus was now being placed on rehabilitative services, in an attempt to bring about similar scale improvements. The panel heard that a great deal of work had recently been done on developing rehabilitative services, although it was felt more work was required to bring about the service developments desired by patients and the Commissioner.
89. The panel was interested as to how work to improve develop rehabilitative service is being progressed.
90. It was said that NHS Middlesbrough had recently commissioned the Stroke Association to conduct 'one to one' interviews in patients homes, to ensure that commissioners have access to much richer and more qualitative information about their experiences of post acute Stroke services. The information obtained from such interviews would be invaluable to Commissioners in understanding where rehabilitative services need to progress.
91. Reference was also made of a piece of Stroke services development work being led by the Managing Director of Middlesbrough, Redcar & Cleveland Community Services (MRCCS). The Panel heard that this project has representation from Commissioners, community services and the South Tees Hospitals NHS Foundation Trust and should develop a set of proposals for commissioners to consider relating to Stroke rehabilitative services.
92. The panel was told that NHS Middlesbrough is keen to appoint to a senior Stroke rehabilitation post, although a tighter NHS funding climate makes such a move more difficult than it has been over the last decade. It was said that NHS Middlesbrough will now only commit to new funding on a non recurring basis and to 'pump prime' a development, such is the lack of growth monies facing the local NHS.
93. On a positive note, it was confirmed that the funding was secured for a Stroke Psychologist which was considered to be an exciting development. Specifically, the Panel heard that the post would be able to assist greatly in dealing with peoples' mental health problems after a Stroke, such as depression. In addition, the post would be able to work with other Stroke staff to develop their skills.
94. The Panel heard that there is also a strong desire on behalf of the local NHS to develop a more robust community stroke team, with greater staff numbers and more specialisms. On this point, it was said that all

available evidence indicates that people recover much more quickly when at home and a particularly strong community stroke team would assist in making this mode of recovery a reality for a greater number of Stroke patients in Middlesbrough.

95. The panel enquired as to at what stage of the Stroke recovery support from the Community stroke team would be available. The panel heard that priority is given to people in early stroke recovery and there is not the sufficient capacity for people 'later down the line' with the Stroke recovery who perhaps suffer a setback of sorts, or go through a time when they require additional support.
96. The panel made enquiries as to the nature of funding for service developments such as Stroke and specifically whether the local authority and NHS Middlesbrough pool their resources sufficiently to deliver the best outcomes.
97. It was said that the way in which central government allocates funding for such projects can be frustrating, with a multitude of 'pots of funding', being granted at various times of the year. It was said that local authority and NHS Middlesbrough join up their funding for Stroke as much as possible, although it is not an exact science. There was clarification that when grant funding was publicised, it was applied for in an attempt to enhance services, although grant funding is time limited, which makes it harder to maintain services when streams of funding dry up.
98. It was mentioned that in the current economic and political climate, any investment in Stroke Services would have to be as a result of a withdrawal of investment in another area of service. To do this successfully, any protagonist would have to make a successful argument that the additional investments in Stroke Services was the appropriate way forward.
99. The panel also asked the Stroke Lead from NHS Middlesbrough about Stroke Awareness in Middlesbrough. The panel heard that there are concerns about the level of Stroke awareness, and specifically the symptoms of Stroke, within General Practice in Middlesbrough and the fact that a Stroke is a medical emergency.
100. In addition, the panel heard that there is a need to develop the local community's knowledge and awareness of Stroke, particularly in BME communities and lower socio-economic groups.
101. In conclusion, the panel heard that whilst financial resources are inevitably a crucial part of delivering effective services, they are not the only important consideration. Also of great importance are topics such as the importance of a high profile lead for Stroke Services, breaking down barriers between teams and psychological support for Stroke patients.

102. At the conclusion of this meeting, the Panel was referred to the outcomes of a lot of work done by NHS Middlesbrough regarding the experiences of recent Stroke Patients. That information was subsequently provided to the panel and is referenced here.
103. The Panel has learned of a process of 'discovery interviews' where patients are asked to consider their experiences of Stroke Services and what could be improved. The documents that the Panel have seen deliberately focus upon what needs to be improved, although patient interviews regarding Stroke services do also contain a great deal of positive comments from people.
104. The areas for improvement highlighted in the discovery interviews are listed as:
 - 104.1 Importance of setting personal goals in discussion with patients
 - 104.2 Desire for therapy at weekends to avoid going backwards and feelings of depression
 - 104.3 Need for psychological help for those patients and carers struggling with depression, anxiety, low mood, emotional and behavioural change.
 - 104.4 Desire for greater intensity/ frequency of therapy for those patients able to tolerate it
 - 104.5 Therapy ending too quickly – evidenced by progress made when patients have then employed private physios afterwards.
 - 104.6 Need a good transitional process when ending therapy, not an abrupt cut off.
 - 104.7 Benefits of outpatient physiotherapy and domiciliary therapy for patients who no longer need to be in hospital.
 - 104.8 Importance of 'no waits' for therapy to start from new teams after transfers between services/ facilities.
 - 104.9 Not all therapists appear to be skilled in stroke treatment or sufficiently experienced.
 - 104.10 Importance of manner and approach with stroke patients: staff need to be able to express information clearly and simply but without appearing insulting
 - 104.11 Difficulties in retaining information for patients with cognition and memory problems, needs addressing through contact with family/ carers and checking.

- 104.12 Perception that wards may not be adequately staffed, especially JCUH at night and this impacts on staff time and approach with patients.
- 104.13 Awareness of stroke and prompt referral from non-stroke wards.
- 104.14 Importance of offering information proactively, rather than patients/ carers asking for it.
- 104.15 Need planned discharge processes, not sudden 'go home today'.
- 104.16 Need support and training for carers on what to expect and how to assist with therapy.
- 104.17 Feeling by patients that GPs should visit them once home/ take an interest in their condition
- 104.18 Need to re-offer the chance to join groups or take up services, as patients may initially decline, but later rethink when they feel better.
- 104.19 Difficult for patients with cognition problems dealing with lots of different staff
- 104.20 Opportunities for peer support are invaluable to assist with mood and motivation
- 104.21 Waiting times for equipment and adaptations at home cause problems.
- 104.22 Criteria for accessing wheelchairs
- 104.23 Discharge transfers between JCUH and Community Hospitals need improvement
- 104.24 Need explanations about medication
- 104.25 Community Hospital wards can feel inappropriate for younger stroke patient.
- 104.26 Need a range of local and tailored social engagement opportunities in the community to improve take up by patients with fatigue, depression, travel difficulties and alternatives well publicised for carers.

- 104.27 More speech therapy needed and opportunities to address dysphasia⁵, which prevents socialisation
- 104.28 Experience of therapy if admitted to general hospital wards or for non-stroke related admissions is not as good.
- 104.29 Timing of visits, to allow working carers to discuss their relatives care or their concerns with staff.
- 104.30 Assistance with continence management needs improvement

Patients' Gold Standards

- 105. The Panel heard that some 'gold standards' were produced as a result of consultation work with patients and carers as part of the South of Tees Stroke Rehabilitation Review (October 2008 – April 2009) and verified with the Positive Strokes Committee (April 2009).
- 106. Those Gold standards for the local Stroke Rehabilitation service from a patient/ carer perspective are:
 - 106.1 Rehabilitation goals are agreed with the patient and are patient led.
 - 106.2 Rehabilitation is available seven days a week.
 - 106.3 Therapy continues until there is no further benefit for the patient.
 - 106.4 Therapy is available at sufficient intensity to meet patient ability.
 - 106.5 Patients and carers are spoken to in an appropriate manner.
 - 106.6 Patients and carers are told what to expect and what will happen next.
 - 106.7 Rehabilitation is provided by specialist therapists trained in stroke care, not by generalists.
 - 106.8 Families and carers are offered training to help with the patients therapy if they wish.

⁵ Dysphasia, or aphasia, is impairment in communication. It's caused by damage to the part of the left side of the brain, which is responsible for language and communication. The brain damage that results in dysphasia is often caused by a stroke, when the blood supply to the brain is interrupted. Infection and inflammation, head injury or a brain tumour may also damage the brain in this way. Please see <http://www.bbc.co.uk/health/conditions/dysphasia1.shtml>

- 106.9 There is a single point of contact for stroke rehabilitation services after discharge.
- 106.10 Patients and carers are able to self refer to the stroke rehabilitation service.
- 106.11 Services should be provided in locations that are locally accessible.
- 106.12 Transport should be provided if patients would otherwise be unable to access services.

Stroke Services Vision

- 107. The Panel heard about a recently agreed Vision for Stroke Services, the standards of which are outlined below.
- 108. To deliver an evidence-based stroke service, which meets the National Stroke Strategy Quality Markers and the NECVN Stroke Rehabilitation Standards, providing high quality rehabilitation and support for stroke survivors to reduce their disability and improve recovery.
- 109. To work as an integrated stroke rehabilitation service through a Partnership Approach, delivering a seamless pathway for stroke patients across all elements of stroke care, whether delivered in primary, community or secondary care settings.
- 110. To deliver local services in a flexible and responsive way, providing a range of options for stroke rehabilitation to best meet the individual assessed needs of patients, reducing length of stay in inpatient facilities and delivering equitable standards in access and quality of care in all settings.
- 111. The integrated Stroke Rehabilitation Service will provide a clear focus for stroke care across the South Tees area, led by a dedicated stroke rehabilitation pathway champion, providing strategic direction and driving forward the improvement of services across the partner agencies.
- 112. To work effectively with all partner agencies, including social care and the voluntary sector, to minimise duplication or gaps in service and demonstrate best value and effective use of resources.
- 113. To ensure there is robust and timely information transfer and communication between/ within organisations, ensuring no delays in handovers between episodes of patient care and developing standardised policies and protocols wherever possible.

114. To provide a service delivered by specialist therapists, dedicated to care of stroke patients, to achieve the best possible patient outcomes:
 - Optimising recovery in terms of physical, communication, cognitive and/or psychosocial abilities
 - Facilitating the individual and family's adaptation to residual disability
 - Maximising independent function, including assessing and/or providing equipment
 - Increasing participation in life roles including those within the community.
115. To deliver well planned, goal oriented rehabilitation at the appropriate intensity and duration for the person, ensuring they reach their optimum rehabilitative potential.
116. To provide appropriate care environments and infrastructure, including dedicated stroke rehabilitation units wherever possible and any specialist rehabilitation equipment/ health equipment required to meet the needs and goals stroke survivors for rehabilitation
117. Existing community services will be unified into a single dedicated service, delivering care in the two stroke rehabilitation units, outpatients and patients own homes, which can follow the patient through their pathway, providing a focus of expertise and continuity. Early supported discharge will be delivered as part of the community team role, to ensure continuity for the patient and to provide a team of sufficient size for service sustainability.
118. Services will be available 7 days per week for inpatient-based stroke services and for any patient going home with an early supported discharge package, to ensure rehabilitative progress is maintained and patients enabled to return home at the earliest opportunity.
119. Staff will rotate between the elements of stroke care to increase professional experience and knowledge, understand the whole patient pathway, aid recruitment and facilitate cover across the stroke rehabilitation service in times of pressure.
120. The stroke rehabilitation service will demonstrate a philosophy of continuous evaluation and improvement, making best use of scarce skills and available resources.
121. The service will provide psychological support for patients and carers with complex problems and input to the multi-disciplinary team caring for stroke patients.
122. The Stroke Service will be patient centred and demonstrate this approach through:
 - Patient led goal planning

- Personalised health care plan
 - A single point of access for patients and carers
 - Self-referral
 - Offering carer training and support
 - Psychological support
 - Provision of timely, high quality information
 - Fair and equitable service delivery including access and waiting times
 - Keyworker role offered
 - A proactive approach to offering information and care
 - Re-offer opportunities
 - Continuity
 - Clarity for patients and carers on what to expect next
 - Tailored and flexible services to meet needs of younger strokes and minority groups
 - Transition planning on transfer between services/ discharge
123. Patients developing or identifying rehabilitation needs after discharge from the stroke rehabilitation service, will be able to re-access the specialist stroke team for reassessment of their needs and provision of therapy as appropriate via self-referral.
124. The service will provide information on the range of services and support available for service users and their carers, to assist them in meeting rehabilitation goals and to manage the impact of the condition on their lives
125. The service will measure quality of life through recognised evidence based scoring systems, across all stages of the pathway and undertake audit across the stroke pathway to demonstrate improvement in patient outcomes.
126. The service will be a source of expert knowledge and advice to support staff and carers in other settings provide safe and effective care to stroke survivors.

Personal Experiences

127. To add some context to the Panel's study of Stroke Services, the Panel had the opportunity to consider the outcomes of an interview with a Stroke patient, about their experiences of services in an acute setting and following leaving hospital. NHS Middlesbrough has kindly provided this.
128. *Mr B felt that his rehabilitation went very well. He understood that it was undertaken in both JCUH, CBH and at home both indoors and outdoors, by MMRT. He particularly enjoyed doing walking practice outdoors as he felt this was a way of "returning to normal". He knew there were different people involved in his therapy but did not understand the difference between OTs and Physios, nor trained staff and assistants. Mr B found rehabilitation undertaken by MMRT particularly good, as they*

assisted him in different ways including to return to gardening and worked on both his upper and lower limb. He took part in indoor bowling with them and in this activity he enjoyed meeting other stroke survivors. Seeing their progress and recovery, gave him hope that he would also improve. Mr B practised exercises at home that had been given to him by MMRT.

129. *In hospital, being given assistance with toileting embarrassed Mr B. Likewise at home, he found using a commode undignified. He disliked the food at JCUH (he was on a puree diet). He felt low in mood at times and got through these periods by making friends with other patients and staff's humour helped too.*
130. *At CBH (which he preferred to JCUH) he felt well informed about what was happening and his wife was invited into Physio sessions, which she found helpful. Staff were re-assuring and knowledgeable. At JCUH however, she thought staff were too busy to explain what was happening to her. At CBH she was told what to expect although she still felt apprehensive about her husband coming home and admits this was due to fear of the unknown.*
131. *Mr B had a lengthy stay at CBH and was upset at being discharged home, as he didn't know if he would be able to cope at home and he dreaded the change of environment, having been in hospital so long.*
132. *As mentioned, his rehab from MMRT was very successful. They were a big support to him in the early days of his recovery. He was happy to be discharged from them, as by then he had gained confidence. He felt re-assured, as he knew he could contact them by phone at any time. Also he was still receiving support from the Stroke Association Family and Carer Support Co-ordinator. Both Mr B and his wife considered her support to be "marvellous – anything you wanted to know, she would tell you". She also helped greatly with benefit advice and form completion as well as providing a grant for them to go on holiday to a caravan with facilities for disabled people.*
133. *Mr B had been referred to GAP by MMRT but there was a lengthy waiting list so he did not pursue it. However, many months later, he saw a poster about GAP in his GP surgery and was re-referred by his GP. He did swimming on the GAP scheme and found it enjoyable and beneficial. Since then Mr B and his wife have continued to set their own rehab goals such as buying a lightweight Hoover so that he could return to assisting with housework and starting to go on holidays again. They also consider tasks such as bed making and hoovering to be a continuation of rehabilitation.*
134. *Mr B was very upset at being told he couldn't drive and declined an offer of referral for assessment at a mobility centre as he felt he did not have confidence to drive again. Both Mr B and his wife found the first year after the stroke the hardest and felt other stroke survivors and carers*

they had talked to, had expressed the same. When he was first discharged home, his wife felt isolated and that she was the only person having to deal with stroke. However, that changed when they were referred to Positive Strokes who they consider to be “lovely people - worth their weight in gold”. They also feel re-assured that if they have any concerns they know they can ring their Stroke Association Family Care Support Co-ordinator.

DRAFT Conclusions

135. On the basis of the evidence and representations considered by the Panel, there seems to be a great deal to be proud of in relation to Stroke Services in Middlesbrough. Whilst services are not perfect, the Panel would commend the progress made in recent years, particularly around the 24 hour access to thrombolysis services available at JCUH, which is by no means replicated elsewhere in the region.
136. On the basis of the evidence considered by the Panel, there seems to be a distinct problem around Stroke and Stroke Awareness, particularly amongst the BME community and more deprived communities. The Panel has noted that this is especially the case with the awareness of symptoms of a Stroke and the urgency with which those symptoms should be treated. The Panel has heard from staff at JCUH that appreciable numbers from North Yorkshire appear to self refer immediately after a Stroke, but much less people from Middlesbrough do the same.
137. Connected to the theme of Stroke awareness is the topic of GP awareness. The Panel has heard, notably from the North East Cardiovascular Disease Network, that not all in General Practice seem to approach Stroke as a medical emergency and that needs to change.
138. The Panel has heard that a significant number of Strokes could be prevented through better proactive healthcare measures such as the monitoring of blood pressure and cholesterol. The Panel feels that the Cardiovascular Disease Screening Programme recently introduced by NHS Middlesbrough should play a considerable role in intercepting certain problems before they manifest themselves as a Stroke.
139. On the basis of the evidence considered, the Panel feels that additional developments should be progressed, specifically around advice for carers, psychological support for patients and carers and support for people’s rehabilitation following discharge from an acute setting. The Panel has heard that such assistance is available for people newly discharged from hospital, although the more time passes by, that support tapers off due to the limited capacity of Community based services. The Panel has heard that more assistance could be required when the reality of post-stroke life has set in, which is very difficult to deliver, due to the pressures of more recent Stroke patients also being discharged from hospital.

140. The Panel would like to highlight that the awareness of the BME community is a critical matter to address. Whilst the BME population of Middlesbrough is actually quite young presently, it will age over time and the proportion of that population being classed as 'older' will also increase. Given the BME community's genetic increased risk to CVD and Stroke, it strikes the Panel that awareness campaigns should begin as soon as possible.

DRAFT Recommendations

141. The Panel recommends that NHS Middlesbrough and Middlesbrough Council instigate a series of targeted awareness campaigns of the symptoms and severity of Strokes. Such awareness campaigns should include information on the services provided designed to deal with Stroke, but also the preventative services designed to prevent Strokes. They should be targeted at particular groups such as the BME community, General Practice and older people. The PBC model would be in an ideal position to progress this matter.
142. The Panel recommends that the capacity of community based services be critically appraised, so that a judgement can be made about whether there is sufficient capacity to provide services for longer term stroke patients, as well as those recently discharged. This should include psychological support, rehabilitative support and carers support and advice.
143. The Panel recommends that Community Councils look to use a part of their budget to publicise Stroke awareness in their areas.
144. That Middlesbrough Council considers whether it currently offers sufficient support to back into work schemes, for Stroke patients of working age. The Panel would like to hear the outcome of this assessment.
145. That NHS Middlesbrough and Middlesbrough Council considers in detail as to whether there is sufficient psychological support for the family of Stroke patients in dealing with the impact of a Stroke. The Panel would like to suggest that existing patient and carer groups, given their expertise and subject interest, are involved as possible partners in delivering such a service.
146. That the South Tees Hospitals NHS Foundation Trust look to improve the social/ lounge area facilities within the Stroke unit at JCUH, to enable patients to have better access to their friends and family, to assist in their recovery.
147. That NHS Middlesbrough & Middlesbrough Council considers whether community teams with a responsibility for post acute stroke services have sufficient capacity to provide appropriate levels of service to all

stroke patients who require assistance, as opposed to simply the most recent Stroke patients.

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