



NHS East Midlands

Next Stage Review

Better heart attack and stroke care

Summary of public and patient engagement



February 2010

Executive Summary

Throughout November and December 2009, Primary Care Trusts (PCTs) in the East Midlands sought the views of patients and the public on proposals to introduce a high-quality, specialist system for assessing and treating heart attacks and strokes across the region.

The PCTs received views from more than **2,000 people**.

- Around **680 people** came to discussion events or meetings to talk about the proposals.
- About **1,500 people** provided feedback through online surveys or on feedback forms sent to them by post or email. Just over 1,000 of these responses were from people in Derbyshire County and Nottingham City.

The discussion events and surveys set out to discover people's views, experiences and expectations around these five questions:

1. What would you expect to happen at the scene?
2. Where would you expect to be taken for treatment?
3. If you had to travel further for specialist care, what issues would we need to take into consideration?
4. If you had to travel to a specialist centre, we would want to move you back to a local hospital for ongoing care once it was safe to do so. What issues do we need to think about to make sure this goes as smoothly as possible for you?
5. What information and support should be available for your family/carer while you are in hospital?

People were told that no decisions have yet been taken on where the specialist heart attack and stroke centres will be located.

Key messages

These are the key messages raised by people across the East Midlands:

People's expectations

- People expected that an ambulance would arrive quickly, and saw this as especially important if longer journey times are to be introduced.
- The majority of people expected to be taken to a specialist hospital, with some accepting that this may mean a longer ambulance journey. Other people felt that it would be better to be taken to an A&E department closer to home.
- People said that the ambulance should be well equipped, and that paramedics should be trained to assess patients accurately and check their suitability for specialist care, in particular being able to apply the FAST test or carry out an ECG.
- People said they would want the paramedics to explain what was happening, where they would be taken, and why. They also expected that relatives,



families or carers would be informed of their heart attack or stroke, and given information about visiting the specialist centre.

- People wanted consideration of the fact that relatives will need to make longer and more complex journeys. They suggested that public transport links be taken into account, parking be made free, and accommodation and childcare be made available. The impact of longer journeys on older people was of particular concern.
- People said that reliable communication systems need to be a high priority, with information available to relatives through a named contact at a central telephone number.
- Continuity of care was important to the people who were consulted. People expected accurate, up-to-date records about their condition and ongoing care would be transferred with them as they left a specialist centre. Some people suggested that specialist centres appoint transfer co-ordinators to make sure transfers out of specialist care go smoothly.
- Patients and their families expect clear, plain-language information about their condition and treatment, with support for people with first languages other than English. People expect to be involved in decisions about their care and to be able to talk to consultants. People see a need for emotional as well as clinical support.
- Rehabilitation services for strokes and heart attacks were also seen as a high priority for improvement.

People's concerns

- People raised concerns about being taken to an unfamiliar hospital some distance from their homes, friends and family. In general, people seemed to feel that this could be acceptable so long as care really was better, travel times weren't excessive, beds were guaranteed, and people had some say in where they were to be treated.
- But there is a fair amount of unease about concentrating specialist care in certain hospitals and 60-minute journey times. People who responded online seemed slightly more likely to express concerns about longer journey times. They were also more likely to mention a specific hospital they would expect to be taken to.
- Some people said they wanted to be treated locally because they have an existing relationship with their local hospital for heart and stroke related problems or for other chronic conditions.
- Several people said they were concerned about the effect of the changes on local hospitals without specialist centres.
- There are worries about the level of co-ordination between specialist centres and local hospitals. People were anxious that transfers be clinically indicated, and not done to free up beds.
- There were also worries about whether the NHS could afford the proposed changes.
- Some people felt that specialist centres might not have access to support services for all the communities in their large catchment areas.
- A few people expected paramedics to get consent from patients, or their relatives and carers, to take them to a specialist centre if it was a long way from their home.



1.0 Background

Throughout November and December 2009, Primary Care Trusts (PCTs) in the East Midlands sought the views of patients and the public on proposals to introduce a high-quality, specialist system for assessing and treating heart attacks and strokes across the region.

This report summarises how the PCTs have engaged with their communities, who they have spoken to, and the range of views expressed.

- Section 1 explains the background to the heart attack and stroke programme, and sets out the goals of the patient and public engagement.
- Section 2 summarises the views and expectations raised at the engagement events.
- Section 3 recommends how the feedback might be used to inform decisions about the quality of care and access to services within a system for assessing and treating heart attacks and strokes.

1.1 Heart attack and stroke proposals

The NHS in the East Midlands is proposing to transform the care people get for heart attacks and stroke by introducing dedicated, high-quality, specialist centres across the region.

A heart attack happens when there is a sudden blockage of an artery that supplies blood to the heart. The best emergency treatment for some types of heart attack is a procedure called Percutaneous Coronary Intervention (PCI). When this is given as the first treatment for a heart attack it is called Primary Percutaneous Coronary Intervention (PPCI). We want to make sure this procedure is available, at short notice, to everyone who needs it.

A stroke happens when the blood supply to the brain is disturbed. Prompt treatment requires urgent access to diagnostic tests, such as a brain scan to diagnose the type and severity of the stroke. Some treatments are only effective if given in the first few hours after a stroke. So, it's essential that tests and treatments are available round the clock, at short notice.

To make sure patients receive the best treatments for heart attacks and strokes, we're proposing that some hospitals specialise in PPCI, or offer specialist urgent stroke care. These hospitals will have skills, experience and equipment to treat patients at short notice, 24 hours a day. Ambulance crews will be trained to recognise appropriate patients and take them straight to a specialist centre.

Specialist care for heart attacks and strokes will mean better emergency treatment and improved rehabilitation. These plans will save lives.

This programme is one of several set up by the Strategic Health Authority in response to the review of health care by the then health minister, Lord Darzi. As a result of the review, NHS East Midlands published its vision in a report called *From Evidence to Excellence* (June 2008). It undertook to "ensure access for the whole population to hyperacute stroke units" and to create "at least two centres capable of providing 24-hour access to primary angioplasty".



1.2 Purpose of involving patients and the public

The next phase of the programme is to consider the proposals from hospitals that wish to specialise in PPCI or stroke care, and recommend which hospitals are best placed to provide these services. Views from the public, patients, carers and their representatives are key to this stage of decision-making, and will inform the shape of the future service.

During November and December 2009, the communications and engagement teams from each PCT carried out a range of events to ask people for their views on how best to provide urgent stroke and heart attack care in the future. The aim of involving people is to help the NHS develop a service that meets the needs and expectations of patients, their families and their carers.

The main objectives of the engagement events were:

- To raise awareness of the proposals for changing the way heart attacks and strokes are managed in the East Midlands, and to explain the reasons behind the changes
- To explain the potential benefits of specialist urgent care for strokes and heart attacks – in terms of improved access, better care, lives saved and long-term disability avoided
- To assess people's concerns and issues regarding the proposals for a specialist heart attack and stroke service
- To find out about people's previous experiences of heart attack and stroke (as patients or carers) and explore how services need to be organised to ensure a high-quality experience
- To gauge people's expectations in terms of the access to and quality of a specialist heart attack and stroke service
- To encourage informed debate about the potential longer journey times to specialist centres
- To develop an ongoing dialogue with the community around service planning for heart attacks and strokes
- To allay potential concerns over the impact of changes on local A&E departments
- To ensure the project meets its duty to involve, set out in Section 242(1B) of the NHS Act 2006.

Once the programme team has made its recommendations and these have been agreed with each PCT, PCTs will be responsible for commissioning care for people in their area.

1.3 Who was involved and what methods were used?

1.3.1 Who was involved?

Each PCT identified the key audiences to talk to in their area, including groups who will be specifically affected by the proposals, voluntary groups and community groups.

Across the region, PCTs received views from more than **2,000 people**.



- Around **680 people** came to discussion events or meetings to talk about the proposals.
- About **1,500 people** provided feedback through online surveys or on feedback forms sent to them by post or email. Just over 1,000 of these responses were from people in Derbyshire County and Nottingham City.

Some engagement activities involved groups who have a particular interest in heart attack or stroke, or who were likely to be specifically affected by the proposals. These included:

- Corby Heart Support Group
- Daventry Over Fifties Forum
- Cardiac Support Group (Nottingham)
- Sherwood Stroke Club
- @astroke group
- Burton Joyce Stroke Club
- Long Meadow Stroke Group
- Nottingham Elders Forum
- Age Concern (Matlock and Chesterfield)

See table 1 for a summary of who was involved in the events, and appendix 1 for full details, including the results of ethnic monitoring.

1.3.2 What methods were used?

Discussion events

Discussion events set out to discover people's views, experiences and expectations.

- Each PCT arranged face-to-face forums with key audiences to encourage discussion and debate. The forums were generally held in non-NHS settings.
- Some of the larger events were promoted on PCT websites and press-released. Examples of press releases in Lincolnshire and Nottingham are in appendix 2.
- The regional team provided a set of presentation slides explaining the proposed heart attack and stroke system and the process of service change (see appendix 3). Members of the regional team, which included the Programme Director, Programme Managerial Lead, Communications and Engagement Manager and Clinical Leads, attended and facilitated the discussion at many of the events.
- Examples of heart attack and stroke scenarios were shared with the groups (appendix 4) to stimulate debate.
- Participants were also asked to complete written forms evaluating the events (appendix 5).

This qualitative approach was selected to encourage meaningful debate. The events allowed PCTs to share details of the heart attack and stroke service and gather in-depth views from people likely to be affected. It also provided the participants with an opportunity to ask questions. The approach was not designed to collect the numbers of people expressing a particular view or concern.

Online survey

An online survey was posted on the NHS East Midlands *Towards Excellence* website



(www.excellence.eastmidlands.nhs.uk), and on some PCT websites, to seek views from those who couldn't attend the groups, or those who attended but wanted to add further comments. Some PCTs promoted the survey through their existing engagement channels.



Table 1 Summary of engagement events for heart attack and stroke

PCT	Activity	Audience	People attending
NHS Nottinghamshire County 7 events Link to online survey	Discussion with @astroke group	People affected by a stroke – patients, carers, families	15-30
	Discussion with Burton Joyce Stroke Club	People affected by a stroke – patients, carers, families	11
	Discussion with Diabetic Support Group and Cardiac Support Group (Nottingham)	People with heart problems People with diabetes	12
	Discussion with Positive Patient Support Group	People with long-term health conditions (and carers)	15-30
	Discussion with Principia Patient Reference Group	Community representatives for Rushcliffe area	16 (10 lay members)
	Discussion with NHS Nottinghamshire County's Patient and Public Advisory Panel	Patients/public/NHS staff	12
	Discussion with Gedling Community and Voluntary Services (CVS) at Gedling Health Network meeting	People from community and voluntary groups	13
	Link on PCT website to Towards Excellence online survey	Public	*

PCT	Activity	Audience	People attending/ responding
NHS Northamptonshire 5 events Leaflet distribution Link to online survey	Meeting with Corby Heart Support Group	People with heart problems and their carers	10
	Discussion with Daventry and District Over Fifties Forum (DOF) – public meeting	Public aged 50+	16



PCT	Activity	Audience	People attending/ responding
NHS Northamptonshire cont.....	Public meeting <i>"Delivering the Future"</i> – held at Kettering Conference Centre	Public/stakeholders	9 completed stroke scenario 8 completed heart scenario
	Workshop <i>"Have your say on heart and stroke care"</i> – held at Wellingborough museum	Public/stakeholders	32
	Distributed information/feedback forms through stalls set up in Corby and Wellingborough shopping areas (2 days)	Public	39
	Link on PCT website to Towards Excellence online survey	Public	*

PCT	Activity	Audience	People attending/ responding
NHS Nottingham City 4 events Leaflet distribution Online survey	Discussion event with Nottingham Elders Forum	City residents 60+	151
	Discussion event held at the Albert Hall	Public/patient groups/citizens health panel	102
	Roadshow for Ekta Luncheon Club	Asian men and women aged over 50 years	35
	Roadshow for Long Meadow Stroke Group	Stroke patients/carers and social care staff	12
	Distributed leaflet /feedback form	– Sent to 113,000 homes – Given to 65 Asian women taking a coach trip – Given to 32 people attending event for citizen's health panel and patient experience group	580
	Online heart questionnaire – on PCT website	Public/patients	16
	Online stroke questionnaire – on PCT website	Public/patients	12



PCT	Activity	Audience	People attending
NHS Derbyshire County 4 events Link to online survey Questionnaires	Discussion event with the Health in Amber Valley Group	Public representatives/other agencies involved in healthcare	*
	Discussion with Chesterfield and North East Derbyshire Multi-Agency group	Community representatives/members of PCT health panel and LINKs local planning group	24
	Discussion with Bolsolver Multi-Agency Group	Community representatives/LINK lay member/patient representatives	20
	Distributed information at a 'Equality Equals Respect' event – Patient Advice and Liaison Services (PALS) 'stall' provided leaflets and feedback forms	Public including Black and Minority Ethnic (BME) groups	* (responses included in 486 below)
	Distributed Information and questionnaires	Patient and community groups/meetings, including Age Concern, Asian Association, Stroke Support Group	486
	Link on PCT website to Towards Excellence online survey	Patients/public/stakeholders	*

PCT	Activity	Audience	People attending /responses
NHS Derby City 1 event	Discussion event held at Derwent Court, Derby	Patient groups/community & voluntary groups/	29
	Information and feedback forms distributed to meetings/events	Community groups including neighbourhood boards and forums, LINK	122

PCT	Activity	Audience	People attending
NHS Lincolnshire 1 event Link to online survey	Discussion event with stakeholders held at Bentley hotel, Lincoln	Patients/patient groups	18 people
	Link on PCT website to Towards Excellence online survey	Patients/public/stakeholders	*



PCT	Activity	Audience	People attending/ responding
NHS Leicestershire, Leicester and Rutland 1 event Online survey Questionnaires	Discussion event at Highpoint Conference Centre	Public/patients – local LINKs, local authority representatives, voluntary organisations, community groups, NHS staff	89
	Online heart survey – posted on PCT website	Public	33
	Online stroke survey – posted on PCT website	Public	21
	Distributed heart attack information and questionnaires	Public/patients – NHS Trust members, Age Concern, Older people's forum	77
	Distributed stroke information and questionnaires	Public/patients – NHS Trust members, Age Concern, Older people's forum	89

SHA	Activity	Audience	People attending /responses
NHS East Midlands Online survey	Online survey on Towards Excellence website (PCT websites directed users to this website)website)	Public/patients/patient groups/community groups/voluntary groups	10 (heart attack) 6 (stroke)

Bassetlaw PCT consulted the public and patients on proposals for urgent stroke and heart attack care in the summer 2009. A summary of these findings is in appendix 6.

1.4 What were people told?

A presentation was produced by the regional team and used by PCTs to introduce the majority of events. The presentation set out what it is possible for the public to influence, the timescale for change and the decision-making process.

The key messages given at the events were:

- In the East Midlands, more than 6,000 people a year have a stroke. There are also around 2,000 people a year who have a heart attack suitable for treatment with PPCI.
- Treatment for a heart attack or stroke can save lives and reduce disability, but some of the best options are most effective if given quickly. Clot-busting drugs for a stroke and PPCI for a heart attack have to be available within a few hours of someone becoming ill.
- There are better outcomes for patients when treatment is given in specialist



- centres, even if this means a longer journey time to hospital.
- At the moment, too few people have access to specialist urgent stroke care or PPCI for a heart attack. The best treatment requires access to diagnostic tests, expert staff and specialist equipment, and all these must be available at short notice. Not all hospitals can currently provide this level of service, and even where it is offered, it's not necessarily available 24 hours a day.
 - The NHS in the East Midlands is proposing to establish centres specialising in the urgent treatment of heart attacks or strokes. Hospitals that include a specialist centre will give patients direct access to dedicated staff and the best-quality treatment.
 - Specialist centres will be accessible 24 hours a day, seven days a week, and be staffed by specialist teams with access to the best facilities.
 - The specialist centres will be supported by local hospitals. These will treat heart attacks that don't need treatment with PPCI, and provide ongoing rehabilitation to heart attack and stroke patients closer to their homes.
 - Under the new proposals, people who suffer a stroke, or heart attack suitable for treatment with PPCI, should be taken directly to a specialist centre rather than to the local A&E, and should reach it within a 60-minute ambulance journey. Ongoing care can be offered closer to home.
 - The paramedic on the scene will identify patients as suitable for specialist treatment and pre-alert one of the specialist centres.
 - The new services are expected to save lives and reduce long-term disability.

The groups were also told that **no decisions have yet been taken on where the specialist heart attack and stroke centres will be located.**

People were also asked if they could be contacted again as plans develop.

1.5 What were people asked to discuss?

Each group was presented with scenarios showing a heart attack or stroke. These included an overweight businessman who thinks his heart attack symptoms are caused by indigestion, and a schoolteacher who is discharged from hospital after a mini stroke, only to have a severe stroke a week later. They can be found in appendix 3.

Each group was then asked to give their views on these questions:

1. What would you expect to happen at the scene?
2. Where would you expect to be taken for treatment?
3. If you had to travel further for specialist care, what issues would we need to take into consideration?
4. If you had to travel to a specialist centre, we would want to move you back to a
5. local hospital for ongoing care once it was safe to do so. What issues do we need to think about to make sure this goes as smoothly as possible for you?
6. What information and support should be available for your family/carer while you are in hospital?

Participants were also asked to give any further comments or raise any other issues they wished.



2.0 Summary of feedback

This section summarises the views provided by people across all the PCT patient and public engagement events.

It gives an overview of the main issues and concerns raised, and then presents feedback received in response to the individual questions asked at each event.

The issues raised were consistent across the events, and there was little variation between PCTs. Issues that were unique to an audience or locality have been highlighted in the report.

Key issues and concerns

Issues and expectations

- People expected that an ambulance would arrive quickly, and saw this as especially important if longer journey times are to be introduced.
- The majority of people expected to be taken to a specialist hospital, with some accepting that this may mean a longer ambulance journey. Other people felt that it would be better to be taken to an A&E department closer to home.
- People said that the ambulance should be well equipped, and that paramedics should be trained to assess patients accurately and check their suitability for specialist care, in particular being able to apply the FAST test or carry out an ECG.
- People said they would want the paramedics to explain what was happening, where they would be taken, and why. They also expected that relatives, families or carers would be informed of their heart attack or stroke, and given information about visiting the specialist centre.
- People wanted consideration of the fact that relatives will need to make longer and more complex journeys. They suggested that public transport links be taken into account, parking be made free, and accommodation and childcare be made available. The impact of longer journeys on older people was of particular concern.
- People said that reliable communication systems need to be a high priority, with information available to relatives through a named contact at a central telephone number.
- Continuity of care was important to the people who were consulted. People expected accurate, up-to-date records about their condition and ongoing care would be transferred with them as they left a specialist centre. Some people suggested that specialist centres appoint transfer co-ordinators to make sure transfers out of specialist care go smoothly.



- Patients and their families expect clear, plain-language information about their condition and treatment, with support for people with first languages other than English. People expect to be involved in decisions about their care and to be able to talk to consultants. People see a need for emotional as well as clinical support.
- Rehabilitation services for strokes and heart attacks were also seen as a high priority for improvement.

People's concerns

- In each event, people raised concerns about being taken to an unfamiliar hospital some distance from their homes, friends and family. In general, people seemed to feel that this could be acceptable so long as care really was better, travel times weren't excessive, beds were guaranteed, and people had some say in where they were to be treated.
- But there also seems to be a fair amount of unease about concentrating specialist care in certain hospitals and 60-minute journey times. Some people in the Derby City and Leicester engagement said they expected to be taken to a specialist centre no more than 30 minutes away. *"I am not happy about specialist centres only in certain hospitals. I feel they should be in all hospitals."* (NHS Nottingham City postal survey)
- People who responded online seemed slightly more likely to express concerns about longer journey times. They were also more likely to mention a specific hospital they would expect to be taken to.
- Some people said they wanted to be treated locally because they have an existing relationship with their local hospital for heart and stroke related problems or for other chronic conditions.
- Several people said they were concerned about the effect of the changes on local hospitals without specialist centres.

"Good idea, but don't rob Peter to pay Paul" (NHS Nottingham City postal survey)

"An excellent idea – if they can be properly funded without detriment to other health care services, either within the hospital or elsewhere." (NHS Nottingham City postal survey)

"I fear these proposals are because you have made up your minds to close Newark A&E." (NHS Nottingham City postal survey)

- There are worries about the level of co-ordination between specialist centres and local hospitals. People were anxious that transfers be clinically indicated, and not done to free up beds.
- There were also worries about whether the NHS could afford the proposed changes. *"Can we afford this sort of rearrangement as things are at the moment?"* (NHS Nottingham City postal survey)
- Some people were concerned about the whether specialist centres would



have enough beds to treat people from across the region.

- Some people felt that specialist centres might not have access to support services for all the communities in their large catchment areas. Some people raised the issue that paramedics need to assess potential language and ethnic needs and pre-alert the specialist centre.
- A few people expected paramedics to get consent from patients, or their relatives and carers, to take them to a specialist centre if it was a long way from their home.
- People at events in some areas appeared to have a strong expectation that specialist care would be provided in their local hospital.

2.2 Summary of responses to the questions asked at each event

Question 1

What would you expect to happen to you at the scene?

A fast response by the ambulance service

People in every group expected that an ambulance would arrive quickly. Although people usually expect a quick response to a 999 call, people see this as even more important if longer journey times are to be introduced.

There were a few discussions about how quickly an ambulance should arrive. Some people in the Derby City and Nottingham City groups said that they would expect an ambulance to arrive within 10 minutes, but most people said “as soon as possible”.

“Arrive within 10 minutes maximum.” (NHS Nottingham City patient and public engagement event, Albert Hall)

Overall, people did not seem to expect the air ambulance to be called for someone having a heart attack or stroke, although some people in the Derby City engagement felt that it should be available to treat and transfer “serious cases”. Some people who responded to the online surveys commented that the air ambulance service should be more readily available and properly funded by the public sector.

The right experts on the scene

People expect a well-equipped ambulance and a highly qualified team capable of diagnosing heart attacks and strokes. High-quality care on site is seen as necessary to enable patients to travel safely in the ambulance.

“Will paramedics be on board every ambulance and trained to know the signs of a stroke and heart attack?” (NHS Nottinghamshire County Gedling CVS health network meeting)

“(I) expect an ambulance to arrive, not just a paramedic.” (NHS Nottingham City patient and public engagement event, Albert Hall)

“Do you have qualified staff to travel and do they have the correct equipment and medication” (NHS Leicestershire, Leicester and Rutland, hard copy questionnaire response)

“Fast arrival of an ambulance and paramedics who have up-to-date training to give the correct treatment.” (NHS Derby City questionnaire)



People expect a paramedic to be first on the scene, although some said they expected a doctor would attend, and travel the longer journey with the patient in the ambulance.

“Have a cardiac or stroke team available for the journey, monitoring the state of the patient.” (NHS Derby City feedback on questionnaires)

Paramedics are expected to accurately assess patients, make decisions about which hospital is appropriate, and relay information about the person’s condition to doctors in the specialist centre. In particular, people sought reassurance that paramedics would be able to do the FAST test for strokes and an ECG for suspected heart attacks.

“Paramedics should carry out the FAST appraisal.” (NHS Leicestershire patient and public event, Highpoint)

“An ECG should be carried out at the scene by a skilled paramedic so they can make (an) informed judgement regarding the best option of treatment” (NHS Lincolnshire, patient engagement event at Bentley Hotel)

On-site treatment and assessment

People expect immediate pain relief, with people at the scene and in the ambulance qualified to give it. They also expect treatment to ease their heart attack and stroke symptoms and prevent further damage.

“Time is crucial – everything needs to be done as soon as possible.” (NHS Northamptonshire, Wellingborough event)

“Ambulance crew (should) use equipment to obtain (a) cardiogram, and may give me treatment – aspirin, pain relief, thrombolysis.” (NHS Derby City feedback on questionnaires)

“Give as much treatment as possible at the scene.” (NHS Northamptonshire, Daventry Over Fifties Forum event)

“Treated by a paramedic able to give a clot-busting drug if appropriate.” (NHS Derby City patient and public engagement event, Derwent Court)

There was some concern about how paramedics would decide which patients to take to specialist centres. There were people in the Nottingham and Derby City events who felt that patients might be taken to these centres unnecessarily.

“For them (the paramedics) not to jump to conclusions unless it is very clear that the patient has suffered a stroke, as it may mimic other conditions.” (NHS Nottingham City patient and public engagement event, Albert Hall)

Good communication – with patients, families and specialist centres

At almost every event, people said they would want the paramedics to explain what was happening, where they would be taken, and why. They wanted clear information and plenty of reassurance. They also expected that relatives, families or carers would be informed of their heart attack or stroke and the location of the specialist centre very quickly, not least because it could take them some time to travel to the centre.

“Communication in the ambulance is important” (NHS Nottinghamshire County, Positive Patient Support Group event)”

“Expect them to tell you what was happening and what they were going to do.” (NHS



Nottingham City patient and public engagement event, Albert Hall)

"I would expect you to make me comfortable, and if you take me for PPCI you need to explain why you are doing this and how far I will need to travel." (NHS Northamptonshire, Corby Heart Support Group event)

There is some concern that relatives could be sent to the wrong place, and an expectation that a reliable system would be put in place for recording where people are taken and communicating this accurately.

"You need to tell my family exactly where I am going." (NHS Northamptonshire Corby Heart Support Group)

People in the Northamptonshire and Derby City events suggested that paramedics carry a card or information pack with details of the specialist centre, including the name, address and phone number of the hospital, directions to the PPCI or stroke unit, information on visiting times, and car parking arrangements. This could be given to relatives and carers.

"Could the crew have an information pack about how to get to the [specialist centre], the procedure, that could be left in the house for a family member?" (NHS Derby City patient and public engagement event, Derwent Court)

People expect paramedics to collect as much information as possible on the patient's medical history, both from the patient and from relatives and carers, and relay this to the specialist centre. Some people were concerned that patients might be taken further away from home without medication they needed for other medical conditions, and it might not be easy for families to reach the specialist centre to visit and bring medications.

'False teeth, glasses, hearing aid, medication go into ambulance with you and come out! (NHS Nottingham City Long Meadow Stroke Group)

Some people felt that paramedics should be able to access a patient's records to check for previous heart attacks or strokes and see where these were treated.

Consent

A few people expected paramedics to get consent from patients, or their relatives and carers, to take them to a specialist centre for PPCI if it was a long way from their home or the place where they have had a heart attack.

"Consent – how is this going to be achieved?" (NHS Derby City feedback on questionnaires)

At some events, people raised the issue that paramedics need to assess potential language and ethnic needs and pre-alert the specialist centre. Some people felt that specialist centres might not have access to support services for all the communities in their large catchment areas.



Question 2

Where would you expect to be taken for treatment?

During the events, people were asked this question once they had listened to a presentation about the proposed new system of specialist care – including the different levels of service and potential benefits – and their comments reflect this. The question attracted a lot of debate, and people clearly had different expectations about where they would be taken if they were suffering a stroke, or a heart attack that could be treated with PPCI.

Specialist versus local care

Most people expected to be taken to a hospital with specialist facilities capable of dealing with their heart attack or stroke. Some people expected that they might have to travel further than the local hospital to receive this specialist care. Other people felt that, on balance, it would be better to be taken to A&E at a hospital closer to home.

“The best possible place – the centre – with the right skills and equipment.” (NHS Nottingham City public and patient engagement event, Albert Hall)

“If I had to travel to get the best treatment, that would be fine with me.” (NHS Northamptonshire, Wellingborough event)

“I think that having to travel further afield when a person is ill is a bad idea. The person has enough to worry about without going to a strange town or district where relatives maybe unable to visit.” (NHS Nottingham City postal survey, Arrow leaflet).

“Most people I speak to will stand by their local hospital.” (NHS Nottingham City public and patient engagement event, Albert Hall)

“My local hospital because all hospitals should be funded well enough to cope with and provide the very best care.” (NHS Leicestershire, Leicester and Rutland)

A mix of views was raised at each event, and there were a few notable differences between different audiences or PCT areas. People who responded online seemed slightly more likely to express concerns about longer journey times. They were also more likely to mention a specific hospital they would expect to be taken to.

Named hospitals

People at events in some areas appeared to have quite a strong expectation that specialist care would be provided in their local hospital.

“The City hospital has taken care of me all of my life. I'm 76 years old and I have full trust in them, and that's where I feel safe.” (A man who thinks the specialist centre needs to be in City Hospital, NHS Nottingham City online survey)

In general, people at the events in Kettering wanted to be taken to Kettering General Hospital for a heart attack. For stroke, they appeared more willing to travel further for specialist care. Most people in the Daventry Over Fifties forum expected heart attack and stroke patients to be taken to the nearest hospital or A&E department.

Most people at the NHS Derby City engagement event said they expect to be taken to Royal Derby Hospital (their nearest hospital). There was a strong feeling that Derby should have a specialist stroke and PPCI centre. A few people did say they would be willing to go to hospitals in Burton or Nottingham, but not any further.



"I strongly urge the management team to consider setting up a heart attack care and treatment centre for our local people." (NHS Derby City Derwent Court event)

"I request Derby to be selected because it has a good reputation." (NHS Derby City Derwent Court feedback on questionnaires)

People at the main Lincolnshire engagement event expressed concern about lengthy journeys to hospitals for patients in the coastal strip area. People also asked, *"-why can't there be two specialist [PPCI] centres in the County?" (NHS Lincolnshire patient engagement event, Bentley Hotel).*

Most people who responded to the NHS Leicestershire, Leicester and Rutland surveys said they expected to be taken to a Leicester hospital. Generally, people expected to go to the Glenfield hospital for heart attacks.

"The Glenfield has an excellent reputation and I am known to staff there." (NHS Leicester, Leicestershire and Rutland online heart attack survey)

"I would prefer Glenfield Hospital as it has an excellent cardiology department which I use." (NHS Leicester, Leicestershire and Rutland heart attack questionnaire)

"The specialist centre should be in Leicester." (NHS Leicestershire, Leicester and Rutland online heart attack survey).

Length of the ambulance journey

There also seems to be a fair amount of unease in some groups and from online responders about 60-minute journey times to hospital. This was particularly the case in the Derby City feedback. Some people in the engagement event and in the questionnaires said they expected to be taken to a specialist centre no more than 30 minutes away.

"Specialist centre, as long as it wasn't over 30 minutes away." (NHS Northamptonshire, Wellingborough market stalls event)

"An hour's journey in an ambulance after a heart attack is too long in my view." (NHS Derby City patient and public engagement event, Derwent Court/feedback on questionnaires)

"I think that having to travel further afield when a person is ill is a bad idea. The person has enough to worry about without going to a strange town or district where relatives maybe unable to visit." (NHS Nottingham City postal survey, sent to 113,000 homes)

"Worried. If treatment is needed urgently it can take a long time to get to a hospital, especially if its on a busy ring road, miles away from the centre of town, and [it's] rush hour." (NHS Derby City feedback on questionnaires)

"(Consider) distance and have enough available specialist stroke/heart attack transport as I understand time is the killer" (NHS Nottingham City postal survey, sent to 113,000 homes)

People in the Derby County events in Bolsover and Chesterfield were concerned that they could be disadvantaged if travelling times became longer than they are now for emergency transfers to hospital.

Question 3

If you had to travel further for specialist care, what issues would we need to take into consideration?

In each event people raised concerns about being taken to an unfamiliar hospital some distance from their homes, friends and family. Many people seemed to feel that



this could be acceptable providing the NHS made sure that:

- The specialist centres really can deliver better care than local hospitals. (*"Would be pleased to be cared for in a specialist centre even if it is not local, providing survival and recovery rates justify it."*)
- The proposed travel times are realistic and take account of traffic, rush hour, weather and road conditions (*"Have you factored in traffic hold ups?"* and *"Time is of the essence and valuable life saving time could be lost if stuck in traffic"*)
- Good quality care is provided by experienced paramedic or medical teams during the ambulance journey
- A bed is guaranteed for all patients taken by ambulance to a specialist centre (*"You must have a bed for me. Don't leave me waiting."* *"Don't leave me on a trolley."*)
- There is capacity to guarantee PPCI for suitable heart attack patients taken to a specialist centre (*"When I had a heart attack, someone was already being operated on'. Can this cause delay?"*)
- The specialist centre is alerted that a heart attack or stroke patient is en route, and given accurate information about that person's condition. Some people were anxious that there could be further delay at the specialist centre
- The right transport (i.e. a well-equipped, warm, comfortable ambulance) is always available to transport very sick people safely for long distances
- Longer journeys don't cause further complications for people who are already very unwell (*"I would feel that I wouldn't have as good a chance of survival if I was transported miles."*) (*How would they stop me dying or deteriorating before I got there?*)
- Delays in getting treatment didn't put people's lives at risk (*"How to keep me alive during the journey?"* *"Whether I would survive the journey without suffering permanent damage."*)
- Enough ambulances are available to travel the longer distances and to attend local 999 calls
- People's medical records are transferred to the specialist centre
- People can have a say in where they have their treatment, and the right to choose to go to a local hospital (*"Patients need the option of refusing to be taken out of Derby."* *"What happens if the relatives want the treatment to be in Derby? Demand!"*)
- Specialist centres have enough staff to provide emotional and practical support to patients whose family and friends may live too far away to visit (i.e. to talk and reassure, to organise toiletries, to check patients have enough to drink and eat).



Consideration for visitors

People expected the proposals to consider that fact that carers, relatives and visitors will need to make longer and more complex journeys to visit people in a specialist centre. This is true for people using cars, but a more important consideration for those relying on public transport. People suggested that:

- Public transport routes need to be considered when deciding where specialist centres should go
- Car parking spaces should be available and free
- Accommodation should be available for families
- Childcare is needed at the hospital to support relatives and carers who may need to be further away from home for longer periods.

“Transport will be an issue for everyone, whether they have a car or not.” (NHS Northamptonshire, Wellingborough stroke event)

“I do not accept the concept of specialist care centres, which provide my relatives with travel difficulties.” (NHS Leicestershire, Leicester and Rutland heart attack questionnaire)

“Myself and my father do not have transport to go further afield. Recently it was suggested my mum go out of Derbyshire for care, which is very hard and long way away.” (NHS Derby City feedback on questionnaires)

“Flexible visiting times to allow visitors to come when it is convenient for them, rather than when it is convenient for the hospital.” (NHS Leicestershire, Leicester and Rutland online heart survey)

“My daughter is in a wheelchair (no legs) and it costs £20 a time each way to hospital. Help to get a visit and pay carer to escort her” (NHS Nottingham postal survey, sent to 113,000 homes)

Some people expected the NHS to specifically consider the impact of the changes on the needs and preferences of older people who may be patients or carers.

“There are huge issues for older people. What happens to people who don’t drive... is there any accommodation for them to stay in?” (NHS Nottingham City, Public engagement event, Albert Hall)

“The site of specialist centres needs to be carefully thought about, as friends and family are likely to be older. Many older people are put off by travelling [long] distances and find parking and negotiating large complexes... [it’s] too much to cope with.” (NHS Derby City, feedback on questionnaire)

“For some older people, travelling might be out of the question.” (NHS Leicestershire, Leicester and Rutland stroke questionnaire)

“(Consider) the worry and stress of travelling out of area at 79 years of age” (NHS Nottingham City postal survey, sent to 113,000 homes)

People at all the events said that reliable communication systems need to be considered a high priority for the proposed system of specialist care. They asked for:

- A reliable system to provide carers and families with accurate and up-to-date information about their loved ones
- A dedicated telephone line and contact person (“a co-ordinator”) to be



available 24/7 to provide information about a person's condition

- A central telephone number so people can find out where a patient is.

Question 4

We want to be able to move you back to a local hospital for ongoing care once this is safe to do so. What issues do we need to think about to make sure this happens as smoothly as possible for you?

There are worries about the level of co-ordination between specialist centres and the local hospitals that stroke and PPCI patients will be transferred to. The key issues raised by the people in nearly all the events were:

- The decision on when to transfer a patient should be based on their clinical condition and not related to costs or bed availability
- Everyone should be given a choice about which hospital they were transferred to (*"Ask people what they would prefer."*)
- The need for reliable communication systems between the specialist centre and local hospitals
- The need to involve patients (and their families and carers) in decisions about the transfer
- The need to move people during the day (preferably before 18.00), and for mealtimes and medication schedules to be considered.

Continuity of care

Continuity of care was important to the people who were consulted. People expected accurate, up-to-date records about their condition and ongoing care plan to be transferred with (or ahead of) them. They also asked for information on language and cultural needs to be communicated. There was a perception that hospitals are often not very good at this.

"Communication between the two hospitals is vital. Will all my medical information arrive safely, accurately?" (NHS Northamptonshire, Daventry over 50s event)

"Good in theory – but elderly being moved about is not good. I would prefer the same standard of care by the same nursing staff throughout my illness" (NHS Nottingham City postal survey, sent to 113,000 homes).

Local hospitals need to be ready to receive patients. People said they wanted to feel that the specialist centre was well-briefed and prepared for them. There were also some concerns that beds might not be available for people when they arrive.

"Ring the hospital to say I'm on my way." (NHS Nottingham City online heart attack survey)

"Availability of ambulance drivers without being kept waiting for hours." (NHS Leicestershire, Leicester and Rutland online stroke survey).



“Seems a good idea – although I have reservations about whether a specialist centre will have sufficient space.” (NHS Northamptonshire Daventry Over Fifties Forum event)

Some people raised concerns about whether high-quality care would be available in the hospital they were transferred to. There was a perception that local hospitals wouldn't have the expertise to manage patients discharged from a specialist centre. A few people sought reassurance that any equipment or devices provided by specialist centres would work at the local hospital.

“Enough nurses with necessary qualifications and knowledge to know if I was about to have another attack.” (NHS Leicestershire, Leicester and Rutland online survey)

“That there is sufficient specialist knowledge in the local hospital, and equipment, should you relapse.” (NHS Nottingham City online heart attack survey)

“If the physio in Derby is not up to scratch, for example, the good work done in the specialist unit may be undone.” (NHS Derby City patient and public engagement event, Derwent Court/feedback on questionnaires)

“Technology and expertise needs to be at local hospital when you are moved back from the specialist centre.” (NHS Derby City patient and public engagement event, Derwent Court/feedback on questionnaires)

Involving relatives, carers and GPs

People felt strongly that specialist centres need to involve carers and relatives (as well as patients) in planning the transfer. This would ensure that relatives were available to support patients during the move. People wanted advance warning of the day and time of the transfer, and for a care plan to be shared with relatives. They also wanted reassurance that the transfer would go ahead as planned, without delays.

“Sufficient notice to ensure visitors are informed, so that there are no wasted journeys.” (NHS Leicestershire, Leicester and Rutland online heart attack survey)

“To be well organised, so that patients are not waiting around.” (NHS Nottingham City online heart attack survey)

“Patient and family should be aware of why the move is happening and what the subsequent steps are.” (NHS Northamptonshire, Wellingborough stroke event)

“We need to make sure that the patient is sent to where there is support from family [or a] carer, be that their local hospital or one near their family.” (NHS Leicestershire, Leicester and Rutland online stroke survey)

People also expressed a desire for ongoing communication between the specialist centre staff and the local hospital. There is a sense that people still want the specialist team involved in monitoring their condition and informing their ongoing care plan.

“Easy access back to specialist care if [the] situation deteriorates.” (NHS Leicestershire, Leicester and Rutland online stroke survey)

People also sought reassurance that the role of their GP would be taken account of in the proposals. There were several discussions about the importance of GPs knowing when a patient has had a heart attack or stroke, where they are being cared for, and when they will be transferred to a local hospital. It was also suggested that heart attack and stroke patients be put in touch with support groups when they were discharged, for advice and guidance.



Organising the transfer

People in some groups expressed concern about the right sort of ambulance being available to transfer people who have had a stroke or heart attack. Some were also concerned about the risk of infection. They expected to be transferred in a clean, comfortable, well-equipped ambulance with trained staff who could deal with a further stroke or heart attack or other medical complications.

“Ambulance should have qualified people able to deal with strokes.” (NHS Northamptonshire, Corby and Wellingborough market stalls event)

Some people who responded to the NHS Leicestershire, Leicester and Rutland online heart attack survey suggested that specialist centres need to appoint transfer “co-ordinators” to liaise with the patient, their family and both hospitals to manage all aspects of the transfer.

“Appoint a co-ordinator to transfer records and personal belongings and to liaise with both consultants” (NHS Nottingham City postal survey, sent to 113,000 homes)

A few people who responded to the Leicestershire online survey did not agree with the need to transfer people out of specialist centres.

“If long-term care is needed, would it not be better to stay with the specialist centres?” (NHS Leicestershire, Leicester and Rutland online stroke survey)

People in the Nottingham, Leicestershire and Lincolnshire events felt that the hospital social worker and community social services should be involved in the transfer, to support people and organise any social care required at home or in the local hospital. Some people commented that patients who have had a stroke can feel very frightened afterwards, so emotional support needs to be provided during the move.

Question 5

What information and support should be available to your family or carer while you are in hospital?

Everyone strongly agreed that good systems of communication are needed to allow patients, carers and families to talk to the health professionals caring for them. People also wanted access to a written care plan.

Communications

Most people asked for “*honest information*” from someone directly involved in patient care. Some people said that this had not typically been their experience during previous hospital stays.

“Honest information from consultants – don't treat families and carers as if they're stupid.” (NHS Nottingham City public and patient engagement event, Albert Hall)

“My father has been in hospital for a week now following a series of TIAs. He and the family are still waiting for information on what is going to happen next.” (NHS Derby City feedback on questionnaires)

In particular, people asked for:



- Families and carers to be given a direct line to someone with up-to-date information about a patient's condition
 - “A named contact through the process, so you always know who you could speak to.” (NHS Leicestershire, Leicester and Rutland patient and public engagement event, Highpoint)*
 - “Could there be a patient’s champion who could talk to patients to check if everything is going okay?” (NHS Derby City public and patient engagement event, Derwent Court)*
 - “A co-ordinator (is) appointed and the patient and family are given the co-ordinators name as the point of contact” (NHS Leicestershire, Leicester, Rutland)*
- Doctors and nurses to be on hand to talk to patients about tests, treatments and prognosis. Patients, carers and families want regular, honest updates about the impact of the stroke or heart attack and the chances of a full recovery, and they want this to come from those directly involved in providing care
 - “Someone to update relatives about a patient’s condition at each visit – without having to be asked.” (NHS Leicestershire, Leicester and Rutland online heart survey)*
 - “As much face-to-face time as possible with their doctor is beneficial.” (NHS Northamptonshire, Wellingborough stroke event)*
 - “Easy access to someone who knows about my case to discuss current state of affairs, prognosis and life after a heart attack” (NHS Leicestershire, Leicester and Rutland)*
- Involvement in the decisions surrounding their care. People also want a choice about where they are moved to once they are well enough to leave a specialist centre, and about the timing of the move.

Information

At every event, people said they wanted clear, high-quality information about the different types of strokes and heart attacks, the treatment they could expect, prognosis, and how to prevent further problems. They also asked for explanations about the different stroke and heart attack services available, and which patients would go where, when and why (*“the pathway”*). People commenting on the heart attack proposals asked for clear explanations of all prescribed medicines – what they are for and how to take them.

“As much information as possible, it is often not given early enough.” (NHS Northamptonshire market stalls heart event, Wellingborough and Corby)

People also see a need for practical information, explaining things like hospital visiting times, public transport, directions to specialist centres, telephone numbers, parking, food and accommodation.

In particular, people asked for information to be available about *“after care”* and *“going home”*. They expected to be fully informed about rehabilitation and ongoing care, including what they should (or shouldn’t) do, what to expect, and how to get help if they needed it, either from the NHS or from support groups. Some people were anxious that patients might be discharged from hospital without carers or families really knowing how to support their loved ones.



“Info about what happens next – the prospect of a disabling stroke can be as difficult to deal with for the family as it is for the patient.” (NHS Northamptonshire Daventry Over Fifties Forum event)

“Referral to the Stroke Association is important. There have been cases where the referral to the Stroke Association was not followed up and the patient was then left without support.” (NHS Northamptonshire Daventry Over Fifties Forum event)

Specifically, people wanted to know how a stroke or heart attack would affect their day-to-day activities – climbing stairs, eating, work or having sex. They also wanted better care, information and support on issues like pressure sores, constipation and dehydration, especially in elderly patients and those without family and carers.

Across the groups, people asked for information to be provided in a way that takes account of religious, language and cultural needs. It was suggested that interpreters be available at specialist centres. One person called for large font size to be used on all leaflets.

Support

At all events, people mentioned the need to provide financial support for carers and families who are expected to travel long distances to visit people in specialist centres. This support might include transport and parking costs.

“Support is needed for parking. It is often impossible to pay with cash, [the ticket machine] doesn't give change, or you have to buy a minimum or maximum amount of time.”

“Parking charges are an insult.” (NHS Leicestershire, Leicester and Rutland)

People also said they would like to see emotional support provided for everyone involved. This included support for carers of people who have had a stroke or heart attack.

“Direct people to the many volunteers who do a lot of good work.” (NHS Northamptonshire, market stalls stroke event, Wellingborough and Corby)

Lots of people saw a need for wider social and practical support, including help completing welfare forms, understanding benefit entitlements, and getting financial support for things like heating. In the Derby City engagement event (at Derwent Court), people suggested that a “*discharge co-ordinator*” could help people sort out the practical implications of going home. This, they felt, would take away the organisational burden from families and carers and allow them time to deal with the emotional side of someone suffering a stroke or heart attack.

“Information about benefits – to some people that might be alien, something they've never done before. It can be very complex, knowing about welfare rights.” (NHS Nottingham City public and patient engagement event, Albert Hall)

3.0 How this feedback might shape the proposed changes to heart attack and stroke services

3.1 Informing service specifications

The feedback provides a snapshot of views from people living in several locations



around the East Midlands. It provides qualitative information and does not quantify how strongly or widely the views raised are shared across the region. Although the PCTs sought to hear from people of different ages and ethnic backgrounds, the profile of the groups does not reflect the diversity of the East Midlands population. It is important, therefore, not to overly generalise the findings.

However, there were some consistent messages raised by key audiences who will be specifically affected by the proposals, voluntary groups and community groups.

Some of the expectations and issues raised are included in the minimum criteria drafted by the project team and Clinical Advisory Group for the urgent stroke and heart attack service. There could now be an opportunity for local commissioners to take the detail from this feedback and develop detailed service specifications and key performance indicators that measure the things that matter most to people.

In particular, the service agreements between commissioners and providers could reflect these key patient expectations and priorities:

A quick journey to the best hospital

- A quick response to an accident by a well-equipped ambulance staffed by trained paramedics.
- Paramedics to pre-alert the specialist centre of a patient's arrival and a guaranteed bed and fast access to specialist care on arrival.
- Patients to be taken to the hospital best equipped to deal with their injuries, even if this meant a slightly longer journey.
- A choice about which hospital a person is transferred to

Reliable communication systems within the urgent stroke and heart attack service

- Reliable communication systems need to be a high priority, with information available to relatives through a named contact at a central telephone number.
- People expect continuity of care, with accurate, up-to-date records about their condition and ongoing care plan to be transferred between hospitals with (or ahead of) them.
- Some people requested a co-ordinator to be a point of contact for the patient and family and manage the transfer to a local hospital.
- People want their GP involved and kept informed of their condition.

Support for families and carers

- Public transport routes to be considered before decisions are made about the location of the specialist centres. *“Good plan, as long as [specialist centres] are accessible to patients without cars who depend on the public transport system.” (NHS Leicestershire, Leicester and Rutland online survey)*
- Support for families and carers while visiting loved ones some distance from their homes. This includes free car parking and help with accommodation.
- Specialist centres to ensure they have support services for all the communities in their large catchment areas.

Information about a patient's condition and prognosis

- Clear, plain-language information about a patient's condition and treatment,



- with support for people with first languages other than English.
- Involvement of patients and families in decisions about care.
- Availability of counselling services for patients, carers and families.

Choice about transfers

- A choice of local hospital
- People also want say in when they are transferred and reassurance that this is clinically indicated.

Expertise and teamwork throughout the system

- Ongoing communication between the specialist centre staff and the local hospital.
- They also expect the local hospital to be highly skilled and equipped to manage their on-going treatment and rehabilitation.

One area that may need further clarification is how patient choice and consent feature in the proposed new pathways for urgent heart attack and stroke. Some people expressed a preference for local care and others asked how they will give consent for procedures such as PPCI and thrombolysis (*“Consent - how is this going to be achieved?”*).

3.2 Developing PCTs communication/media messages

The feedback could also help to shape ongoing communication activities by PCTs and NHS Trusts proposing to offer urgent stroke and heart attack care.

Promote the benefits of specialist care

There’s an ongoing need to promote clear and strong messages on the potential clinical benefits of specialist care for heart attacks and strokes. Some people in the groups expressed concern about whether heart attack or stroke centres really can deliver better care than local hospitals. There seemed to be more concern from those responding to the online survey compared with those in the engagement events who had listened to a presentation.

Many of the people who provided feedback had been affected by a stroke or heart attack and others mentioned related chronic health problems. For some, the potential benefits of specialist care do not outweigh the desire to be treated in a hospital where they are known and have been treated previously.

Clear case studies that illustrate how people may travel through the heart attack or stroke system will help to support the messages. It would be helpful if these could emphasise the rapid transfer back to local hospitals and the high-quality of care there.

Build trust and reassurance

Ongoing communication activities should also seek to build trust and offer reassurance about the speed of response from paramedics, the expertise of those attending the scene and the safety of ambulance journeys. Including supportive quotes from EMAS and paramedics will help to reassure the public.

It might be helpful to point to successful heart attack and stroke systems elsewhere



to support messages about the safety of ambulance journeys.

It's also important to emphasise that the proposals are for a system of care and not just specialist centres. People at the events raised concerns about the coordination of care and the quality of local heart attack and stroke centres. There appears to be a perception that people will be discharged from specialist centres too early, in order to release beds, and sent to local hospitals without the skills and equipment to help them recover. Communication activities need to build trust in the system of care and highlight that local heart attack and stroke units are not second best, but the best place for ongoing care and rehabilitation.

Q&A

People at the events consistently raised the same sorts of questions and it might be useful to plan a Q&A based on these:

- How will paramedics know whether I need to be treated at a specialist centre?
- Is it safe to travel in an ambulance for 60 minutes if I've had a heart attack or stroke? What will happen if my condition deteriorates?
- Wouldn't it be better to get specialist care more quickly?
- What if someone doesn't want to go to a specialist centre for PPCI – can they choose to be taken elsewhere
- Why can't all hospitals have specialist centres for urgent stroke and heart attack care?
- Will a bed be available when I arrive at the specialist heart attack or stroke centre? Will the staff be ready for me?
- When I'm transferred, do the local units have the expertise to deal with my ongoing care?
- Where will the specialist heart attack and stroke centres be located?
- Which hospital will I be taken to?
- That's an hour away from my home, how will my family travel to see me each day? Will there be anywhere for them to stay? Will they be able to park?
- How long will I stay in the specialist centre?
- Which local unit will I be transferred to? Will the hospital be equipped to help me recover from my heart attack or stroke? If my condition deteriorates, will I go back to the specialist centre?
- What will happen to the elderly in these proposals? Will they be taken to hospitals far away from home?
- Is there anywhere for my family and friends to stay at the hospital?
- How will a specialist centre know about my previous treatment or other chronic conditions?

4.0 Appendices

Appendix 1

Table of heart attack and stroke engagement events held by PCTs in the East Midlands

These tables summarise the number and audience for each PCT engagement event. People in some events completed equality monitoring forms, and this information is provided in the table. The * symbol denotes where this information was not collected or provided.

PCT		Audience	People attending
NHS Nottinghamshire County	Discussion with @astroke group	People affected by stroke – patients, carers, families	15-30
	Discussion with Burton Joyce Stroke Club	People affected by stroke – patients, carers, families	11
	Discussion with Diabetic Support Group and Cardiac Support Group (Nottingham)	People with heart problems	12
	Discussion with Positive Patient Support Group	People with diabetes	15-30
	Discussion with Principia Patient Reference Group	Community representatives for Rushcliffe area	16 (10 lay members)
	Discussion with NHS Nottinghamshire County's Patient and Public Advisory Panel	Patients/public/NHS staff	12
	Discussion with Gedling Community and Voluntary Services (CVS) at (Gedling Health Network meeting)	People from a mix of community/voluntary groups	13
Link on PCT website to Towards Excellence online survey	Public	3	



Target groups – Information and the online survey link were sent to these groups:

Friendship Club for the Elderly (Kirkby in Ashfield)	Carers Advisory Group (2) (North & South)
St Pauls Church Group (Carlton)	Nottingham Stroke Club
New Leaf Meetings (Warsop Primary Care Centre)	The Open Door Project (Nottingham)
Keyworth Distribution Community Concern Trust (Keyworth)	Rushcliffe Asian Community Association (Rushcliffe)
Broxtowe African Caribbean Elders Group (Broxtowe)	Ashfield & Mansfield Locality Engagement Group (Mansfield)
Mansfield & Ashfield Carers Support Group (Mansfield)	Broxtowe Locality Engagement Group
Breathe Easy Group (Kirkby in Ashfield)	Better Health for Hucknall Group
LINK Executive Group	Newark & Sherwood Locality Engagement Group
Ashfield & Mansfield Health Involvement Network (Mansfield)	Nottingham Cardiac Support Group
Mansfield CVS (Mansfield)	Bassetlaw Cardiac Support Group
Sherwood Stroke Club (Sherwood)	Ollerton Health Group
Partnership Development Team (British Red Cross) (Nottingham)	Friendship Group for Over 60's
Radford Care Group	



PCT	Activity	Audience	People attending/ responding	Gender/ Ethnicity	Age
NHS Northamptonshire	Meeting with Corby Heart Support Group	People with heart problems and their carers	10		55-75 10
	Discussion with Daventry and District Over Fifties Forum (DOF) – public meeting	Public aged over 50	16	*	50 +
5 events Leaflet distribution	Public meeting “Delivering the Future” – held at Kettering Conference Centre	Public/stakeholders	9 (considered stroke scenario)	*	*
	Workshop ‘Have your say on heart and stroke care’ – held at Wellingborough museum	Public/stakeholders	8 (considered heart scenario) 32	5%	35-45 45-55 55+ 7 13 12
	Distributed information/feedback forms through ‘stalls’ set up in Corby and Wellingborough shopping areas (2 days)	Public	39	*	*
	Link on PCT website to Towards Excellence online survey	Public	*	*	*



Roadshow for Long Meadow Stroke Group	Stroke patients/carers and social care staff	12	White British (7) Black British (2) Black Caribbean (2) White Irish (1)	31-49 50-60 65-75	1 5 6
Distributed leaflet /feedback form	Public – Mailshot to 113,000 homes – Given to 65 Asian women taking a coach trip – Given to 32 people attending an event for members of NHS Nottingham's Citizen's Health Panel and Patient Experience Group	580	Male (202) Female (306) Not stated/other (63)	18-30 31-49 50-64 65-74 75+ Not stated	18 111 167 135 133 11
Online heart questionnaire – on PCT website	Public/patients	16	Disabled (132) Not disabled (387)		
Online stroke questionnaire – on PCT website	Public/patients	12			



PCT	Activity	Audience	People attending/ responding
NHS Derbyshire County	Discussion event with the Health in Amber Valley Group	Public representatives and other agencies involved in healthcare	*
	Discussion with Chesterfield and North East Derbyshire multi-agency group	Community representatives – members of PCT health panel and LINKs local planning group	24
	Discussion with Bolsolver multi-agency group	Community representatives, LINK lay member, patient representatives	20
3 events Link to online survey Questionnaires	Distributed information at a 'Equality Equals Respect' event organised by Chesterfield Borough Council.	Public including Black and Minority Ethnic (BME) groups	*
	Local Patient Advice and Liaison Services (PALS) held a "stall" at the event and handed out leaflets and feedback forms.		(responses included in 486 below)
	Distributed information and feedback forms to target groups **	Patient and community groups/meetings, including Age Concern, Asian Association, Stroke support group	486
	Link on PCT website to Towards Excellence online survey	Patients/public/stakeholders	*

** Information and feedback forms were distributed to these groups – 486 responses were received:

Age concern (Matlock and Chesterfield)	Muslim Welfare Association	British Red Cross – Walton hospital
ACCA Group	Chesterfield Filipino Community	CAMTAD
Chesterfield and Clay Cross	Alzheimers Society Dronfield	Midlands Amputees Association
Clay Cross and District Older People Forum	Alzheimers Society Chesterfield	Health panel
Chinese Association	Bolsover Elderly Self Help	Tibshelf Luncheon Club



Chair of Understanding Minority Matters Group	Stroke Support Group	Waistwise Group
Asian Association	Volunteer Centre	Gypsy liaison group
Derbyshire County Council 50plus Forums	Citizens Advice Centre	Unemployed workers centre

PCT	Activity	Audience	People attending /responses
NHS Derby City 1 event	Discussion event held at Derwent Court, Derby	Patient groups/community groups/voluntary organisations	29
	Information and feedback forms distributed to meetings/events	Community groups	122

Presentation and/ or information and questionnaires distributed at these meetings or events:

- Health and Social Care Forum – 5 November 2009 (20 people)
- Mickleover Neighbourhood Board – 12 November 2009 (10 people)
- Alvaston Neighbourhood Forum – 16 November 2009 (40 people)
- Normanton Neighbourhood Board – 16 November 2009 (15 people)
- Carers Conference – 17 November 2009 (30 people)
- Sahara Men's Lunch Club – 24 November 2009 (14 people)
- Golden Age Group – 24 November 2009 (15 people, 30 questionnaires)
- Hindu Temple Women's Lunch Club – 24 November 2009 (15 people)
- West Indian Community Centre – 25 November 2009 (25 people)
- Derwent Neighbourhood Forum – 25 November 2009 (16 people)
- Arboretum Neighbourhood Board – 25 November 2009 (14 people)
- Chaddesden Stroke Club – 25 November 2009 (20 people)
- Sahara Women's Lunch Club – 25 November 2009 (11 people)
- Spondon Neighbourhood Forum – 2 December 2009 (25 people)
- Lil Muslimah – 2 December 2009 (8 people)
- 50 Plus Forum – 3 December 2009 (25 people, 10 questionnaires)



- NHS Derby City Annual Review – 3 December 2009 (80 people)
- Arboretum Event – 5 December 2009 (20 people)
- British Heart Foundation Fun Run – 6 December 2009 (60 people)
- Sinfin Neighbourhood Board – 9 December 2009 (20 people)
- Normanton Neighbourhood Forum – 10 December 2009 (25 people)
- Mackworth Neighbourhood Forum – 14 December 2009 (22 people)

PCT	Activity	Audience	People attending	Ethnicity	Age
NHS Lincolnshire 1 event Link to online survey	Discussion event with stakeholders at Bentley hotel, Lincoln	Patients/patient groups	35 people	*	*
	Link on PCT website to Towards Excellence online survey	Patients/public/stakeholders	*		



PCT	Activity	Audience	People attending/ responding	Age	Ethnicity
NHS Leicestershire, Leicestershire and Rutland 1 event Online survey Questionnaires	Discussion event at Highpoint Conference Centre	Public/patients, Local LINKs, local authority representatives, voluntary organisations, community groups, NHS staff	89	16-19 20-29 30-39 40-49 50-59 60-69 70-79 80+	Asian or Asian British (16) Indian (5) Black or Black British (6) African (1) Caribbean (1) Mixed Heritage (1) White & Asian (1) White British (209) White Irish (1) Other (5)
	Online heart survey – posted on PCT website	Public	33		
	Online stroke survey – posted on PCT website	Public	21		
	Distributed heart attack information and hard copy surveys	Public/patients e.g. NHS Trust members, Age Concern, Older people's forum	77	16-24 25-34 35-59 60-74 75 +	Total for all surveys: 2 (1%) 9 (4%) 58 (27%) 74 (35%) 70 (33%)
	Distributed stroke information and hard copy surveys	Public/patients e.g. NHS Trust members, Age Concern, Older people's forum	89		

Total number of people attending events or responding to surveys: 309

For the online and printed surveys, respondents were also asked about previous heart attacks and strokes, their gender and postcode:

Postcode address location	Hard copy and online surveys response
Leicester City	92 (50%)
Leicestershire and Rutland	89 (48%)
Out of area	4 (2%)



Gender	All responses
Male	68 (30%)
Female	161 (70%)
Have you suffered a stroke/heart attack?	Hard copy and online surveys response
Yes	31 (15%)
No	181 (85%)
Has a member of your family suffered a stroke/heart attack?	Hard copy and online surveys response
Yes	111 (53%)
No	100 (47%)



Appendix 2



Lincolnshire Teaching Primary Care Trust

Cross O'Cliff
Bracebridge Heath
Lincoln
LN4 2HN
Tel: 01522 515521
Fax: 01522 540706

NEWS RELEASE: 13 November 2009

Draft

PATIENTS SPEAK UP AT HEALTH EVENT

Last year 1,200 people in Lincolnshire suffered from a stroke and an estimated 11,500 will have experienced a TIA (transient ischaemic attack), which is caused by lack of blood flow to the brain.

On 12 November 2009 NHS Lincolnshire asked patients and carers from representative stakeholder groups to help the on-going work to shape services for stroke and heart attack patients across the county.

The stakeholder event took place at The Bentley Hotel, Lincoln to gain insight which will further define stroke and heart attack services in Lincolnshire from the on set and the first seven days of hospital care.

Feedback from the event will contribute to the surveys, patient experience groups and events have already taken place locally and regionally.

Insert quote from stakeholder.

Jim Heys, Assistant Director of Strategic Planning and Health Outcomes for NHS



Lincolnshire said:

“The feedback we took from this event has proved invaluable in shaping health care services that meets the needs of our patients. We are working towards improving prevention of strokes and heart attacks, investing in hospital care and developing community based rehabilitation services.”

ENDS

Media Contact: Communications team 01522 515326

Subscribe to our newsfeed at www.lincolnshire.nhs.uk or follow us on Twitter

<http://twitter.com/nhslincolnshire>.

Notes to Editors:

1. 13886 figures from The Information Centre for Health and Social Care (June 2008)
2. Stroke is the third leading cause of death in the UK and the single largest cause of adult disability in England.

PR 181



12 November 2009

Public get chance to improve heart attack and stroke care across the East Midlands

The local NHS wants public and patient views on how services for heart attack and acute stroke patients can be improved in Nottingham and across the East Midlands.

Members of the public are invited to hear about plans to improve urgent care, which will help save lives, at an event on Thursday 3 December, 10am-2pm at The Albert Hall, North Circus Street (off Derby Road) in Nottingham City Centre.

Approximately 2000 people a year in the East Midlands could benefit from a specialist heart attack treatment called Primary Percutaneous Coronary Intervention (PPCI). New proposals seek to improve care for heart attack patients by creating specialist heart centres which could deliver PPCI treatment to more patients. This will save more lives, cut the risk of a further heart attack and speed recovery.

Strokes are the UK's third biggest killer, affecting approximately 6,000 people a year in the region. Plans to improve stroke care include several specialist centres that can offer the most up-to-date and effective urgent treatment. This will be supported by public awareness campaigns helping people to spot the signs of stroke, and improved rehabilitation meaning stroke patients are less likely to be dependent on others for long term care.



/cont'd

Chief Executive of NHS Nottingham City and regional project sponsor Andrew Kenworthy said:

“This is an open invitation for people in Nottingham to help us plan better services for heart attack and acute stroke patients. This engagement event will enable us to hear your feedback and suggestions on plans for regional specialist centres providing urgent care. We need to ensure that any changes to NHS services include the input of local partners and the experience of our patients and local population.”

Andrew Kenworthy will introduce the event, after which there will be presentations on current examples of heart attack and stroke care, patient perspectives and an outline of the proposals for improved services in the region. Lunch will be provided.

Whilst this is an open invitation, those wishing to attend are asked to RSVP to Pam Edwards, Public and Patient Involvement, NHS Nottingham City on 0115 883 9203 or email pam.edwards@nottinghamcity.nhs.uk

---ENDS---

Issued by: COI News and PR East Midlands on behalf of NHS Nottingham City.

For further information or interviews, please contact:

Laura Gurnett, Account Manager
Phone: 0115 852 4358
Email: laura.gurnett@coi.gsi.gov.uk

Note to Editors:

The current proposals for improved urgent care were proposed as part of the NHS in the East Midland's vision *Towards Excellence* published in June 2009, to ensure patients can receive the most up to date and effective treatment as quickly as possible. This was published in response to Lord Darzi's national Next Stage Review – a clear view for improving health care over the next decade.

For further information, visit: www.excellence.eastmidlands.nhs.uk



Appendix 3

Presentations used at the events
(as a separate document)



Appendix 4

Heart attack Scenarios

Scenario 1 - Mr J

It is Friday afternoon and Mr J has had a busy day at the office. He is anxious about Monday morning's meeting. He works in a stressful job and has been overweight for a number of years.

On and off for a number of months he has had what he thought was indigestion. At 6 o'clock his 'indigestion' returns but the feeling is unbearable and is extending across his chest. He is finding it difficult to breathe and he is sweating. His friend, who has popped round to watch a DVD, notices the pain and anxiety on Mr J's face and calls the ambulance.

Scenario 2 - Mrs P

Mrs P has always been fit, walking and swimming every week. She is 65 and her family has a history of high cholesterol. One day Mrs P starts to feel a pain in her chest. She starts walking to a friend's house to get a lift to the shops. She stops to see if the pain goes off. After a few minutes she starts walking again but the pain is getting worse.

A passer-by notices Mrs P and asks if she needs some help. Mrs P refuses the offer of an ambulance, but calls a taxi. The taxi takes her to her local Accident and Emergency (A&E) department, but the symptoms appear to be dying off. Mrs P asks herself if she should be wasting the hospital's time.

Stroke Scenarios

Scenario 1 - Mr C

One day Mr C feels unwell and notices that his speech has become slurred. He works at a school, and, while he is talking to his pupils, a colleague notices that he appears to have lost his normal communication skills and calls an ambulance. Mr C is a 40-year-old man with a family history of high blood pressure (hypertension).

The ambulance staff assess Mr C. He appears to be okay now, but, due to his symptoms and his colleague's observations, he is taken to hospital. On arrival at the hospital A&E department he is assessed; his blood pressure is 165/90 (high) but he has otherwise fully recovered within 40 minutes and is referred back to his GP. A few weeks later Mr C has a disabling stroke.

Scenario 2 - Mrs D

Mrs D was having breakfast with her husband, listening to *Today* on Radio 4, and was suddenly unable to communicate or move her right side as well as usual. She is



a 75-year-old woman, and a smoker for the past 60 years. Her husband calls 999. The ambulance paramedics assess the problem using FAST – see below – and establish that she has had a stroke.

FAST

- Face – Has their face fallen on one side? Can they smile?
- Arm – Can they raise both arms and keep them there?
- Speech – Is their speech slurred?
- Time to call 999. If you see any single one of these signs.



Appendix 5

Heart attack evaluation form

Date :

.....
.....

1. Overall how interesting did you find this event? (please tick)

very interesting	
interesting	
not interesting	
not at all interesting	

2. Overall how relevant did you find this event? (please tick)

very relevant	
relevant	
not very relevant	
not at all relevant	

3. Did you understand what was being asked of you? (please tick)

Yes	
No	

If NO, what more could we have done to improve make the event for you?

.....
.....
.....
.....

If YES, did you feel you could contribute as much as you wanted to? (please tick)

I was able to fully contribute	
I could contribute but not as much as I wanted to	
I did not feel able to contribute	

4. Did you find presentations useful ? (please tick)

Yes	
No	

6. Please add any further comments which could help us to improve the way we discuss our proposals in future

.....
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.....



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As we move forward with proposals for heart attack services we want to continue to include patients and the public.

If you would like to be kept informed about the progress we are making or would like to be included in any future events please fill in your details below:

Name :

.....

.....

Address :

.....

.....

.....

.....

.....

.....

Email:

.....

Thank you for taking part



Appendix 6

Bassetlaw PCT engagement with the public and patients on urgent stroke and heart attack care

This appendix summarises some of the key feedback from Bassetlaw on proposals for urgent stroke and heart attack care.

1.0 Heart attacks

- PCTs carried out a full 3 month consultation on the North Trent Network of Cardiac Care Strategy in September 2008 (supported by Cardiac Network Staff).
- The consultation covered proposals for specialist heart attack centres with access to PPCI and improved cardiac care in local hospitals.
- The consultation included Cardiac Support Groups, Public Groups, OSCs.
- Public and Patient engagement involved an information booklet, questionnaire, workshops and attendance of meetings.
- The Cardiac Network User Group were involved throughout the development of proposals for improving cardiac care (including the PPCI service).
- Feedback from BassetlawPCT on the consultation is below:

Consultation feedback from Bassetlaw health community

Emergency Care for Heart Attack

The main view of having a heart attack centre with access to PPCI for the whole of the network based at the Northern General Hospital was very positive. Having a specialist centre was thought to be a good use of skills and resources. Travel times, difficulties for visitors, parking and flexibility of visiting hours were particular concerns for those living in the Bassetlaw Area. They also highlighted the need for good communication with both the patient and the family.

There were, however, several points that were highlighted and echoed throughout the feedback.

- Transport costs could pose difficulties for people from the South of Bassetlaw. Transport times could be long.
- Ambulance rides for the patient could be quite lengthy.
- *"Good idea – experienced people dealing with you that know a lot about this – 'the expert'."*



- *"Having someone who knows what they are doing is important. Gives you (the family of the patient) confidence, the more they do the more experienced they get making sure people know what has happened as soon as possible because they may have to be the main carer for people."* (Patient)
- *"Robust liaison/communication even out of hours. Ambulance people need to know what the process is to be able to communicate this to the patient to re-assure."* (Patient)
- *"Very good, like the idea of being treated straight away."* (Patient Group)
- *"Do not want to de-stabilise local services."* Concern was expressed that local staff will be deskilled with PPCI service. Need to adequately care for patients who are not eligible for this service. (Patient Group)
- *"Want to be re-assured at every stage – lack of information and poor communication is generally an ongoing issue, this becomes worse during emergency situations. Would like to be re-assured of the level of care being provided during transfer."* (Patient Group)
- *"Excellent – as far as I am concerned the NGH is by far the best and most suitable place for emergency heart care."* (Patient)
- *"Information – medication and side effects, full and frank explanation of what to expect following a heart attack to both victim and family. Rehab is important for regaining confidence and alleviating fear of another attack!"* (Patient)
- *"Is it always best to rush a patient into a procedure, can it sometimes be better to allow people to prepare?"* (Patient)
- *"Flexible visiting hours."* (Patient)
- *"Patient is getting the best care available."* (Patient)

Highly Specialised Care for Heart Problems

The feedback showed that people are very keen to have specialised care available to them via their local hospital. Interestingly, there was a large amount of concern raised in Bassetlaw in particular that the NGH should be preserved as a specialist centre, and people would not want to risk this by introducing the DGHs as local specialised centres.

It was considered to be very important to both patients and family to have care provided as close as possible to home where clinically appropriate, but they equally wanted to know that their family are receiving the best care possible, and if this is at a distance then people will travel for that care.

People raised the question of how the standard of clinical care would be kept the same at all hospitals.

There were a number of additional points raised, including:



- *"Much better- have had the experience of a non-driving wife of a patient who had to ask for lifts everyday – not easy."* (Patient)
- *"If this can be done without destabilising Sheffield's expertise then it is a good idea. Sheffield is near, I like the thought of this. Will it drive the waiting lists up though?"*
- *"If services were nearer, wouldn't have a problem but wouldn't want to destabilise existing services."* (Patient Group)
- *"Need to keep people fully informed. More information is needed. Lack of communication is a problem; doctors need to spend more time communicating the results and implications of test results. Information should be given in a timely manner by a specialist."* (Patient Group)
- *"Initially not a good idea due to the thinning out of specialist skill and serious cost implications. But if you can realistically find the skills and the money to provide six centres of excellence in this area, then go ahead."* (Patient)
- *"Honest feedback from the consultant cardiologist about future prognosis, and honesty [regarding] some of the lifestyle changes that need to be made both for the patient and potentially for other family members to prevent re-occurrence."* (Patient)
- *"Confusion over having the Northern General as specialised centre then saying it can be done at the local hospitals?"* (Patient)
- Location of services is important – Heart Attacks are time critical ailments.
- Some people might think that the treatment and care is more important than the location of the hospital (Patient)

2.0 Urgent stroke care

- PCTs carried out a consultation on the North Trent Stroke Strategy project
- The consultation sought feedback on the quality markers set out in the national stroke strategy. These included plans for providing urgent specialist care for stroke.
- The key engagement event was held in June 2009 ("Working together to Develop Stroke Services in Bassetlaw" held at Bawtry Hall
- Feedback from BassetlawPCT on the consultation is below:

Consultation

QM 7. Urgent response

We want everyone with suspected acute stroke to be sent immediately by ambulance to a hospital with a specialist stroke unit.



QM 7a What do you think about these plans?

- Want to see a local specialist stroke unit capable of delivering a thrombolysis service. Discussion around small numbers of people eligible for this service. *“Even if only two lives are saved it is important.”*
- Concern expressed about a postcode lottery ,the group advised that they would like to see the same level of service being offered in Bassetlaw as in the other health communities across the region.
- Personal experience of assuming things were more serious because of transfer to another unit – negative experience of high anxiety.
- Personal positive experience of being able to stay with patient 24/7 when on the stroke unit.
- Better for travelling and being able to visit and support patient if the service is local.
- Very positive experiences shared around the level of support and the experience with local stroke unit.
- Negative experiences shared around level of care and support whilst on the ward before transfer to the unit. It was felt this was as a result of lack of knowledge and expertise and the environment being busy and there was a lack of time spent with the family supporting them.
- Would like to see direct admission to the unit being introduced.
- Personal experience of long waits from call for help to diagnosis and admission to stroke unit.
- Time is of the greatest importance, and if having to travel to other centres, concern was expressed about the possibility of this delaying things for the local stroke victims.
- Personal experience of the different strokes being treated differently ,bleed strokes treated quicker because they are transferred to another hospital for treatment.
- Positive experiences shared around the treatment care delivered by the local ambulance service
- Overwhelming support for local services and a local thrombolysis service for stroke, it was felt that the existing expertise in A&E CCU and the ambulance service around thrombolysis for heart attacks could be tapped into and utilised.
- Concern expressed about having a centre of excellence that this centre being overloaded, especially in light of the plans for cardiac care.
- These are positive plans but this will all depend on having a 24 hour team to



support it.

- Want specialist care services locally.
- Want a centre of excellence in our local health community.

QM 7b Is the location of the hospital that provides specialist care for stroke problems important to patients and their families?

- Absolutely it is important ,experience of waiting for 18 hrs until got onto a stroke unit - concern expressed about getting this down to three hours.
- Time is really important. The service needs to be as local as possible.
- Local care, local services for the local people.
- Response time needs to be really rapid.
- Mixed feeling about the location of the centre of excellence, because concern was expressed about available funding to support the development of a local centre and the identified need for it be of the same standard as all the other centres across the region wouldn't want the standard to be compromised as a result of striving for a local centre.
- Would be willing to travel if required.
- Concern expressed around Sheffield becoming designated centre of excellence feeling expressed that it may become overloaded.

QM 7c What else would matter to patients who need specialist care, and their families?

- General knowledge and awareness raising needed across the board required.
- Stroke is not an elderly condition and people need to know this.
- Need to target a younger audience older people tend to have this awareness and know someone who has had a stroke all the group members were aware that their rel was having and stroke and recognised the signs and symptoms.
- Access to rapid diagnosis is really important.
- Need to know as soon as possible what the diagnosis is.
- Need to be kept informed.
- Important that I could stay and that there was accommodation available.
- Attitude of the staff and culture on the unit /ward is important allow me to get involved in the care.
- Different culture on the ward: *"no place for a stroke victim"*.



- Identified need that families with young children will need greater support.
- Concern expressed about the transfer of info with experiences shared around this getting lost on transfer.
- Admission back to the receiving hospital should be directly into a stroke unit not admissions ward.
- Want to see frontline staff trained in neurological care and want specialised staff on the stroke unit.

Feedback from engagement event in Bawtry Hall

This is a collation of the comments and recommendations made at the major Stroke Consultation Event attended by stroke survivors, their carers, and staff from a wide range of organisations.

Management of stroke in a Hospital Setting

Current position /perceived gaps for Bassetlaw

a)Urgent Response

- Ambulance
- EMAS crews are FAST trained
- deliver FAST clinical assessment
- have up to date knowledge.
- Response in rural areas not as good as in the city due to geography and funding.
- All known suspected strokes are treated as CAT A by ambulance service. Issue was raised around appropriate identification of 999 calls. It was acknowledged that full understanding by staff, call handlers and the public is needed in order to appropriately make call to the ambulance service.
- FAST has an 80% success rate in diagnosing a stroke.
- Concern was expressed about whether the sentinel audit is showing a true picture for Bassetlaw?

b)Assessment

- It was felt that people don't get fully assessed within 24 hours.
- Access to physio and SALT not quick enough.
- CT Scanning: currently not given next slot, but next available slot. On-call service give a verbal report.



- CT scans are available within 24-48 hrs but there are long waits for Doppler scans.
- No weekend scanning service available in Bassetlaw. Emergency scans are available at Doncaster Royal Infirmary.
- A&E are felt to be well trained but there was a lack of local knowledge expressed around whether the ROSIER score was used.
- Right assessment of people on diagnosis was felt to be only partly true.
- Depression scoring is done by Drs and OTs (30pt score).
- Stroke-specific depression scoring tools are available.
- Carer and Observer scales – observer could be nurse.
- VIMS & VAMS are used (pictorial assessment tool).
- Lack of clinical neuro-psychology.
- MUST tool is in place.
- Risk assessments mechanism in place.
- People are receiving structured assessment by specialist staff.
- Patient experience was shared suggesting a long period of time for initial assessments to happen (non urgent).
- Possibly an education issue.
- Trust is needed within the team and not undermining previous decisions.
- The role of technology has a part to play and the utilisation of other scanners. There are recognised issues around transport for this with the question raised that a 999/CAT A response would be required.
- Patient diagnosed to be taken straight to a 24/7 stroke unit.

c)Treatment

- It was felt the stroke unit is currently not meeting the standards set out in the stroke strategy:
- Patients are not routinely admitted direct to the unit
- Non-stroke patients are on the unit and stroke patients are on other wards
- There is limited availability of specialist trained staff supporting the unit and delivering specialist care.



- No specialist service provision for severe strokes
- access to diagnostics and staff numbers were raised as a concern this was felt to be affecting the quality of care being delivered
- lack of support for the development of specialist nursing skills
- There is a minimal SALT service and no specialist dietician.
- Long waits for swallow screen assessments, no formal protocol
- There is a lack of equipment and space to support clinical practice and the specialist monitoring of patients
- No appropriate seating
- No Consultation /Private room
- No easily available cardiac monitoring equipment. Have to refer to ITU /CCU.
- The unit has the following in place:
 - BP monitoring equipment
 - neuro specialist trained physio services
 - Beds and hoists in situ
 - Route to thrombolysis.
- Combined stroke /rehab unit with recognised protocols.
- Poor access to thrombolysis services. Opinion shared that having a local thrombolysis centre may ensure stroke is given a higher priority. It was acknowledged that things may change around this in the future.
- Different views around level of service provision were expressed by service users and service providers. It is generally felt that an inconsistent level of service is available 7 days a week.
- Learning from Doncaster – direct admissions, and athrombolysis service in place. Training and education around this service is part of the training education programme at the trust and part of induction.
- A&E to be the first step, then scanned, then therapy
- Safety issue concern was expressed around the lack of doctor availability on MAU/C2.
- Commissioning – still pay for the care patients receive.
- Current treatment standards have been set but are not being met there are



differences with in-house practice especially between the consultants.