Review of Hyper-Acute Stroke Services

Patient and carer engagement – autumn 2019

Report Prepared for NHS Liverpool Clinical Commissioning Group

November 2019

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1. Introduction

The NHS in Knowsley, Liverpool, South Sefton, Southport & Formby and West Lancashire is reviewing local hyper-acute stroke services – the hospital care provided immediately after someone has a stroke.

Currently, hospital stroke services in north Mersey are delivered at the Royal Liverpool Hospital (with rehabilitation services on the Broadgreen site), Aintree University Hospital, and Southport Hospital. The Walton Centre doesn't have a stroke unit, but it provides a type of treatment called thrombectomy – a special procedure suitable for some patients whose stroke has been caused by a blood clot. Local clinicians have developed a case for change which sets out the vision for a comprehensive stroke centre; bringing together teams providing hyper-acute services with those able to offer thrombectomy.

As part of the process to develop options for the future of services, two co-design workshops have taken place with teams from the Royal, Aintree and Southport hospitals, and the Walton Centre. A group of stroke survivors have also been involved in these workshops. A third workshop is planned for the end of November 2019.

Local NHS commissioners were keen to gather feedback from those who had experience of hospital stroke services, so that this can help inform options development and the production of a pre-consultation business case. The Stroke Association offered to support patient engagement using their existing network of groups covering Liverpool, Sefton and Knowsley.

2. Engagement Approach

The Stroke Association proposed five local groups of patients and carers who had used local hospital stroke services. Conversations took place during late October/early November 2019 with the following groups:

Merseyside Life After Stroke Group
Southport & Formby Peer Support
Knowsley Peer Support
Liverpool Stroke Café
South Sefton Life After Stroke Group

The Stroke Association does not have a regular peer support group in West Lancashire, so patients from this area who had previously had contact with the Stroke Association were invited to take part in a one-off feedback session.

The structure for these six engagement sessions was:

- Short presentation on the case for changing hyper-acute stroke services in north Mersey
- Facilitated discussions around a small number of key questions (set out below)

- *Do you think it's a good idea to bring local stroke services together in the way we have talked about, so that the most urgent stroke care is provided in a single location rather than in three different hospitals?*

- *How would you feel about having your urgent treatment at a hospital that might be further away from where you live, if it means you can get better care?*
- *What challenges/problems could bringing local hyper-acute stroke services together create for patients?*
- *Is there anything else we need to think about from a patient's perspective when developing potential options for hospital stroke services in Knowsley, Liverpool, Sefton and West Lancashire?*

NHS Liverpool CCG helped oversee planning of the process, assisted in facilitation of sessions, and compiled a report of the engagement.

3. Research Methodology

Conversations were held with groups of patients and carers at the six sessions detailed above. The engagement facilitator outlined the purpose of the meeting and the background to the proposed changes to hyper-acute stroke services – emphasising the importance of listening to patients and their carers about their experiences of local stroke services. This was followed by round table conversations with patients and carers led by a staff member of NHS Liverpool CCG; the number of individual table discussions depending on the overall size of the group. While the presentation given at the start of each session made clear that the review is looking at hospital stroke services, and this was the focus of the four questions outlined above, comments made by participants were not limited to hospital care. The questions therefore provided a starting point for conversations, rather than a rigid framework.

The conversations were recorded in the form of notes, and these form the basis of this analysis. The number of patients and carers involved is summarised in Table One:

Table One: Patients and Carers Involved

Stroke Association Groups	No of Groups	No of Patients	No of Carers/Volunteers
Merseyside Life After Stroke	**7**	**39**	**7**
Southport & Formby Peer Support	**1**	**11**	**3**
Knowsley Peer Support	**1**	**9**	**2**
Liverpool Stroke Café	**3**	**9**	**3**
South Sefton Life After Stroke	**2**	**5**	**4**
West Lancashire (Past Members)	**1**	**7**	**3**
Total	**15**	**80**	**22**

See Appendix 1 for respondent profile.

3.1 Thematic Analysis

The recorded conversations were analysed using ‘thematic analysis’. The aim of thematic analysis is to identify themes or patterns in the data that are important to the objective of the project or identifying interesting side issues. This analysis moves away from simply summarising the responses to the four questions but looks for ‘themes’ that provide deeper insights and meanings about the experiences of stroke survivors and their carers.

4. FINDINGS

4.1 Introduction

Each of the comments recorded at the group sessions has been categorised into one of five thematic themes.

Comments were recorded by a number of different note takers, and are a combination of direct quotations from participants and summations of key thoughts/ideas voiced during discussions.

4.2 Theme One: Personal Experience of the Quality of Care

Positive	Negative/Concerns
"Neuro was amazing care." Survivor said, "I received brilliant care at Aintree Hospital" as she was seen, treated and discharged promptly. "I would be concerned if one location could achieve the same quality of treatment." "Depression at the beginning is unreal. It's good to be with a specialist that understands." "Diagnosed very quickly – stroke spotted by paramedic and was thrombectomised quickly." "When I had a stroke a response car came and did the initial assessment and called an ambulance. The diagnosis was fast and efficient. Request from response car had made significant impact on speed of ambulance." "It took ambulance an hour to arrive but were quick to take him to Whiston, treating it as code Red. He received excellent care and was in bed after 72 hours and receiving visitors." "After much delay by doctor and receptionists eventually arrived at Broadgreen stroke unit – care was brilliant." "Broadgreen is a brilliant hospital. I feel secure there. Would the new location be just as good?" "Care was brilliant but 111 was not adequate in getting patients the help they need." "Had no trouble getting physio and other care."	"Had poor treatment at Southport" "Stroke Association – can't praise them enough – invaluable – consultant very different." "Somebody said there was no help at all after Southport hospital." "Don't believe I would have been sorted by hospital." "Patient was in Whiston Hospital for two weeks. Care after that was OK – but his wife said they didn't get him up enough." "3 years ago, I had good aftercare, but the physio should have been for longer as I am starting to go backwards." "I experienced delays in getting a stroke diagnosis – took four days – told there wasn't enough staff to do a scan." "Weekend experience – delays being seen." "Physio can be hit and miss – they had lots of potential to improve but no physio – frustrating." "Aftercare not good." "Rehab at Venmore awful – all very old people." "Physio at home was good but it was too short."

"Husband had stroke in the morning – clot busting treatment didn't work for him – but giving people the chance of it working is important." "When my husband had a stroke – went straight to hospital, scanned straight away and in a ward within an hour." "Had twice weekly physio visits for one year." "Had physio and rehab in hospital, but not when they went home. Did a supermarket visit with rehab staff before she left hospital." "Whiston is very good – wouldn't want to change that."	"Depending on personal circumstances you can feel very isolated when signed off from hospital care." "Staff in hospitals poor. Was in hospital over a Bank Holiday weekend and was left in bed." "Therapy needed for longer in Sefton." "Rehabilitation – I was meant to receive 3 months physio but only received four visits." "Waited 3 hours for an ambulance, meaning they weren't able to get thrombolysis by the time they arrived." "Therapy provision in Sefton inconsistent – was told you're not a priority." "People get discharged with social care from one agency – this can be changed to a cheaper service later. This has big impact on people with communication difficulties." "Survivor said consistency of care is very important but doesn't happen and concerned about lots of different carers coming into your home." "There are not enough doctors who are trained at an adequate level." "Son rang 111 when I was showing signs of a stroke, but time wasted giving them details – poor service that shouldn't be used." "Receptionists need to be better." "Hospitals don't adequately cater for stroke patients. Was diabetic and had heart problems. Staff should take into account other health problems." "Speech therapy is not good enough – need more staff as speech therapy is very important." "Had to transfer from one hospital to another – was not happy with this."

	"Daughter had a stroke – ambulance service a disgrace – waited 3 hours for one to arrive." "Paramedics thought my wife suffered a second stroke, but it was burst appendix – they need to be better trained." "My friend had to wait at Aintree A & E for two and half hours." "My daughter had a stroke six weeks after having a baby – family had to take care of baby – didn't get enough support." "Community care is hit and miss depending on where they will go." "My wife's mental health was impacted just as was mine. Took 14 weeks to sort out our care package." "Felt that survivors were discharged too quickly – adequate care not in place." "We didn't get any aftercare after being discharged." "We don't get any community rehabilitation where we are – it's considered optional." "There was no support for my daughter and her age group." "Had to go through MP to get help." "Had really poor hospital treatment at Walton – had both a stroke and brain tumour." "Lady being treated at ICU – treated for kidney issue when it was a stroke." "Mother waited two hours for an ambulance." "Mother sent home with a migraine – returned next day and was diagnosed with a stroke." "Once you leave consultant care you can feel 'left' – feels like you get all or nothing." "Once you get out of hospital you're left to your own devices."

	"No focus on carer – no one asks if you need support to?" "Feel isolated afterwards." "Not all support is helpful." "Your life as a carer has changed dramatically – not enough recognition of this." "There was no urgency to get him to hospital." "Gone to Southport by car – wife was found to have had a TIA and sent home. She had a second significant stroke a week later. Not given any warning a TIA can be precursor to a stroke." "Went to Southport hospital unable to speak – staff thought she was drunk. Husband eventually drove her to hospital in Leicester." "Services have to change for the benefit of everyone, including patients' families." "Doctors should also be trained in people skills."

4.3 Theme Two: Reaction to Bringing Local Stroke Services Together

Positive	Negative/Concerns
"Good idea to have someone specialist, face to face."	"Aftercare equally important – other hospitals would need good speech therapist, physio etc."
"Excellent idea (had poor treatment at Southport)"	"Everyone should have same access – no postcode lottery."
"Patient happy with one comprehensive stroke centre."	"Can see no reason for change."
"If operations were guaranteed to take place within 72 hours – everyone could benefit – because it needs to be done so quickly."	"Aftercare in the new service should be as good as the Neuro Centre."
"Patient had a stroke 5 years ago, aged 33. Went to Neuro Centre at Aintree from A & E – she thinks reorganisation a good thing."	"Too big is not good. In Liverpool, no hospital is that far away – so distance is not an issue in Liverpool."
Patient, who had a mini-stroke and treated at the Royal said, "I'm OK with bringing stroke services together as long as it's not too far."	"Concerns about the quantity of people going to one location for the stroke care, which could lead to delays in being seen."
"Excellence is more important than distance."	"Concerns about sufficient beds and medication at one location to accommodate more stroke sufferers."
"It would give patients a better chance of recovery if there was a centralised service."	"Concerns there would be fewer healthcare professionals looking after a larger group of patients."
"Having one location is good, as all Stroke specialist will be in one hospital."	"The new service would have to be 24 hours in order to ensure all sufferers have access to care at any given time."
"It would be a good idea so long as patients were seen as quickly as possible."	"A concern that this new service will involve cuts to existing services."
"Makes sense if we can make it better."	"Will there be enough capacity? Still have people in corridors."
"Sensible to make a centre of excellence."	"People are told that funding has been cut so staff aren't available."
"Single location might make it easier for patients – rather than multiple places for different things."	"Centralisation of services will not work and would prefer all 3 hospitals to offer the treatment needed."
"Makes sense to have all procedures in same location."	"Concerns about whether the one location would be able to cope with demand?"
"Need to end lottery based on where people are taken."	
"Need to think about effect on partner and family. If services are centralised, then there would be more advice and help for family."	

"Where you receive your urgent care doesn't matter." "As long as we get the best possible care in the acute and community therapy." "Don't feel location of the centralised stroke unit would be problematic." "It may work if internal infrastructures allow for the hospital to make the patient transfer to the urgent care centre." "Support the principal of a well-staffed single stroke unit." "Don't care where it is so long as the best treatment and care is available." "Rotation of specialists – would be good for them to gain experience." "Stroke patients won't care about where they receive care if they need it." "If better care is guaranteed, it is fine." "Good, if more specialist care would be available." "People who are having strokes won't care what happens at the time of stroke." "Good idea if it meant patients didn't need to be transported from hospital to hospital." "Good idea but would like to be transferred closer to home after acute treatment." "Good idea to have specialists in one place." "Seems obvious about having centre at Aintree – having the Walton Centre and HASV next to each other." "Carer favoured one location after wife went to one hospital then transferred to another." "Going to go anywhere if you're going to get care."	"Treatment needs to be available in every hospital – as soon as you're given the treatment, you are on the road to recovery." "Wouldn't it be better if there were adequate services across all regions." "I would prefer to be local." "Concerned about number of patients going to one location." "Having family with you is extremely important – they must be able to visit." "Isn't it riskier having it all in one place – what if it ends up being closed down?" "If 500 patients go to one unit instead of 100 how will that location cope?" "Is there going to be enough space in one existing building?" "Would there be enough machines, equipment etc. at the one location to accommodate all patients?" "Biggest fear about closing down hospitals." "Ambulance can wrongly diagnose you – so you end up in the wrong place." "Concerned about overcrowding."

"Would prefer if it meant they didn't have to wait to get to A & E". "Don't mind as long as it's specialist care." "Survivors agreed that it was better to be sent to specialist centre." "One location wouldn't be a problem as they would move out of that location soon afterwards." "I think it would be better." "Creating more focus across hospitals could make a massive difference to patients." "If it saves your life you wouldn't care where you went." "A centralised unit might make it easier to offer more support." "Excellent idea." "People need to understand that you are necessarily in hospital for a long time – the important thing is where you need to be to get the right treatment." "Families should be prepared to put up with inconvenience so that people can get the care they need." "Having a central place for stroke will allow staff to learn from each other and be together as a team."	

4.4 Theme Three: Reaction to Bringing Local Stroke Services Together (Sub Theme: Transport/Distance)

Positive	Negative/Concerns
"Travel to Aintree from Southport not a problem." "Patient doesn't mind travelling if it helps." "One survivor said people are used to travelling." "Wouldn't mind travelling further to get better care if it was within their means." "Location of care is not as important as receiving the best care possible." "OK with it as long as it was within 10-mile radius." "OK with going further away for treatment if it meant better care." "It would be better if it was centralised around Fazakerley (Aintree)."	"Would rather be back at Southport so family can come visit." "Travel by family as well as ambulance needs to be considered." Patient said, "it is not a good idea." Treated at Walton. Nervous, poor sight and deaf. "Travel is an issue." Patient, who had a mini-stroke and treated at the Royal said, "I'm OK with bringing stroke services together as long as it's not too far." "Only problem is if a family can visit. Ormskirk to Aintree would be a reasonable distance." "Location is important as timing is key. Must get there in about half an hour." "Just lengthens the time it takes to get to hospital." "Difficult to drive after a stroke so having care close by is important." "It would put more stress on the families of stroke sufferers if the location of the centralised service was further away from them." "Suggestion there should still be some stroke services at various locations across Merseyside otherwise some would have to travel all the way to receive emergency medical treatment." "It depended on how far, as different distances are manageable for different people." "Would prefer to receive care at the closest hospital to them." A survivor said, "the new location must be easy to get to, and that there are public transport links in place to facilitate this for everyone in Merseyside."

	"Can we rely on ambulances to transport people to the stroke centre?" "Concern about the impact of travel time – too far to go in the ambulance." "Mobility difficult for people after a stroke – can't drive." "Travel is an issue – more visitors if family are closer." "Travel is an issue after stroke – can't drive. Need more support to use public transport. Reliant on taxis." "Privatisation of the paramedic services and cut backs mean patients will not be able to get themselves to urgent care centre if further away from home." "Ambulance response times would need to be considered." "Time delay in transferring patients." "Wouldn't be happy going all the way to Southport because of travel." "Would patients be at risk of dying on the way to hospital." "Parking would have to be considered." "More concerned about our relatives and them travelling to visit us in hospital." "Wouldn't it be harder for ambulances to travel further distances." "Must take into consideration families and their travelling and parking costs." "Took issue with time it would take to get a patient to this location when they've had a stroke." "There needs to be good transport links to this one location." "No, not fair on family members to travel to."

	“Longer transfer times for ambulances to travel.” “Considerations should be made for family members.” “I’d prefer closer to where I live so I can be visited by friends.” “It would be difficult getting visitors.” “Where would it be? Would it be feasible to take people further?” “Carer remembered huge costs of driving to hospital to visit husband – suggested there should be help with this.” “If you’re going to travel further to hospital then the symptoms of stroke need to be recognised straight away.”

4.5 Theme Four: Post Stroke Support Services.

Positive	Negative/Concerns
"Physio was amazing. Discharged before 6 months but they're always there for you." "Found it very useful to have an explanation why stroke causes low mood – information helps acceptance both for families and survivors." "Peer support is really important – benefitted very much from the stroke club – which is no longer active."	"Aftercare equally important – other hospitals would need good speech therapist, physio etc." "Recovery can take years – some do pay." "One couldn't read or write. Needed support – felt dumped." "Memory/emotional support hard for wife and family – don't get a break." "Impact on family (son and wife). I'm fine but it's not fair on wife – she doesn't understand." "Aftercare is difficult – needs to be more consistent and the same for everyone. Now it is too patchy." "Friends and families need to be better informed about what is happening to the individual receiving treatment for their stroke." "Aftercare process was a little rushed and could be better explained for patients who are being discharged." "Post stroke psychological support service – should be available in the form of outreach – including counselling." "Felt there needs to be more support for family members who have given up their jobs to support a stroke survivor, who feel like they have to fight for everything." "Financial burden on patients' families." "More concerned about our relatives and them travelling to visit us in hospital." "Stroke survivor knew someone who didn't know who to see after being discharged." "Rehab is the key – ongoing and appropriate rehab." "Early supported discharge – very short input. Had four sessions of physio and OT. Still struggle and felt more therapy would have

	helped transform him back into healthy young man." "Two-month wait for mobility equipment." "Need to address the discrepancy of care for those who have suffered major v minor stroke. Those with mild strokes are merely thrown out – aren't given enough rehab." "You need someone to talk to who knows stroke – general counselling isn't always right." "Had to wait long time for psychological support then three changes of therapist. Has meant she hasn't been able to come off anti-depressants." "It took 12 months to get physio. When the occupational therapist felt there wasn't enough progress being made, they took her off their list and is now paying for weekly support."

4.6 Theme Five: Post Stroke Support Services (Sub Theme: Stroke Association)

Positive	Negative/Concerns
"Stroke Association great afterwards. Helped with who to see – wouldn't have made it without them." "They came once a week to the house – can't praise them enough. They were invaluable." "Stroke Association came in to help with speech." "Great feedback for Stroke Association – really value support." "They look forward to this group and similar experiences like it." "Support from Stroke Association stopped us from feeling abandoned." "Very important for Stroke Association and other things to continue." "People spoke about support from Stroke Association as being excellent." "Only been able to see someone from the Stroke Association once, but she had really helped." "Several people spoke very warmly about the Stroke Association representative."	"Stroke Association volunteers could do more – go into hospitals, inspiring people that they can get better." "As a Stroke Association volunteer, my concern is the stress on emergency services, times and costs." "People reported finding out about events/support groups via word of mouth – not much sign-posting."

5. Main Findings

5.1 Thematic Analysis

A thematic analysis of the comments made by stroke patients and carers identified five key themes, namely:

- Personal experience of the quality of care
- Reaction to bringing local stroke services together
- Reaction to bringing local stroke services together – sub-theme: transport/distance
- Post stroke support services
- Post stroke support services – sub-theme: Stroke Association

5.2 Personal Experience of the Quality of Care

There are stroke patients who report 'excellent' and 'brilliant' care at Broadgreen, Aintree and Whiston hospitals. They would expect the proposed central facility to provide treatment and care equal to or better than the existing provision.

By contrast, there are stroke patients who report poor treatment, both during the early diagnostic stage of their stroke and during their stay in hospital. Their criticism focused on both the lack of trained staff and poor quality of staff at all levels.

The main criticism by stroke patients focused on the immediate aftercare following their discharge from hospital. Uncertainty about what help is available, accessing help, insufficient help and poor standards of aftercare were cited as deficiencies in aftercare provision.

5.3 Reaction to Bringing Local Stroke Services Together

There was 'strong' support for the concept of bringing local stroke services together in a single location. Both patients and carers could see the benefits of developing a 'centre of excellence' staffed by specialists and providing a comprehensive range of support services at one centralised location. If a well-resourced specialist stroke unit could be guaranteed this might override concerns particularly about access for both patients and families.

There was scepticism about the ability of the NHS to create a centralised stroke unit that could guarantee better service. This view was based on the personal experience of patients relating to the shortages of experienced staff and other shortcomings in service delivery.

Several stroke patients did disagree with the concept of centralisation, favouring instead the existing provision of the three providers of stroke services. They were concerned about the elimination of stroke services close to home and doubted the ability of a centralised unit to cope with the volume of demand, particularly at a time of financial constraints and staffing shortages. They favoured increased investment in existing provision.

5.4 Reaction to Bringing Local Stroke Services Together – Sub Theme – Transport/Distance

The main concern about bringing local stroke services together was the issue of 'distance' and the ability of emergency crews to get the patient to hospital in time. There were examples of patients waiting lengthy periods for an ambulance to arrive or family members experiencing difficulties in accessing appropriate guidance on what actions to take. Some

patients, and their carers, worried that should the proposed central facility mean longer travelling times this could have serious health implications.

There was also the issue of friends and family support. It was noted how crucial friends and family support was to the patient in the immediate aftermath of a stroke and any centralised location must have efficient public transport links and adequate car parking space.

5.5 Post Stroke Support Services

Aftercare was a key concern of most patients and carers. Current aftercare is criticised on several dimensions – inconsistent, inadequate for needs of some patients, poor standards of care, difficulty accessing help, financial and other pressures on the family and knowing what help is available.

People consistently reported a lack of physiotherapy/occupational therapy support, and some were paying for this privately. Others reported feelings of depression, anxiety and a sense of being isolated after their stroke. There were also reports of the lack of support for family members, some of whom faced considerable life changes – e.g. having to give up work and the associated loss of income following their loved one's stroke.

5.6 Post Stroke Support Services – Sub Theme – Stroke Association

The Stroke Association has provided valuable support services to some patients and their carers.

6. CONCLUSION

I. A majority of both stroke patients and their carers were in favour of bringing stroke services together in one single location. They could see the benefit of developing a 'centre of excellence' staffed by specialists and providing a comprehensive range of support services at one centralised location.

II. However, there was both concern and some scepticism from stroke survivors and their carers that such a centre could operate without substantial changes being made to the current structure relating to admissions and post stroke support services. Much of the criticism about the treatment of stroke patients was about getting to the hospital in the first place and what happened immediately after being discharged in terms of the quality, quantity and range of support services

III. The families of stroke patients made the point that any centralised centre must have good communication/transport links and adequate car parking facilities.

IV. Stroke patients and their families viewed the treatment of stroke survivors as a process that should move smoothly from one phase to the next. The current treatment of stroke patients does not achieve that objective for all patients. Whilst the engagement was originally designed to get specific feedback about the potential for centralising hospital stroke services, the conversations ranged over a much broader set of issues. Respondents wanted to talk about their experiences of stroke care and life after stroke, which highlighted opportunities for improvements across several areas. Some stroke patients experienced delays in getting to hospital once stroke symptoms were confirmed and others complained about the lack of aftercare and support after leaving hospital. These shortcomings can have long lasting impacts.

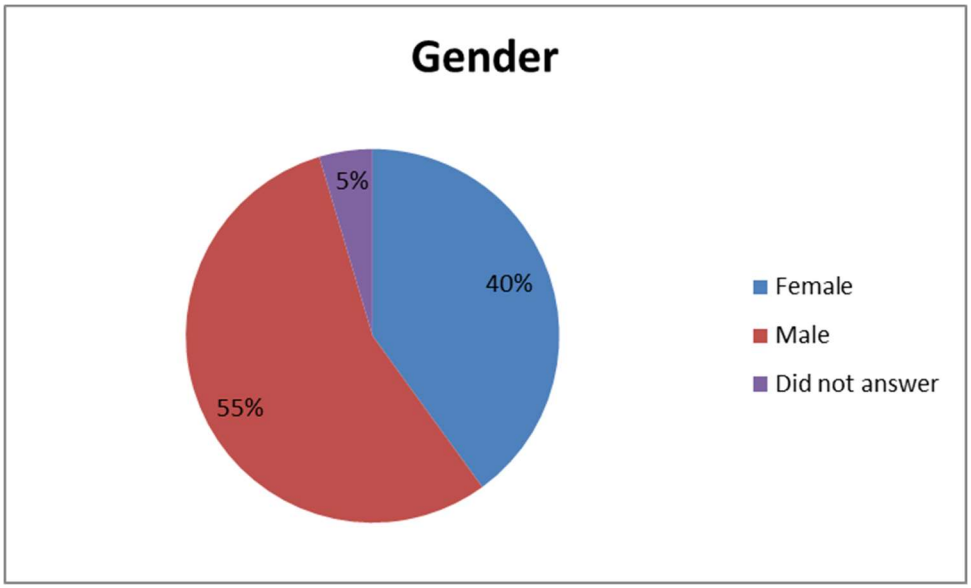
V. The experience of stroke survivors and their families was not defined by their hospital care alone. The review should also consider how these wider issues impact on patient outcomes, including rehabilitation support, and how they plan to be addressed.

VI. There are a minority of stroke patients who disagree with the concept of centralisation, favouring instead the existing provision of the three providers of stroke services. They were concerned about the elimination of stroke services close to home and doubted the ability of a centralised unit to cope with the volume of demand, particularly at a time of financial constraints and staffing shortages. They favoured increased investment in existing provision.

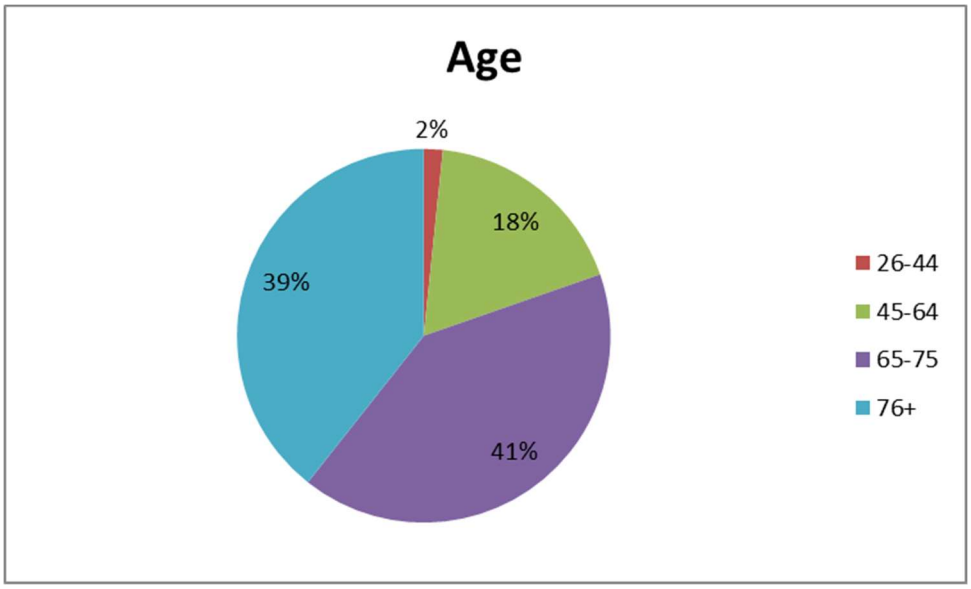
APPENDIX I. Profile of Respondents

People at the six sessions were asked to complete a short equalities monitoring form. The information collected is shown below.

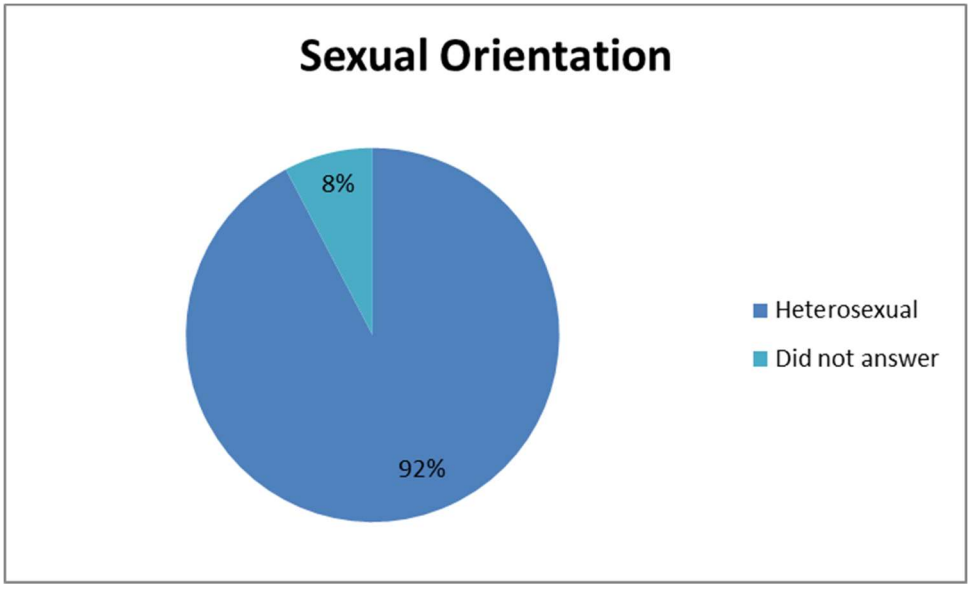
1. **Gender (n = 65)**



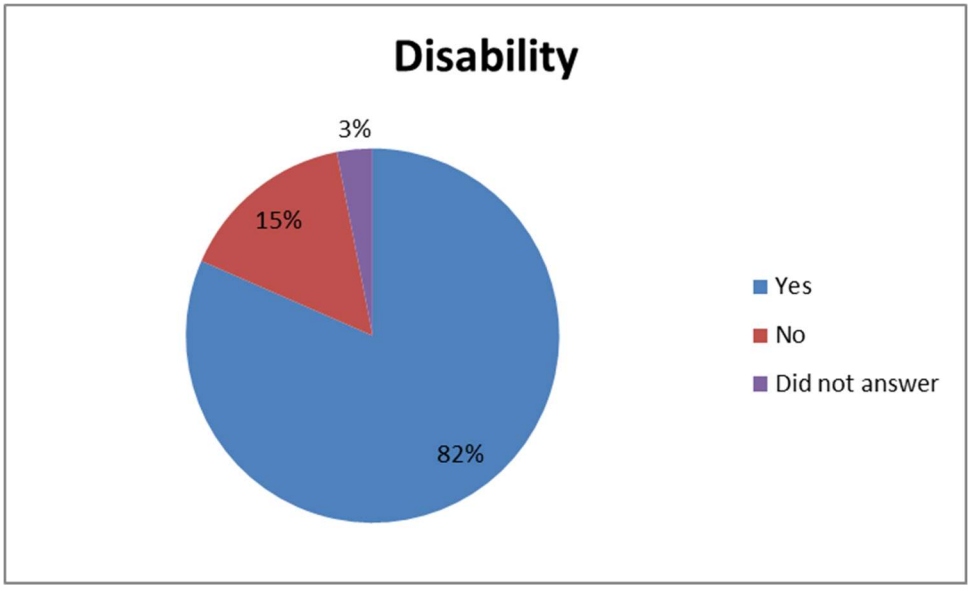
2. **Age (n = 61)**



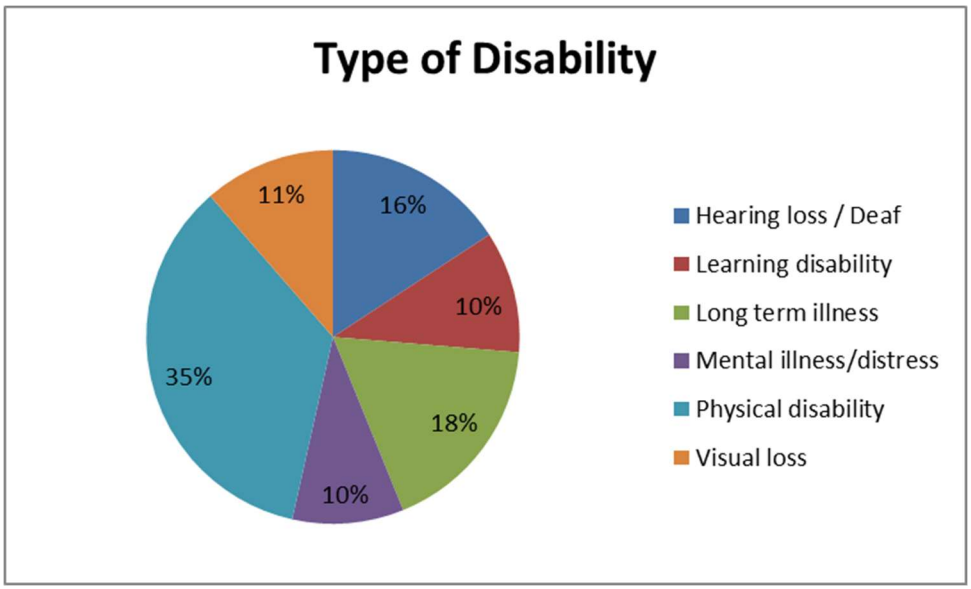
3. **Sexual Orientation (n = 65)**



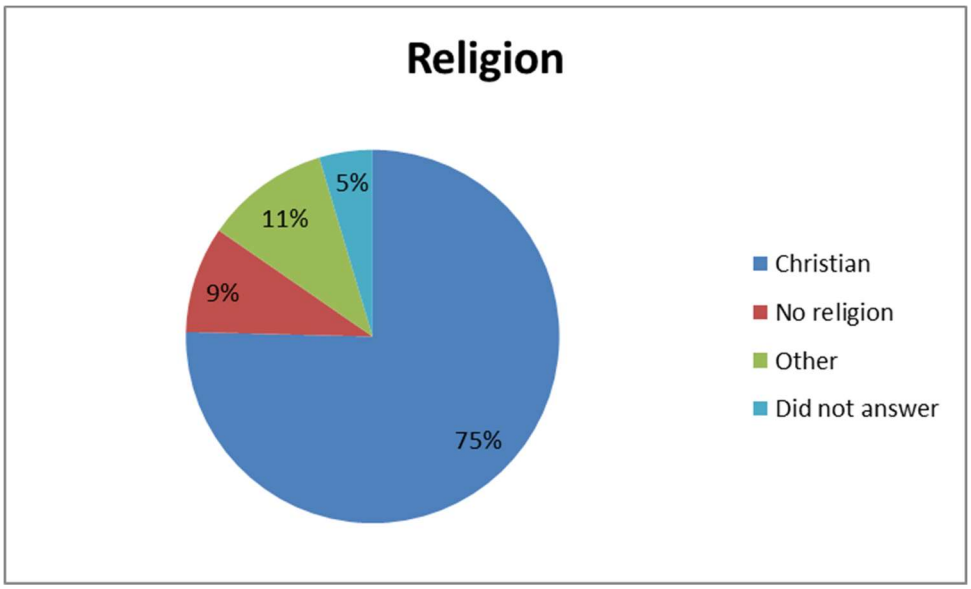
4. **Disabled People (n = 65)**



5. **Nature of Disability (n = 114)**
N.B. 53 people reported at least ONE specific disability. In total these 53 people reported 114 individual disabilities.)



6. **Religion (n = 65)**



7. **Ethnicity (n = 65)**