



# BNSSG Stroke Services Reconfiguration

Engagement – Themes and Summaries

February 2020 – April 2021

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# Background

The local NHS is carrying out a review of stroke services in the region. It is vital that this review incorporates the needs and views of those with lived experience of these services as well as those working within them.

To date, this public engagement has taken place over four distinct phases:

- February / March 2020 – Exploratory phase of public engagement
- June / July 2020 – Building and testing ideas
- September / October 2020 - Feedback on draft proposals for consultation
- January / February 2021 – Targeted engagement with seldom heard and higher risk groups for feedback on draft proposals

## Phase 1

Between 4<sup>th</sup> February and 11<sup>th</sup> March 2020, an initial phase of engagement was conducted involving those recovering from stroke, clinicians, members of the public, carers and those from the third sector.

The primary purpose of this phase of engagement was to explore what matters most to those with lived experience, carers and staff in relation to stroke recovery and rehabilitation.

In order to explore this, the programme has conducted its own engagement sessions and has attended numerous existing support groups across Bristol, North Somerset and South Gloucestershire.

During each session, attendees were asked to consider four questions:

- When thinking about stroke services, what matters to you?
- What are the future aspirations of those with lived experience and those working within stroke services?
- How did stroke services help meet your aspirations and what matters to you?
- How could stroke services improve to meet some of these needs?

This report summarises the overall findings which were uncovered as a result of this work.

## Engagement Process

Between 4th February and 11th March 2020, ten initial meetings were held at which NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (CCG) collected feedback on behalf of those recovering from stroke, clinicians, members of the public, carers and those from the third sector.

Of those who were recovering from a stroke, there was a broad mix between those who had their stroke recently and those who had a stroke in the past. Of the latter group, the majority focussed on support they had received recently.

Eight of these meetings already existed and were attended by the CCG, while a further two were organised by the CCG itself.

During this period, the CCG received 443 pieces of feedback representing 153 individual attendees. Attendees primarily fed back through verbal communication which was transcribed by CCG staff and other volunteers. In situations where this was not possible or preferred, attendees were able to write down their views and experiences.

A list of meetings attended to date is below:

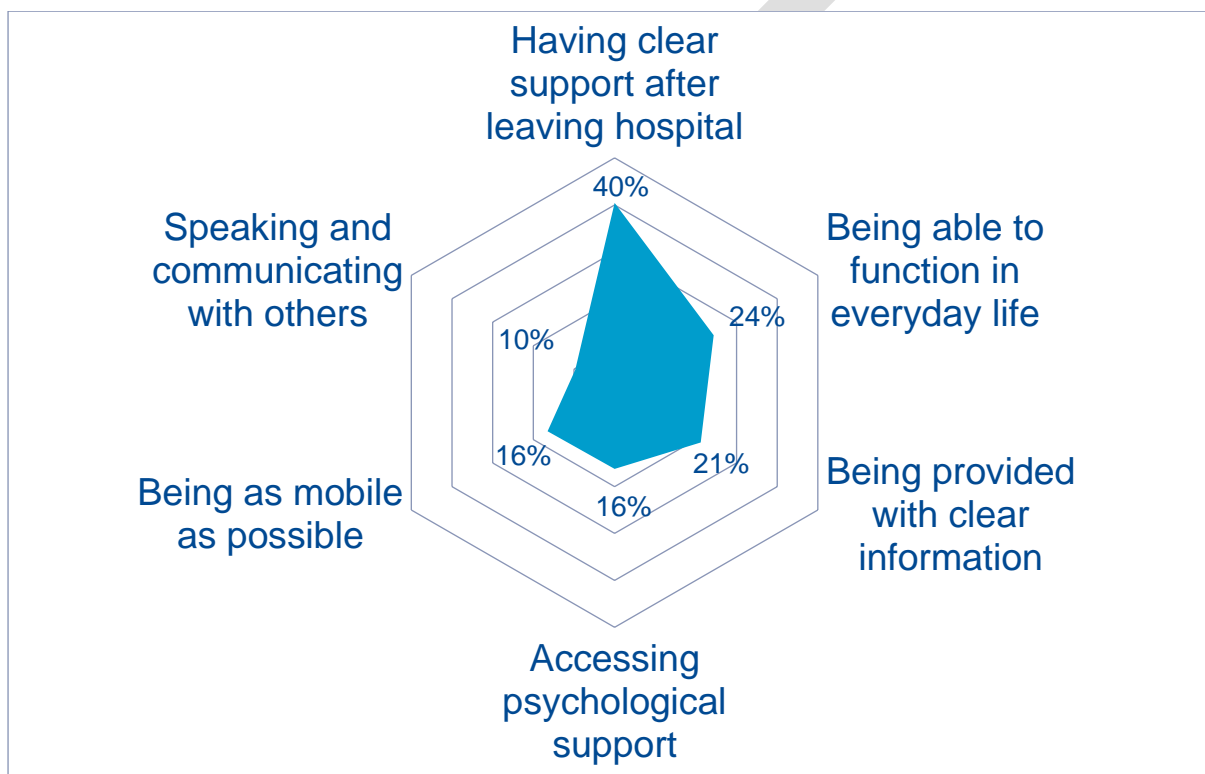
Stroke Services Pre-Engagement meeting - Public Session	04/02/2020	12:00-14:00	New Room, Horsefair	Bristol
Stroke Services Pre-Engagement meeting - Clinical Session	04/02/2020	15:00-17:00	New Room, Horsefair	Bristol
Bristol After Stroke (Fishponds Group)	19/02/2020	10:00-11:00	Colliers Gardens	Bristol
Bristol After Stroke (Bedminster Group)	20/02/2020	10:30-12:30	St Monica Wills House	Bristol
UWE ReVoice Choir drop-in	26/02/2020	14:00-15:00	Glenside Campus, Frenchay	South Gloucestershire
Weston Speakability Group	02/03/2020	11:00-12:00	Seventh Day Adventist Church	North Somerset
Weston Active Stroke Group	03/03/2020	10:00-12:00	Worlebury Golf Club	North Somerset
South Gloucestershire Conversation Group (Yate)	05/03/2020	10:30-12:00	Ridgewood Centre, Yate	South Gloucestershire
Nailsea Stroke Survivors Club	11/03/2020	10:00-11:00	Nailsea Methodist Church	North Somerset
Different Strokes - Bristol Exercise Group	11/03/2020	11:30-12:30	Bristol Lawn Tennis Club, Redland	Bristol

This report has been prepared by the Insights and Engagement Team at the CCG and summarises common themes in the responses received, following feedback collation and analysis. The material reflects people's opinions and perceptions in relation to stroke care and rehabilitation.

## Responses Received

The figure below indicates the most important factors for individuals who are recovering from stroke, working in stroke services, caring for someone with stroke or volunteering with those recovering from stroke.

These factors were discussed in relation to what people felt was most important about stroke recovery; their future aspirations; how stroke services had supported them and where stroke services could have been improved to do so.



## Having Clear Support after Leaving Hospital

Of the 443 pieces of feedback that were received during this phase of initial public engagement, **179 (40%)** of them related to having clear support after leaving hospital.

The majority of these 179 pieces of feedback related to receiving support after being discharged from hospital. Specifically, many respondents felt they did not receive sufficient levels of support once their stay in hospital was complete, while others believed that the link between the care they received in hospital and out-of-hospital could have been improved.

Lots of pieces of individual feedback described not being given a choice around when post-hospital support would end, and this often led to situations in which people felt isolated and unprepared for life after stroke.

“It feels like there is a void when it comes to support after you have left hospital [...] everything was fine until support from the ESD (Early Supported Discharge) team finished.”

*Individual with lived experience*

Another key theme was being able to see the same group of staff consistently, and building relationships between staff and patient on an ongoing basis. This issue was felt to be particularly relevant for those who are housebound or dependent.

“There is a reliance on individual members of staff – if they go, the person in recovery is often left stranded.”

*Voluntary sector*

Many pieces of feedback were generally positive about their experiences in hospital, their experiences of being discharged and the support provided by the voluntary sector.

The remainder of feedback which related to the support received after leaving hospital related to factors around receiving additional reviews beyond six months, the accessibility of appointments and being frustrated in terms of the delays experienced leaving hospital or accessing support in the community.

## Being Able to Function in Everyday Life

Of the 443 pieces of feedback that were received, **108 (24%)** of these related to functioning in everyday life and the individual being able to live as actively as they could following their stroke.

It was felt that services should enable individuals to do this, and a key component of this involved understanding individual patient need. Feedback recognised that there was a large level of variance between each person who has a stroke, and that each person had different goals and capabilities. There was high praise for support services which took individual needs and goals into account.

“My six-month review felt like a ‘tick in the box’ rather than somebody thinking about my own requirements.”

*Individual with lived experience*

Accessing peer support was deemed to be a vital part of recovery, and respondents felt that this was highly important in ensuring that an individual can function socially after their stroke.

“Social functioning is very difficult with Aphasia. It is important to have groups set up for people with Aphasia so that they feel supported.”

*Individual with lived experience*

Other feedback which related to everyday functioning valued enabling recovery at home. Some individuals had positive experiences of this; while others aspired to receiving this support or felt they should have received it at an earlier time.

Some comments related to receiving greater support in terms of transitioning between hospital and home, while others praised home adjustments they had received which helped with their mobility after leaving hospital.



## Being Provided with Clear Information

Of the 443 pieces of feedback that were received, **94 (21%)** of these related to individuals – both those in recovery and those who are carers or family members – being provided with clear, timely and sufficient information following a stroke.

A range of respondents felt that their support could have been improved by receiving more information about recovery after hospital, including a directory of places where they could access support.

Other pieces of feedback stated that individuals were provided with an information pack, but felt that a more gradual stream of information following discharge would have been more appropriate. Others stated that a central information point would be useful, which those recovering from stroke could access as their needs change.

There was praise for members of hospital staff who provided information to patients around aftercare and where to access it. However, respondents often had experiences of not receiving enough information at this stage.

“Once I left hospital it seemed like there was a brick wall [...] a lot of people appear to be left to their own devices.”

*Individual with lived experience*

Further pieces of feedback which related to being provided with clear information focussed on how well informed carers and family members were during the recovery of a loved one. Many felt that extra support and information for carers and family members would link directly to increased confidence and capability.

“Focus on carers – care within families creates huge conflict due to stress and fatigue. It’s the experience of changing from being a partner to being a carer overnight – this is not really recognised.”

*Clinician*

“Family members and carers need to know what to expect [from looking after someone after a stroke] and should be communicated with.”

*Family member and carer*

Remaining feedback in this area focussed on ensuring staff who do not always deal with stroke possess greater awareness of risk factors, with the aim of preventing stroke.

## Being as Mobile as Possible

Of the 443 pieces of feedback that were received, **73 (16%)** of these related to improving mobility following a stroke.

Some respondents' main concerns were related to physical mobility and accessing support through physiotherapy, while others commented on accessibility and transport.

Lots of feedback referenced the benefits of physiotherapy, whether it was accessed in hospital or after they had been discharged. Some respondents praised physiotherapy which was centred on their needs, as it allowed them to do the things they could do before their stroke.

Some respondents noted that the benefits of physiotherapy were more prevalent for those who accessed support early and those who accessed it on an ongoing basis rather than for a short period of time.

A number of pieces of feedback recognised the difficulty in accessing physiotherapy beyond a certain point of their recovery. For those who felt they required additional physiotherapy, there was a mixture of individuals who did not seek additional physiotherapy, those who sought community groups and those who paid for private treatment on an ongoing basis.

"I didn't get asked about stopping physio support – I was well enough to do the basics but I wasn't monitored or asked about what I wanted to be able to do."

*Individual with lived experience*

Additional feedback also related to being mobile enough to attend social occasions or access public spaces easily. For those with less severe effects following their stroke, some feedback related to being able to drive again or leaving the house easily on a regular basis.

Further comments in this area related to individual motivation and goal-setting following a stroke. These respondents felt that having a target to aim for – which was set by the individual recovering from a stroke – was far more likely to improve outcomes following physiotherapy.



## Accessing Psychological Support

Of the 443 pieces of feedback that were received, **72 (16%)** of these related to accessing psychological support. Those who discussed this as part of their feedback referenced the importance of mental wellbeing in relation to isolation, confidence and independence.

Self-motivation and confidence were commonly referenced by respondents as key factors which aid stroke recovery. It was noted by some respondents that having this motivation is very important in terms of long term recovery, as the person recovering has to adapt to a change of needs over time.

“The mental image that you will get better and improve is critical.”

*Individual with lived experience*

Individual feedback also referenced how beneficial psychological support can be in terms of improving physical recovery. Often, respondents discussed that increased confidence and self-motivation would lead to an individual being more willing to try and improve physical mobility or allow them to become more adventurous with social outings.

Other pieces of feedback discussed – in relation to their experience – the lack of psychological support available to them and carers. Some feedback referenced that they would have liked to receive more psychological support, while others suggested they struggled to receive any during their recovery. Those with Aphasia also noted how difficult it was to receive psychological support if their condition was severe.

“Motivation is a basic core skill which will have a huge impact on mental wellbeing and feelings of independence.”

*Clinician*

Psychological wellbeing was also directly linked to feedback around loneliness. This was significant for those recovering from a stroke and those caring for an individual. In contrast to their earlier feedback around the importance of peer support, some respondents struggled with feeling alone, associating this with worry and poor wellbeing.

## Speaking and Communicating with Others

Of the 443 pieces of feedback that were received, **43 (10%)** of these related to communicating with others, and the importance of speech and language. Feedback specifically centred on speech and language therapy as well as social interactions and opportunities to speak.

Many individuals giving feedback praised their own experiences of speech and language therapy, while others said they would have preferred more regular and / or longer term support for speech and language. Others talked about speech and language as a key source of frustration for them in day-to-day life.

Further feedback in this area discussed the benefit of having social interactions in which an individual could practice holding conversations.

“The biggest frustration is knowing what you want to say, but not how to say it.”

*Individual with lived experience*

“I like having opportunities to practice speaking in a safe environment where no one will finish sentences for you.”

*Individual with lived experience*

## Other Notable Themes

As well as the six themes already referenced in this report, a regular discussion point for respondents was the inequity of stroke support across Bristol, North Somerset and South Gloucestershire.

Respondents felt that a situation in which support was accessible in one area but not another led to confusion for those recovering from stroke and unnecessary strain for those who didn't have support available to them. For example, respondents referenced instances of people travelling across the areas to access particular support groups.

Respondents felt that it would be beneficial to establish a set of minimum standards across the area, particularly in relation to care which happens after leaving hospital.

“Services can often involve a postcode lottery. ‘Where do you live?’ is often the first question [for those recovering]”

*Voluntary sector*

## Summary

Between 4th February and 11th March 2020, ten initial meetings were held at which NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (CCG) collected feedback on behalf of those recovering from stroke, clinicians, members of the public, carers and those from the third sector.

During this period, the CCG received 443 pieces of feedback representing 153 individual attendees.

Of the 443 pieces of feedback that were received during this phase of initial public engagement, **179 (40%)** of them related to having clear support after leaving hospital.

The majority of these 179 pieces of feedback related to receiving support after being discharged from hospital. Specifically, many respondents felt they did not receive sufficient levels of support once their stay in hospital was complete, while others believed that the link between the care they received in hospital and out-of-hospital could have been improved.

**24%** of feedback related to functioning in everyday life and the individual being able to live as actively as they could following their stroke.

It was felt that services should enable individuals to function, and a key component of this involved understanding individual patient need.

**21%** of these comments related to individuals – both those in recovery and those who are carers or family members – being provided with clear, timely and sufficient information following a stroke.

Another key theme was improving mobility following a stroke. **16%** of feedback was attributed to this.

Some respondents' main concerns were related to physical mobility and accessing support through physiotherapy, while others commented on accessibility and transport.

**16%** of feedback related to accessing psychological support. Those who discussed this as part of their feedback referenced the importance of mental wellbeing in relation to isolation, confidence and independence.

**10%** of comments focussed on communicating with others, and the importance of speech and language.

In addition, a regular discussion point for respondents was the inequity of stroke support across Bristol, North Somerset and South Gloucestershire.

## Next Steps and Further Engagement

This is an iterative document, and further work to understand the needs of those recovering from stroke, clinicians, members of the public, carers and those from the third sector has developed accordingly.

Following the initial public engagement referenced in this report, the following three steps will be taken to broaden our engagement and validate these initial findings:

### Understand the Needs of Those Most at Risk

Alongside this piece of public engagement, the continuing development of an Equality Impact Assessment for the Stroke Reconfiguration programme will help to inform future engagement work with the public. The Equality Impact Assessment will allow the CCG to understand – according to local data – which demographic groups may be more at risk of a stroke or may have a higher prevalence of risk factors.

Initial analysis uncovered a higher incidence rate of stroke in areas of North Somerset, and so far the outreach engagement work has started to reflect this, by actively seeking engagement from individuals in this area. It is vital that future engagement opportunities are offered equally to those across the three localities of Bristol, North Somerset and South Gloucestershire to enable us to fully understand the effects of the service change for individuals across the region. Through thorough planning and monitoring of engagement activities we must make certain that those living in North Somerset, South Gloucestershire and Bristol are proportionately involved within the engagement process. Geographic and demographic monitoring has and will continue to be used throughout the engagement activity to identify possible themes and to highlight where further engagement is required with specific groups or locations.

While our initial engagement has taken prevalence of stroke according to geography into account during this initial phase of engagement, we will look to use more targeted approaches in order to reach those most at risk and from seldom heard groups. We can identify these groups through the Equality impact Assessment and by looking at demographic monitoring data. In order to reach these groups we will ensure our engagement strategy is well planned and fully accessible, taking into consideration the format and delivery of any engagement activities. We will also work with partnership community and voluntary organisations with strong connections into these communities, local community leaders and consider tailored targeted messaging approaches to access these groups. It is also important that we offer support where needed to allow engagement to take place. For example, offering translations and interpretation for those who don't speak English as a first language, and offering a variety of ways to give feedback such as over the telephone, hand written and electronically. We shall also look to invite community leaders and members of these groups to take a more active role within the programme, for example by inviting them to join working group meetings or signposting them to various appropriate user groups. We want to ensure all voices are given the opportunity to be heard during this engagement process, and by identifying the

groups most at risk we can carefully plan the approach ensure robust and meaningful engagement takes place to allow these groups the opportunity to feedback in the shaping of stroke services for BNSSG.

## **Work with People to Establish, Test and Build Ideas**

A smaller group of individuals with lived experience will be brought together in order to consider the implications of this feedback when thinking about how stroke services could work in the future.

As the programme progresses, this group will then look to establish, test and build new ideas in collaboration with those who work in stroke services. While this group will give us rich feedback and generate ideas for the future, it is recognised that a larger scale validation of these ideas will be required at a later date. As we move into the consultation it is important that we engage with an appropriately reflective sample size of people to validate outcomes from the pre-consultation engagement. Details of the consultation plan can be found in Appendix 7.

The feedback gathered throughout the engagement process will be discussed and shared with the wider programme groups and board for reflection. Working with the programme board to shape questions and ideas to be explored during engagement enables the collection of feedback that is valuable and applicable to help aid decision making within the programme. By listening to what is important to the public, and discussing and building ideas with them, co-production of proposals that reflect the public's voice can be created.

## **Build upon Initial Engagement**

In addition to more targeted engagement approaches, we will be continuing to update those who have provided feedback so far. Ensuring that individuals feel they are sufficiently involved throughout the entire process will be critical from a public engagement perspective. Working together with groups and individuals throughout the process by providing updates and gathering further feedback allows the development of ideas and shaping of proposals in a collaborative manner.

There are also groups and areas which will require further engagement as we progress. We will look to build upon some early engagement in South Gloucestershire, for example, and visit groups who could not accommodate us in this initial phase. We want to make sure that all voices are heard during the engagement process, so by monitoring demographics and geographic location of those taking part we can look to provide engagement activity and feedback that is proportionate and reflective of the population of BNSSG.

## Phase 2

### **Building Ideas and Solutions – June and July 2020**

Feedback collected during this phase of public engagement has sought to generate ideas and solutions to improve stroke services in Bristol, North Somerset and South Gloucestershire, in addition to building upon initial public engagement earlier in the year. This second phase of public engagement was split into 3 parts:

#### **1) Interviews to establish the impact of COVID-19 on service delivery**

The aim of this activity was to establish the impact of temporary changes to service provision as a result of COVID-19; this was required due to changes taking place as a result of COVID-19 presenting a large gap in our understanding to date. Between Thursday 7th July and Wednesday 15th July 2020 seven interviewees with experience of stroke support during this period were interviewed, with a particular focus on how this support compared with face-to-face support an individual had received previously.

These interviews were conducted via phone call, and participants were recruited via the three hospital trusts in the region, as well as voluntary sector organisations who promoted the interviews to potential participants. The interview content was developed in conjunction with public representatives from the Stroke HIT group, while a portion of the interviews were also conducted alongside these individuals. This allowed those with experience of stroke to ask participants more detailed questions about their experiences, as well as follow up on any remarks which had not been picked up by the interviewer.

The individuals with experience of stroke who were interviewed as part of this piece of work had experienced a range of exposure to remote support as a result of the COVID-19 pandemic, and were at different stages of their recovery.

In particular, those who were in the early stages of recovery following a recent stroke reported that many of their interactions with health and care services remained face-to-face during this time. This face-to-face support also changed as a result of the pandemic, with staff adequately protecting themselves and the person receiving treatment when visiting the individual.

Those who were receiving ongoing support, however, reported that many of their interactions with stroke support services had shifted to remote interactions during this time. This was true for those who had received both individual and group support before and after the outbreak of COVID-19 in the UK.

#### **Remote Support is Convenient for Some and Provides Flexibility**

Those who had experienced remote support during the COVID-19 outbreak, either in the form of phone conversations or video appointments, did feel that there were tangible benefits in receiving this kind of support. One of the key pieces of feedback for this type of support was that individuals did not necessarily need to worry about

travel or the accessibility of physical spaces. However, these benefits were reliant on individuals having good access to digital technology at home. Some reported that they were able to do more independently as a result of the move to remote support.

“One of my favourite things is being able to just pop next door [for a group session].”

*Individual with lived experience*

While physical, face-to-face peer support has also been very limited in recent months, another benefit which was raised about remote support was the ability to easily meet others from different areas and make connections with those who live in different places.

Individuals who gave positive feedback around remote support also felt that the way video sessions were run was key to their success. As an example, some reported that natural, unstructured conversations were much more useful than ‘round table’ type discussions where each individual was encouraged to contribute by a facilitator one-by-one. Being able to ‘raise your hand’ on platforms such as Zoom helped with maintaining conversation flow. Interviewees also suggested that creative activities which made the most of digital technology were much more effective than trying to replicate face-to-face activities online.

In relation to ‘one-to-one’ support, those who fed back suggested that greater flexibility around what was covered in each session and the practitioner seeing things from a different perspective were key benefits. Being able to record sessions and watch again afterwards was very useful for some interviewees.

Other interviewees had received a mixture of remote and face-to-face support, particularly in relation to those who had experiences changes to physiotherapy. These individuals said they could see a ‘mixed economy’ of support being helpful for others in future. One suggested model for operating in this way was 1 in every 4 sessions being face-to-face.

Those who did give positive feedback around remote support also acknowledged that extra support for staff to conduct remote sessions would be beneficial and resources should be allocated to accommodate this. Individuals said that a different skillset was required to provide remote support, and so education in this area for staff was highlighted as an area for improvement. This was deemed relevant both for physiotherapy and remote counselling.

Those who had received less remote support during this time did report that they had been informed by staff around what their future treatment may look like, particularly in relation to remote support. This was deemed a useful exercise for the individuals

and their families, and these individuals said that they would be open to receiving remote support as time goes on.

**However, Remote Support also Excludes Others and Should Not Be Seen as a 'Replacement' for Face-to-Face Interactions**

There were also expected drawbacks of remote support which were raised during the interviews. These included recognition that conversation flow was significantly impacted by remote video conferencing, including turn taking and interruptions. Those who had taken part in groups specifically for those with aphasia stated that they found this part of the transition from face-to-face to remote conversations slightly easier, due to having greater awareness of conversation flow in face-to-face meetings.

While there were suggestions that remote support could be a useful addition to face-to-face support, there was a consensus that it would not be an effective substitute for face-to-face meetings. Primarily, this was due to the technology excluding a number of friends and peers who were not able to access the digital technology used by others.

Others referenced that setting up or joining a meeting can cause additional stress, particularly when the individual is not used to using the technology. It was also noted that group dynamics can be more difficult to manage for the participant and the person leading the group.

“I don’t like the technical side – getting ready for the meeting is the most stressful part!”

*Individual with lived experience*

While not directly related to the provision of remote support, other pieces of feedback referenced the importance of being able to practice particular movements and exercises in the outside world, which was restricted during the COVID-19 outbreak.

The purpose of undertaking these interviews was to provide a better understanding of the changes to remote services taking place as a result of COVID-19. Whilst the long term provision of these services is still uncertain due to COVID-19, the information gathered during these interviews can be reflected on as the stroke reconfiguration programme progresses and clarity over how services shall be delivered with consideration to COVID-19 becomes available.



## Phase 2

### 2) Remote co-design group

This group was run by a senior Speech and language Therapist, seconded from Sirona Care and Health, who has worked for many years with people affected by stroke. Below are the summarised notes from the design group meetings.

**Notes from zoom co-design meeting 12/8/20**  
**Present: 6 stroke survivors and 1 family member**

#### **Training**

- It's vital to be specifically trained
- Staff need training specific to the stroke unit
- Staff trained in psychological impact of stroke
- How to speak to stroke survivors. Someone said to me "Be quiet, don't talk"
- Some nurses and HCAs better than others

#### **Flexibility in rehab**

- No two people are the same. Treatment should be for the individual with their own needs. Things change and need to be re-evaluated. Your focus changes (on things that are important)
- Feels like there is a protocol to follow which makes therapy seem rigid and inflexible. This loses the personal touch.
- Therapy needs to be on time and for duration that is promised
- Timetabled on the unit so that you can plan rest periods
- Should be guided by stroke survivor
- No one said it's finished it just petered out
- Concerns about one big service being rigid and inflexible
- Left with a sheet of exercises – not great
- I try to walk a little bit further everyday

#### **Communication**

- Improve communication when you leave hospital. Really poor in the past few months. It's difficult to get in touch, I feel abandoned.
- Would be good to have a lead nurse/therapist to talk to. Different set of nurses every day
- Would be good to have a keyworker in the unit and at home
- BIRU had a key member of staff designated to you which was good.#
- It was good that we had E as a keyworker as she would give us lots of information
- I'd like to be able to just pick up the 'phone to someone who understands what I am going through
- Bristol after Stroke are good at this
- The Stroke Association have been amazing. If I'm having a bad day then I can

get help

- Clearer names on uniforms. It's confusing when you have had a stroke and you have to start all over again with another name. The less confusion the better
- At Weston the communication was excellent
- When you leave the institution you are cut off then
- I feel let down by my GP. I'd like a named GP so I don't have to explain my situation every time
- Booklets are helpful

### **Carers**

- Attention is on the stroke survivor but there is a big impact on the partner and family
- Stroke affects us all and my life has been changed as much as his (carer)
- There wasn't support for my family member in the early days
- It's not just me that's had the stroke but the whole family

### **Information**

- Would be good to have one place to find information
- A directory of services
- Somewhere to ask questions
- Teams who come out the home should have a full book of it
- Need to know the options and a support network
- Email or online would be good
- Its wrong that only some people know about things

### **Psychology**

- Training is very important
- Help from going into the arts. Art group, music, dance, singing. Helped to open up talking about things.
- Important to look at the psychological effect. It's like bereavement. Impact on your new normal. You need lots of patience.
- It's vital to find positives
- It's up to me to achieve a bigger goal
- Frustration and fatigue make you irritable

### **7 day therapy**

- At the weekends it all just stopped
- I didn't have physio everyday. As an inpatient you just have to take it on the chin
- The wards are so busy
- The gym was empty at the weekend
- It takes all Monday for staff to get up to speed. New patients were prioritised so had no physio that day

- Could there be an exercise group on a weekend? You could advertise 'come to the gym at 4pm on a Saturday'
- I asked for things to do but it's not the same as having a physio there
- Stroke survivors could make their own groups e.g. craft group. Good therapy for the stroke survivor too
- Must be 7 days a week in hospital
- Weekends are expensive to staff I would rather have M-F for longer

### **Goals**

- Nebulous targets where are you going? How are you going to get there?
- Life goes on when you're home

### **Environment**

- Food is important. You need treats to look forward to. My family brought in fish and chips every week. You could have fish and chip night like normal life
- Food in Weston was lovely
- Environment is important. Garden would be good for fresh air
- Television was low quality and couldn't watch sport

### **Notes from co-design meeting 16/09/20**

**Present: 6 stroke survivors, 1 family member, Emma Richards and Rob Jones from CCG**

**Discussion around inpatient rehab and transfer home**

#### **Inpatient rehab**

- Fabulous regime at BIRU, well organised daily timetable. I was given an objective to walk up and down the stairs then I would be eligible for a home trial. Had a weekend stay at home and then agreed exodus date. They arranged a party on my leaving date with all the staff. I really liked the hydro pool for physiotherapy as the water gave you support.
- Physio is the only reason I'm up and walking. Brilliant Monday to Friday.
- The 'dark side' of the rehab unit could do with modernisation
- Didn't like physio. Felt held back. We felt that the physio didn't have confidence and he could have been pushed harder.
- Physio could be mindful of family member's role. Instead of saying not to touch the equipment, show them how to use it.
- Speech therapy were brilliant in hospital and with follow up calls
- I had physiotherapy almost every day in the gym
- It was useful to have advice on paperwork e.g. PIP

#### **Weekend rehab**

- Brilliant rehab Monday to Friday but blank timetable on Saturday and Sunday
- On Friday afternoon they said "cheerio" and b\*ggered off. You build yourself

up Monday to Friday and then nothing for 2 days. It's one step forwards and two steps back.

- Gyms were empty at the weekend. A wasted opportunity
- It costs money but could you do circuit training? Just for an hour on Saturday and Sunday? In Nailsea they have 15 or 16 stroke survivors with physios or health care experts.
- It would make a huge difference to moral and wellbeing and get people home quicker. All the patients I talked to thought it was a good idea.
- (would you not want a rest at the weekend?) NO! You don't have a rest in your life at the weekend do you?!
- We were all bored at the weekend, when loved ones go home you are bored
- The people attending an optional session at the weekend are likely to be those who are more motivated so will get more out of it

#### Group therapy

- The best thing was group physio, we supported each other and cheered each other on. The biggest moment was seeing someone being able to walk across the room unaided. It's nice to have people cheering you on. It's slightly competitive which is good. Was good to have different ages and abilities.
- I know it's wrong to say but it's good to see people worse off than you and also people who are improving.
- (one group member had group physio at BIRU and two others weren't offered it)
- Group therapy was OK
- Group physio should be open to anyone not just those in hospital. You could even charge a small amount for it
- Art groups would be good
- Everyone wants more physio

#### Transfer home

- When I was ready to leave my home wasn't ready and needed to be adapted. They said that I might need to go to a care home but at my age there weren't any suitable. I met the social worker once a couple of weeks before I left and met her once. It felt forced and rushed at the end.
- Came home on weekend leave at Christmas and regularly after that. WE gradually made changes based on his needs ourselves. The OT came to check things
- Had to fight with the social worker. My 'temporary' care package is still in place years later.
- Important the family are consulted about leaving hospital
- They didn't discuss the plans to go home with me. All aspects of life should be on paper and discussed with me. I don't think they did that at all. I should have a copy too.
- They couldn't keep it in their heads that I had diabetes. It would be better to

have a named nurse and given time to talk.

- All humans are different so why shouldn't they have a different plan.
- The first couple of weeks were good but then the ongoing therapy has withered. I think I slipped through the net and had to get a private physio.
- Communication from the rehab team has been poor
- I wasn't rushed when checking my home and it was professional. I had a discharge letter with a list of dos and don'ts, who would be visiting and a month's supply of medication. The community team introduced themselves on the ward.
- The OT did a thorough review and arranged for equipment to be ordered
- ESD only saw me in the home. They didn't check my life outside of the home.
- Very little communication with family at time of discharge. I wasn't told what time I would be leaving and my daughters needed to pick me up.
- I had to wait for 3 hours in the departure lounge for medication and another patient had been there since the day before
- Could they send notes to the departure lounge earlier?
- No follow up from BIRU
- Disparity of therapy provision between physio and speech therapy. We only had a few physio sessions.

#### Review

- I had a phone call from hospital to see how I was but I wasn't prepared for it. There are lots of things I could do with asking about but didn't ask. I was discharged from the team and was the first phone call I've had since March.
- I've seen the stroke consultant 4 times since I've been out of hospital
- No one seems to look after my overall care. My GP hasn't done a lot to follow up
- A printed directory of information would be really useful

#### General comments

- It's a postcode lottery
- Bodytone at the leisure centre has been good
- Communication is hugely important

#### **Notes from co-design meeting 14/10/20**

**Present:** x5 stroke survivors

#### **Discussion around community rehab**

- We were warned that we might not get much support or if we did that it would be short term but experience was a bit of both. Speech therapy was excellent. Good support from speech therapy including information about groups and research. We were disappointed with physio though. There wasn't any structure or plan.

- I didn't know that there were set things to do (to improve physical activity). Speech therapy were excellent but I didn't know I should be working on physical things as well. They took my blood pressure and talked to me but that was it.
- I had a good physio to start with but when he left the next one was not as good. After 2 months she said "it's up to you to do it yourself" I now have a private physio
- OT has helped a lot with things like equipment. It's good to have their contact details in case I need them
- I was very happy with physio and OT. When I got home they met me and made a list of goals short term, medium and long term. They were written down and we reviewed them every month. I saw them 2 or 3 times a week for 5 months
- We discussed a termination date which we were all happy with and then on the day of termination we went through everything again. Without them I would have struggled
- It was good to practise getting on and off the floor
- Speech therapy was excellent. I wouldn't mind being seen in at home or as an outpatient.
- I didn't know about other things, I should've walked more to start with. They didn't think of things that happen outside of the home
- The motamed at BIRU was great. Good to have a specific rehab instructor at the gym.
- Physios can teach the partner how to do things and how to help. In some places they are reluctant to
- 1:1 therapy is good when you first come out of hospital
- If there is more finance then invest in community physio
- If (he) didn't have a partner then what would he do?

*What makes a good therapist?*

- Someone open and able to chat with you
- Professional and caring
- Treatment adapted to individual need. Not just a set of standard exercise sheets
- Has to be individual
- Person-centred goals

*Potential for being at home earlier*

- The thought of your partner coming home from hospital is terrifying. I needed the time he was in BIRU to cope with what would need to change at home and be ready for him at home. But he wanted to get home as soon as possible
- Its sometimes more difficult for the carer
- Some people don't have partners to support them

### **Review and advice**

- Follow up is really important. Once every 3 or 4 months to see where you are. It helps to get to know what you should and could do.
- *Could it be with a keyworker and then refer to another service?* Yes. But it depends on what you need. It would need to be the physio that you saw before. Avoid having to tell your story over and over again. That's especially true for people with aphasia.
- The review person needs to know you. In 5 or 10 minutes you can be talking about "me" rather than rushing it at the end.
- Some general advice would be good to prevent falls, getting off the floor, increasing general activity for those without significant physical problems after their stroke
- Important to use it or lose it. *Were you told about the need to use it or lose it/use it to improve it?* 1. Yes my physio did. 2. Yes. 3. I don't remember being told about repetition. 4. I don't remember that.
- I have Botox injections every 3 months but it's a really long journey. Follow up is really useful.
- (he) had Botox in hospital but never had any follow up.
- We need to be able to complain and say good things too

### **Life after stroke**

- My physio and OT gave me ideas of things to do once therapy had stopped and I go to a stroke specific gym once a week.
- I had a list of exercises to do but needed someone to push me so got a private physio
- It would be great to have a gym to go to that is specific for stroke. Happy to travel. A group overseen by a physio would be great. It's a really positive experience for partners to be involved in the gym too
- It's a positive experience to do exercise. Gives you a positive attitude
- I wish I'd known more about services available
- A keyworker would be good. If you are having a down day it's good to pick up the phone to someone
- Its 3 years since my stroke and I rarely speak to anyone. A telephone review would be good every 6 months just to see how things are going
- A directory of clubs or a booklet with phone numbers
- Post stroke is a lonely world. It's good to speak to someone who understands
- *Peer befriending* – needs to be someone who has had a stroke. It's the common denominator between us all. Good to have something not too serious but just to have a chat with someone.

Discussed how long it would be until changes were made. Emma will keep the group updated but in the next year or two things will start to change. We agreed that the co-design group should "cut the ribbon" on the new service with left handed scissors if needed!

**Example of full comments from an individual (HH – who has marked aphasia following stroke) Sep 2020**

**The hospital routine**

There should have been a routine day layout, which is laid out for patients  
**A Named** linked nurse or practitioner who you could ask for help  
with a badge

The **named nurse** should tell/communicate to their patient all the information  
below - a leaflet is not enough

- When the meals and when the medicines come
- When the doctors or other staff were due to come
- When visitors can come and staff help to arrange that
- What time and which people there are who can help with a phone

**Before The transfer**

Your **named nurse** ought to discuss with the patient

your move to **home / what else/ where else**

any **things** you need to prepare /you are concerned about including

any **people** \*you need to prepare with anything you are concerned about

any **other** are about e.g. adaptations/finance/travel/pets anything else you are  
concerned about

\*( the people should be the companion/ partner / friend  
those close/ seen by the patient)

The **named nurse** should collate

any of the tests done including language and communication

any of the question sheets any dementia or other

any of the response to the day routine

The **named nurse** should prepare collate and transfer to one document for all to  
read

a) the patient

b) the family \*

c)the support from the NHS

Then there **should be a meeting with the named nurse** and a) the patient b)  
the family c) the support from the NHS So that there is a **working plan**.

There should be information for the patient and the family\* what the purpose, the  
link and the review goals of the NHS Team are.

Copies of the document should be available to **all at the meeting** and  
when its prepared **the working plan**

**The transfer of the person/patient should not be made unless the working  
plan is in place**

**Transfer to the Team**

**The NHS team should have the working plan (and the patient and family\*)**



so each group see what is working ( and keep records ) It should be clear that either the patient, the family\*or the NHS Team can alter the working plan at a FULL meeting there should be regular meetings

There should be in the Working plan : notes and papers on

*communication*

*mobility*

*family/social \**

*physical*

*mental*

*financial*

*other*

*review of plan so far and next review date*

## Phase 2

### 3) Feedback survey

#### **Stroke Services Reconfiguration – Online Survey Results**

During July and August 2020, a short, focused online survey was developed in order to broaden feedback from those who may not have contributed to earlier phases of engagement for the Stroke Reconfiguration Program. Prior to the development of this survey, the programme had primarily engaged with those already familiar with voluntary or third sector support, and it is important to recognise and hear from those who are not part of support groups already.

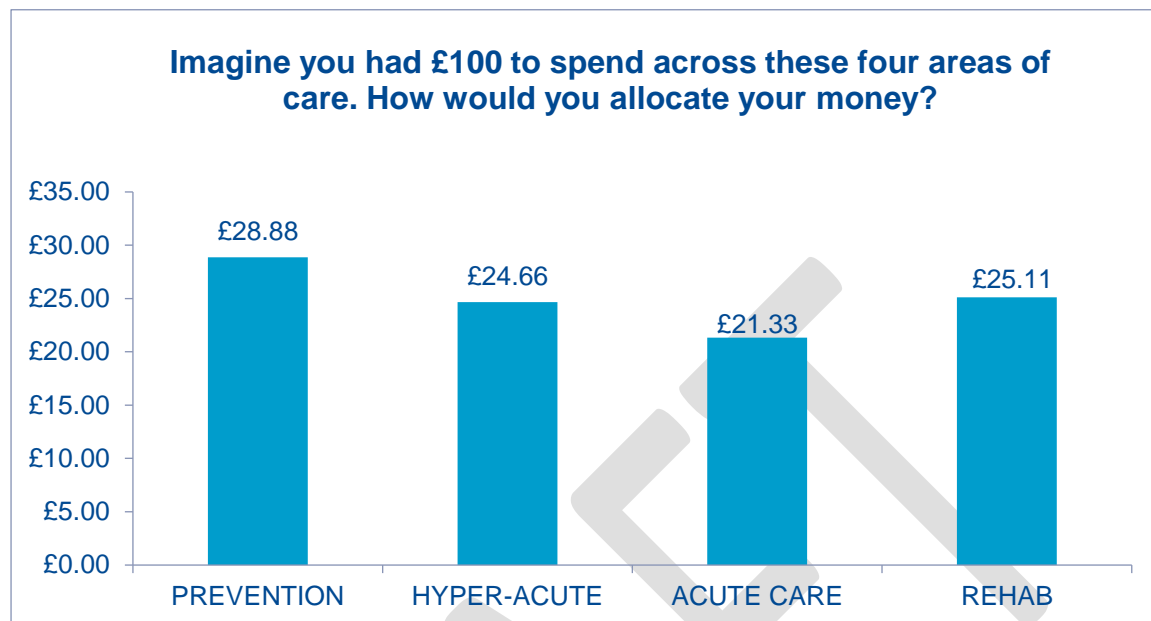
The survey was distributed electronically due to the coronavirus pandemic. It was distributed via established networks and also to the [Healthier Together Citizens' Panel](#). The majority of the responses to this survey were received from people or contacts of people on the Citizens' Panel.

The purpose of this survey was to reflect people's opinions and perceptions in relation to stroke care and rehabilitation, and to validate information gathered in the previous phase of engagement. The Survey covered a range of topics including perceptions on the importance of different aspects of the stroke pathway, feelings towards a single location for stroke services and the importance of receiving support close to home.

Demographic monitoring was also in place to profile our respondents, with the aim of establishing initial demographic trends ahead of any larger public engagement or public consultations taking place at a later date.

## **Feedback on peoples' priorities across the Stroke Pathway**

*When asked how they would distribute £100 of money across the stroke care pathway, the respondents showed a fairly equal distribution of money.*

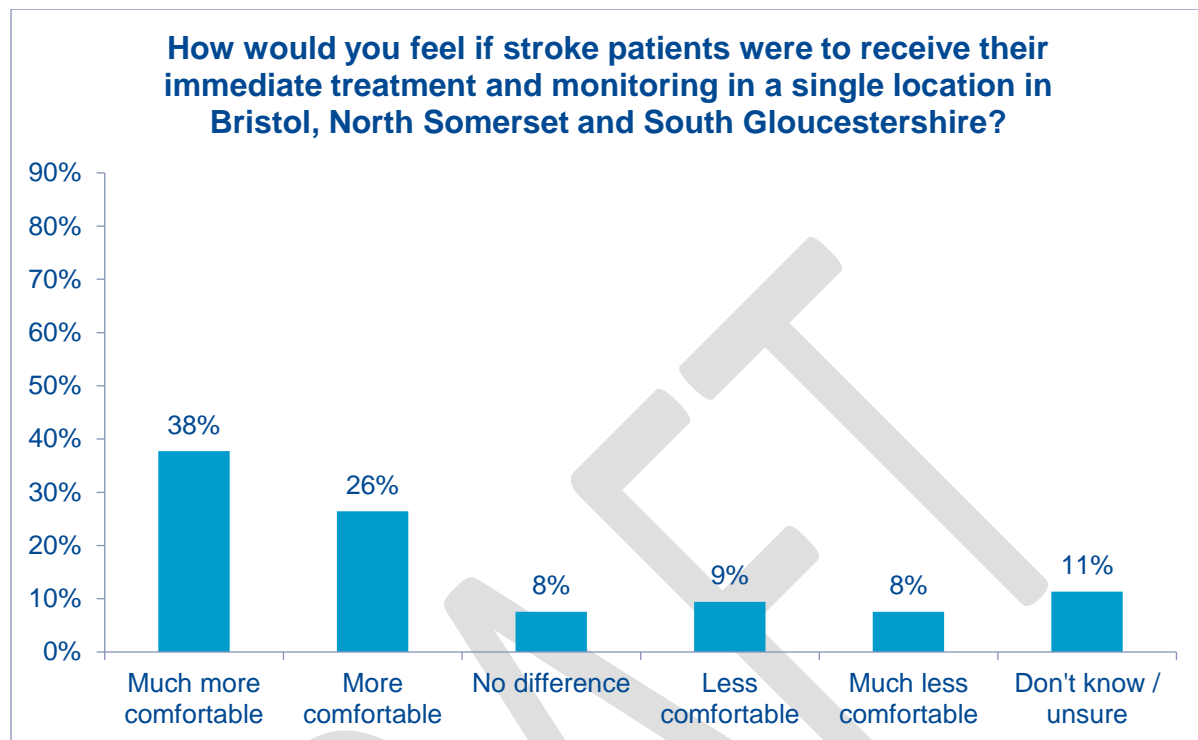


Generally there was an even split across the 4 areas, with a slightly higher amount being distributed to prevention, and slightly lower amount to acute care. This response indicates that respondents perceive that money should be fairly evenly shared across the 4 stroke pathway areas. The Stroke Reconfiguration Program is focusing on a proposed change to hyper-acute and acute care. It is therefore important that considerations are made around how these changes can impact services for prevention and rehab, as this data highlights how both are perceived as equally important areas of the pathway to people.

A common theme from both the initial public engagement and remote co-design group was the importance of support and care after leaving hospital. 40% of respondents from the initial public engagement felt that having clear support after leaving hospital was the most important factor for individuals who are recovering from stroke. Feedback also showed that people felt that physiotherapy and psychological support after a stroke was of particular importance. The remote co-design group recognised 'The importance of introducing physiotherapy as early as possible' as one of key areas of focus which should be considered as part of the stroke reconfiguration programme. This attention on the importance of rehab support and post hospital care should be considered when reconfiguring how stroke services are delivered.

## **Feelings towards a Single Location for Immediate Treatment and Monitoring**

*Almost two thirds (64%) of respondents are much more or more comfortable with a single location for immediate treatment and monitoring*



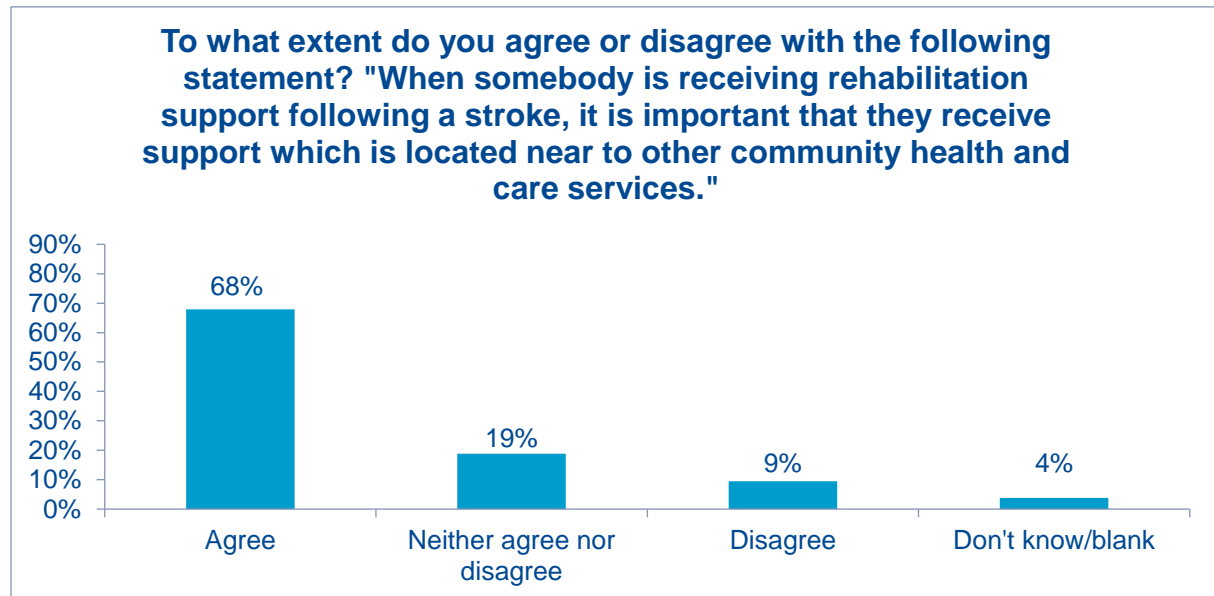
When asked about feelings around a single location for immediate treatment and monitoring, 64% of respondents stated that they would feel more comfortable with the idea. The main reasoning for this response related to the perception that a single location would be a centre of excellence offering specialised care, leading to more efficient treatment and better outcomes for patients. This impression was also supported by feedback from the initial public engagement, whereby being able to see the same group of staff consistently, and building relationships between staff and patient on an ongoing basis was highlighted as a preference. Having a single location as proposed in the stroke programme, would allow for this consistency of staff and approach.

From the 17% who answered as 'less comfortable' or 'much less comfortable', their main concerns were associated to issues around transport, including access, cost, time and stress. Linking to this, there were also several responses citing the negative knock on effects for friends and family who may have to travel further either when transporting them to and from appointments, or when visiting them during in-patient stays.

These insights show that whilst there is general support for a centralised location for immediate treatment and monitoring, concerns around access and travel need to be considered. It is also important to note that this survey did not specify the location and this will likely influence responses and feedback in future consultation activities.

## **Importance of Rehabilitation Support Being Located Near Other Community Health and Care Services**

*68% of respondents were in agreement that it is important for rehab support to be near other community health and care services*



For respondents who agreed that rehab needs to be located near to community services, this was mainly driven by perceived ease of access and comfort. Patients' general mobility, health and stress/anxiety levels when recovering from a stroke were also mentioned frequently, emphasising the importance of the rehab support being easy to access and nearby other community health and care assets.

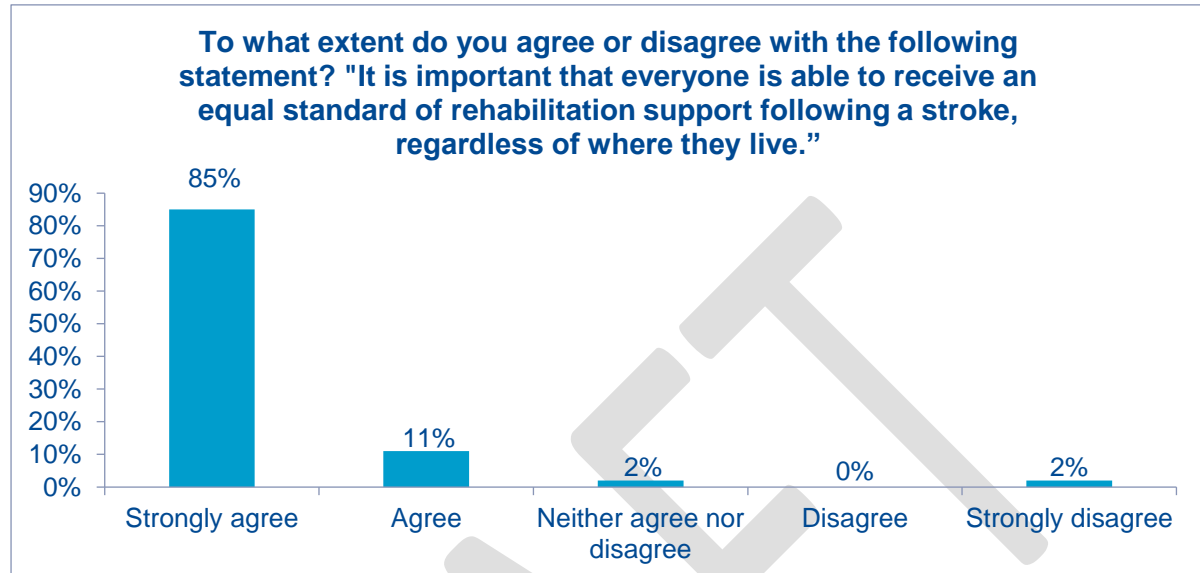
"It would make sense to be able to access services in one place, or close together, to reduce travel anxieties"

For those who were more neutral or disagreed with the statement, this was mainly driven by the view that the priority should be on quality of care, rather than location. Many also reported that they did not see a clear relationship between where services are located in relation to stroke services and positive outcomes for each individual.

"I don't think it makes a difference if the support is located at home or near another community service, it just needs to be the right rehab given at the right time for the patient"

## The Importance of Equal Standard Rehabilitation Support, Regardless of Where You Live

*85% strongly agree that patients should receive equal rehabilitation regardless of where you live across the region*



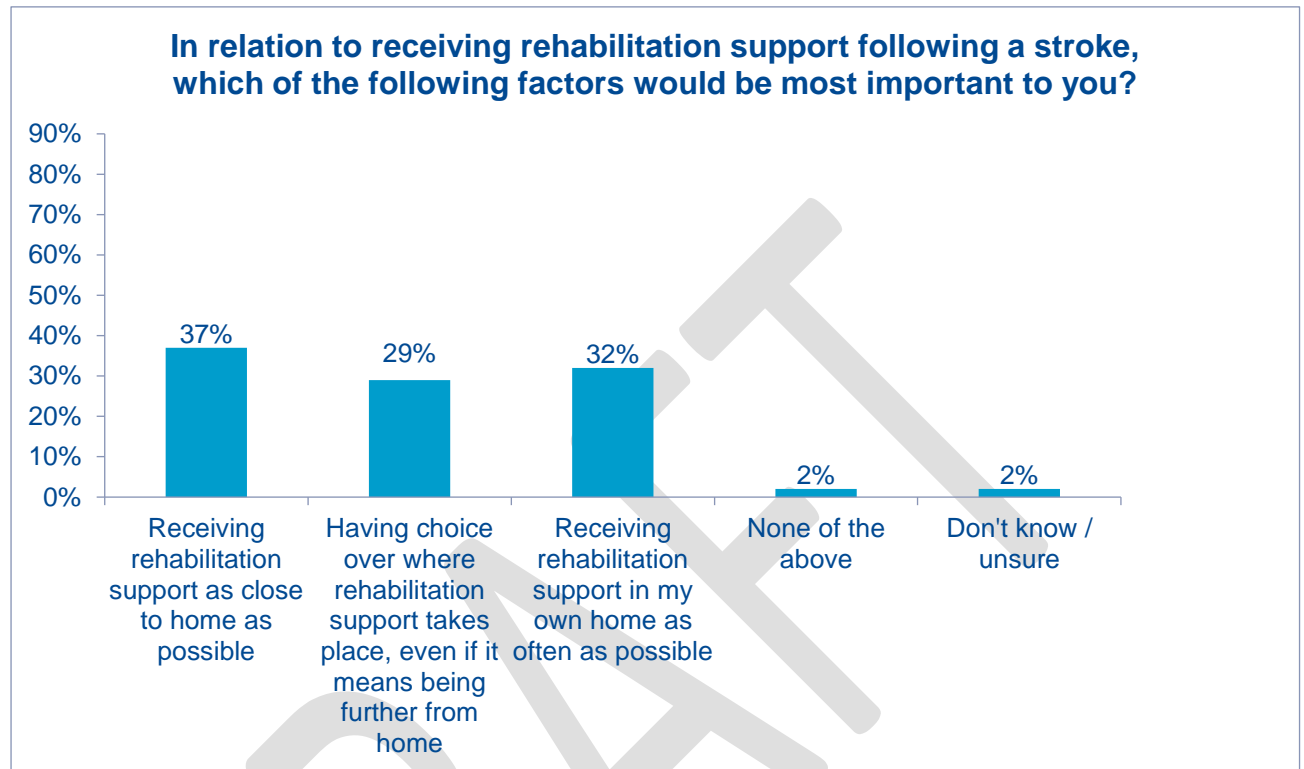
The response to this question indicates how respondents strongly regarded the importance of equitable treatment across Bristol, North Somerset and South Gloucestershire, with 96% agreeing that it is important. Main drivers for this response included comments relating to importance of equality and that where you live shouldn't affect the level of treatment you receive. This also aligns to feedback which was gathered in the remote co-design group which highlighted a perceived inconsistency in the quality and quantity of information support across Bristol, North Somerset and South Gloucestershire for those recovering from a stroke.

This insight depicts that there must be a consideration for consistent rehabilitation support and information across the region. Whilst the stroke reconfiguration programme is focusing on the centralisation of hyper-acute and acute care which should lead to equitable treatment for all patients regardless of where they live, it is also worth considering how prevention and rehabilitation support and can also achieve a consistent level across Bristol, North Somerset and South Gloucestershire.

**"There should be no postcode lottery to receiving good quality stroke care"**

## **Preference on Location for Receiving Stroke Rehabilitation Support**

*There was no clear preference in terms of the location where rehabilitation support is provided, with respondents' preferences being driven by perceptions or preferences around access, comfort and quality of care.*



37% of respondents indicated that receiving rehabilitation as close to home as possible was their preferred response. The reasoning for this choice largely came down to issues with travel and patient comfort, with a number of respondents stating how travelling far can be both difficult and stressful for patients who have had a stroke.

Having a choice over location of rehabilitation, even if it means being further from home was the favoured option from 29% of respondents. Many stated the reason for this was that they felt that quality of care and treatment was a priority, and that they wouldn't mind travelling if it meant better care and outcomes. The importance of patient choice was also highlighted as a driver for this answer.

32% stated that they would prefer rehabilitation to take place in their home as this is where they feel most comfortable and safe. There were also several comments mentioning that rehabilitation in the home would also allow tailoring of sessions to the environment which patients spend most of their time in, with a view to making activities of daily living easier for patients in the context of their own home.

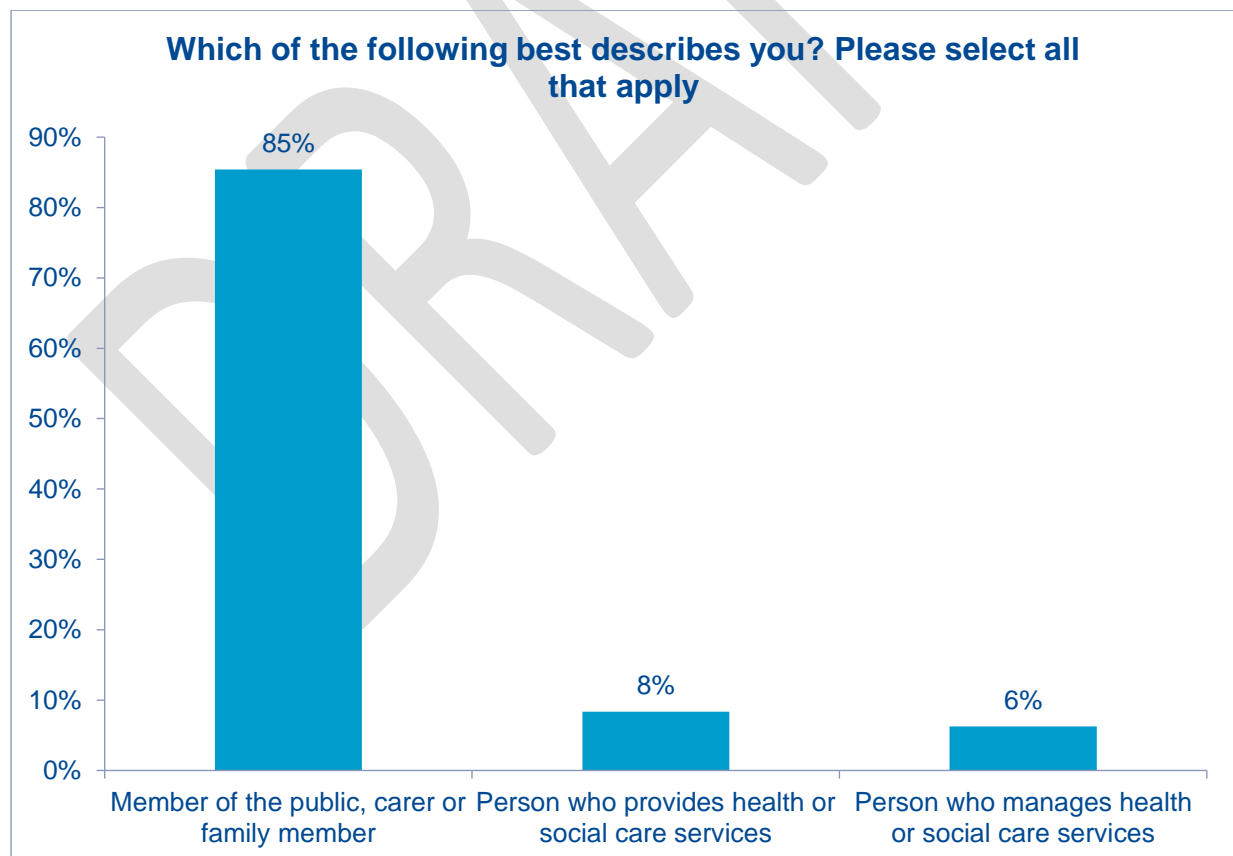
This split across the responses shows the importance of patient choice and flexibility for rehab delivery. It also indicates that patient needs including mobility, comfort and rehab requirements need to be considered when changing where rehab support is delivered. Across the initial public engagement it was noted that there can be a

large level of variance between each person who has a stroke, and that each person has different goals and capabilities. This suggests that perhaps a patient-centred design approach for rehabilitation support should be adopted, with the patients' needs being reflected when deciding where their rehabilitation support should take place.

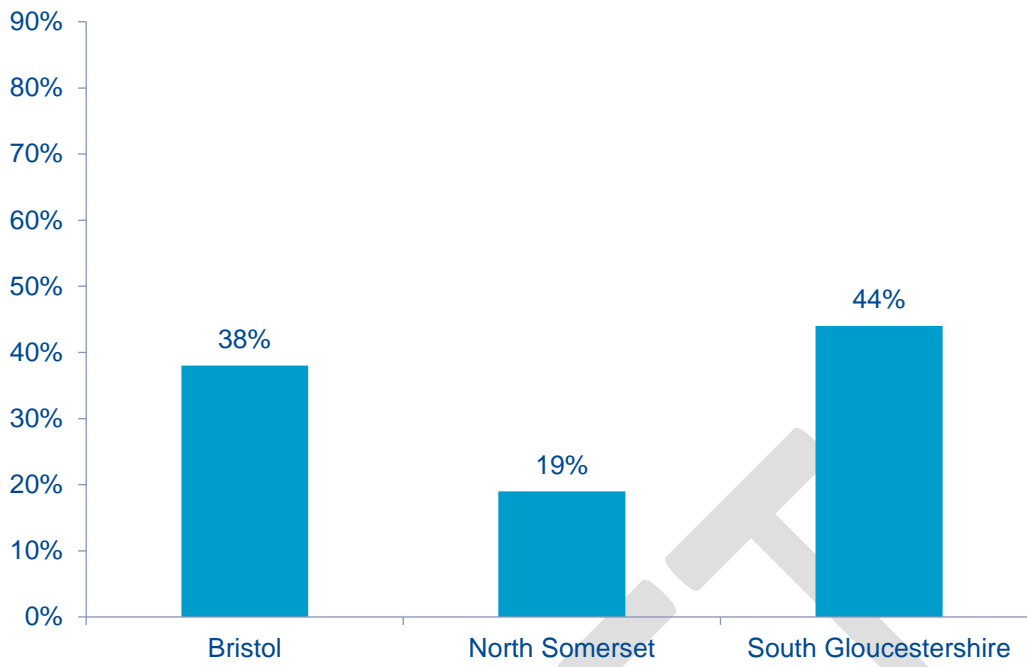
### **Demographic Monitoring**

Through this phase of engagement, demographic monitoring will allow us to identify gaps in public engagement, both for this phase and future phases related to the BNSSG Stroke Reconfiguration Programme.

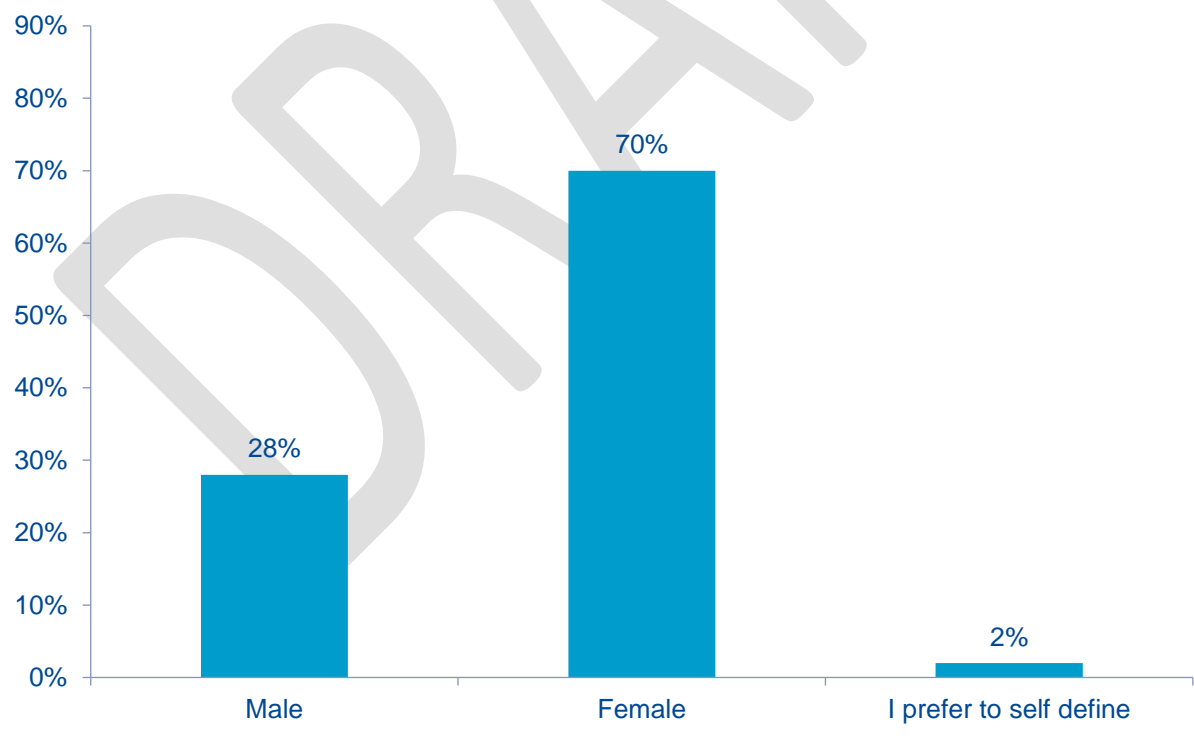
Whilst analysing survey results, individual questions were analysed by demographic groups, for example age; however there were no significant differences noted on any of the responses. It is also important to note that this survey had a sample size of 53 respondents, which is not sufficient to draw significant conclusions from at this stage. The monitoring of ethnicity also highlights the need for more targeted future engagement from those from Black, Asian and Minority Ethnicity community groups.



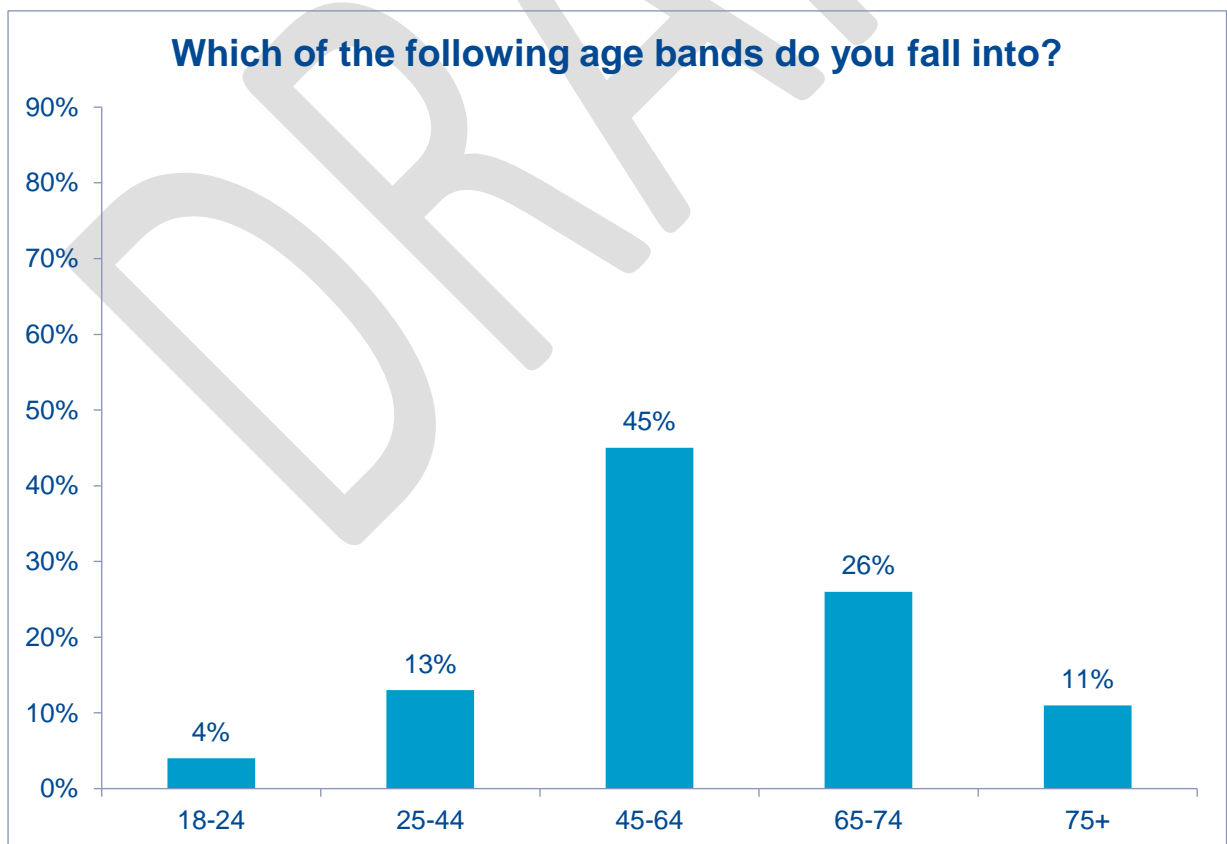
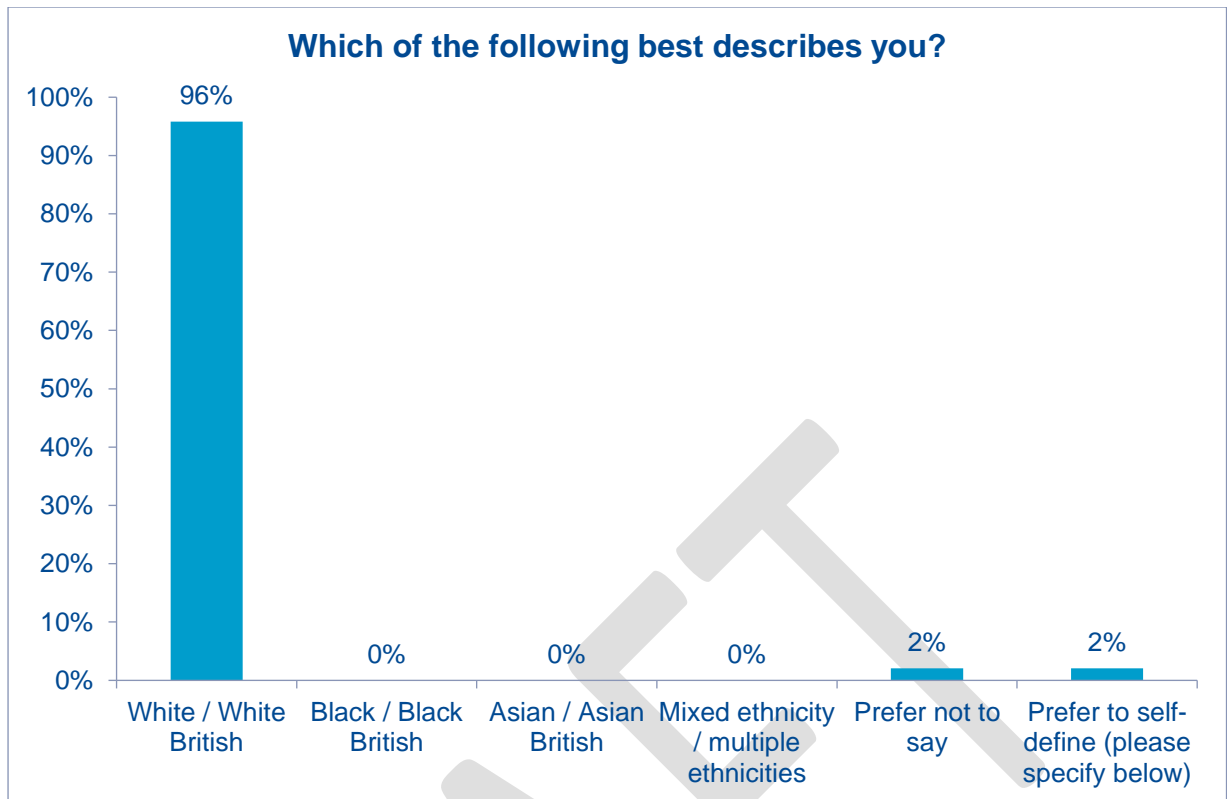
### Which of the following areas do you live in?



### Which of the following best describes you?







## Phase 3

### Feedback on draft proposals for consultation – September and October 2020

During September and October 2020, 18 people (from each of the three local authority areas) with lived experience of stroke, or impacted by it, were sent (emailed) summaries of the key chapters within the draft pre-consultation business case for the reconfiguration of BNSSG stroke services. They were asked to give open comments on the proposals. The responses are collated in the table below.

Theme	Specific comments	Action taken
<b>General regarding the PCBC</b>	<ul style="list-style-type: none"> <li>- Easy to read, informative and make a good case for the proposals.</li> <li>- Generally agree with all, well written.</li> <li>- Good plan in principle</li> </ul>	Comments fed back to Stroke Programme team
<b>Family members /carers</b>	<ul style="list-style-type: none"> <li>- It all affects the people around the person with stroke as much as the person themselves.</li> <li>- Clear since COVID how much negative impact there is on carers and families</li> <li>- The role and impact on carers 'routinely' get forgotten</li> <li>- Carers often actually 'do' the majority of rehab <i>and</i> care</li> <li>- Formal mentoring or guidance of carers is needed for coping with a d/c home – impact of dealing with cognitive, physical and personality changes of loved ones</li> <li>- Real risk of the carer themselves becoming sick in providing the care for the person with stroke</li> <li>- There should be some form of assessment of family member to check before d/c home that they are 'up-to' the task of managing with the care element of looking after someone at home.</li> <li>- Mustn't overlook the considerable worry and impact on partners/spouses – need good regular communication</li> </ul>	<p>In planning how people leave hospital, we have drawn up clear risk assessment and checklist for a safe discharge and this includes checking with family/partner/spouse or others.</p> <p>In planning improved links with voluntary sector (charity) organisations, we plan to include links to services that offer respite to carers.</p> <p>We have written into the pre-consultation business case that family members/carers should be involved in rehabilitation as early as possible including teaching, demonstration and guided practice of relevant tasks.</p>
<b>HASU</b>	<ul style="list-style-type: none"> <li>- How will we show that it will make an impact</li> <li>- If at SMH then will need more space and more staffing (experience of wards 'over-run' and staff 'struggling to provide basic care' and family members being left to do basic nursing tasks for their relative patient)</li> <li>- Support for this model but sceptical due to financial obstacles</li> <li>- SMH is fine but BRI is more central</li> <li>- Central HASU will remove the 'postcode</li> </ul>	The proposals remain for a single hyper-acute stroke unit at Southmead hospital. The staffing model has been proposed and is still under scrutiny as is the funding to support this.

	lottery' currently and would drive development of expertise so clearly beneficial for patients.	
<b>Transfer of patients between sites</b>	<ul style="list-style-type: none"> <li>- needs to be “quickly and safely”</li> <li>- Patients being transferred should go with a specialist stroke nurse at all times</li> </ul>	These comments will guide the details in proposals about how patients are transferred from one site to another.
<b>Option 2</b>	<ul style="list-style-type: none"> <li>- patients moving between sites (for BRI ASU) may experience less continuity of care ‘and distress’</li> <li>- It remains problematic for relatives to visit BRI due to poor parking</li> <li>- The minimal amount of travel for a patient between sites should be the case.</li> <li>- All information for a patient should be transferred electronically so that receiving staff can “hit the ground running”</li> </ul>	Options 1 and 2 are still both in the proposals for consultation in summer 2021.
<b>ICSS</b>	<ul style="list-style-type: none"> <li>- need to be clear that integrated means medical, social and community services</li> <li>- Getting home is a real boost</li> <li>- Great importance that staff work with family members/carers r.e. rehab for the patient.</li> <li>- There shouldn't be a postcode lottery across the hospitals/region as there is now.</li> <li>- Good/sufficient information on community services – nothing missing. If this can be delivered then great.</li> <li>- Clear support for the 7day model of therapy provision in the ICSS</li> <li>- In favour of being offered 6 month and 1 year and annual reviews – compared to current “drop off the radar”</li> </ul>	<p>Significant work has been done in response to these comments in the clinical design sub-group for the ICSS. Many clinicians have been involved in refining the proposals for sub-acute bedded units and community teams.</p> <p>The proposals are set out to ensure equity of provision across the region.</p> <p>Staffing models for 7-days a week and the funding to support this have been proposed and remains under scrutiny.</p>
<b>Public awareness of Stroke services</b>	<ul style="list-style-type: none"> <li>- The public is general aware that there is currently not parity of service across BNSSG</li> <li>- Raise awareness via press, social media, clinic and GP surgery notice boards and video screens, local radio and TV. These could include regional incidence statistics for stroke to bring the message home</li> <li>- Improving awareness might improve fundraising possibility</li> <li>- Immense number of people who know nothing about stroke – the message should be as strong as that of ‘cancers’ r.e. severity</li> </ul>	<p>There has been a re-concentrated focus on work for prevention of stroke by the programme team.</p> <p>There is also planned ongoing focused engagement work with people at higher risk of having a stroke. This will occur before the planned consultation period.</p>

<b>Staffing</b>	<ul style="list-style-type: none"> <li>- Some issues accessing sufficient SALT, OT and PT currently and in the past – important to know that there would be enough trained staff to deliver all the services. Worry that moving staff from other sites/areas may leave other areas short</li> </ul>	Staffing for the acute stroke units, the sub-acute units and the community teams has been set at a level that will allow rehabilitation to occur over 7 days a week and to meet national clinical guidance.
<b>Prevention</b>	<ul style="list-style-type: none"> <li>- Need for increased monitoring of other conditions which cause an increase in stroke risk e.g. head injuries (acquired or as a result of surgery) and migraine</li> <li>- Older people are not the only people at greater risk</li> <li>- Prevention strategy must be pushed harder</li> <li>- Unclear from PCBC what needs to be done and how to improve prevention – “it’s better to prevent a stroke than treat one” so disappointed not more info.</li> <li>- Perhaps stroke needs to be mentioned more explicitly as a risk when treating high blood pressure</li> </ul>	<p>There has been a re-concentrated focus on work for prevention of stroke by the programme team.</p> <p>There is also planned ongoing focused engagement work with people at higher risk of having a stroke. This will occur before the planned consultation period.</p>
<b>ASU</b>	<ul style="list-style-type: none"> <li>- Advice to look through data from previous stroke frequencies and also look at capacity of all hospitals and ambulance service</li> <li>- Good service here will be invaluable as most recovery made in the early days following stroke</li> <li>- One centre of excellence will demand greater acknowledgement (and possibly better targeted funding) <b>“so prefer option 1”</b></li> </ul>	Capacity assessments and modelling (including patient data from the last few years) have formed a key part of the proposals for the new service. It is upon this that costings and resources have been modelled for the new service
<b>Parking</b>	<ul style="list-style-type: none"> <li>- Issues at both BRI and SMH need to be considered</li> <li>- Personal experience of lack of ambulance availability for hospital appointments and easier for family members to deliver patient to hospital (easier SMH than BRI)</li> <li>- Allowing carers to have access to Blue Badge would help. Even the energy exerted crossing a car park can be critical to someone disabled following stroke</li> </ul>	It is not directly within the remit of the stroke programme to influence parking provision at different sites but this is a clear message that can be shared as work continues.
<b>A&amp;E</b>	<ul style="list-style-type: none"> <li>- Personal experience of treatment for TIA and stroke being given outside of</li> </ul>	Most recently updated clinical guidance underpins the

	national guidance timeframes	whole set of proposals and assessment against key clinical guidelines and standards has been completed. The proposals maintain that delivery of a TIA service will continue at each site and the training and education that is required for this will be in place.
<b>Imaging</b>	<ul style="list-style-type: none"> <li>- Likely need for increased staffing to interpret results of scans. Personal experience of delay due to unavailability of staff to interpret scan images.</li> </ul>	Inter-dependencies with imaging has been considered.
<b>Southmead</b>	<ul style="list-style-type: none"> <li>- Personal experience of staff at this hospital poorly communicating between specialities, including outpatients.</li> </ul>	Work to develop a specialist stroke workforce will include specialist training and education which will address communication amongst other things.
<b>Training and education</b>	<ul style="list-style-type: none"> <li>- Time in hospital is a missed opportunity to impart knowledge and skills on partners/carers in preparation for transition to coping alone at home.</li> <li>- Training required for staff r.e. 'dealing with a patient with previous head injury'</li> <li>- Support from Psychologist needed by family members approaching d/c</li> <li>- Training for all staff should include helping people with pre-existing head injury</li> <li>- Perception of lack of information or ability to answer questions currently by some staff – combined with tendency to make assumptions and 'accusations'</li> </ul>	<p>Work to develop a specialist stroke workforce will include specialist training and education. As part of this training, it is envisaged that clinicians with specialist knowledge and patient experts would be used to deliver some training.</p> <p>Improved and increased Psychological support services will feature in all parts of the proposed staffing for the new stroke services.</p>
<b>GPs</b>	<ul style="list-style-type: none"> <li>- Personal experience of poor 'taking over' of managing medication</li> <li>- Needing to 'fight' to get GP appointments and sometimes double appointments so not feeling rushed</li> <li>- Limited information in the GP surgery about stroke</li> </ul>	As part of the ongoing work on community services, discussions are being had with primary care providers (GP practices) to understand how post-stroke follow-up reviews are carried out and how stroke keyworkers can link with social prescribers and ensure that GPs have access to all the information they need about community stroke support services.

<b>Transition home</b>	<ul style="list-style-type: none"> <li>- Personal experience of gap in service when arrived home.</li> <li>- On planning d/c - need to work with family members who will be providing care</li> <li>- Thorough assessment of the home prior to d/c is essential</li> <li>- Possible delay in equipment ordered arriving.</li> <li>- Personal experience of poor home assessment leading to problems later.</li> <li>- Consideration for the 'turning of a home into a workplace'</li> </ul>	<p>The ICSS community stroke service will work closely with patients and their families and carers before, during and after discharge home to ensure that there is no 'gap' in service.</p> <p>Consideration has already been given to aligning criteria for safe discharges by clinicians working with the stroke reconfiguration programme. Assessment of the home environment will form a part of this.</p>
<b>Information for carers</b>	<ul style="list-style-type: none"> <li>- Need better provision of information.</li> <li>- Personal experience of poor responses to request from information.</li> </ul>	<p>How information is provided to patients and their family/carers, particularly as they approach leaving hospital, is being reviewed as part of the planning for the ICSS services.</p>
<b>Therapy over 7 days</b>	<ul style="list-style-type: none"> <li>- Very welcome.</li> <li>- Will need more staffing than currently</li> <li>- Personal experience of cancelled/rearranged appointments due to insufficient staffing.</li> </ul>	<p>Staffing for all parts of the proposed new pathway are for a full 7 days a week service.</p>
<b>Voluntary / community services</b>	<ul style="list-style-type: none"> <li>- A sitting service / respite would be a very good thing for those caring for people with stroke.</li> <li>- BAS is excellent – particularly their volunteer home visitors who understand the impact of stroke so can be someone to talk to empathetic without embarrassment.</li> </ul>	<p>We have had and will continue to have very close working with partners from the local and national voluntary sector organisations to plan future community services.</p>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>- Consider an outcome relating to carers (experience?) as clear knock on effect to person with stroke</li> </ul>	<p>Outcome measures for the future stroke services have been thoroughly discussed and a list of proposed measures includes both patient reported measures and patient experience measures. The possibility of adding a measure of carers' experience, in addition to the already proposed, will be taken to the clinical design group for debate.</p>

## **Summary:**

- Feedback was received from 8 service users across three services user groups, incorporating views from people living in each of the locality areas of BNSSG.
- Comments about the business case as a whole, and its accessibility, were positive.
- A strong theme emerged regarding impact and implications of stroke services for carers of people with stroke. That they are often forgotten in planning ongoing care and support.
- Therapy provision over 7 days per week was unanimously welcomed.
- There is generalised acceptance and support for the new acute services proposals
- Parking is highlighted as a significant issue for family, carers and others visiting people in hospital.
- The proposed service improvements were generally welcomed with recommendations for good information sharing, true integrated teams and close working with family and carers of anyone with stroke for best outcomes. A significant opportunity for conducting this training and education of family and carers was highlighted as being before a patient leaves hospital.
- Another strong theme emerged about training and education for the new stroke specialist workforce – this being very important.
- The prevention element of new services is identified as very important and potentially needing more work or at least further explanation.
- It was suggested that there should be an improvement in primary care services' information sharing about stroke and the services that are on offer.

Detail from this feedback has been used to guide the development of proposals and has influenced detail in the pre-consultation business case – as detailed in the actions within the table. This collation and summary document will be shared with individuals who have offered comments and feedback on the proposals.

## Phase 4

During January and February 2021 a fourth phase of targeted engagement took place involving those from seldom heard groups and high risk groups. This included individuals from Black, Asian and Minority Ethnic (BAME) communities who had lived experience of a stroke, and individuals with health conditions such as sickle cell disease, diabetes and high blood pressure which increase the risk of stroke. BAME community leaders were also interviewed, alongside health professionals specialising in the management of particular conditions such as sickle cell disease. We found during this phase of engagement that by building relationships and involving active community leaders, opportunities for further engagement with individuals from these groups were opened which we will continue to explore as we move towards consultation. It has also offered the opportunity for community leaders to be invited to sit in stroke programme meetings, to act as a voice for their community and to be involved in the co-production of ideas and concepts.

Research shows that people from black or minority ethnic groups are almost twice as likely to experience a stroke as white people and, as well as people with South Asian background, tend to have a stroke ten years earlier than white people. Given this higher risk it was therefore vital that we consult and listen to individuals from this community in the development of the stroke reconfiguration program proposals. Demographic monitoring during previous engagement phases have also highlighted the need to actively engage with those from BAME communities and high risk groups who have been under represented in the engagement activities prior to these interviews.

Participants were recruited to take part through targeted engagement via established community and voluntary networks across Bristol, North Somerset and South Gloucestershire e.g. Bristol and Avon Chinese Women's group, The Car Forum and African Voices Forum, and through the [Healthier Together Citizens' Panel](#). Community leaders were also approached to share the information around the proposals and the opportunity to feedback with their community group. To ensure this opportunity was accessible for those for whom English was not a first language, translations were supplied and interpreter services were offered.

10 interviews have been conducted during this phase of engagement, including 6 members of the BAME community with lived experience of stroke, 3 individuals with health conditions making them higher risk, and a sickle cell nurse, also from a BAME background. The purpose of these interviews was to gather feedback on the proposed options for the number and location of hyper acute stroke units (HASU), acute stroke units (ASU) and sub-acute units (SSARU), to explore feelings on travel to healthcare services, and to understand what is important when it comes to stroke prevention services.

Please see report below which highlights the key themes and findings:



## **Travel and access for health care services**

When asked how far they would be willing to travel to access a speciality service, participant's answers ranged between 45 minutes to an hour and a half by car, taxi or bus. However there was an overall preference stated by the majority for services to be as close to home as possible due to convenience. This preference was so strong for a couple in the high risk groups who regularly access health care services that they told of how they chose their homes based on proximity to services such as local GP practice or hospital.

Those with lived experience of stroke also highlighted how travelling longer distances can be difficult and stressful, particularly if using public transport. They shared how there was a lack of confidence in getting the bus and spoke about worries of falling or getting stuck if travelling alone. Those in the higher risk groups also stated buses can be expensive and unreliable, and that some services are not well connected to local health care services. Two of those who are recovering from stroke said that they would use a taxi service to get to appointments which can be expensive, particularly when travelling further distances or attending regular appointments. With the stroke reconfiguration program proposing to change the number and location of stroke service facilities, it is important that the travel impact on those using the service and visiting friends and family are considered.

## **HASU Proposal Feedback**

The general feedback received when asked about feelings on the centralised point at Southmead Hospital for the HASU was that the notion of a HASU was a good idea as it would provide specialist care and would help provide better outcomes for stroke patients. Half of respondents thought that Southmead Hospital would be a good base due to its facilities for the HASU; however concerns were raised about travel and access. For those living in Bristol, Southmead Hospital was described as an accessible location with good transport links. Conversely the increased travel for those living further away in North Somerset and South Gloucestershire was recognised by all those interviewed, and concerns were voiced about the implications of increased travel time for the patient and family. Half the interviewees questioned if those having a stroke travelling from the furthest points in the area would be negatively affected as it would take longer to get them to treatment. One individual stated "Immediate treatment is the most important thing when having a stroke and having one unit may jeopardise peoples care". Another shared that clear messaging to all ethnic groups around recognising a stroke and FAST is extremely important in the acute management of a stroke.

"I think it's a very good idea to have a centralised unit that is dedicated to stroke treatment. I believe this to be very important as you will have the staff and treatment dedicated to this specialism. In my case my stroke wasn't diagnosed until 5 days later as the staff at Southmead in the Day Assessment Unit hadn't realised that I had suffered a stroke. Whilst I was going through a stroke the midwife didn't pick up on the symptoms too. I feel that there also needs to be more training and awareness among staff too."

*Individual with lived experience of stroke during pregnancy*

Discussions then took place exploring what participants perceived to be the most important considerations during the emergency early treatment and care for stroke. One frequently mentioned consideration was the need for highly trained staff that can make you feel comfortable and reassured as a patient. Additionally the need for family to be informed and supported by staff during this phase of the pathway was also highlighted as it can be a highly upsetting and difficult time for the family. As part of the stroke reconfiguration programme there will be a specialist stroke workforce which will not only increase the quality of care for the patient, but will also result in staff who are highly trained and experienced in dealing with stroke patients families and offering them support. One participant who is a nurse specialising in sickle cell disease also shared the importance of education for medical staff in understanding how having sickle cell need to be treated.

### **ASU Proposal Feedback**

When asked about preference for the number of ASU sites, all of those who were interviewed thought having two units would be better than one. Reasoning for this included more options for the patient and their family, less travel for some, and also more capacity of beds. Concerns regarding the fact that both units would both be located in Bristol were raised by almost all the participants with questions asked as to why the unit at Weston General Hospital would be removed. Implications around travel were mentioned particularly for those living in South Gloucestershire and North Somerset. In contrast however a third of those interviewed did think both the BRI and Southmead Hospital would be the most suitable locations for the ASUs due to their size and ability to cope with a large capacity of patients. The idea of prioritising quality of care was supported by these participants who advocated that the decision should come down to whether the outcomes for the patient would be improved by having a reduced number of ASU locations.

“I think two units would be better as it offers more choice of where to go for the patient. Southmead and BRI seem like good options for location as they are the biggest hospitals in the area. If you took away the one at Weston General Hospital I do understand it might be harder for people who have to travel further. Ultimately though you want to receive the best possible treatment and I hope that this service change will provide that”

Interviewees were then asked what they thought was important about this inpatient rehabilitation stage whilst staying at an ASU. Responses consistently mentioned the importance of well trained staff along with family being nearby, informed and supported. This is similar feedback to the important considerations during the HASU immediate care stage. A couple of individuals with lived experience of a stroke spoke about how this stage can be really scary, and that having highly trained staff there to support and guide you is key to making you feel comfortable and reassured. One person said “Having staff who were experienced in working with stroke patients was really vital for me as my communication had been affected. It made a big difference in making sure my needs were being met.”

An additional point brought up by a couple of participants from the high risk group was that during these unprecedented times where hospital visitation may be limited

due to Covid-19, having online video chat support for family to be able to communicate with the patient and the health care professionals is really important. It allows the family to stay involved and informed, and can offer reassurance about their relatives care and treatment. Due to the uncertain nature of Covid-19 and the timescales of returning to normal activity, the use and access of video technology within the inpatient stroke services may be a potential avenue to explore.

### **SSARU Feedback**

It is important to note that during the time of these interviews final proposals relating to the number of SSARUs had not been confirmed, and the proposals were still offering two or three SSARUs for consideration.

All of the interview participants fed back that they believed having three sub-acute units would be preferred over having two. They also felt that the three proposed locations of the units (Weston Hospital, South Bristol Community Hospital and in an adapted care home setting in South Gloucestershire) were well dispersed across Bristol, North Somerset and South Gloucestershire, providing more equitable accessible for patients and their families. This then has positive implications on their time, wellbeing and finances in relation to travel. When asked about the idea of having two SSARUs, the main response received was that it would be unfair on those living in South Gloucestershire having to travel further.

A couple of participants with lived experience of stroke spoke about the importance of family being nearby to visit at this stage, not only for the patients wellbeing but also to help prepare them for the patient coming home and the additional requirements which they may need to address. Another also spoke about the need for streamlined discharge processes when a patient leaves a SSARU, with ongoing care, support and rehabilitation being well planned and monitored. Additionally one participant with lived experience of stroke stated that support when leaving hospital should be offered to everyone, and that from their experience patients from BAME groups were not being told about support serviced. Any leaflets or materials given out to individuals as they leave hospital should formatted in an accessible way and given to everyone regardless of their demographics. This is vital to ensure an equitable offer of support services to all.

“Ideally 3 would be best. At this stage you want to be as close to home as you can and you want it to be easy for family to visit. The three locations mentioned seem fair.”

When asked whether location of treatment or quality of treatment should be prioritised for ongoing care after discharge, the overriding theme was that the patient’s condition and needs should be considered before deciding where treatment takes place, and that high quality treatment should be delivered consistently whether at home, near to home or in a health care setting. This response is consistent with findings in the phase 2 survey where it was highlighted that following a stroke each

person will have different goals and capabilities, and these needs should be reflected on when deciding where their rehabilitation support takes place.

### **Stroke Prevention Services**

The majority of those interviewed were able to identify the lifestyle changes that can be made to reduce your chances of having a stroke, and many spoke about the changes they have made to their own lifestyles either as a result of having a stroke or due to their health conditions putting them at higher risk. This included being strict with their diet, exercising regularly and reducing the amount of alcohol they drank.

When asked what is important about stroke prevention services the overall theme was that they should be free and easy to access. There was a mixed response between whether a group or individual session would be preferred as some felt it was important to have the support of a group to encourage each other through making a change, whereas others said they would rather do it on their own with the support of a professional. A couple of respondents said how referral from the GP would be helpful to help them identify which services to use. Three participants also emphasised how a focus on prevention needs to start first with the younger generation being educated on the importance of staying fit and healthy, and avoiding lifestyle choices which may increase your chances of having a stroke. Currently the stroke reconfiguration programme proposals are focusing on the treatment and rehabilitation following a stroke; however throughout the pre-consultation engagement the importance of prevention has been highlighted and should undergo further consideration regarding its role within the programme.

“There are so many great services out there which I would seriously advocate to anyone who might be at risk. Any services should be easy to find or quick referral process. I think a group scenario is best as you can work together to support each other. With Covid-19 happening services should still be available, even if they are online”

Another theme which came up was about there is a lack of prevention awareness within the BAME community. One participant shared “I now know a lot more about how my lifestyle choices affect the risk of stroke but generally the BAME communities in Bristol may not be aware. I didn’t know anything about stroke or how lifestyle choices can impact a stroke before I had a stroke. These services are very important in raising awareness and prevention. Even now, there isn’t much awareness about this within BAME communities and you need a much more targeted approach to share this info and raise this awareness with marginalised communities”. Another participant asked about whether messaging can be translated and whether TV campaigns showing recognition of stroke symptoms, for example the FAST campaign, can be translated and put on specific TV channels.

## **Conclusion and Next Steps**

To conclude, this phase of engagement has highlighted some key themes to be built upon and explored as engagement continues. It has also offered the opportunity to build relationships and connections with groups and individuals from seldom heard communities and high risk groups which will be important to continue to develop as we move in to the consultation phase.

We will continue to work with community leaders, alongside community and voluntary organisations, to share communications and to promote the opportunity to take part in any upcoming engagement activities. During the consultation, we shall link with trusted community and faith leaders to deliver engagement events and share information around engagement opportunities, as this has proved to be a successful method of engagement throughout phase 4.

We shall also endeavour to make sure our approach to engaging with seldom heard and higher risk groups is highly accessible, and shall refer to our EIA to inform any considerations that need to be taken forward into the consultation.

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# Stroke Programme staff engagement approach: February 2021 Update

## Background

The Bristol, North Somerset & South Gloucestershire (BNSSG) Stroke Programme is reviewing the delivery of stroke care across the region to understand how changes to the stroke pathway can bring about improvements to patient outcomes.

To address the case for change, clinicians of all professions, people with lived-experience of stroke, voluntary sector workers, social care staff, and service managers have been working together to redesign the stroke service provided to people in the area.

Changes in the programme have the potential to affect acute and community services across the area and require a public consultation to assess how proposals will impact different people.

## Latest development

A Pre-Consultation Business Case (PCBC) for the Stroke Programme has been developed. This was approved by the Healthier Together Executive Group and the PCBC and public consultation plans will now be reviewed by NHS England and Improvement and the Joint Health Overview and Scrutiny Committee (JHOSC) of the area's local authorities. These are key milestones on the way to public consultation.

The Healthier Together Executive Group endorsed the recommendations for public consultation provided by the Acute Care Collaboration group, which oversees the Stroke Programme's board on 5<sup>th</sup> Jan 2021. They recommended to proceed to NHSEI Stage 2 Assurance and the Joint Health Overview and Scrutiny Committee with two options for acute hospital stroke care.

- **It is proposed that a single Hyper-acute stroke unit (HASU) with specialist thrombolysis and thrombectomy services, allied to neurology and neurosurgical services, will be introduced at Southmead Hospital, North Bristol Trust, (NBT).**

### **Two options for ASU care are put forward for consideration:**

- **Option 1:** a single ASU, co-located with the HASU on the Southmead Hospital site is the clinically preferred option for stroke care.
  - **Option 2:** an ASU on the Southmead site and a second ASU at Bristol Royal Infirmary (BRI). This additional ASU would also support inpatients under other specialities (e.g. Bristol Heart Institute) who cannot be transferred for specialist stroke care. Both ASU's would be supported by the single HASU proposed at Southmead Hospital.
- Anyone from the BNSSG area that has suffered a stroke and needs inpatient hospital care following immediate treatment would have a length of stay at Southmead Hospital on the HASU (average length of stay = 3.5 days).

- **Under option 1**, anyone needing ongoing inpatient treatment beyond the hyper-acute phase would “step down” to the single ASU co-adjacent to the HASU within Southmead Hospital (average length of stay = 6 days).
- **Under option 2**, people from the NBT catchment area needing ongoing inpatient treatment beyond the hyper-acute phase would “step down” to the ASU co-adjacent to the HASU within Southmead Hospital, people from the BRI and Weston Hospital catchment areas would “step down” to ASU care provided within the BRI.
- **Under option 1**, anyone needing specialist stroke support that cannot be transferred to the single HASU and ASU at Southmead Hospital as a result of critical interdependencies with other BRI specialities would be cared for by an onsite medical and therapy team at the BRI.
- **Under option 2**, anyone needing specialist stroke support that cannot be transferred to the single HASU and ASU at Southmead Hospital as a result of critical interdependencies with other BRI specialities would be cared for by the BRI based stroke team.

**Under both options**, if there is ongoing rehabilitation and/or care needs that can only be met as an inpatient once a patient is medically fit for discharge, this would be provided at one of two subacute rehabilitation units (SARUs). It is recommended that Weston Hospital is proposed as a fixed point for one of the two sub acute rehab units.

- The location of the second sub-acute unit will be determined as part of the consultation process. Possible locations for this are South Bristol Community Hospital or Frenchay Hospital (with interim arrangements)
- HT Executives recommend naming a ‘preferred’ option based on the Clinical Senate advice which indicated Option 1b

### **A staff first approach**

The proposals for changes to stroke services will impact our workforce, specifically those working within stroke, therefore it is important to ensure that they are the first to know about the details of the PCBC through the programme team and their own line managers before they are presented to the Joint Health Overview and Scrutiny Committee on 5 March 2021.

With this in mind we will proactively update staff and other key internal stakeholders before any information is in the public domain. Outlined below is a suggested approach and the principles that will inform our staff engagement.

This will build on previous staff engagement; the last update given to staff was in early December 2020 where information was shared on the work to date via a written update and two staff events, the recordings were then shared for those who couldn't attend an event.

As we move into this next stage of consultation it is important that we engage with staff and ensure we enable a two way dialogue and that information and updates are timely and accessible to all staff. This needs to be particularly targeted at those directly affected by the proposals.

## Key messages

- The Healthier Together Executive Group has endorsed the recommendations for public consultation provided by the Acute Care Collaboration group.
- The recommendations for public consultation are ... (as above)
- Thank you to the many clinicians and staff who have been involved in the pre-consultation phase of the programme, contributing to and helping to design the proposed solutions.
- We are keen to hear your views, ideas and concerns throughout. Please get in contact with us or share your ideas through the engagement opportunities or your line manager.
- We are planning a formal public consultation on the proposed changes between June and August 2021.
- Implementation of any changes as a result of the consultation will begin in April 2022 at the earliest.

## Our Approach

The proposals impact on several core staff groups and it is important that we have trusted voices leading this work. Working with the Programme team we need to identify several key spokespeople from clinical and nursing backgrounds. Recognising the challenges of this time of year, system pressures and the impact of the pandemic we need to make the information as easy and accessible to everyone as we can. With this in mind we will produce a short video update with key spokespeople sharing the programme update, an overview of the PCBC, key programme milestones and what this means for staff.

This will include the presentation to be shared at JHOSC so that everyone going into the public domain is available.

The video, and slide deck, will be shared with stroke teams via line managers and directors. It will also be shared with those who have already engaged with the programme as well as being made more widely available to other health and care staff.

Clinical leaders will then host a Q&A for anyone wishing to ask questions – these will be hosted online to maximise attendance and enable people from each organisation to attend.

### Timeline:

- W/C 15 February: align spokespeople and prepare outline of presentation and video content
- 22 February: Record video and edit ready for sharing with staff groups by 26 February. Write briefing to accompany the video for managers with key messages to support the video. Agree email address for questions to be submitted to the programme team to develop staff Q&A



- 1 March: Cascade messages directly to all those already engaged in the programme and who have contributed to the engagement events. Share materials via stroke team leaders to include in weekly briefings and team meetings.
- 03 March: System communications leads to share on their established staff channels to ensure all health and social care staff are updated. This includes copy of slides, the video and accompanying briefing.

Following JHOSC we will work with system communications leads and the stroke programme to ensure that regular timely programme updates are provided and that staff are aware of all opportunities to get involved and have their say on the consultation.

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