
Aneurin Bevan Community Health Council

Engagement Report

Community Rehabilitation Support
Services for Stroke Survivors

February 2023



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Introduction & background

As a Community Health Council, with a statutory duty to monitor and scrutinise health services, we wanted to hear from people who access NHS Services in the Community, after having a stroke.

We previously tried to engage with people who had received treatment as an inpatient after having a stroke. However, we only received 5 responses. As a CHC it was important that we continued our efforts to engage with the community to gain feedback from people about the service they received or continue to receive.

For this project, a survey was created and published via our social media channels and website. The survey was also sent to our external stakeholders to increase circulation. The survey was live from November 2022 – January 2023.

We also hosted a face-to-face drop-in session, which took place at our offices in Cwmbran. The purpose of this session was to give people the opportunity to share their feedback in a different way, rather than completing a survey online. CHC volunteers were available to speak with people at this drop-in session. One person attended.

The CHC would like to thank everyone who took the time to share our survey on social media or via email.



Feedback we received

Responses

16 people filled in our survey and gave their experience of accessing NHS services in the community to support their stroke recovery.

We heard from stroke survivors and those who care (or previously cared) for someone recovering from a stroke.

We asked people which hospital they had been discharged from after they had suffered a stroke. This is because we wanted to find out if those who were discharged from a hospital outside the Aneurin Bevan area, had been made aware of the NHS services available to them in the community.

Communication

Three people who filled in our survey were discharged from a hospital outside the Aneurin Bevan area, but now live in the area. Two of these people told us they did not feel they had been made aware/offered any community rehabilitation support services to help assist their recovery.

One person gave further comments; *"Insufficient direction to these services has been offered to me as a patient, as I am a long-term stroke survivor, not discharged within ABUHB. My GP surgery has not pointed me to any stroke support services and there has been no proactivity from ABUHB to communicate with me on my stroke rehabilitation journey. I have therefore felt very alone as a stroke survivor."*

People who were discharged from a hospital in the Aneurin Bevan area told us they were informed about community rehabilitation support services by the following:

- GP
- The Stroke Association
- Hospital Staff
- Local Community Support Groups
- Hospital
- Physiotherapists

Access to Services

We heard from people who accessed the following NHS Services to help support their stroke rehabilitation needs:

- Community Stroke Team
- Physiotherapy
- Occupational Therapists
- Spasticity Services
- Counselling Services
- Specialist Nurses/Doctors
- Speech and Language Therapists
- Living Well after Stroke Service
- Orthotics and mobility aids
- Early Support Stroke Discharge Service
- The Niwrostiwt (Neurological Conditions Recovery College)
- Community Support Groups (Not NHS funded)
- GP Services
- Psychologist
- Dieticians
- Ophthalmology
- Podiatry/Foot care

Receiving care

We wanted to find out how people rated their experience of receiving care/treatment/support from NHS Services. We found out the following:

Most people who accessed the Community Stroke Team, Occupational Therapists, Early Support Stroke Discharge Service, and GP Services rated their experience as *"good"*.

It was disappointing to find out that people who accessed Spasticity Services, Counselling Services, Living Well after Stroke Service, The Niwrostiwt (Neurological Conditions Recovery College) rated their experience as *"very poor"*.



Others rated their experience of accessing the following NHS Services as *"ok"*: Specialist Nurses/Doctors, Speech

and Language Therapists, Orthotics and mobility aids, Ophthalmology and Podiatry/foot care.

Additional comments:

"Again, I express concern that ABUHB shows no interest in identifying, communicating with, or treating long-term stroke survivors living in the community. We feel abandoned."

"I have not received stroke support in the community, the information is very poor, I have not been referred to any community stroke facility team & didn't know about them. Spasticity services are a joke. No intervention has been offered despite my pestering. It's inappropriate to be seen under a care for elderly unit as a younger stroke survivor."

"Community support group excellent, others not really used."

"In 2012 my wife suffered a stroke and has recently died. After her stroke we were not made aware of the help and support available from the Stroke Association. I have now been the secretary of a Stroke Support Group (area redacted) for over ten years but have still not been able to form any relationship with the hospital over stroke survivors about to be discharged and the help and support we can provide."

"5yrs post stroke left with very poor communication skills deteriorating communication & increase in short term memory loss, concentration, reading and activity skills-mobility issues. Totally unsupported following hospital discharge no-one health professional interested or prepared to offer ongoing help & support resulting in post stroke survivor becoming a prisoner in their own home!"

"When I left hospital after 1.5 years, I didn't have any info on support I could have. My son had to get help from Pontypool councillor to get a discharge package to allow me to live back in my home."

"The nursing care in the acute stroke ward in the Gwent should learn to listen to the patients, every day I told them they were hurting my shoulder and took no notice. Finally got transferred to St Woolos for intensive physio to my relief care was far better."



It's important that people feel they have access to NHS services that benefit their needs. Therefore, we asked *"Are there any additional NHS Services you feel would benefit your needs, that are not accessible to you now?"*

Yes: 12 No: 4

It was clear when reviewing the responses to this question that most people would like better communication about what NHS Services they can access on discharge from hospital and in the wider community.

Comments:

"Long-term stroke survivors need more effective communication; GP surgeries should have automatic systems that engage stroke survivors with ABUHB services."

"Effective spasticity treatment, Botox, and follow-on neuro-physio. GPs being trained to refer stroke survivors in the community to correct channels for support & intervention."

"Some info of support services before I left hospital would have been good."

"Long term speech therapy support. Psychologist support to help patient understand more about the type of stroke and how to help to accept conditions affected and how to deal with these, day in day out and support self-help."

One person told us that they felt if they were introduced to a representative of a local stroke group, his wife's recovery as well as his own, would have been much quicker. They both feel if this had happened, their need for support from the hospital would have been reduced.

This person is also a secretary of a local stroke support group, which is a registered charity. They felt that being able to meet with willing stroke survivors prior to their discharge would have helped their knowledge and understanding of what support is available in the community.

It's important that people are treated with dignity and respect when accessing NHS Services. Therefore, we asked *"When accessing NHS Services in relation to your stroke rehabilitation needs, do you feel you are treated with dignity and respect?"*

It was positive to read that 13 of the 16 respondents told us they did feel they were treated with dignity and respect. However, two people did not feel this way.

One person told us they felt that staff need to learn to *"slow down and listen"* when communicating via telephone with stroke survivors who have cognitive impairments.



Emotional/physical well-being

We wanted to find out if people who were accessing NHS Services in relation to their stroke recovery were supported with any emotional and/or physical well-being needs. It was disappointing to read that only four people felt supported in this way.

One person told us that they joined a stroke group in their local area, and they also joined many online groups to do peer mentoring.

"I was not supported at all, and I had to ask after both of my strokes"

Another person who had a stroke 12 years ago told us that they have *"always had to apply for any treatment, I have never been sent for a check-up."*



It's important that people know who they can contact should they require any support or advice from an NHS service in relation to their stroke rehabilitation needs. When we asked this question only four people knew who they could contact, meaning more than half of the people who filled in this survey, did not know who they could contact.

Additional comments:

"Always directed to GP who with the greatest respect have absolutely no clue and ability to help & support."

"At the time of my strokes, I had no advice or help given to me. I had to ask for everything."

"I didn't know there was anywhere (to contact) – it was not advertised"

We received mixed responses when we asked, *"When accessing NHS Services, are reasonable adjustments made to suit your needs?"*

Positively, eight people told us that reasonable adjustments are made to suit their needs. However, seven people told us that this did not happen for them when accessing NHS Services.

One person said their physiotherapist and social worker made reasonable adjustments for them.

Making decisions about care

We also asked people *"Do you feel that you/relatives are involved in decisions made about your care?"*

Similarly, we received mix responses to this question. Seven people felt they were involved but nine people did not feel involved in decisions made about their care.

Comments:

"There was no involvement, and my relatives were not asked as I was left to fend for myself after leaving the hospital."

"My daughter is very supportive"

Stroke rehabilitation

The final question we asked people was *"Do you feel that the NHS Services you currently access, support your stroke rehabilitation?"*

Six people felt that yes, the NHS Services they access support their stroke rehabilitation. Although nine people did not feel this way. No further comments were given.

Other comments:

"Information for stroke survivors upon discharge can be effective in ABUHB. Services for long-term stroke survivors are catastrophically poor. There is a terrible lack of information, both in GP Surgeries and on the ABUHB websites"

"I wouldn't know where to turn for post stroke care, it's hard enough getting an appointment with my GP."

"I feel I should have a check up to see if I'm still alive"

"I was not given any information or follow up until my GP got involved to ask for me. After my first stroke I complained of pain in my neck and found I had a cervical spine injury which wasn't picked up at the time"

when having a CT scan. I had the scan at Nevill Hall 2 months after being at home. I was referred back to UHW Cardiff. In June 2005 7 months later, I had an MRI scan and a doctor asked me what treatment did I have for my brain haemorrhage. I told them nothing as no one had said I had one. They also couldn't find my records. I also found I had hydrocephalus when I went back to Cardiff December 2005 for pressure on the brain, they wondered why I was walking around holding onto everything and asked where my sticks were. I said I never had any. I had to ask for walking sticks and a frame also if I could have physio as I was left with no after care"

"I think there is a need for more support whilst in hospital and more info about brain injury as I did not know anything. I think if I could have spoken to somebody that has gone through the same, I would have had a better understanding of what I was facing."

Response from Drop-in event



As mentioned at the beginning of this report, the CHC organised a drop-in session for people to speak with our volunteer CHC members to give their feedback face to face. The drop-in session was hosted in November 2022.

One person attended the session. This person was associated with a local support group, and they kindly took a batch of our surveys to distribute to the members of their support group.

We received the following feedback from the attendee:

- Lack of information
- No link between NHS Services and Social Care support

"You don't know what support you're entitled to when you have a stroke."

This person also told us about their idea for a "register for stroke survivors". People who have had a stroke and were willing to go on a "register" would enable them to communicate with people who have been through a similar experience to them and share information resources that could help their recovery.

Conclusion

A common theme was identified when reviewing the feedback for this survey. People commented about the lack of information about NHS Services they can access in the community, to help support their stroke rehabilitation. However, people rated their experiences as "good" when accessing NHS Services such as Community Stroke Team, Occupational Therapists, Early Support Stroke Discharge Service, and GP Services.

The findings highlight where improvement is needed such as:

- People not knowing how or who to contact should they require any support or advice from an NHS Service.
- People not feeling supported with their emotional and/or physical well-being needs.
- Having more information readily available for people who want to know what NHS Services they can access in the community to help support their rehabilitation needs.
- Specific rehabilitation services as highlighted in this report.

Recommendations

- 1)** The CHC would be pleased if the positive feedback in this report could be shared with relevant people/teams.
- 2)** The CHC would like to understand how and where information can be accessed if someone would like to know what NHS Services they can access in the community. It would be reassuring to know that the information is offered by staff rather than being requested by the person.
- 3)** The Health Board is asked to consider the feedback from people who feel they are not supported with any emotional and/or physical well-being needs in relation to their stroke rehabilitation.
- 4)** The Health Board is asked to set out their plans to address the issues raised in this report.

Thanks

The CHC would like to thank everyone who took the time to share their views with us, we hope the feedback influences healthcare services to recognise and value what they do well and to enable them to act where they need to, as quickly as they can, to make things better.

We would also like to thank our CHC members who volunteered to participate in our drop-in session.



About the Community Health Councils (CHCs)

CHCs are the independent watchdog of the National Health Service (NHS) within Wales. CHCs encourage and support people to have a voice in the design and delivery of NHS services.

CHCs work with the NHS, inspection, and regulatory bodies. CHCs provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

CHCs receive feedback from the public in many ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, videoconferencing, and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.



Contact details



Aneurin Bevan Community Health Council
Raglan House
William Brown Close
Llantarnam Business Park
Cwmbran
NP44 3AB



01633 838516



Enquiries.AneurinBevanCHC@waleschc.org.uk



www.aneurinbevanhc.nhs.wales



@Bevanhc



CIC Aneurin Bevan CHC

Equality and Diversity Survey Results

Preferred Language																	
English			Other			Not answered											
6			0			10											
Gender																	
Woman/ Girl		Man/Boy		Non- binary		Prefer not to say		Other		Not answ ered							
2		5		0		0		0		9							
Do you consider yourself to be a trans person?																	
Yes			No			Prefer not to say			Not answered								
0			7			0			9								
Sexual Orientation																	
Asexu al		Bisex ual		Gay		Le sb ia n		Heterose xual/ Straight		Pans exua l		Prefer not to say		Oth er		Not answ ered	
0		0		1		0		6		0		0		0		9	
Month and Year of birth																	
Jan		Feb		Mar 1950- 60		Apr 1960- 70		May 1930- 40		Jun 1950- 60		Jul 1940 -50		Aug 1930 -40			
0		0		1		1		1		1		1		1			
Sept		Oct		Nov 1940- 50		Dec				Not answ ered							
0		0		1		0		0		9							

Ethnicity				
Asian or Asian British:				
Bangla deshi	Chine se	Indian	Pakistani	Other
0	0	0	0	0
Black or Black British:				
African		Caribbean		Other
0		0		0
White:				
Welsh/English /Scottish/Nort hern Irish/British		Gypsy of Irish Traveller	Irish	Other
6		0	0	0
Other Ethnic group:				
Arab		Prefer not to say		Other
0		0		0
Religion or belief				
Buddhism	Christianity	Hinduism	Islam	Judaism
0	5	0	0	0
Sikhism	Atheism	No Religion	Prefer not to say	Other religion or belief
0	0	2	0	0
Not answered	9			

Do you consider yourself to have a disability?

Yes	No	Prefer not to say	Not answered
5	2	0	9

Do you look after, or give any help or support to a family member, friend, or neighbour because of a long-term physical disability, learning difficulty, mental ill-health or problems related to old age?

Yes	No	Prefer not to say	Not answered
1	6	0	9

Are you currently pregnant or have you been pregnant in the last year?

Yes	No	Not answered	Prefer not to say
0	7	9	0

Equality Impact Assessment

Please complete the following table to state whether the following groups will be adversely, positively, differentially affected by the policy/activity or that it will have no affect at all

Impact	None	Negative	Positive	Comments
Protected Characteristics				
Age	x			
Disability	x			All CHC surveys are available in a different format upon request.
Sex	X			
Race	X			
Religion/Beliefs	X			
Sexual Orientation	X			
Gender reassignment	X			
Marriage and civil partnership	X			
Pregnancy and maternity	x			

Other characteristics to consider				
Welsh Language			x	Reports & Surveys published bilingually
Other Languages		x		Reports & Surveys can be published in required language on request
Human Rights	x			
Poverty level	x			
Persons with dependents	x			
Rural residence	x			
Gypsy and traveller communities	x			
Digitally vulnerable		x		Survey was only available online. However, if a person contacted the CHC office, printed copies would be sent without delay.

Risk Assessment

Are there any risks arising from the implementation of this policy? N/A
What measures are in place to manage or remove these risks? N/A
Welsh Language This document/policy has been assessed in line with our Welsh language requirements for standards: i) 37,38 ii) 69,70,71

In coming to our impact determination, we sought advice/reviewed the evidence of/considered:

All CHC public facing documents are available in Welsh & English.

The CHC undertakes an Equality Impact Assessment for all public documents and identify them as positive for Welsh translations.

Outcome

Positive impact –

Standards 37, 38 – All public documents are produced and published bilingually in Welsh and English.

Standards 69-71 - We undertake Equality Impact Assessments for all public documents and identify them as positive for Welsh translations

Negative Impact – None

Accessible formats

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.