

Working in partnership



# Stroke Patient Reported Experience Measures (PREMs) Survey 2022/23

Local Pathway Report for  
University Hospitals of Morecambe Bay  
NHS Foundation Trust



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## Foreword

**Juliet Bouverie OBE**

**Chief Executive Officer**

**The Stroke Association**

**“I am proud that the Stroke Association and NHS England have published the findings of the first national Stroke Patient Reported Experience Measures (PREMs) survey covering the patient experience along the whole stroke pathway from acute care through to community rehabilitation, life after stroke, and any potential return to work.**

My thanks go to all those who’ve worked so hard to make this project a success: it’s a huge achievement and is something I’m delighted to have been personally involved in.

As a stroke community we’re all committed to understanding and improving the quality of services for people affected by stroke which we currently do through excellent data and audit programs such as the Stroke Sentinel National Audit Programme (SSNAP). However, these have tended to focus predominantly on measuring access to required levels of service.

This PREMs enables a focus on the patient experience, finally giving ‘parity of esteem’ to this really important aspect of quality. I would describe this patient reported experience data as a potential ‘game-changer’.

As CEO of the Stroke Association – which exists to support and advocate for stroke survivors - I’m passionate about ensuring we listen first-hand to stroke survivors and act upon what they tell us matters. In delivering the survey, we have worked with stroke survivors to understand their experiences and the things that mattered to them during their personal stroke journey. We have involved stroke survivors during the project delivery and will continue to do so, now we have the results available to us.

We know there will be lots of benefits arising from this Stroke PREMs and I would encourage everyone to take time to examine the results and consider what this means and how they can use the findings to improve stroke services even further. We are now able to understand what themes are emerging. We can see how different stroke survivors’ experiences vary and can identify areas that stroke survivors tell us we are doing really well at, and conversely which areas we might want to focus on. In addition, the local reports provide a fantastic opportunity for quality improvement and will hopefully stimulate further discussions and collaboration along the stroke pathway.

In delivering this first Stroke PREMs survey, we have reminded ourselves that this was a pilot. Inevitably, we have learned (and will continue to do so) important lessons about the process and how to improve for subsequent occasions. We welcome feedback from stakeholders, but also look forward to hearing from the wider stroke community about what they have done as a result of having these PREMs findings.”



**Dr Deb Lowe**

**National Clinical Director for Stroke Medicine**

**NHS England**

**“Thank you to all the stroke survivors and their carers, hospital and community clinical teams, coding and administrative leads, for enabling this first ever national Stroke Patient Reported Outcome Measures (PREMs) survey to be completed. This is a ground-breaking project facilitated by close partnership working between the National Stroke Programme at NHS England and the Stroke Association.**

This project and suite of reports will inform those delivering care in our stroke units and community services, those leading and commissioning networks of care in our Integrated Stroke Delivery Networks (ISDNs) and Integrated Care Systems (ICSs), and those making funding and policy decisions at a national level. Hearing from our patients gives us an opportunity to reflect upon how far we have come but also on how far we still must go to reduce unwarranted variation, reduce health inequalities and provide holistic patient centred care.

The holy grail of quality improvement is linking knowledge of delivery of clinical pathways with patient outcomes and patient experience. We can easily make the mistake in healthcare of assuming we are delivering what our patients want or need, but only by asking and listening to them can we understand if there are gaps, and what we can do better. We started this journey with the Getting It Right First Time (GIRFT) Stroke Programme in 2018 and now have a National Stroke Programme within NHS England with clear ambitions and targets to improve the end-to-end stroke pathway as set out in the National Stroke Service Model and Integrated Community Stroke Service Model.

The last three years have been extremely hard for everyone working across the health and care system, and the direct and indirect impacts of the COVID-19 pandemic have undoubtedly made it even more challenging to drive quality improvements along the stroke care pathway. We should use our experiences to build resilience, both personally and within our teams and communities, to be even stronger and with an increased resolve to make a difference. I see this every day as a Stroke Doctor in my local hospital and across the country in my role as National Clinical Director. I never cease to be amazed by the dedication and commitment of all the nurses, therapists, doctors, key workers, administration staff and managers.

We must use data to continue to drive quality improvement ensuring that the performance and organisational data that we have from our excellent National Stroke Audit is used to greatest effect. How data is used to support the development of services within the new commissioning landscape is vitally important. We must also remember that quality of a service is so much more than your ‘SSNAP score’ and this report is a reminder of this. The power of the patient and public voice should never be underestimated, remembering that if we put our stroke survivors at the centre of everything we do, we will never lose our way.”



### Jackie Jones

#### Stroke Survivor and Stroke Association Volunteer

**“As a stroke survivor I was only too pleased to be able to represent the survivors in this project.**

The key message of the Stroke Association: **We're here to support people to rebuild their lives after stroke**, is why this survey has been undertaken.

When I had my stroke I was scared as I did not really understand what had happened, so the part of the survey that looks at the acute phase must include the voice of the patient as with hindsight, they may be able to understand what support they received: medical, information and therapy.

Rehabilitation can be hard, but once again it is so important for the survivor's voice to be taken into account. The fact this could be personalised was invaluable for me in my recovery. However, as a Stroke Association volunteer I have come to realise that not everyone had the same positive experience as myself. However, some survivors are cared for by a number of trusts which could mean care is less joined up than it could be.

The outcome of this survey based on the experience of survivors will, I hope, improve the survivors' experience during their journey from the acute phase to discharge.

Above all the voice of the survivors and their carers must be at the heart of any improvements that are brought about as the result of this survey.”



# Background and need

**This survey, run by the Stroke Association in partnership with NHS England, is the first national Stroke Patient Reported Experience Measures (PREMs) survey undertaken in England.**

The purpose has been to undertake a national survey across England which captures the patient experience of stroke care; to use the survey findings to inform quality improvement activity at local, regional, and national level – in line with the NHS's statutory responsibility for quality improvement.

This initial survey is a pilot survey and the intention is that learnings will be taken forward into the implementation of an annual survey programme.

The survey has been developed in partnership between the Stroke Association and NHS England and with the Stroke PREMs Advisory Group, made up of clinicians from across the stroke pathway, Integrated Stroke Delivery Network (ISDN) managers and stroke survivors. Quality Health, an IQVIA business, was commissioned to advise on methodology and undertake the fieldwork and analysis of the survey data.

## Purpose of the PREMs survey and how to use the findings

The purpose of this project was to pilot both the survey and the operational elements of capturing a PREMs for the stroke population. Also, to understand longer and more sustainable options to embed this into policy and practice. Conducting the survey has provided better insight and understanding as to how to capture the experience of stroke survivors across the stroke pathway, including their acute admission, rehabilitation, and life after stroke services. The survey was designed to provide information to stroke units, Integrated Stroke Delivery Networks (ISDNs) and Integrated Care Systems (ICSs) with regard to patient experience, to inform local quality improvements.

Given that this is a pilot survey to measure patient experience, findings should not be used for benchmarking or performance management of services. Findings should be used by clinicians and ISDNs to identify themes, and to define and prioritise quality improvement projects that would make the most difference to people affected by stroke.

# Methodology

## Sampling and eligibility

All adult patients (aged 18 and over), with a confirmed primary diagnosis of stroke, who had been admitted to hospital as inpatients for stroke related treatment, or who were seen as day case patients for stroke related treatment between 16 May 2022 and 16 September 2022 were eligible for the survey. This was so that patients were between 4 and 8 months post diagnosis when they were sent the questionnaire in January 2023. This timeframe was chosen to balance the fact that people are able to give better feedback on recent events that are clear in their memories with the time taken for patients' initial recovery and progression through the stroke care pathway. If a patient was seen twice in an Acute stroke unit for a stroke in that period, they were contacted about their most recent admission.

'Section 251' support has been provided by the Secretary of State for Health and Social Care, following advice from the Confidentiality Advisory Group (CAG). This allowed Trusts with Acute stroke units to provide the personal details of eligible patients to Quality Health without obtaining patient consent. Regulation 5 of the 2002 Control of Patient Information Regulations provide a lawful basis under common law for confidential patient information to be processed for medical purposes.

Patients were able to opt out by contacting their Trust before the data was shared or by contacting Quality Health during the fieldwork period. Trusts also removed patients who had opted out via the National Data Opt Out. Exemption from this was not obtained for this pilot project.

To further improve the accessibility of the survey for stroke survivors, large print versions were available on request and the online version had options to increase font size, change background colour and save progress to return to if fatigued.

## Survey method

The fieldwork for the survey was carried out between 16 January 2023 and 18 April 2023.

The survey used a mixed mode methodology. Questionnaires were sent by post to the patient's home address, followed by up to two reminder letters (to non-responders only). The letters included a link and unique password to allow the patient to complete the survey online, should they prefer to do so. Quality Health ran a national freephone helpline for patients, supporting completion of the survey through text, phone, or through a translator for those whose first language was not English.



### How to read this report

This report follows the order of the questionnaire to objectively present the results of the survey and to reflect the patient experience along the pathway. The report is split in to the same three sections that the questionnaire examined: acute stroke unit, community-based care, and employment before and after stroke.

#### Scoring methodology

An at a glance summary of scores is provided for questions 7a, 7b, 7c, 9a, 9b, 9c, 9d, 13a, 13b, 13c, 14a and 14b. These questions;

1. Use the Likert scale rating system (e.g. questions that provided a set response scale and ask to what extent they agree with a statement.)

AND

2. Relate to the care they received along the stroke pathway.

A binary scoring method was used, and scores were calculated using the total number of positive responses as the numerator and the total number of positive and other responses as the denominator. For the appropriate questions, the responses 'strongly agree' and 'agree' have been identified as 'positive responses' and 'neither agree nor disagree', 'disagree' and 'strongly disagree' have been identified as 'other responses'. Responses such as 'not sure' were excluded from the calculation. The resulting scores - presented as percentages - are reported on within this report and across the survey's other outputs.

#### Patient Cohort

All results in this report are from the responses given by patients whose Acute care (for their most recent admission) was provided by University Hospitals of Morecambe Bay NHS Foundation Trust. Patient responses to the questions relating to community-based care will refer to wherever they received that treatment, therapy or care, which may span several Integrated Care Systems (ICSs).

It is important that the results follow a cohort of patients along their pathway of care, rather than reporting on different groups of patients for questions that relate to different parts of the pathway. For that reason, two sets of reports have been produced:

- This one, which focuses on a patient cohort from a single acute Trust.
- A second set focussing on the ICS where the patient received their community-based care.

Reports can be accessed on Sentinel Stroke National Audit Programme (SSNAP) website ([www.strokeaudit.org](http://www.strokeaudit.org)).

#### Suppression

To protect the identity of respondents and support result reliability, suppression rules have been applied to the results. Where the total number of responses to a question or where the base size for any group or sub-group (e.g. a specific demographic) is less than 11, results for the question are suppressed, indicated by an asterisk (\*).



### Limitations

Due to the pilot nature of the survey, care should be taken when interpreting the results. As with any survey, the number of responses received for each individual question should be noted, as results relating to smaller volumes of responses will be subject to larger levels of uncertainty than those with larger volumes of responses. This is because survey results are based on a sample of information, and so have an inherent level of uncertainty.

The PREMs survey is not intended to benchmark results against one another, therefore people should refrain from making direct comparisons between providers, ICBs or to the national results.

No statistical testing has been undertaken for this pilot survey. Therefore, this report does not state whether any score is statistically significantly higher or lower than another score. Care should be taken when comparing between questions as a small difference in score may be due to random variation rather than a true difference in patient experience across those areas.

It should be noted that no exemption from the National Data Opt Out was secured for this survey. This is secured for other national patient surveys and is desirable as it allows the whole patient cohort to be contacted. As this pilot survey has not received an exemption from the National Data Opt Out, the results of the survey cannot be said to be representative of the target population. This is because we do not know who, from our target population, has opted out and therefore never received a survey. Therefore, it is impossible to compare the results of one organisation with another.

No weighting or adjustment has been made to the results in order to correct any demographic or other bias in the respondent group. The relative response rates of different demographic groups should be taken into account when interpreting the data.

“Weighting” refers to a set of statistical adjustments, made to survey data after they have been collected, to help improve the representativeness and utility of the results produced from that data. Weighting is typically used to help account for respondents having an uneven chance of being selected (or not selected) to participate in the survey, and to help account for differences between those who respond and those who do not respond to the survey.

## Supplementary reports

Alongside this report, the following outputs have been produced for this patient cohort:

- A set of frequency tables of the responses alongside the scores.
- A detailed results spreadsheet which contains demographic breakdowns of the results.
- A sanitised list of free text comments received from the patient cohort in relation to their stay on the acute unit (Q10), their community-based care (Q16) and anything else they wanted to mention (Q21).

A national report of the findings has also been published, alongside frequency tables and a detailed results spreadsheet for the whole national patient cohort.

Reports can be accessed on Sentinel Stroke National Audit Programme (SSNAP) website ([www.strokeaudit.org](http://www.strokeaudit.org)).

## About the respondents

Of the 63 completed surveys returned from the sample of 149, 5 were excluded for the following reasons:

<b>Moved / not known at this address</b>	0
<b>Ineligible</b>	0
<b>Deceased</b>	5

The response rate was 44% (63 valid responses from a usable sample of 144).

Completed questionnaires were received by post from 56 respondent(s) (89% of responses); and 7 (11%) chose to complete their questionnaires online. No respondents used IQVIA's Freephone helpline to give their responses; and no respondents used IQVIA's translation/interpreting services to give their responses.

## Respondent demographics

Role in survey completion	Number of respondents	Percentage of total respondents
Stroke Survivor	56	90%
Carer	6	10%

Number of strokes	Number of respondents	Percentage of total respondents
One stroke	51	86%
Two strokes	6	10%
More than two strokes	2	3%

Time since most recent stroke	Number of respondents	Percentage of total respondents
Less than 4 months ago	5	9%
4 - 6 months ago	20	36%
7 - 8 months ago	23	41%
More than 8 months ago	8	14%

Type of stroke	Number of respondents	Percentage of total respondents
Stroke caused by a blockage, referred to as an ischaemic stroke	34	71%
Stroke caused by a bleed, referred to as a haemorrhagic stroke	14	29%

## Respondent demographics - continued

Age group	Number of respondents	Percentage of total respondents
< 60 years	3	5%
60 - 69 years	16	28%
70 -79 years	20	35%
80 - 89 years	16	28%
90+ years	2	4%

Gender	Number of respondents	Percentage of total respondents
Male	32	55%
Female	26	45%
Non-binary	0	0%
Prefer to self-describe	0	0%
Prefer not to say	0	0%

Ethnicity	Number of respondents	Percentage of total respondents
White	61	97%
Mixed / Multiple ethnic backgrounds	0	0%
Asian / Asian British	1	2%
Black / African / Caribbean / Black British	1	2%
Any other ethnic group including Arab	0	0%
Prefer not to say	0	0%

## Respondent demographics - continued

Sexual Orientation	Number of respondents	Percentage of total respondents
Heterosexual or straight	57	97%
Gay or lesbian	1	2%
Bisexual	0	0%
Other	0	0%
Prefer not to say	1	2%

IMD Quintile	Number of respondents	Percentage of total respondents
Quintile 1 (most deprived)	8	13%
Quintile 2	7	11%
Quintile 3	12	19%
Quintile 4	24	38%
Quintile 5 (least deprived)	12	19%

## Acute Stroke Unit Care

This section of the report contains the responses to questions 6 to 9 about the time spent in the acute stroke unit, immediately after the stroke.

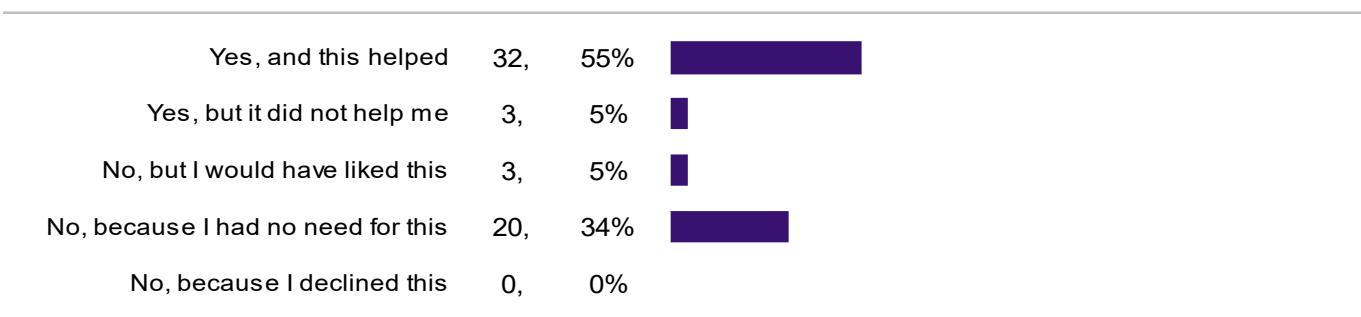
## Acute stroke unit care

### Time on acute stroke unit (Q6 - Q7)

**Question 6: What treatment or therapy were you offered and did it help your recovery?**

#### Physiotherapy

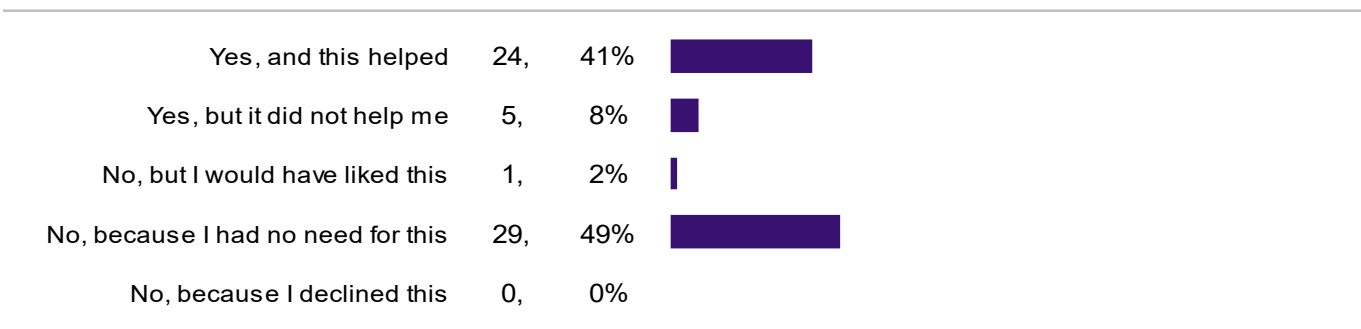
**Q06a\_1: Please think about the time you spent on the acute stroke unit. What treatment or therapy were you offered and did it help your recovery? Movement and mobility (Physiotherapy).**



Based on 58 responses.

#### Speech and language therapy

**Q06a\_2: What treatment or therapy were you offered and did it help your recovery? Talking, communicating, cognition and swallowing (Speech and Language therapy).**



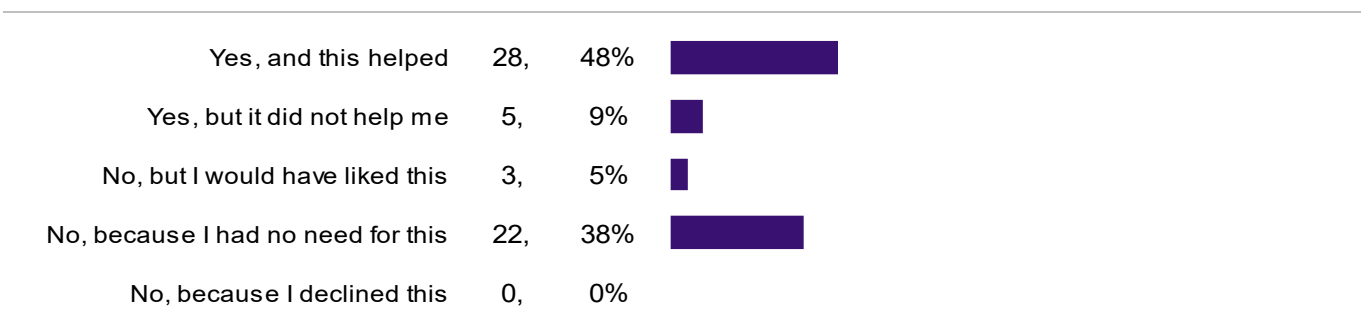
Based on 59 responses.



## Time on acute stroke unit - continued

### Occupational therapy

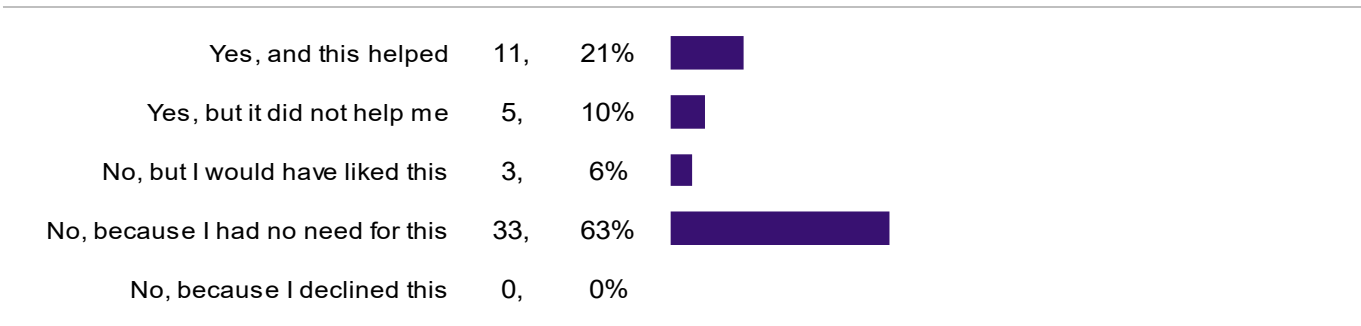
**Q06a\_3: Please think about the time you spent on the acute stroke unit. What treatment or therapy were you offered and did it help your recovery? Independence with personal care and practical tasks (Occupational therapy).**



Based on 58 responses.

### Dietetics

**Q06b\_1: What treatment or therapy were you offered and did it help your recovery? Food and drink (dietetics).**

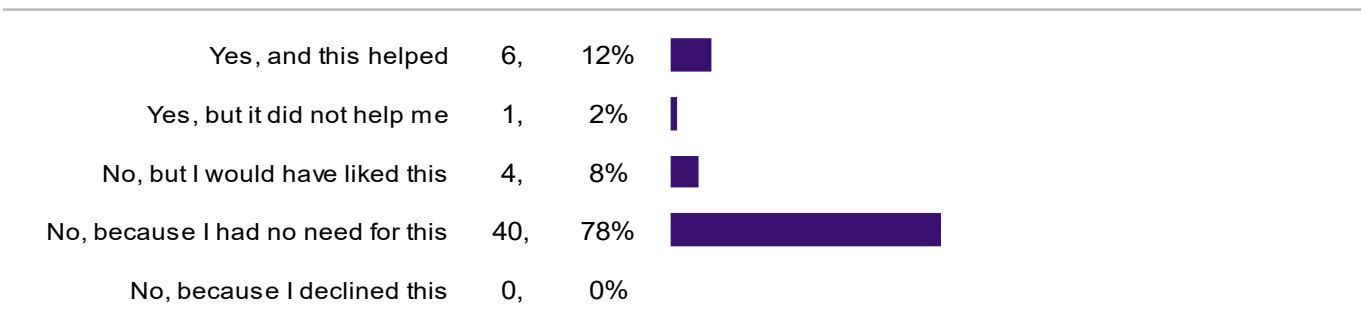


Based on 52 responses.

## Time on acute stroke unit - continued

### Audiology

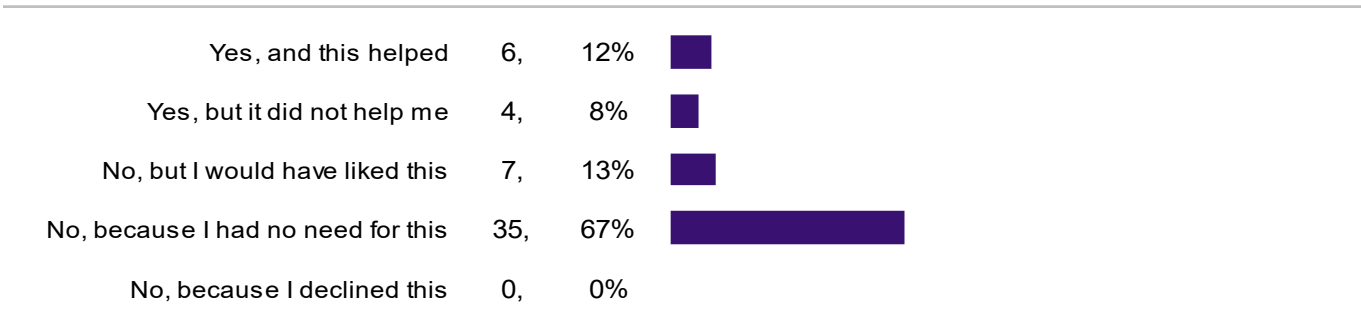
**Q06b\_2: Please think about the time you spent on the acute stroke unit. What treatment or therapy were you offered and did it help your recovery? Hearing changes (audiology).**



Based on 51 responses.

### Orthoptics

**Q06b\_3: What treatment or therapy were you offered and did it help your recovery? Sight and vision changes (orthoptics).**

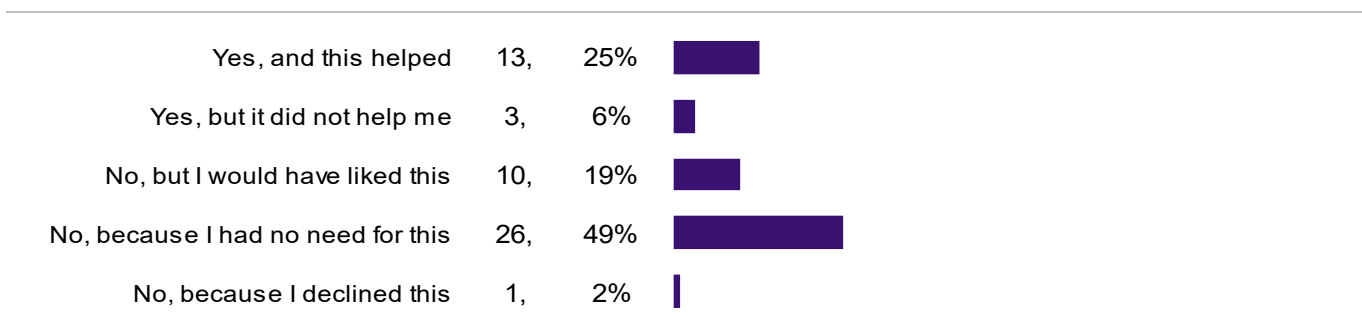


Based on 52 responses.

## Time on acute stroke unit - continued

### Psychology, psychiatry and counselling

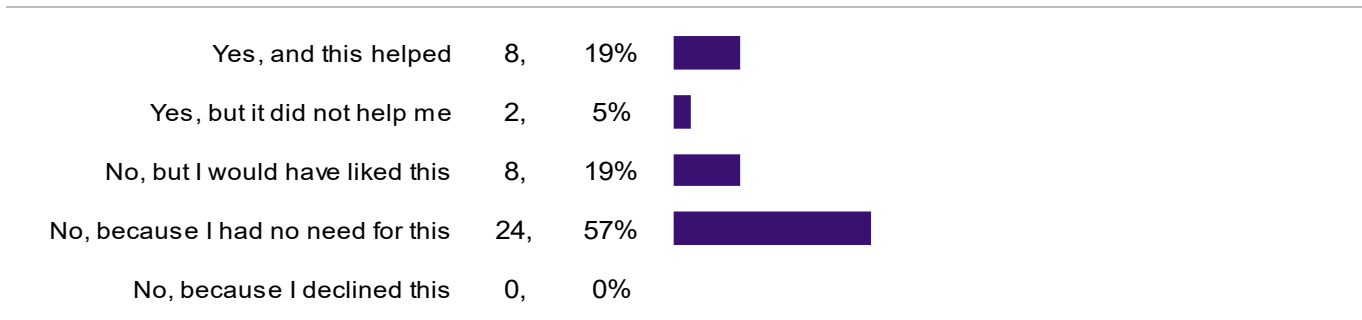
**Q06c\_1: Please think about the time you spent on the acute stroke unit. What treatment or therapy were you offered and did it help your recovery? Emotions, moods, personality and motivation (psychology, psychiatry and counselling).**



Based on 53 responses.

### Personal care record

**Q06c\_2: What treatment or therapy were you offered and did it help your recovery? A personalised care record. This might be known as a patient passport or patient record.**



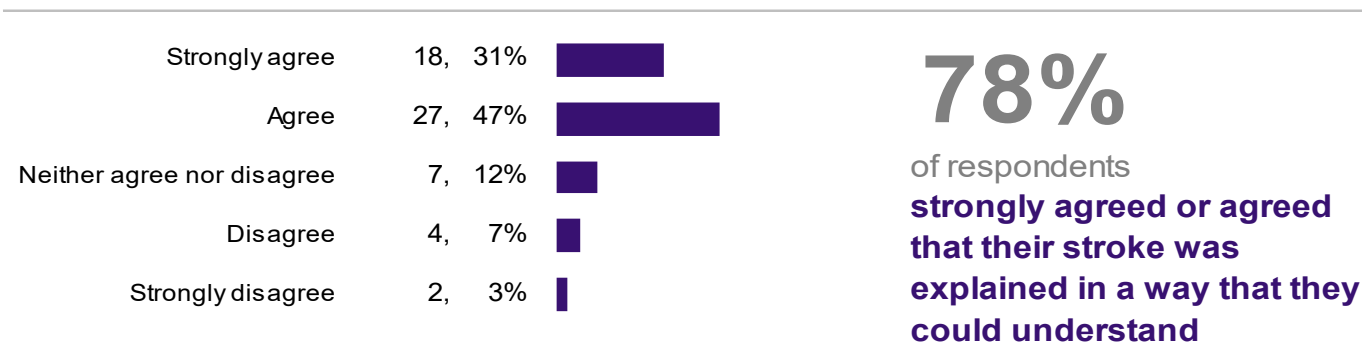
Based on 42 responses.

## Time on acute stroke unit - continued

**Question 7: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements. What treatment or therapy were you offered and did it help your recovery?**

### Explanation of the stroke

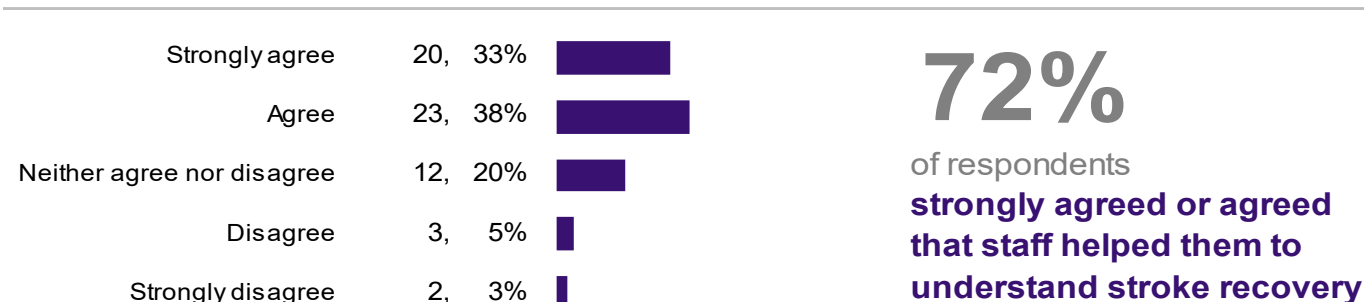
**Q07a\_1: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: My stroke was explained in a way that I could understand.**



Based on 58 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

### Understanding stroke recovery

**Q07a\_2: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff helped me to understand about stroke recovery.**

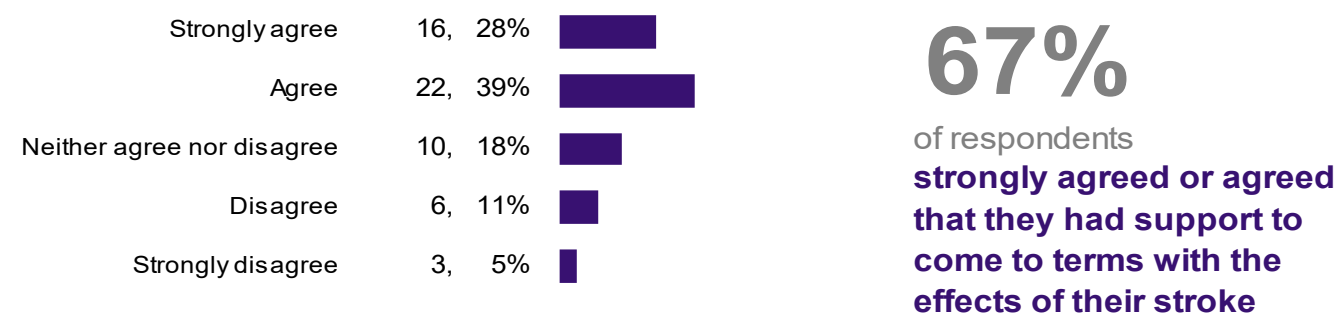


Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Time on acute stroke unit - continued

### Coming to terms with the stroke

**Q07a\_3: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I had support to come to terms with the effects of my stroke.**



Based on 57 responses. Those answering 'Not sure' (4) excluded from percentage calculations.

### Treated with respect and dignity

**Q07b\_1: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff treated me with dignity and respect.**

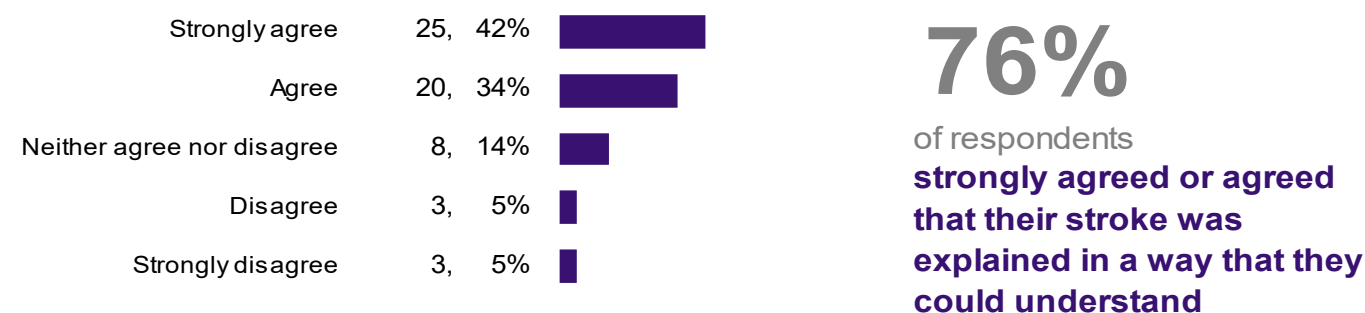


Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Time on acute stroke unit - continued

### Understanding impact on life

**Q07b\_2: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff understood how my stroke would affect my life.**



Based on 59 responses. Those answering 'Not sure' (2) excluded from percentage calculations.

### Support to express needs and wants

**Q07b\_3: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: There was support to express needs and wants e.g. using the toilet, meal and drink options.**

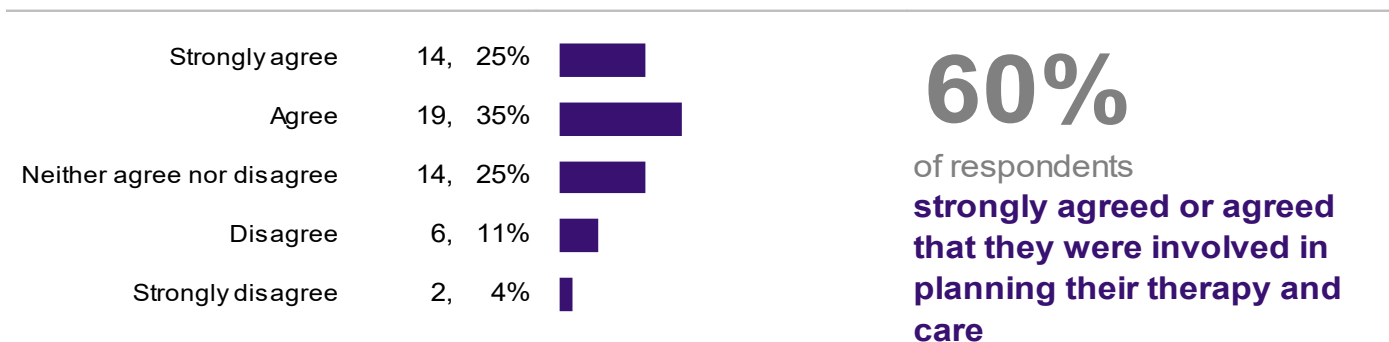


Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Time on acute stroke unit - continued

### Involvement in planning therapy and care

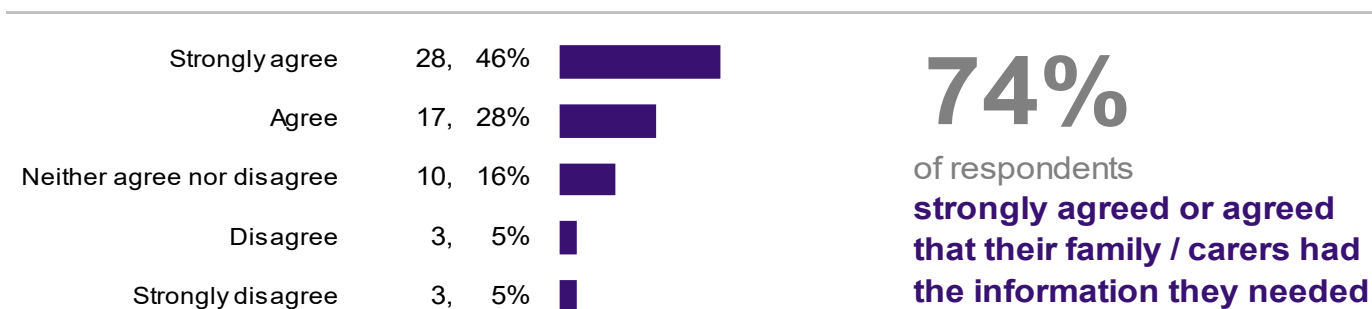
**Q07c\_1: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was involved in planning my therapy and care.**



Based on 55 responses. Those answering 'Not sure' (5) excluded from percentage calculations.

### Family / carers had the information they needed

**Q07c\_2: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: My family / carers had the information they needed about my stroke and hospital stay.**



Based on 61 responses. Those answering 'Not sure' (0) excluded from percentage calculations.



## Time on acute stroke unit - continued

### Further support

**Q07c\_3: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was told where I could get further support if I needed it.**

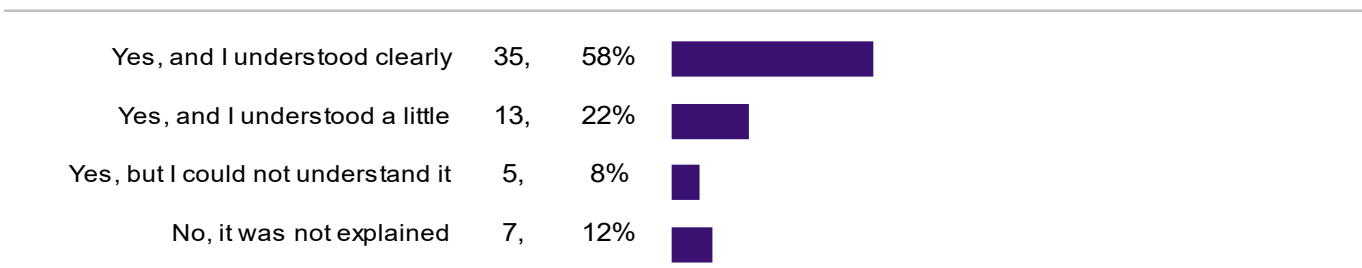


Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Leaving the acute stroke unit (Q8 - Q9)

### Explanation and understanding of medication

**Question 8: On leaving the acute stroke unit, were you given an explanation about your medication? Did you understand what it was meant for and how to take it?**



Based on 60 responses.

## Leaving the acute stroke unit - continued

Question 9: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements.

### Involvement in decision making

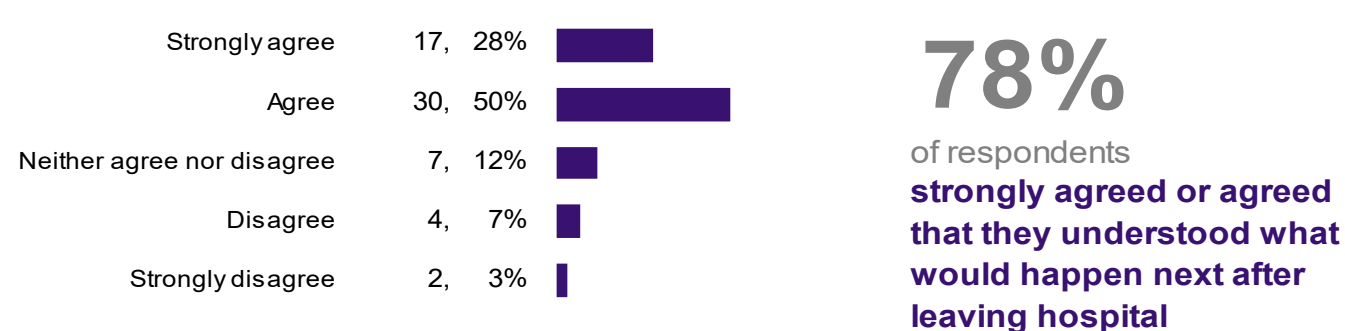
Q09a: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was involved with decisions about leaving hospital.



Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

### What would happen after leaving hospital

Q09b: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I understood what would happen next after leaving hospital.



Based on 60 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Leaving the acute stroke unit - continued

### Family / carers knew what would happen after leaving hospital

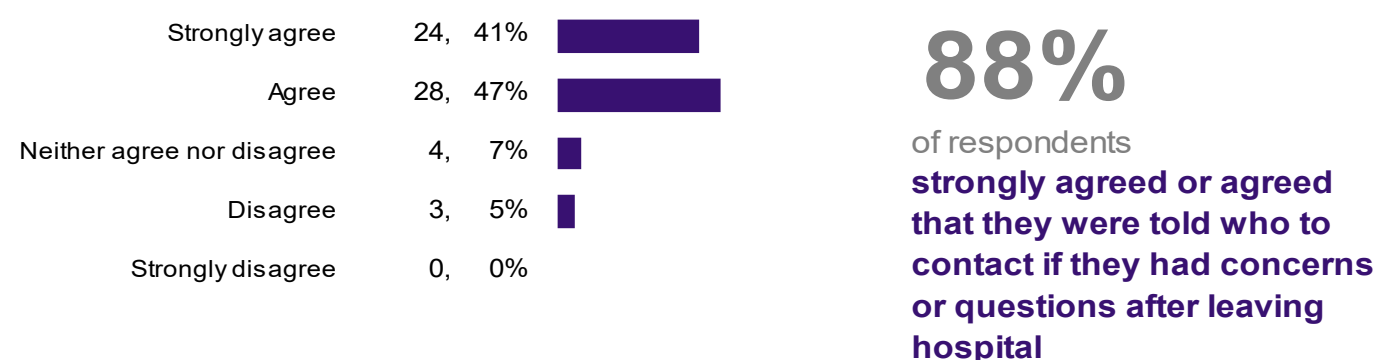
**Q09c: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: My family and carers were told what would happen when I left hospital.**



Based on 59 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

### Concerns or queries

**Q09d: Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was told who to contact if I had concerns or questions after leaving hospital.**



Based on 59 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

**Please note that Q10 is a free text response and is not included in this report.**

## At a glance - acute stroke unit care

This stacked chart shows those questions where a binary scoring has been undertaken, showing them in questionnaire order. It shows the 'positive score' by combining the responses 'Strongly agree' and 'Agree'.

Question	Base	Score	
Q7a_1. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: My stroke was explained in a way that I could understand.	58	78%	
Q7a_2. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff helped me to understand about stroke recovery.	60	72%	
Q7a_3. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I had support to come to terms with the effects of my stroke.	57	67%	
Q7b_1. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff treated me with dignity and respect.	60	95%	
Q7b_2. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: The staff understood how my stroke would affect my life.	59	76%	
Q7b_3. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: There was support to express needs and wants e.g. using the toilet, meal and drink options.	60	77%	
Q7c_1. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was involved in planning my therapy and care.	55	60%	
Q7c_2. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: My family / carers had the information they needed about my stroke and hospital stay.	61	74%	
Q7c_3. Thinking about your stay on the acute stroke unit, please state how much you agree with the following statements: I was told where I could get further support if I needed it.	60	85%	
Q9a. Thinking about leaving the acute stroke unit, please state how much you agree with the following statements: I was involved with decisions about leaving hospital.	60	72%	
Q9b. Thinking about leaving the acute stroke unit, please state how much you agree with the following statements: I understood what would happen next after leaving hospital.	60	78%	
Q9c. Thinking about leaving the acute stroke unit, please state how much you agree with the following statements: My family and carers were told what would happen when I left hospital.	59	69%	
Q9d. Thinking about leaving the acute stroke unit, please state how much you agree with the following statements: I was told who to contact if I had concerns or questions after leaving hospital	59	88%	

## Community Based Care

These sections of the report contain the responses to questions 11 to 15 about the treatment and rehabilitation received after leaving the acute stroke unit. This could have been therapy at home, in a rehabilitation unit or outpatient appointments at a hospital or clinic.

## Community based care

### After leaving the acute stroke unit (Q11 - Q15)

Question 11: When you left the acute stroke unit, where were you discharged to?

---

Home	53,	85%	<div></div>
To a relative / friend's home	4,	6%	<div></div>
Residential care	0,	0%	
A rehabilitation unit	3,	5%	<div></div>
A different ward in the same hospital	1,	2%	<div></div>
A local / community hospital	1,	2%	<div></div>

---

Based on 62 responses.

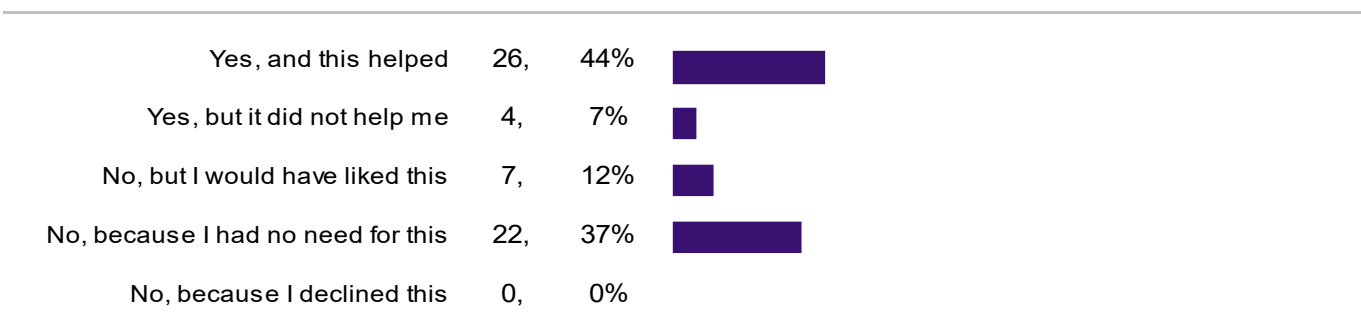


## Community therapy / treatment

**Question 12: What community therapy or treatment were you offered and did it help your recovery?**

### Physiotherapy

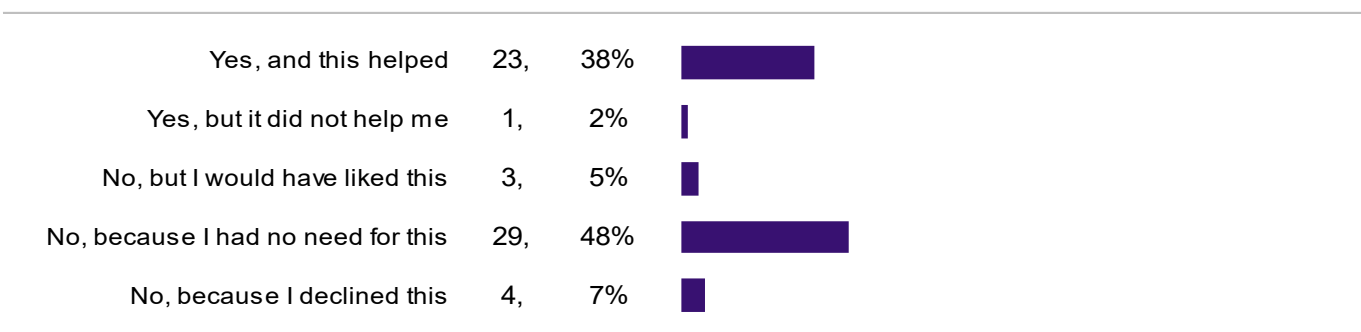
**Q012a\_1: What community therapy or treatment were you offered and did it help your recovery? Movement and mobility (Physiotherapy).**



Based on 59 responses.

### Speech and language therapy

**Q12a\_2: What community therapy or treatment were you offered and did it help your recovery? Talking, communicating, cognition and swallowing (Speech and Language therapy).**

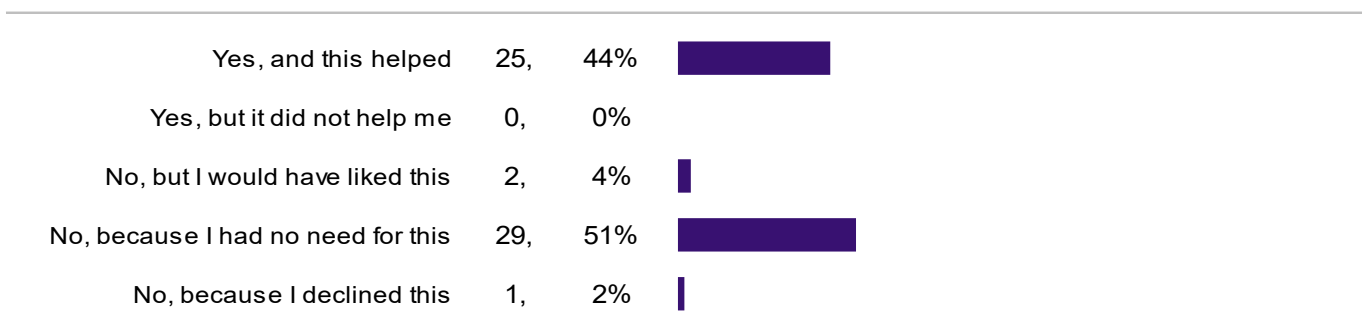


Based on 60 responses.

## Community therapy / treatment - continued

### Occupational therapy

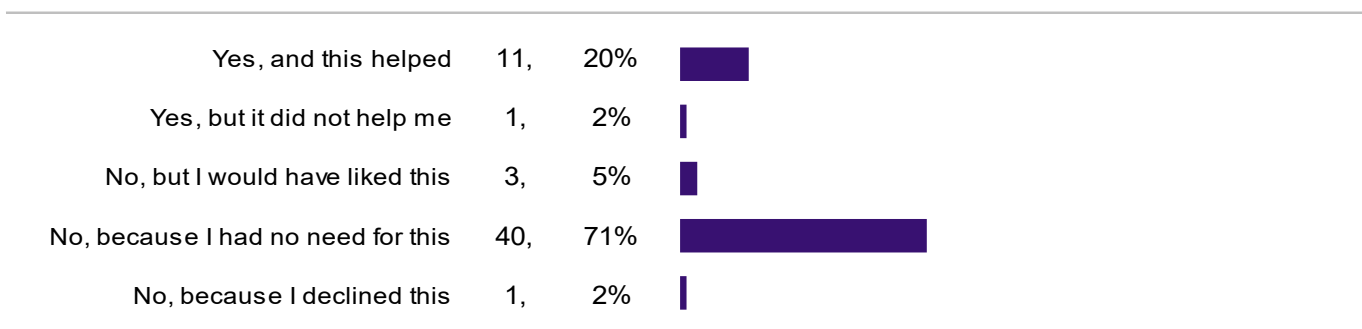
**Q12a\_3: What community therapy or treatment were you offered and did it help your recovery? Independence with personal care and practical tasks (Occupational therapy).**



Based on 57 responses.

### Dietetics

**Q12b\_1: What community therapy or treatment were you offered and did it help your recovery? Food and drink (dietetics).**

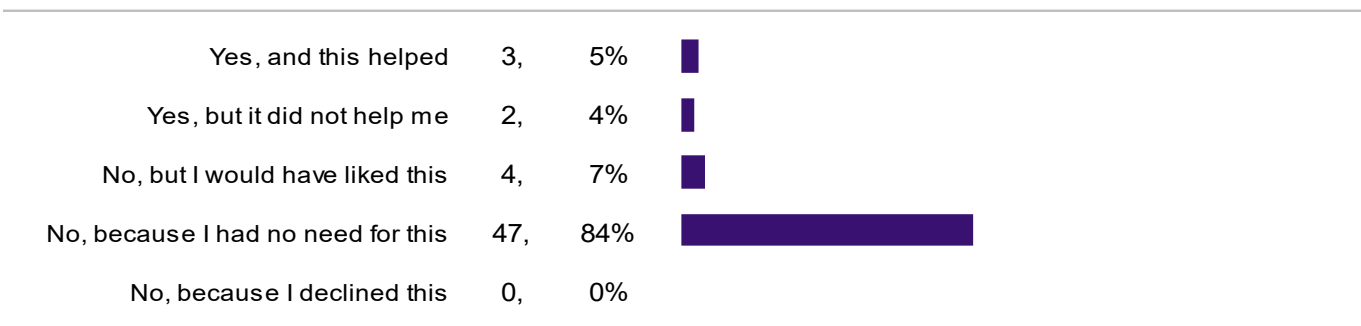


Based on 56 responses.

## Community therapy / treatment - continued

### Audiology

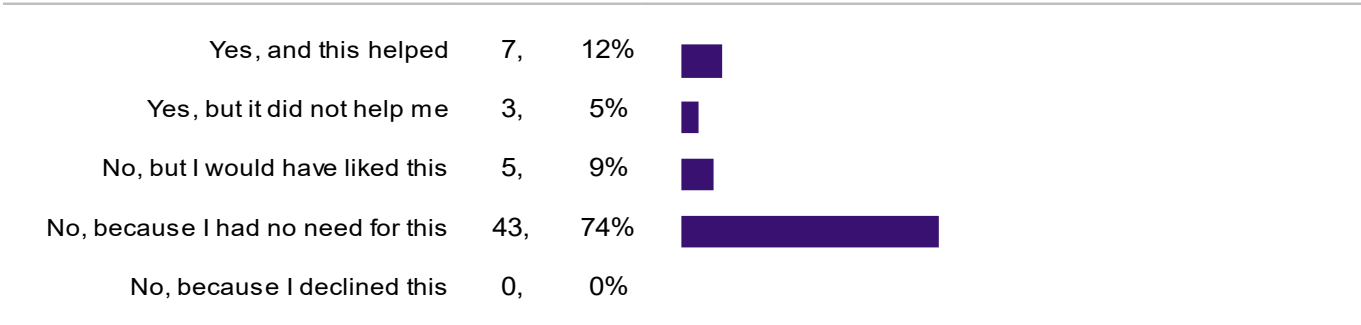
**Q12b\_2: What community therapy or treatment were you offered and did it help your recovery? Hearing changes (audiology).**



Based on 56 responses.

### Orthoptics

**Q12b\_3: What community therapy or treatment were you offered and did it help your recovery? Sight and vision changes (orthoptics).**

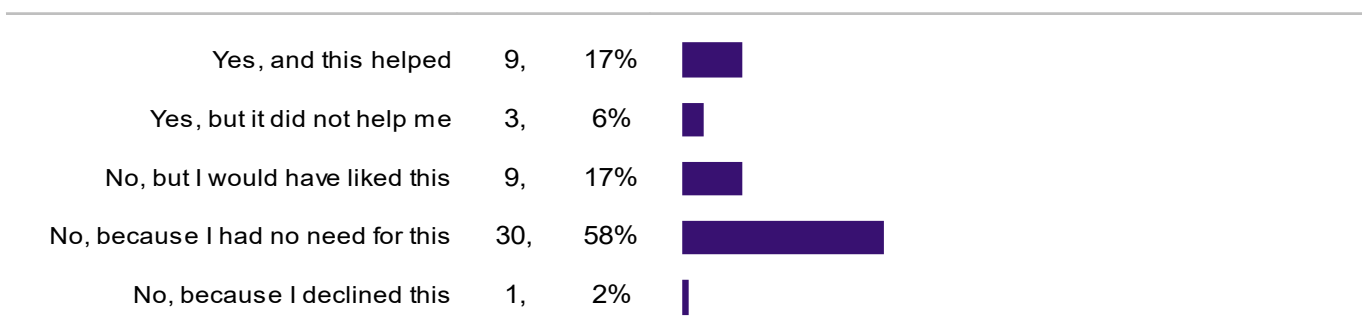


Based on 58 responses.

## Community therapy / treatment - continued

### Psychology, psychiatry and counselling

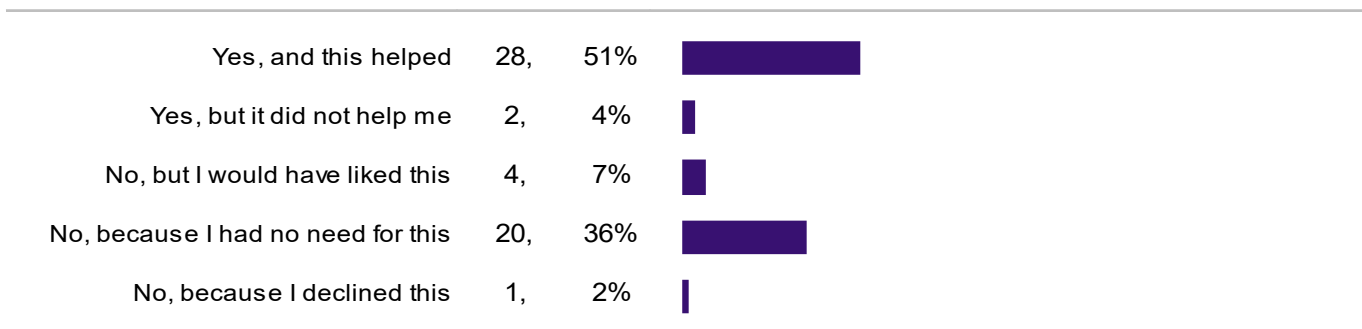
**Q12c\_1: What community therapy or treatment were you offered and did it help your recovery? Emotions, moods, personality and motivation (psychology, psychiatry and counselling).**



Based on 52 responses.

### Medication from a pharmacist

**Q12c\_2: What community therapy or treatment were you offered and did it help your recovery? Pharmacist (medication)**

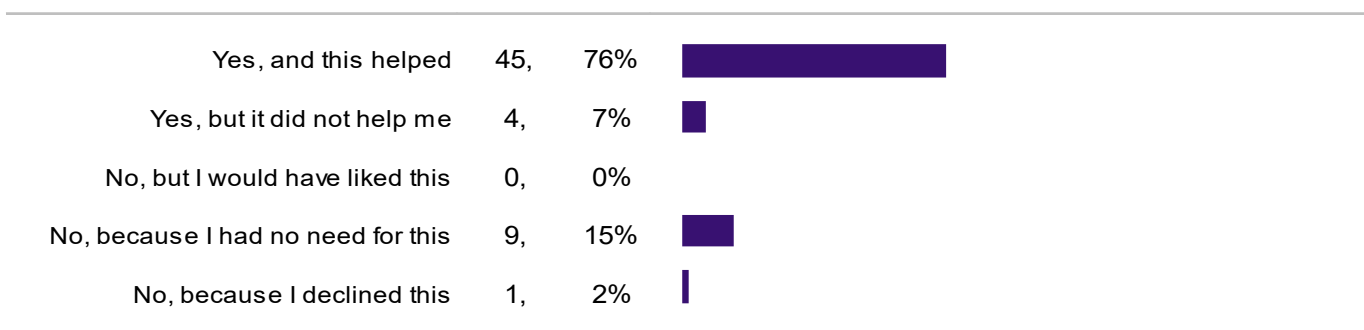


Based on 55 responses.

## Community therapy / treatment - continued

### Stroke Association support workers

**Q12c\_3: What community therapy or treatment were you offered and did it help your recovery? Contact with a Stroke Association Support Worker (this could have been face to face or over the phone).**



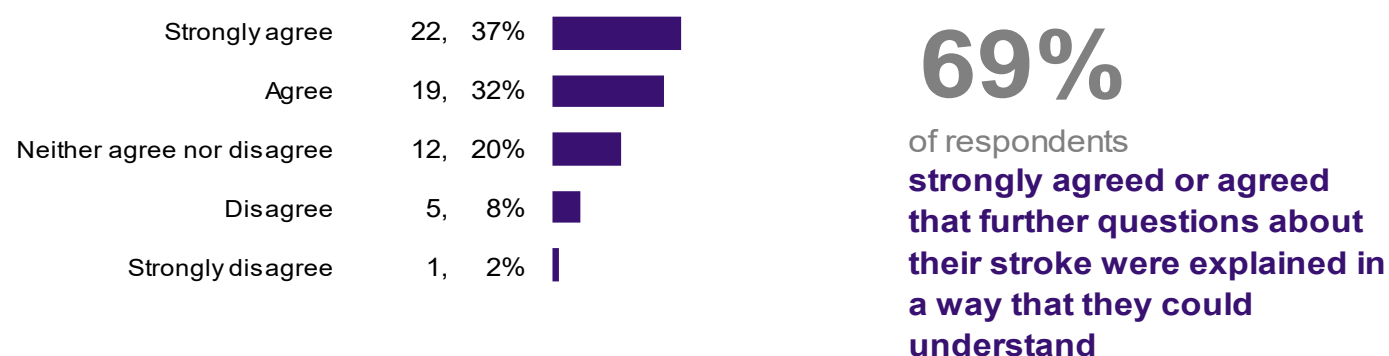
Based on 59 responses.

## Community therapy / treatment - continued

**Question 13: Thinking about your community therapy / treatment, please state how much you agree with the following statements.**

### Further questions about the stroke

**Q13a\_1: Thinking about your community therapy/treatment, please state how much you agree with the following statements: Further questions about my stroke were answered in a way that I could understand.**



Based on 59 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

### Understanding stroke recovery

**Q13a\_2: Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff helped me to understand about stroke recovery.**

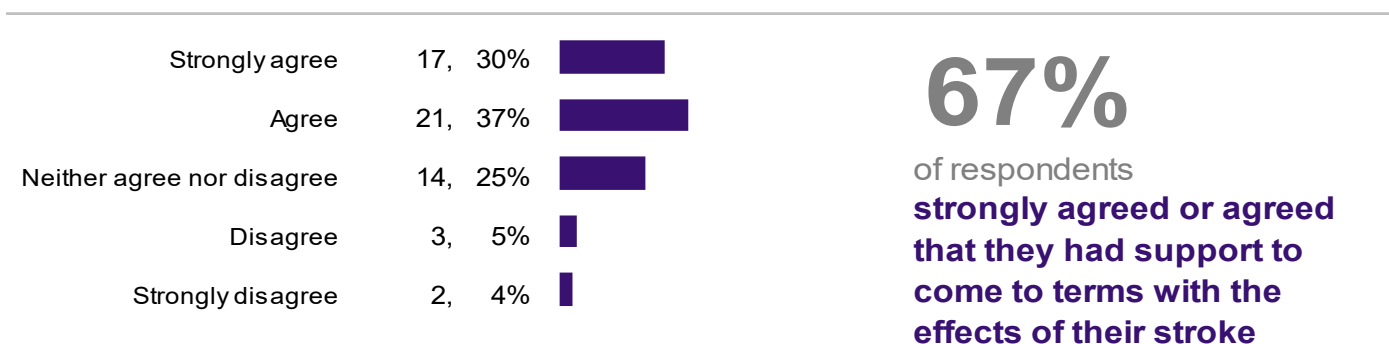


Based on 58 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

## Community therapy / treatment - continued

### Coming to terms with the stroke

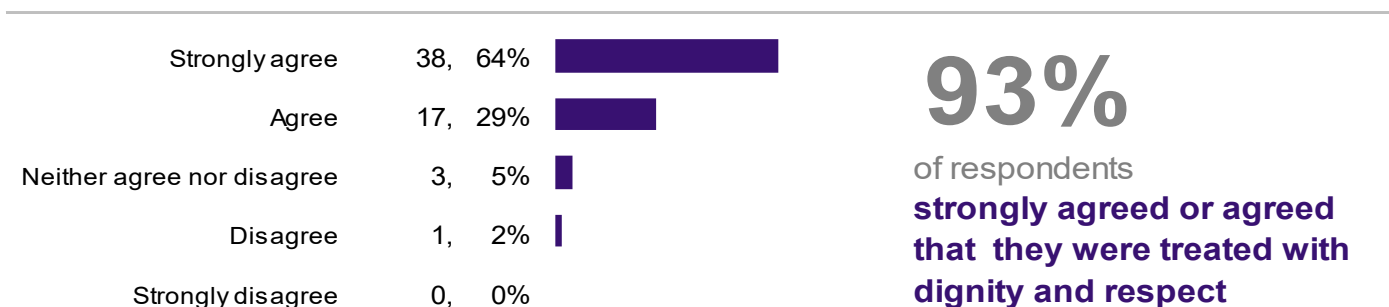
**Q13a\_3: Thinking about your community therapy/treatment, please state how much you agree with the following statements: I had support to come to terms with the effects of my stroke.**



Based on 57 responses. Those answering 'Not sure' (4) excluded from percentage calculations.

### Treated with respect and dignity

**Q13b\_1: Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff treated me with dignity and respect.**



Based on 59 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Community therapy / treatment - continued

### Understanding impact on life

**Q13b\_2: Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff understood how my stroke would affect my life.**



Based on 58 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

### Community therapy and treatment started quickly

**Q13b\_3: Thinking about your community therapy/treatment, please state how much you agree with the following statements: My community therapy and treatment started quickly after I left the stroke ward.**



Based on 58 responses. Those answering 'Not sure' (1) excluded from percentage calculations.



## Community therapy / treatment - continued

### Support to express needs and wants

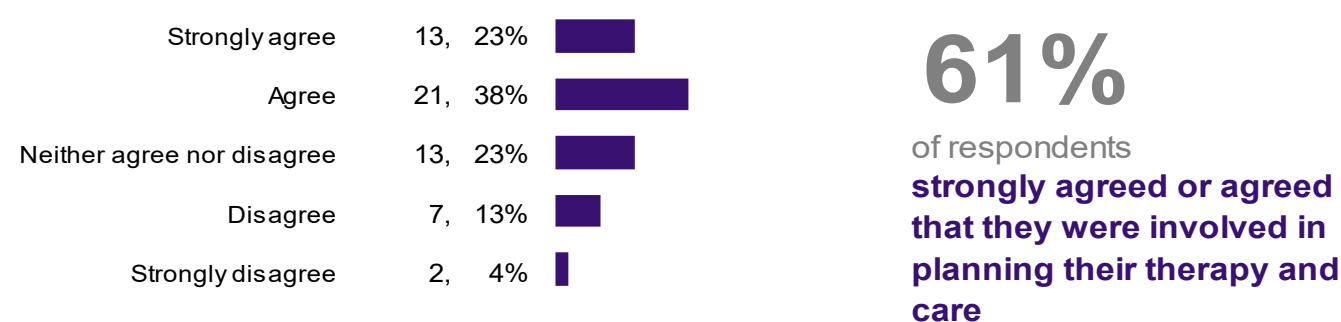
**Q13b\_4: Thinking about your community therapy/treatment, please state how much you agree with the following statements: There was support to express my needs and wants e.g. days and times of therapy to manage fatigue.**



Based on 55 responses. Those answering 'Not sure' (4) excluded from percentage calculations.

### Involvement in planning therapy and care

**Q13c\_1: Thinking about your community therapy/treatment, please state how much you agree with the following statements: I was involved in planning my therapy and care.**



Based on 56 responses. Those answering 'Not sure' (2) excluded from percentage calculations.

## Community therapy / treatment - continued

### Family / carers had the information they needed

**Q13c\_2: Thinking about your community therapy/treatment, please state how much you agree with the following statements: My family / carers were given information about my therapy and how to help me.**



**64%**

of respondents  
**strongly agreed or agreed  
that their family / carers were  
given the information they  
needed**

Based on 58 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

### Further support

**Q13c\_3: Thinking about your community therapy/treatment, please state how much you agree with the following statements: I was told where I could get further support if I needed it.**



**81%**

of respondents  
**strongly agreed or agreed  
that they were told where to  
get further support**

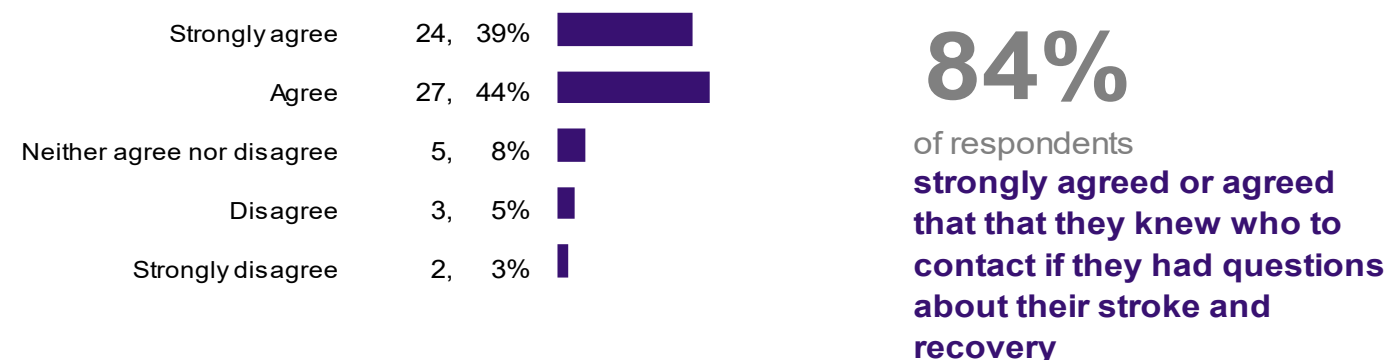
Based on 58 responses. Those answering 'Not sure' (2) excluded from percentage calculations.

## Community therapy / treatment - continued

**Question 14:** Thinking about your community care, please state how much you agree with the following statements.

### Questions about stroke and recovery

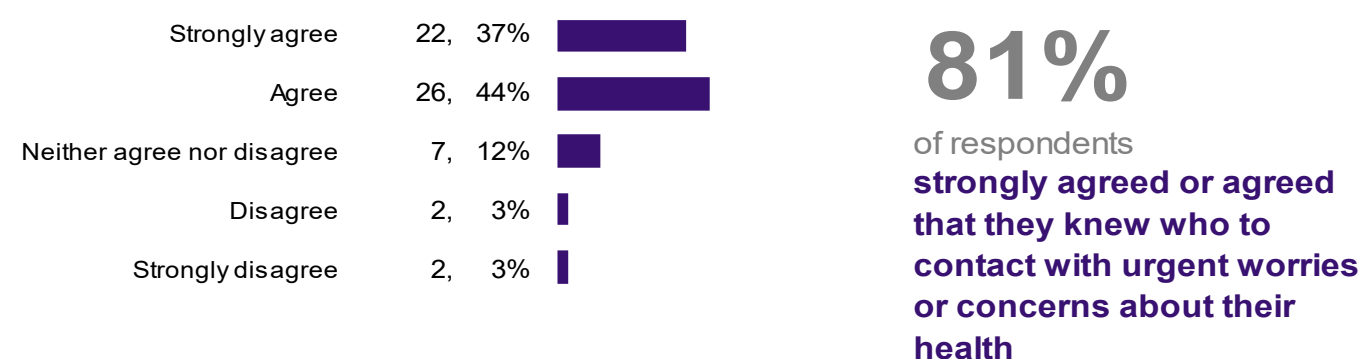
**Q14a\_1:** Thinking about your community care, please state how much you agree with the following statements. I knew who to contact if I wanted to ask questions about my stroke and recovery.



Based on 61 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

### Urgent worries or concerns

**Q14a\_2:** Thinking about your community care, please state how much you agree with the following statements. I knew who to contact if I had urgent worries or concerns about my health.



Based on 59 responses. Those answering 'Not sure' (1) excluded from percentage calculations.

## Community therapy / treatment - continued

### Recovery journey

**Q14a\_3: Thinking about your community care, please state how much you agree with the following statements. I felt ready to continue my recovery journey on my own.**



# 75%

of respondents  
**strongly agreed or agreed  
that they felt ready to  
continue their recovery  
journey on their own**

Based on 57 responses. Those answering 'Not sure' (2) excluded from percentage calculations.

### Return to work

**Q14b\_1: Thinking about your community care, please state how much you agree with the following statements. I felt supported with my return to work.**



# 36%

of respondents  
**strongly agreed or agreed  
that they felt supported with  
their return to work**

Based on 36 responses. Those answering 'Not sure' (5) excluded from percentage calculations.

## Community therapy / treatment - continued

### Returning to hobbies / activities

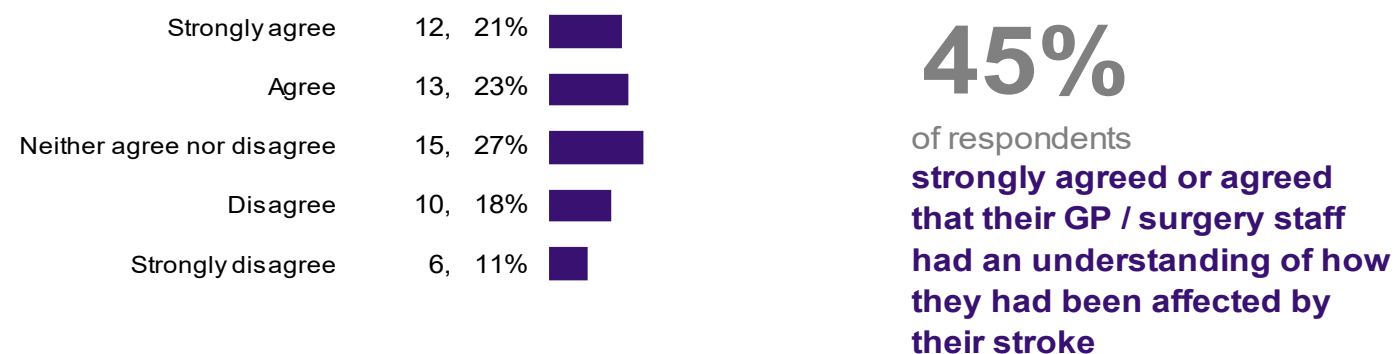
**Q14b\_2: Thinking about your community care, please state how much you agree with the following statements. I felt supported to return to hobbies / activities that matter to me.**



Based on 51 responses. Those answering 'Not sure' (2) excluded from percentage calculations.

### GP / surgery staff's understanding

**Q14b\_3: Thinking about your community care, please state how much you agree with the following statements. I felt my GP / surgery staff had an understanding of how my stroke had affected me.**



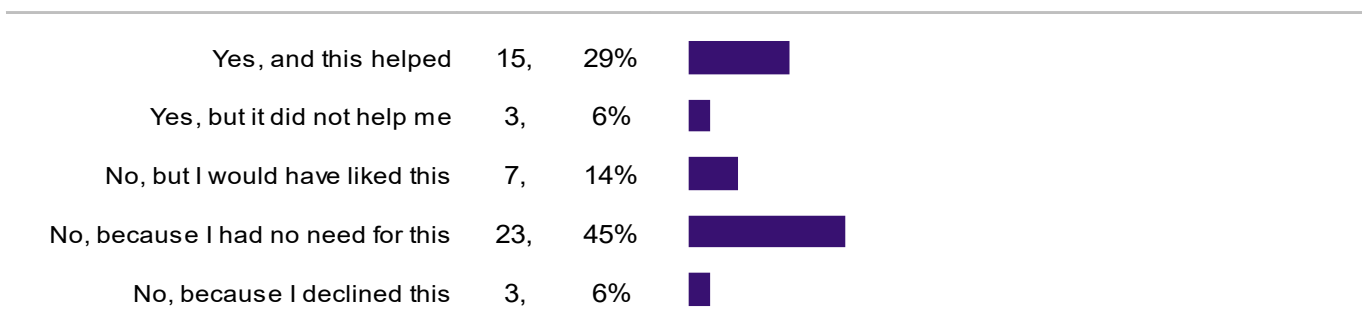
Based on 56 responses. Those answering 'Not sure' (3) excluded from percentage calculations.

## Community therapy / treatment - continued

Question 15: Thinking about your community care, please state how much you agree with the following statements.

### Virtual and / or online appointments

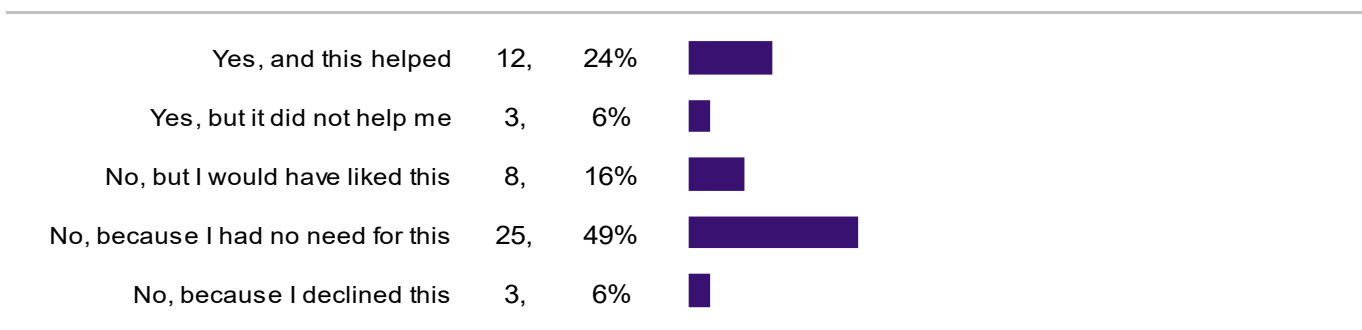
Q015a\_1: Thinking about your community care, please state how much you agree with the following statements. Virtual and / or online appointments.



Based on 51 responses.

### Virtual and / or online therapy

Q15a\_2: Thinking about your community care, please state how much you agree with the following statements. Virtual and / or online therapy.

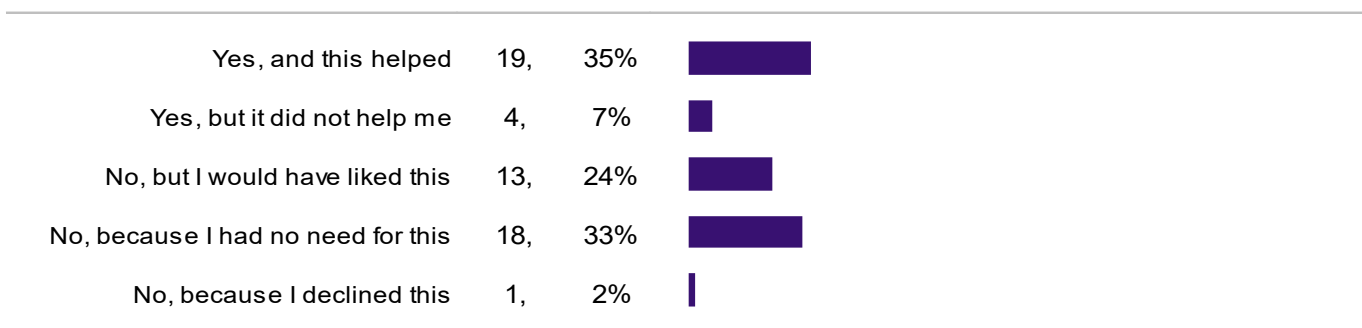


Based on 51 responses.

## Community therapy / treatment - continued

### Advice and support with monitoring blood pressure

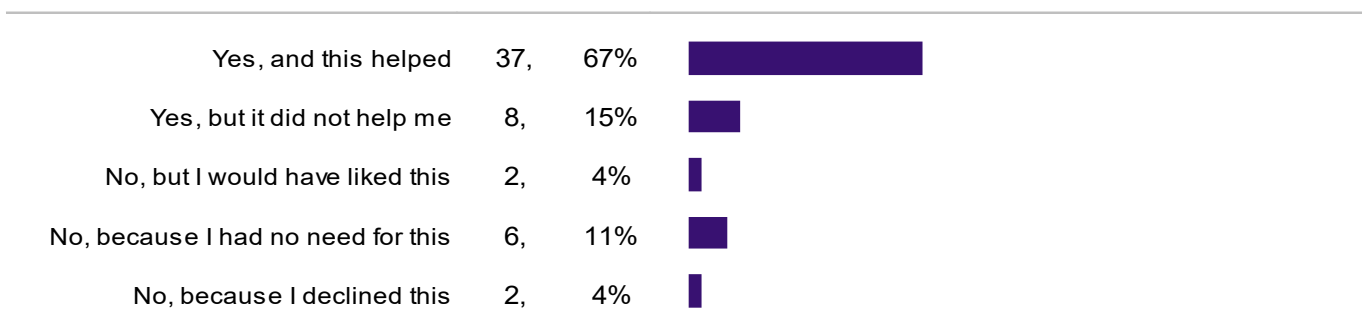
**Q15b\_1: Thinking about your community care, please state how much you agree with the following statements. Advice and support with monitoring my blood pressure independently.**



Based on 55 responses.

### Support from the Stroke Association

**Q15b\_2: Thinking about your community care, please state how much you agree with the following statements. Advice and support with my recovery from the Stroke Association.**

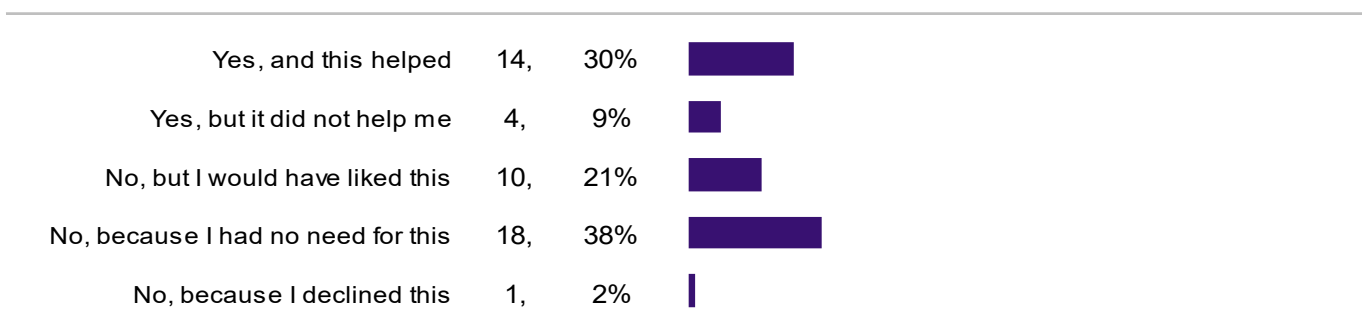


Based on 55 responses.

## Community therapy / treatment - continued

### Non-NHS support

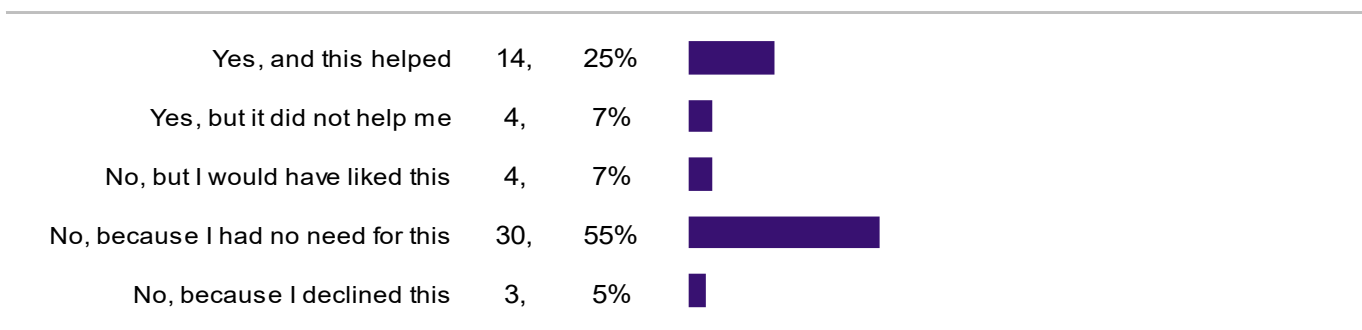
**Q15b\_3: Thinking about your community care, please state how much you agree with the following statements. Advice and support with my recovery from other non-NHS organisations e.g. Headway, local stroke organisations.**



Based on 47 responses.

### Healthy lifestyle programmes

**Q15c\_1: Thinking about your community care, please state how much you agree with the following statements. Programmes to help with healthy lifestyle e.g. help with stopping smoking, healthy diet or exercise.**



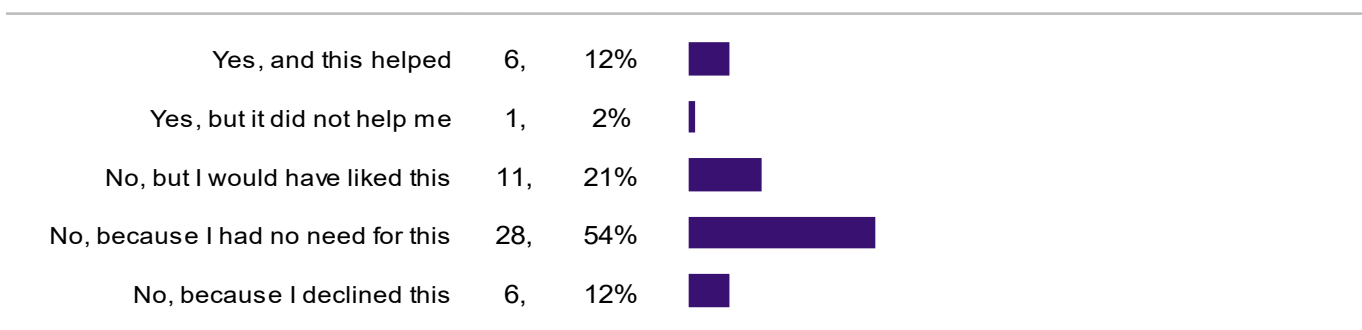
Based on 55 responses.



## Community therapy / treatment - continued

### The opportunity to talk with other stroke survivors

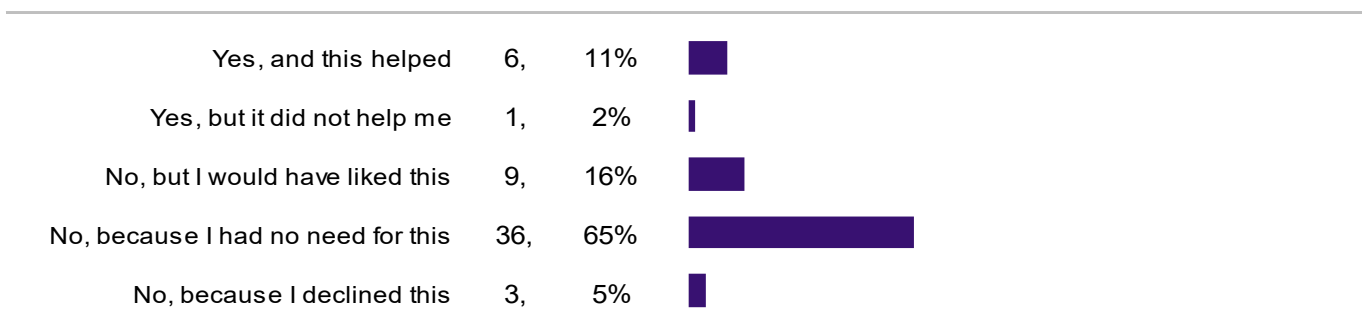
**Q15c\_2: Thinking about your community care, please state how much you agree with the following statements. The opportunity to talk with other stroke survivors (this could have been face to face, over the phone or online).**



Based on 52 responses.

### Advice and support from other organisations

**Q15c\_3: Thinking about your community care, please state how much you agree with the following statements. Advice and support with benefits / financial worries from other organisations e.g. Citizens Advice, Job Centre.**



Based on 55 responses.





**Please note that Q16 is a free text response and is not included in this report.**

## At a glance - community based care

This stacked chart shows those questions where a binary scoring has been undertaken, showing them in questionnaire order. It shows the 'positive score' by combining the responses 'Strongly agree' and 'Agree'.

Question	Base	Score	
Q13a_1. Thinking about your community therapy/treatment, please state how much you agree with the following statements: Further questions about my stroke were answered in a way that I could understand.	59	69%	
Q13a_2. Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff helped me to understand about stroke recovery.	58	72%	
Q13a_3. Thinking about your community therapy/treatment, please state how much you agree with the following statements: I had support to come to terms with the effects of my stroke.	57	67%	
Q13b_1. Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff treated me with dignity and respect.	59	93%	
Q13b_2. Thinking about your community therapy/treatment, please state how much you agree with the following statements: The staff understood how my stroke would affect my life.	58	78%	
Q13b_3. Thinking about your community therapy/treatment, please state how much you agree with the following statements: My community therapy and treatment started quickly after I left the stroke ward.	58	67%	
Q13b_4. Thinking about your community therapy/treatment, please state how much you agree with the following statements: There was support to express my needs and wants e.g. days and times of therapy to manage fatigue.	55	62%	
Q13c_1. Thinking about your community therapy/treatment, please state how much you agree with the following statements: I was involved in planning my therapy and care.	56	61%	
Q13c_2. Thinking about your community therapy/treatment, please state how much you agree with the following statements: My family / carers were given information about my therapy and how to help me.	58	64%	
Q13c_3. Thinking about your community therapy/treatment, please state how much you agree with the following statements: I was told where I could get further support if I needed it.	58	81%	
Q14a_1. Thinking about your community care, please state how much you agree with the following statements: I knew who to contact if I wanted to ask questions about my stroke and recovery.	61	84%	
Q14a_2. Thinking about your community care, please state how much you agree with the following statements: I knew who to contact if I had urgent worries or concerns about my health.	59	81%	

## At a glance - community based care - continued

Question	Base	Score	
Q14a_3. Thinking about your community care, please state how much you agree with the following statements: I felt ready to continue my recovery journey on my own.	57	75%	
Q14b_1. Thinking about your community care, please state how much you agree with the following statements: I felt supported with my return to work.	36	36%	
Q14b_2. Thinking about your community care, please state how much you agree with the following statements: I felt supported to return to hobbies / activities that matter to me.	51	53%	
Q14b_3. Thinking about your community care, please state how much you agree with the following statements: I felt my GP / surgery staff had an understanding of how my stroke had affected me.	56	45%	

## 6 Month Review Appointment

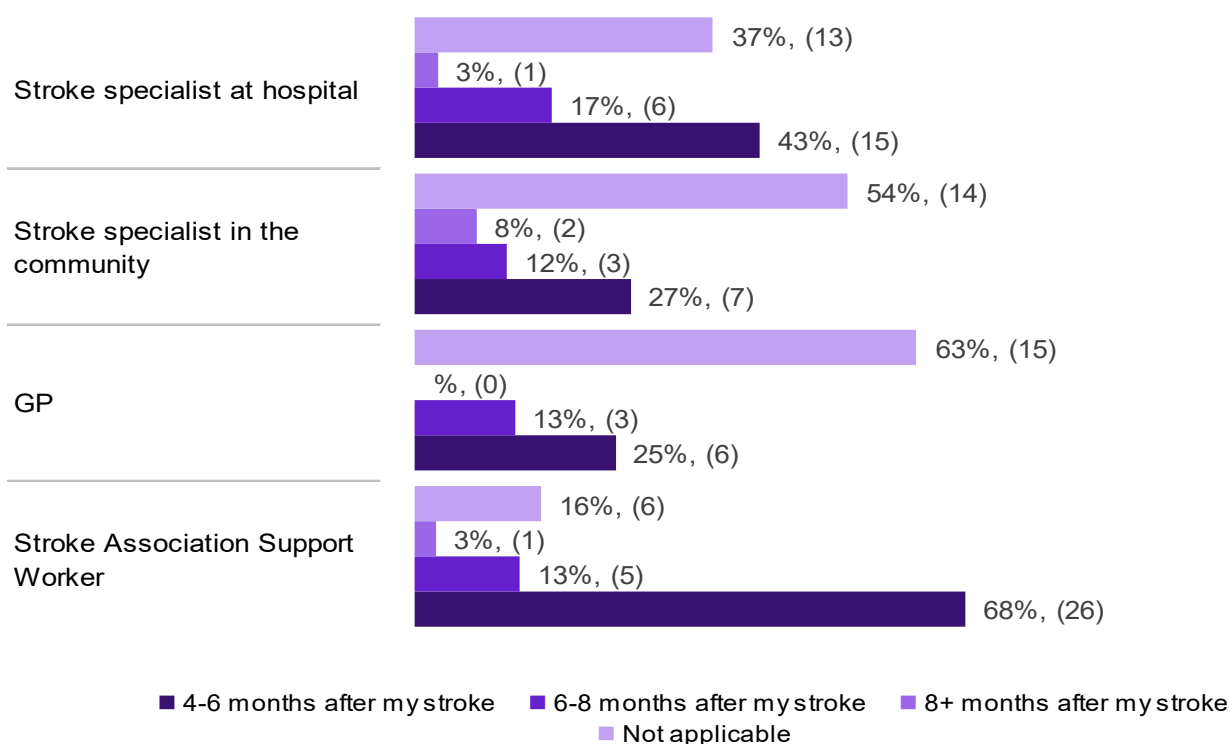
These sections of the report contain the responses to questions 17 and 18 about a 6 month review appointment.

## 6 month review appointment (Q17 - Q18)

### Were you offered a 6 month review appointment?

**Question 17: Were you offered a review appointment 6 months after your stroke? Please tell us who this was with and when it happened.**

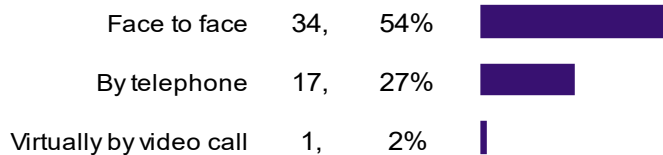
Respondents were asked whether they were offered a review appointment 6 months after their stroke, and to say when the appointment happened and who it was with.



## 6 month review appointment - continued

### How did your 6 month review appointment occur?

Question 18: If you had a six month review following your stroke, how did it happen?



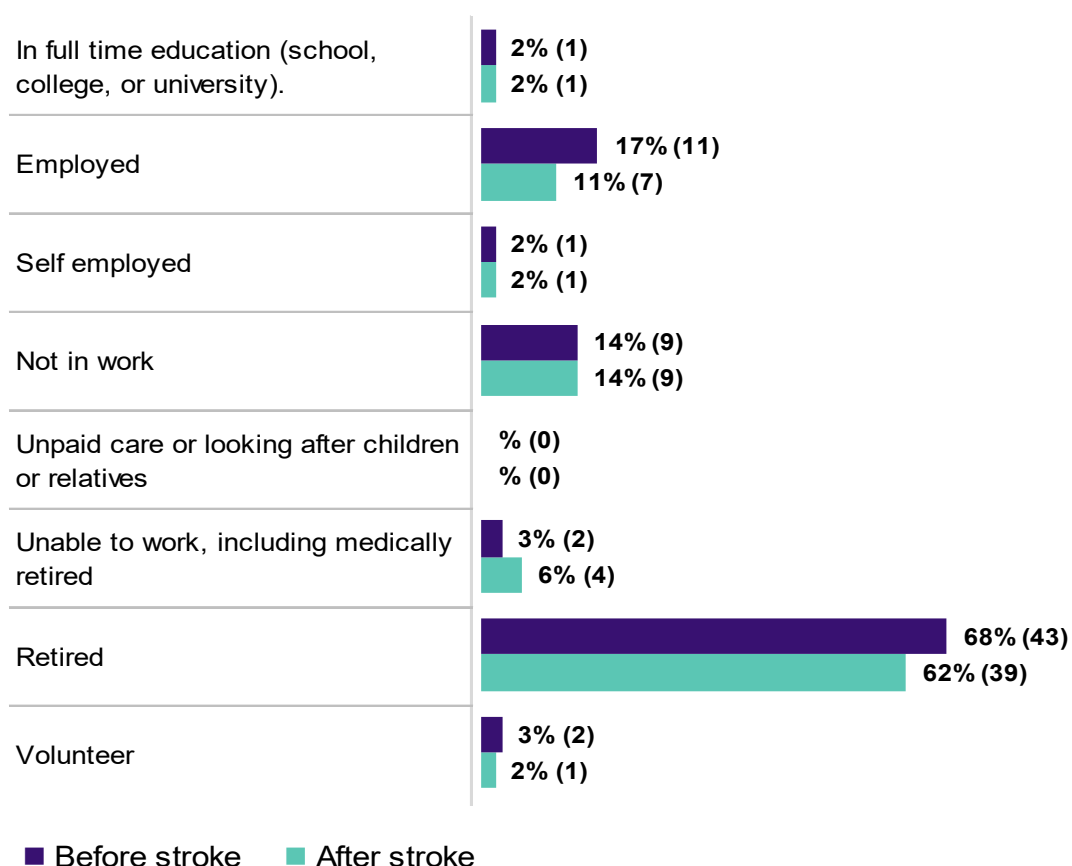
Based on 52 responses.

## Education and Employment

This section of the report contains the responses to questions 19 to 20 about employment status before and after the stroke. Those who were employed before their stroke were asked further questions about the available support to return to work.

## Education and employment (Q19 - Q20)

**Question 19: What was your employment / education status before and after your stroke? Tick all that apply.**





## Education and employment - continued

**Question 20: Please state how much you agree with the following statements.**

Question 20 was asked to respondents who were employed or self-employed before their stroke.

### Returning to work is important

**Q20a\_1: Please state how much you agree with the following statements. Returning to work is / was important to me.**

---

Strongly agree	6,	55%	<div></div>
Agree	2,	18%	<div></div>
Neither agree nor disagree	1,	9%	<div></div>
Disagree	0,	0%	
Strongly disagree	2,	18%	<div></div>

---

Based on 11 responses. Those answering 'Not sure' (0) excluded from percentage calculations.

### Employer is supportive

**Q20a\_2: Please state how much you agree with the following statements. I feel that my employer is supportive and understanding of my stroke.**

---

Strongly agree	*	*
Agree	*	*
Neither agree nor disagree	*	*
Disagree	*	*
Strongly disagree	*	*

---

The base size for this question is less than 11, results have been suppressed.

## Education and employment - continued

### Career development

**Q20a\_3: Please state how much you agree with the following statements. I feel that I still have opportunities to develop my career after my stroke.**

Strongly agree	*	*
Agree	*	*
Neither agree nor disagree	*	*
Disagree	*	*
Strongly disagree	*	*

The base size for this question is less than 11, results have been suppressed.

### Support from therapy team / GP

**Q20b\_1: Please state how much you agree with the following statements. My therapy team / GP provided support with my return to work.**

Strongly agree	*	*	 <p>of respondents strongly agreed or agreed that their therapy team / GP provided support with their return to work</p>
Agree	*	*	
Neither agree nor disagree	*	*	
Disagree	*	*	
Strongly disagree	*	*	

The base size for this question is less than 11, results have been suppressed.

## Education and employment - continued

### Support from the Stroke Association


**Q20b\_2: Please state how much you agree with the following statements. The Stroke Association provided support with my return to work.**

Strongly agree	*	*	 of respondents <b>strongly agreed or agreed that the Stroke Association provided support with their return to work</b>
Agree	*	*	
Neither agree nor disagree	*	*	
Disagree	*	*	
Strongly disagree	*	*	

The base size for this question is less than 11, results have been suppressed.

### Support with return to work

**Q20b\_3: Please state how much you agree with the following statements. Other organisations provided support with my return to work e.g. local Council schemes.**

Strongly agree	*	*	 of respondents <b>strongly agreed or agreed that other organisations provided support with return to work</b>
Agree	*	*	
Neither agree nor disagree	*	*	
Disagree	*	*	
Strongly disagree	*	*	

The base size for this question is less than 11, results have been suppressed.

**Please note that Q21 is a free text response and is not included in this report.**

## Appendix

This section of the report contains the technical details relating to the report.

# Appendix 1: Technical details

## Sampling and eligibility

Participating Trusts supplied a list of eligible patients from their patient administration system (PAS).

### The list included:

- All adult patients with a confirmed primary diagnosis of stroke, specified by an ICD-10 code of I60, I61, I62, I63, I64 in the first diagnosis field of their PAS record\*. Note that this includes all sub-categories of these codes, with the exception of those listed in the exclusions list further down.
- Admitted patients: that is, inpatients and day cases with admission dates between 16th May 2022 and 16th September 2022.
- Patients aged 18 and over on the date they were admitted.
- Inpatient episodes or day case attendances where the patient was being seen in relation to / for treatment of their stroke diagnosis.

### The list excluded:

- Those with an ICD10 10th Edition code of 165 and 166, 167, 168, 169 and G46.3 and G46.4.
- Deceased patients.
- Non-stroke patients and non-confirmed stroke patients including patients who have been given a holding diagnosis code pending results.
- Any inpatient admissions / day case attendances which were **NOT** in relation to the patient's stroke.
- Patients known to be current inpatients.
- Children or young persons aged under 18 years at the time of admission.
- Private patients (non-NHS).
- Patients without a UK postal address, incomplete addresses or unusable addresses.
- Any patient known to have requested through the National Data Opt Out process that their details are not used for any purpose other than their clinical care.
- Any patient known to have requested that their details are not used for any purpose other than their clinical care if this information is collected by their Trust.
- Any patient who has informed their Trust, in response to communications about this survey during the dissent period, that they do not wish to be included in the survey.

\*Following feedback from clinicians during the sampling process the decision was made to remove patients with codes I60 and I62 and their sub-codes from the sample before questionnaires were sent out.

A declaration of the correctness of the sample was signed by the data lead from the Trust and the sample received was thoroughly checked by Quality Health. In the 24 hours before the questionnaires were sent out, Quality Health undertook a check for deceased patients using the Demographic Batch Service (DBS).

# Appendix 1: Technical details - continued

### Data fields provided

The personal data requested about each patient was minimised so as to only include the fields necessary for carrying out the research. Each Trust was asked to supply the following data fields.

For the purposes of determining eligibility, de-duplicating records, removing deceased patients and posting out the questionnaires:

- Name
- Address including postcode
- Date of hospital admission and discharge
- ICD-10 code
- NHS Number
- Date of Birth

Information for analysis of survey results:

- Age (derived from date of birth)
- Ethnicity
- Gender
- Treating NHS Trust at point of admission
- Commissioner Code (to determine the ICS where rehab treatment was received).

### De-duplication of sample

It was recognised that a patient may have been admitted more than once for Stroke treatment during the sampling timeframe and may have been seen at different hospitals or Trusts.

The samples were checked for duplicate records using the NHS number and name fields. This was carried out firstly within each Trust's sample file and then across all sample files nationally. The record for the most recent admission was retained.

### Questionnaire development

As this was the first survey of its kind for stroke survivors, the project team took examples of questions used for other national patient experience surveys as a starting point for questionnaire development. The Stroke Association ran Patient Involvement groups with volunteers between 6 months and 6 years post-stroke with varying stroke effects, to ensure the patient voice was prominent throughout.

The project team reviewed the draft questionnaire resulting from the patient involvement discussions and once the content was broadly agreed, the questionnaire was cognitively tested with a separate group of volunteers, who reported that the survey was easy to follow and understand and covered all aspects of their care.

Due to the pilot nature of the survey, along with resource limitations, not all questionnaire suggestions could be implemented at this time, but it is intended that a review will be undertaken at the end of the pilot and improvements will be made before any roll out to an annual programme.

## Appendix 1: Technical details - continued

### Analysis variables

Variables were derived and grouped as follows:

- Any patient who has informed their Trust, in response to communications about this survey during the dissent period, that they do not wish to be included in the survey.
- Role in survey derived from Q1 in the questionnaire. Two groups: Stroke survivor; Carer or friend or family member of a stroke survivor.
- Number of strokes derived from Q2 in the questionnaire. Three groups: No more than one stroke; Two strokes; More than two strokes.
- Time since most recent stroke derived from Q3 in the questionnaire. Four groups: Less than 4 months ago; 4 – 6 months ago; 7 – 8 months ago; More than 8 months ago.
- Type of stroke derived from Q4 in the questionnaire. Two groups: Stroke caused by a blockage, referred to as ischaemic stroke; Stroke caused by a bleed, referred to as a haemorrhagic stroke.
- Effect of stroke on daily life derived from Q5 in the questionnaire. Four groups: A lot; Quite a lot; A little; Not at all.
- Age derived from Q22 in the questionnaire and grouped into five age bands: < 60 years; 60 – 69 years; 70 – 79 years; 80 – 89 years; 90+ years.
- Gender derived from Q23 in the questionnaire. Five groups: Male; Female; Non – binary; Prefer to self – describe; Prefer not to say.
- Ethnicity derived from Q25 in the questionnaire where respondents indicate which ethnic group they belong to. Grouped into six ethnicity bands: White; Mixed / Multiple ethnic background; Asian / Asian British; Black / African / Caribbean / Black British; Any other ethnic group including Arab; Prefer not to say.
- Sexuality derived from Q26 in the questionnaire. Five groups: Heterosexual or straight; Gay or lesbian; Bisexual; Other; Prefer not to say.
- Deprivation in the form of IMD quintiles derived from the patient's postcode of residence. With 1 being the most deprived and 5 being the least deprived.