North Durham Clinical Commissioning Group
Durham Dales, Easington and Sedgefield Clinical Commissioning Group
Darlington Clinical Commissioning Group

PHASE 2

Acute and Community Stroke Rehabilitation Service Review - Patient Engagement

May and June 2019

Tina Balbach, Engagement Lead

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Introduction

Any successful service change benefits from a period of sustained engagement with members of the public, patients, carers and stakeholders. Indeed one of the four key tests of any proposed service change is to ensure robust patient and public engagement has taken place.

It is really important for the CCGs to understand people's experiences of stroke rehabilitation across County Durham and Darlington. The CCGs want to understand what currently works well and what could be improved, especially with regards to rehabilitation from a patient and carer perspective.

It is extremely valuable to receive views on what is important to the local population, as the CCGs can use this information alongside clinical opinion to determine how future service provision may be commissioned. By engaging with those who have used services, the CCGs can begin to understand how the decisions they make have an impact on those using the services.

At this stage of the review the engagement needs to focus on people's experiences of services at the University Hospital of North Durham (UHND) Bishop Auckland Hospital (BAH) (if applicable) and within the community. Once we understand any future options for the service model we will undertake a consultation exercise which will be open to members of the public. During this time we will outline the current service and the proposal for future stroke rehabilitation services and seek their views on this.

The following report details the feedback received within phase one (as an executive summary) and phase two of the engagement process; highlighting key themes. This information will be used to inform the overall decision making process regarding future provision for stroke rehabilitation across County Durham and Darlington.

Executive summary

The information below is a summary of phase one and phase two of engagement.

Phase one

During November and December 2018, across County Durham and Darlington, a period of eight weeks of engagement was undertaken by North Durham (ND), Durham Dales, Easington & Sedgefield (DDES) and Darlington Clinical Commissioning groups (CCGs) with past and current service users, families and local stakeholders to gather views about stroke rehabilitation services.

A range of engagement activities were carried out which included an online survey, local focus groups, service user engagement meetings and targeted engagement with groups with protected characteristics.

Key points emerging from the online survey are;

- Over 67% (67.24%) of people who responded to the survey were patients, 25% were a family member/carer and 8% were 'other', which incorporated a partner, nurse and a stroke survivor
- Most respondents (20.88%) were at University Hospital of North Durham for one to two days
- Nearly 58% (57.95%) of patients felt that they were discharged from University Hospital of North Durham at the right time
- Over 41% (41.38%) of patients felt they or their carer / family member were involved as much as they wanted to be in their discharge, whereas the same amount (41%) felt they were not involved as much as they wanted to be
- The majority of patients (55.29%) felt they did not receive enough information in relation to the Community Stroke Rehabilitation Service before they were discharged from University Hospital of North Durham
- Three quarters of patients (77.38%) were transferred to Bishop Auckland Hospital following their stay at University Hospital of North Durham.

  The more negative comments included:
    - being on their own after discharge
    - the lack of information given
    - didn't receive any community service once left Bishop, you are on your own

- When asked about what could be improved, respondents said:
    - counselling should be offered at the end of the treatment,
    - more blocks of speech and language therapy are needed
    - giving out consistent information
    - More information in general around coping after stroke

- When asked about if they had any further comments on their experience of the service, respondents said:
    - “Amazing, if I didn't have this service I wouldn't be where I am”
    - “Excellent. I didn't need therapy as I had a small TIA which didn't affect my speech, movements or cognitive functions”
    - “In the hospital I was left to my own devices, as it was only a mini stroke, they didn't seem to bothered, stroke team contact was weeks and weeks apart with regards to visits to the house or a phone call every three weeks”
    - “The therapies team are amazing and fantastic. I wish there was a service - something to go to after the therapy has finished”

- The majority of patients (73.96%) said that they received continuity of care – seem mostly but the same team of therapists

Key points emerging from the qualitative feedback are in relation to;

- Communication challenges
- Emotional wellbeing and support
- Inconsistency of community rehabilitation provision
- People would appreciate a longer period of therapy once discharged from a hospital setting

Phase two

During May, June and July 2019, across County Durham and Darlington, a period of seven weeks of engagement was undertaken by CCGs with current service users, carers and families to gather views about their experiences and stroke rehabilitation services. This was done to further enhance the information already collected and to ensure that we targeted particularly those who had recently suffered a stroke to understand their experiences.

On behalf of the CCGs, the Stroke Association sent a letter with an accompanying survey to over 150 individuals within County Durham and 45 in Darlington who had been offered a six month review. The survey was also available online through a SurveyMonkey link. The letter also detailed contact details for patients / carers who needed support with completing the survey.

A summary of the key points emerging from the online survey are;

Over 76% of patients or family were involved in setting their treatment goals

79 people shared their views

Letters were sent to over 190 current patients of the Stoke Association

79% of patients told us they were involved as much as they wanted to be in their discharge plan

72% of respondents said that they received continuity of care

- Nearly eighty (79) people completed the survey with the majority 94% (73) being patients and 6% (5) being a family member or carer
- When asked if they had any other comments on their experience of the service at UHND over 37 patients / carers responded:

  Positive
    - "They were very caring and friendly"
    - "I was treated with gentle care and respect even when I fell behind the toilet door. The understanding even extended over the nights."
    - "I received the best of care by courteous professional staff, I can't commend them highly enough"
    - I have nothing but praise for ward 2 stroke ward"
    - "Exceptionally well cared for".
    - I hope the stroke unit continues to be ay UHND as it is easily accessed by public transport to all the outlying areas which makes visiting and follow up appointments much easier if only one bus is required".

  Negative
    - "Rushed to move on"
    - "lacked any rehab, next steps were not discussed"
    - "No therapy, sat for 2 hours waiting to go home because a nurse on duty didn't give me the paperwork"

- “I am still waiting for the therapy, both speech and physical it would be better if someone gave you a clue on what to do on the physical instead of leaving you to wait”
- “
- “I saw a physiotherapist once whilst I was in hospital. No speech therapy or explanation or other support groups”.

Key points emerging from the qualitative feedback are in relation to;

- Good care and compassion of staff
- Communication challenges
- Information
- Inconsistency of community rehabilitation provision
- Timespan of therapy
- Emotional wellbeing and support

Purpose of engagement (phase two)

Phase two of the engagement took place between May and June 2019. This engagement was in addition to the 2018 work carried out to hear views from patients/carers and families around their experience following a stroke. The 2019 engagement focused more on those patients who had experienced a stroke more recently i.e. in the past year.

Engagement methodology (phase two)

The engagement work was carried out in conjunction with the Stroke Association who were instrumental in pulling together patient details.

CCGs commission the Stroke Association to deliver six month reviews to patients who have suffered a stroke. As a result they have a wealth of information regarding patients who have recently had experience of stroke services in County Durham. They also deliver the stroke recovery service in Darlington which again gives them the advantage of having access to a rich source of data.

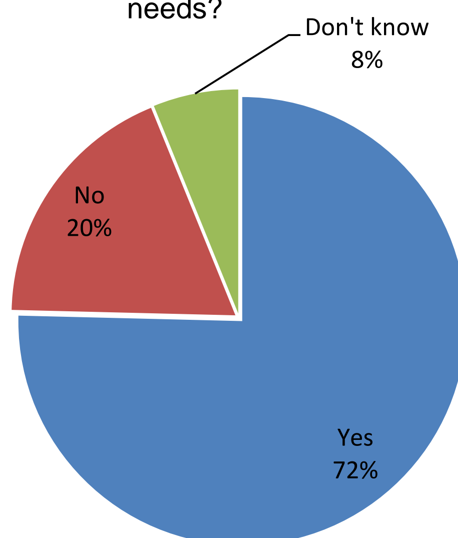
The Stroke Association sent out a letter and questionnaire with an offer of support for people for people who needed it to complete the questionnaire.

The questionnaire focused on their experience during the hospital stay in the acute ward at UHND it also focused on peoples discharge in terms of the destination and their level of care following their inpatient stay. This included those people who were cared for at Bishop Auckland Hospital as part of their pathway as well as those who went straight home from UHND. There was a specific focus on the level of therapy input as well as being involved in care planning and self-care to manage their condition. The engagement exercise also offered the opportunity for people to outline any other feedback as part of their experience.

Phase 2 engagement findings – May / June 2019

University Hospital of North Durham experience

- ***Discharge planning*** - over 79% (62) of patients/family member/carer were involved as much as they wanted in planning their discharge from the University Hospital of North Durham (UHND). Whereas 15% (12) said they were not as involved as they wanted to be and 5% (4) saying they didn't know.
- ***Discharge destination*** - On discharge from UHND the majority of patients 64% (49) patients went home, 33% (25) went to Bishop Auckland Hospital and 3% (2) went to intermediate care eg: a community hospital / residential home or another service.
- ***Therapy input -*** when asked if they received enough therapy to meet their needs at UHND, 72% (54) said yes they had, 20% (15) said no they hadn't and 8% (6) said they didn't know.



- ***Other comments re: UHND -*** When asked if they had any other comments on their experience of the service at UHND over forty (41) patients / carers responded:

  Positive
  - "They were very caring and friendly"
  - "I was treated with gentle care and respect even when I fell behind the toilet door. The understanding even extended over the nights."
  - "I received the best of care by courteous professional staff, I can't commend them highly enough"
  - I have nothing but praise for ward 2 stroke ward"
  - "Exceptionally well cared for".

- I hope the stroke unit continues to be ay UHND as it is easily accessed by public transport to all the outlying areas which makes visiting and follow up appointments much easier if only one bus is required”.

Negative
- “Rushed to move on”
- “lacked any rehab, next steps were not discussed”
- “No therapy, sat for 2 hours waiting to go home because a nurse on duty didn’t give me the paperwork”
- “I am still waiting for the therapy, both speech and physical it would be better if someone gave you a clue on what to do on the physical instead of leaving you to wait”
- “I saw a physiotherapist once whilst I was in hospital. No speech therapy or explanation or other support groups”.

Bishop Auckland experience

For those people who were discharged to Bishop Auckland Hospital, we asked they received enough therapy to meet their needs, 35 people responded and the majority, 21 people said yes. Others gave their views detailed below:

Other comments re: Bishop Auckland Hospital (BAH) - When asked if they had any other comments on their experience of the service at BAH people commented:

“I was well looked after in both Durham and Bishop Auckland on both occasions and the help has helped me to remain positive”.

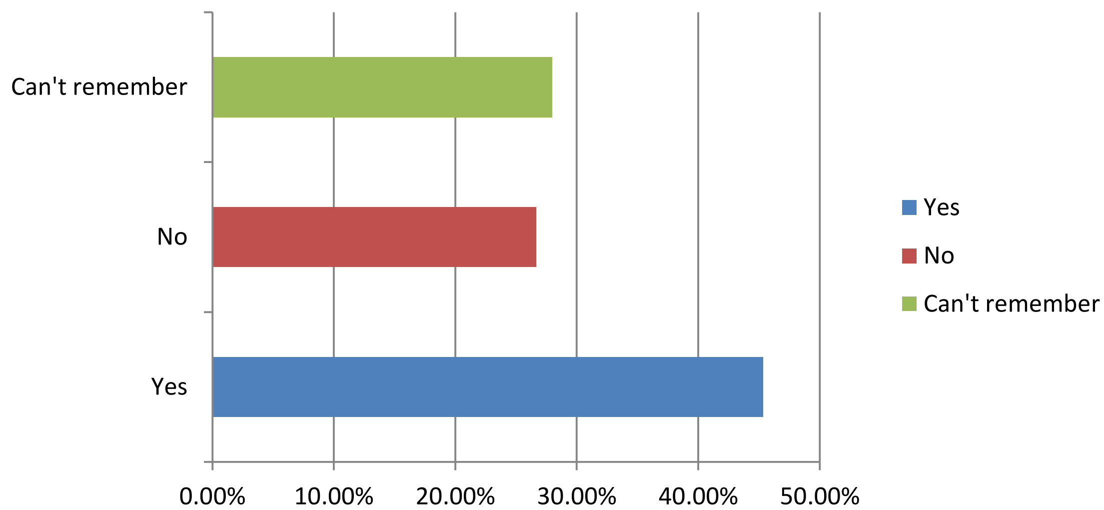
“I received a lot more (therapy) at Bishop Auckland than at UHND”.

“I was able and encouraged in use of equipment (parallel bars, stairs and traffic crossing)”.

“Excellent therapy at Bishop Auckland”.

Community Stroke Rehabilitation Team

- Out of the 75 respondents, over 45% (34) said that they were contacted by a member of the Community Stroke Rehabilitation team within 24 hours of their discharge from hospital. Whereas 27% (20) said they were not and 28% (21) said they couldn’t remember.

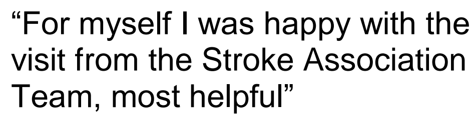


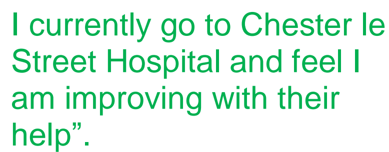
- When asked if members of the Community Stroke Team arrived as planned for visits over 83% (60) respondents stated always, 7% (5) saying usually or rarely and 10% (7) don’t know or other.

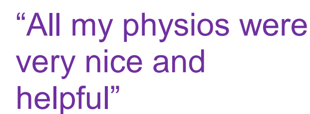
- Out of the 69 respondents, almost three quarters of patients / carers / family 72% (50) said that they received continuity of care eg: seen mostly by the same team of therapists. 13% (9) said no they hadn’t and 14% (9) said they didn’t know.

Comments received included:

Positive





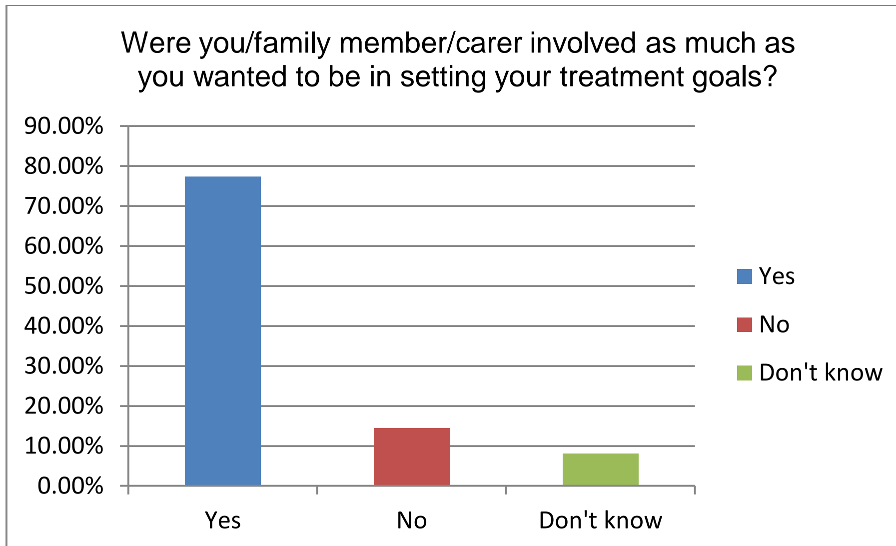


Areas of improvement:

- “It was about four months before I received help from a very good speech therapist after returning home from Bishop Auckland Hospital”.
- “I think I should have been referred to physio. I did a self-referral”
- “Only had one visit”
- “Need more rehab”
- “The quickness of therapy (still waiting)”
- “general attitude of some nurses would be a great help”
- “A better understanding after discharge of what the rehab programme is and the goals that are trying to be achieved within a certain timeframe”.

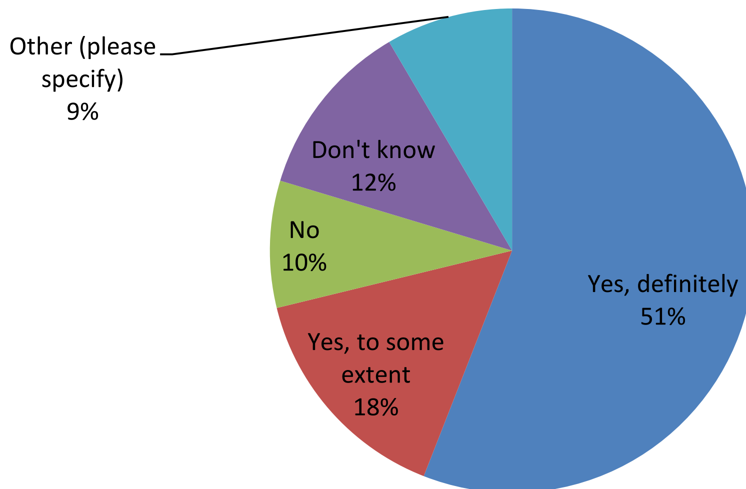
Care planning

- Nearly 77% (52) of respondents said that they felt involved as much as they wanted to be in setting their treatment goals. Fourteen per cent (10) said no and 9% (6) said they didn't know.



- When asked about whether respondents felt that they received enough therapy/rehabilitation to meet their needs over 67% (47) said yes they had, 20% (14) said no they hadn't and 13% (9) said they didn't know.
- Almost half of respondents 46% (32) said that they felt supported in managing their condition, 41% (28) said that they did to some extent and 7% (5) said no and 6% (4) said they didn't know.
- Out of 68 responses, over half of respondents 51% (35) said that they found it beneficial to receive their therapy at home and 18% (12) said yes to some extent. Over 10% (7) said no, they did not and 12% (8) said they didn't know and of the 9% (6) who stated other gave reasons such as did not need therapy at home and having therapy at a centre.

Did you find it beneficial to receive your therapy at home?



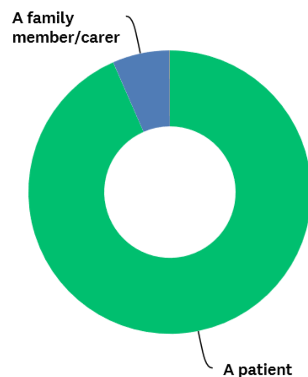
When asked if there was anything we could improve on, 41 people responded with a range of suggestions such as:

- Improved communication with patient and family members especially if there are other health conditions
- Training and supervision of staff
- Patients felt they were well looked after
- Getting more rehabilitation
- Quicker therapy
- More information required from staff

Demographics

Detailed below are the demographics of the 71 people who completed the survey.

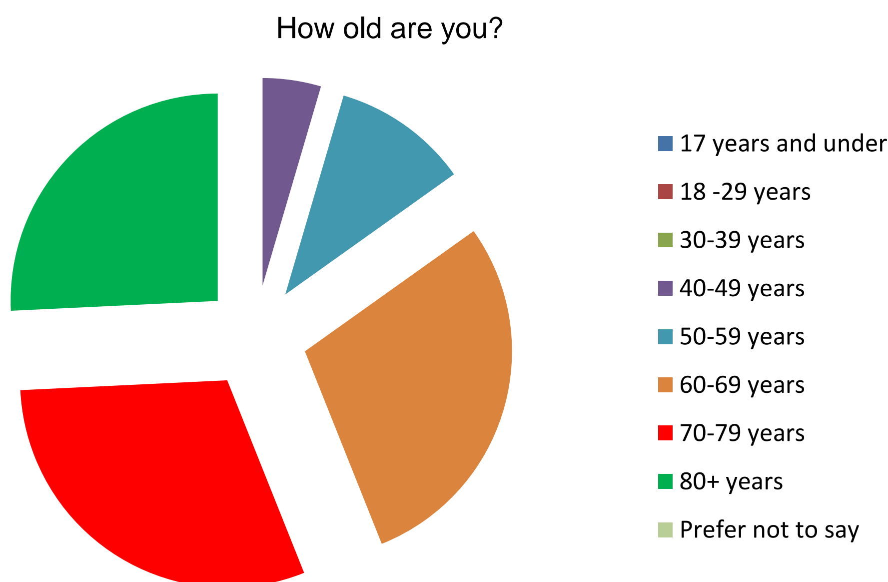
- Most people who completed the survey were the patient 94% (73) and 6% (5) were a family member/carer (Q1).



- Out of the 71 who responded to the question about their gender, over half (56%) of respondents were males with (44%) being female.

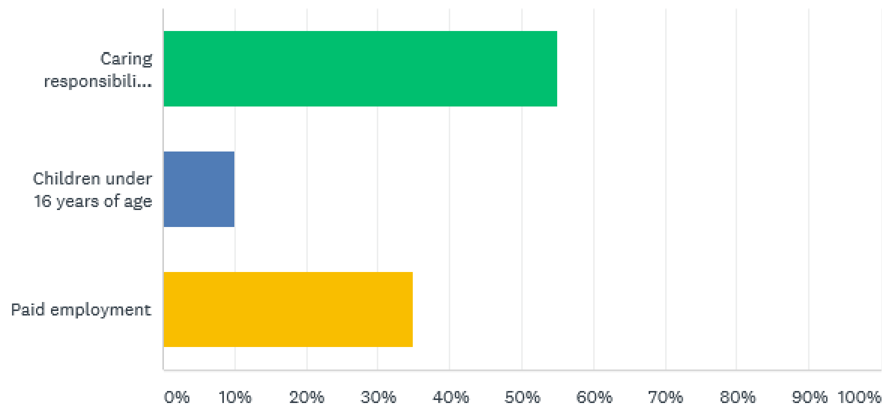
Age range of patients

- The majority of respondents, 30% (21) were between 70-79 years of age, closely followed by 28% (20) who were between 60-69 years of age. Just over 27% (19) were 80-89 years of age, with 15% (11) being between 40 – 59 years of age



Caring responsibilities

Twenty people responded to the question about caring responsibilities. Over 50% (55) said they had caring responsibilities for a family member, friend or neighbour, 10% said they had children under 16 years of age and 35% had paid employment.



Disability, long term illness or health condition

Over sixty five people (67) answered the question around whether they had a physical or mental impairment, which has lasted or will last at least 12 months and affects your ability to carry out normal day-to-day activities. Over fifty (57%) said that they did whereas over 43% said that they did not.

The people who said they did have a disability, long term illness or health condition told us that they had problems with their memory, eye sight, Chronic, Obstructive, Pulmonary Disorder (COPD), problems with their mobility, back problems, unsteadiness, shaking and loss of confidence, mental health problems, suffered a stroke and arthritis.

Most respondents, 89%, said they were White British, 94% said they were heterosexual and 86% said they were Christian and 9% said they had no religion.

Postcodes

The table below highlights, by postcode, where the 60 respondents who answered this question live.

CCG	Postcodes	Count	Percentage %
North Durham CCG	DH1, DH1 5,DH2, DH3, DH7 9, DH7 6, DH7 7, DH7 8, DH8 6, DH8 7, DH9 7	23	38%
DDES CCG	SR8, TS21, DH6, DL12, DL12, DL13, DL14, DL15,DL16, DL17, DL4 2, DL5 7	25	42%
Darlington CCG	DL1 4, DL2 1, DL3 6, DL3 8, DL3 9, DL11	12	20%

Thank you

On behalf of Durham Dales, Easington and Sedgefield and North Durham and Darlington Clinical Commissioning Groups, we would like to thank all of those who have contributed to this engagement including:

- The stroke patients, their families and carers who took the time to share their experiences with us or completed the survey
- The Stroke Association