



## County Durham and Darlington NHS Foundation Trust Stroke Rehabilitation Services Report from patient experience evaluation, December, 2009

### 1.0 Introduction

This report will update partners on both the format and first phase results from the evaluation of patients and carers' experiences of stroke rehabilitation services at County Durham and Darlington NHS Foundation Trust (CDDFT). It will summarise emerging trends from patient and carer feedback and will make recommendations for future action, including a second stage evaluation exercise.

### 2.0 Background

#### 2.1 *Seizing the Future hospital service changes*

County Durham and Darlington NHS Foundation Trust's Seizing the Future project proposed significant changes to the way local hospital services in County Durham and Darlington are configured. Following the approval of the proposals by NHS County Durham in March, 2009, the service changes were implemented with effect from 1 October, 2009. The changes involved consolidating acute care at Darlington Memorial Hospital (DMH) and the University Hospital of North Durham (UHND) with planned care and rehabilitation being provided from Bishop Auckland Hospital (BAH). The aim is to ensure that patients have access to specialist rehabilitation which will help them to make a quicker recovery.

Prior to the 1 October, patients suffering a stroke were primarily treated at Bishop Auckland Hospital and the University Hospital of North Durham, both of which had designated stroke units. A limited number of stroke patients received acute care at Darlington Memorial Hospital, although most were transferred to Bishop Auckland Hospital at the earliest possible opportunity. As of 1 October, 2009, all patients experiencing a stroke have been treated at the University Hospital of Durham or Darlington Memorial Hospital when they are at their most seriously ill and are then transferred to Bishop Auckland Hospital for rehabilitation care when they are fit to do so.

#### 2.2 *Policy drivers*

Both legislation and Department of Health policy reinforces the need for patients, carers and the public to be actively involved in the planning, development and review of local health services. Section 242(1b) of the NHS Act 2006 and the Local Government and Public Involvement in Health Act 2007, highlight the need for service users' to be involved, particularly when the change to local health services is deemed to be significant. Other legal and policy requirements include:

- the NHS Constitution
- NHS Operating Framework 2009/10
- World Class commissioning

- Quality Accounts
- Care Quality Commission standards

### 3.0 Objectives of patient experience evaluation

The aims of the patient experience evaluation are to:

- Evaluate the impact of hospital-based stroke rehabilitation service changes on patients' and carers' experience, from their perspective, establishing an initial baseline and evaluating performance thereafter
- Identify potential areas of stroke rehabilitation services requiring further improvement
- Inform the development of the North of England Cardiovascular Network's (NECVN) top ten priorities for stroke rehabilitation services
- Recruit patients and carers to service user engagement forums being developed by CDDFT and the NECVN

### 4.0 Patient experience evaluation process

*4.1 PHASE 1: to establish a baseline of patient and carer experiences of pre-Seizing the Future stroke rehabilitation services and to identify any issues not already planned to be addressed by the changes*

#### *4.1.1 Planning and organisations involved*

A partnership approach was taken to planning and implementing the patient experience evaluation exercise. CDDFT led the exercise with significant input from the NECVN to satisfy mutual organisational aims. NHS County Durham and Darlington provided patient, carer and public engagement guidance, support and resources. The North East Stroke Association (NESA) was commissioned to obtain patient and carer feedback in order to ensure objectivity and impartiality throughout.

Commissioners of stroke rehabilitation services were involved in agreeing the content and framework for the exercise. The following service commissioners and/or providers were also informed of the exercise:

- Durham County Council's stroke services co-ordinator
- NHS County Durham and Darlington's older people's services commissioner
- Clinical Director
- Physiotherapy service providers
- Speech and Language service providers

#### *4.1.2 Patient eligibility criteria*

Patients who received hospital-based stroke rehabilitation care between 1 April and 1 October, 2009 were invited to participate in the exercise. Their carers were also invited to take part. Invitation letters were sent to 100 randomly-identified patients, with an equal balance of patients who had been treated at UHND, DMH and BAH.

#### *4.1.2 Format*

Patients and carers were offered different ways in which to become involved in order to maximise participation. Individuals were invited to take part in one of the following:

- Focus group discussion in North of county
- Focus group discussion in South of county

- Home interview
- Telephone interview

#### 4.1.3 Sample size and participation breakdown

A target of between 5-10% of the annual number of stroke patient survivors was agreed at the outset. 27 people took part in total, equating to between 4.5-5.5% of the annual CDDFT throughput of 500-600 surviving patients. This represents a 27% response rate to the initial invitations. The individuals involved experienced length of stays of between 5 days and several months. Participation can be broken down as follows:

Patients	Carer	Joint patient & carer	Admission & rehab at UHND	Admission & rehab at BAH	Admission and initial rehab at DMH	Focus group	Discovery interview in home	Telephone discovery interview
15	9	3	12	13	2	17	8	2

#### 4.1.4 Timeframe

Date	Activity
September, 2009	Identification of eligible participants
October, 2009	Invitation letters sent to potential participants
November 2009	- North & South Focus groups - home and telephone interviews
December 2009	Report writing
January 2010	Feedback to participants*

\*to be undertaken

*4.2 PHASE 2: to evaluate the experience of patients and carers using stroke rehabilitation services post-Seizing the Future changes, to compare with previously established baseline and to identify any remaining issues to be addressed*

The patient experience evaluation exercise, as undertaken in phase 1, is to be repeated from March, 2010 onwards. Patients and carers who have experienced services between 1 November, 2009 and 31 March, 2010, should be invited to participate. Suggested timescales are as follows:

Date	Activity
April, 2010	Identification of eligible participants
April, 2010	Invitation letters sent to potential participants
May, 2010	- North & South Focus groups - home and telephone interviews
June, 2010	Report writing
July, 2010	Agreed action and feedback to participants

#### 4.3 Content of patient experience evaluation

The patient experience evaluation exercise obtained feedback on the full patient journey from the point that individuals first experienced stroke symptoms, through to their discharge from community stroke rehabilitation services, if applicable. While the primary objective of the activity was to evaluate the hospital-based rehabilitation, the exercise provided a valuable opportunity to understand how patients and carers experience all aspects of stroke services. The NECVN and NHS County Durham and Darlington commissioners were also keen to evaluate community rehabilitation services and it was prudent to avoid unnecessary duplication.

A thematic framework for both the focus groups and discovery interviews was agreed. This fragmented the stroke patient journey into key sections and included obtaining feedback on:

- The first 24-hours (symptoms, seeking medical attention, tests and diagnosis)
- Professionals involved (therapy, medical and nursing staff)
- Therapy input (physio, occupational, speech and language, dietetics and others)
- Leaving hospital (discharge and community rehabilitation)
- Information and communication (at all stages of patient and carer journey)
- Involvement of patient and carer in their own care

Standards contained within the National Stroke Strategy underpinned the framework and were used to tailor specific questions.

## **5.0 Findings**

### **5.1 The First 24 hours**

#### *5.1.1 Symptoms:*

Most patients experienced typical stroke symptoms such as slurred speech, numbness on one side of the body, facial weakness, blurred vision and dizziness. Around a third of participants connected the symptoms to a possible stroke as a direct result of the current FAST television awareness campaign. Many participants recognised their experience as being symptomatic of a stroke due to a previous stroke or TIA. At least two individuals did not connect their symptoms to a stroke.

#### *5.1.2 Seeking medical attention:*

Despite making the connection between their symptoms and those of a stroke, the significance of speedy action was not appreciated by all participants. A small number of participants reported waiting to see if symptoms subsided prior to seeking medical help. The local GP was primarily the first port of call of patients and carers in the north of the county while more people elected to dial 999 in the south. Many approached their GP prior to dialing 999. One patient rang NHS Direct for help and experienced a wait which 'felt like hours' before an ambulance was requested to attend. Several participants in the north of the county made their own way to hospital, although this was never the case in the south. Participants shared mixed experiences of professionals' knowledge about stroke prior to their admission to hospital, both positive and negative. Several patients across the county reported being treated for ailments other than a stroke by their GP, resulting in delayed hospital admissions, although these experiences were in the minority. One patient described how: 'I knew I had had a stroke but the doctor did not'. Most patients and carers who used North East Ambulance Services (NEAS) reported positive experiences about the paramedics' response times, manner and their skills; 'the ambulance crew were fantastic'. Several lengthy waits were reported in Accident & Emergency (A&E) at the University Hospital of North Durham, both in terms of being treated in A&E and before being admitted to a ward. One patient reported that they felt they were not prioritised, while another was told that bed shortages were a reason for the delay.

#### *5.1.3 Suspected & confirmed diagnosis:*

Many patients in both the north and south of the county were given a suspected stroke diagnosis by paramedics, where ambulance services were used. Others were given a

suspected diagnosis shortly after presenting at hospital, primarily in A&E in the south and upon admission to the Stroke Ward in the north. Confirmed diagnoses were given to the majority of patients and carers within 24-hours of presentation at hospital, however, one patient in the south reported receiving a confirmed diagnosis at an outpatients' follow-up appointment three months' after discharge.

Patients and carers reported mixed experiences about the timing, delivery and support given at the point of diagnosis. There was a general consensus that giving a suspected or confirmed diagnosis upon presentation at hospital was appropriate for carers and relatives. However, many patients felt that the diagnosis was too early for them as they did not fully understand the diagnosis due to the stroke symptoms. A small number of patients at Bishop Auckland Hospital reported being given information books about stroke but this was not a common occurrence across the three hospitals. Patients and carers also reported very little proactive information-sharing on the part of professionals. As one participant highlighted, "We asked questions of the staff but they did not really tell us all the information about what was happening". While some patients and carers were confident in asking questions of staff and were happy with the answers, others reported being given little or no opportunity to ask questions. Although it is difficult to pinpoint whether this lack of information was most prevalent in A&E or on the hospital ward, the negative impact of the lack of information at the time of both suspected and confirmed diagnosis was strongly felt. One participant said: "Professionals don't seem to recognise the fear we feel at this stage – there seems to be a lack of awareness of how we are feeling" while another said: "There was a desperate lack of reassurance at this stage".

#### *5.1.4 Tests, investigations and admission:*

All but one patient recalled having a CT scan within 24 hours, ranging from half an hour after arrival at BAH to 'fairly quickly' at UHND and 'straight away' at DMH. More patients in the north of the county reported being given explanations as to why a scan was being conducted i.e. 'to see if you have had a bleed'. Some patients in the south were given explanations upon the patients' admission to the Stroke Ward, rather than in A&E. Several participants in the south were unclear about what the scan involved, however, with one patient reporting that they felt very frightened as a result; "I felt pushed about a bit..... it was a very efficient service but it would take nothing to be pleasant and explain....needs just a little bit extra from the staff". A minority of patients in the south recalled being given a swallow assessment, however, many conceded that this may be due to their cognisance at the time. One patient at BAH experienced being given solid food after the assessment determined food should be liquid only. Patients admitted to DMH could either not recall being given swallow test or reported receiving it upon their transfer to BAH. Most patients presenting at UHND or BAH were transferred directly to the Stroke Ward, however, some recalled unsettling and upsetting moves between wards, most notably from DMH to BAH Stroke Unit and then to BAH's Ward 17 and also from UHND's Ward 3 to the Stroke Unit.

## **5.2 Professionals & environment**

### *5.2.1 Environment*

Patients and carers in the south of the county reported a more positive experience of stroke rehabilitation services than their counterparts in the north. Positive comments about BAH included: "what a smashing place...cannot speak highly enough" and: "I thought BAH was stunning. I was proud of it, I was in good hands". BAH's Stroke Unit was singled out for particular praise with positive comments including: "The stroke unit was A1. I was so pleased with treatment there...efficient, skilful, the best care" and "they didn't half look after you well in there". A number of patients reported therapeutic benefits from being given access to the hospital gardens. One participant said: "we were allowed to sit outside on sunny days" while another said: "I went up and up everyday, felling better and better all the time".

### *5.2.2 Staffing levels*

While praise for BAH's stroke ward was forthcoming, there was a general consensus that the unit was extremely busy. One perceived consequence of this was a carer's report who said: "My mum had to wait 30 minutes for a bed pan which was then too late." Similarly, several participants experiencing rehabilitation care at UHND, felt that all services were short staffed which they perceived to be due to funding cut-backs. These comments were made with specific reference to therapy staff and shortages were particularly felt at weekends; "It was as if they closed down over a weekend." Furthermore, patients reported disruptions throughout their general care. For example one patient said: "A nurse would be seeing to me, then suddenly disappear to see to someone else."

### *5.2.3 Professionals: general*

Two thirds of participants reported an understanding of whom the professionals on BAH's stroke ward were and what their roles were: "I understood who was who on the ward and what they were doing with me". Others said they could not see name badges, however, were not told who was who and were left to make assumptions: "as far as I know it was all doctors and physios". All participants reported being treated with dignity and respect and many expressed confidence in professionals knowledge and skills. The praise did not extend to ward 17 at BAH, however, where a minority of participants reported negative experiences with limited explanations and unwelcoming staff. One patient described how they felt afraid on the ward: "I felt abandoned, I was moved when I was half asleep and very confused", while another reported that the "service was good but it felt like Borstal" due to doors being locked. Seeking consent for treatment, therapy and procedures appeared to be most prevalent at UHND with patients in other areas reporting: "I just let them get on with it and they did" or "staff just came and told me what they were going to do". On UHND's stroke ward, flexibility in visiting times was also reported to be extremely beneficial for carers. However, a minority of participants felt that rehabilitation was not as focused as it could have been. One carer felt that her relative was "mostly just left sitting" while another said: "When on the Stroke Ward we felt we could have been on any ward. We didn't feel as if we were on a specialised Stroke Unit".

### *5.2.4 Medical staff*

Mixed experiences of the level of medical input were shared by participants. Only three patients recalled seeing a 'doctor' daily with patients in the south reporting seeing a stroke consultant more frequently than patients in the north. Patients at UHND highlighted a notable lack of stroke consultant care at weekends. A carer also reported not knowing who her relative's consultant was and said: "I didn't see any doctors". Where a stroke consultant was seen, individuals felt that this input was invaluable: "I felt nothing was a problem to him, he answered all my questions straight away" and "He was marvellous and knew his stuff". Across all three hospitals, there was a general consensus that more medical input would be beneficial: "I would have loved to see him everyday but he is a very busy man."

### *5.2.5 Nursing staff*

Patients and carers reported mixed experiences of nursing care. At BAH, nursing staff on the stroke unit were positively praised: "the sisters on the ward were very helpful" while one patient also found benefits from rehabilitation assistants who "took the time to talk to me". At UHND, patients and carers experienced diverse levels of care, from nursing staff who explained everything step-by-step and were integrated parts of the rehabilitation team to one report of being woken at midnight for medication and nurses who were perceived not to be prompting the patient to eat or drink. The most common concern across all three hospitals was around a lack of information or nurses not being proactive enough in sharing information, particularly with relatives of patients. At UHND, this led to a lack of confidence in the skills and knowledge of non-therapy professionals. While participants conceded that their care was never compromised in any way, many felt that a lack of teamwork hindered communications, with professionals concentrating on their specific roles and not sharing the information with the other professionals involved in their care; "I asked a nurse for information on whether I could drive again, she did not know the answer and had to go and seek the information".

## 5.3 Therapy

Experiences of therapy input across both UHND and BAH were largely reported to be beneficial. Most participants received primarily physiotherapy and occupational therapy with only a minority receiving speech and language therapy or dietetics input. No patients reported receiving a seven-day therapy service. Some patients and carers felt that the level of therapy was satisfactory: "nothing could have been improved about my therapy. It was first class and I would like to send a Christmas card to the staff as I am so grateful, even the cleaners and porters were excellent." However, most felt that recovery could be further enhanced by more therapy. A large proportion of participants were unsure as to which therapists they had seen with little explanations given as part of therapy sessions. One patient suggested that therapists make notes from therapy sessions for patients so that they have a record of who they have seen and what they have done.

### 5.3.1 *Physiotherapy:*

Most experiences of physiotherapy took place on the Stroke Wards at either UHND or BAH. No physiotherapy was reported by those patients cared for on Ward 17 at BAH or by those cared for initially at DMH. Physiotherapy started soon after admission to the Stroke Ward at both hospitals for the majority of those patients who received it, mostly within a day or two. Only a handful of patients felt that the wait was inappropriate; one at BAH who experienced having a walking test 11 days after admission, a second at BAH who said that staff holidays resulted in minimal physiotherapy input and one at UHND who reported receiving physiotherapy only once during their hospital stay. Few patients reported being given explanations as to why they were receiving physiotherapy. One carer at BAH reported requesting a splint for their relative which was never received. Differing durations of physiotherapy were experienced with patients at BAH appearing to receive slightly more at between 30-60 minutes per session, which was felt to be sufficient by most, compared to reported 15-30 minute sessions at UHND which some patients felt were too short. Sessions were reported to be daily for some patients and 3-4 times per week by others. No physiotherapy was given at weekends to patients at BAH. Patients also reported little choice of times for physiotherapy with a couple of reports at BAH of sessions being cancelled. A minority of patients felt that more physiotherapy may have helped them to return home sooner.

Participants received physiotherapy in a range of environments including at the bedside and in the gymnasium. One patient from the south in the county commented that group physiotherapy sessions in the gym perhaps limited the attention of the physiotherapist to individuals. Conversely, a carer reported how being able to accompany her relative to the gym was particularly beneficial. Most who experienced physiotherapy felt it enhanced their rehabilitation and also helped to "take my mind off things". One patient reported: "I felt like a dope but it was all good as it really worked" while another said: "Therapy was fun and a good laugh too". Another patient reported how being given a football was both enjoyable and helped to improve his co-ordination. Mixed responses were received as to whether or not individuals were encouraged to practice exercises in between physiotherapy sessions. Several patients reported being given specific tasks to practice i.e.: "staff encouraged practicing skills but didn't allow anything unsafe", however, relatives were often unaware of this. Furthermore, few patients reported other members of the hospital care team encouraging them to practice these exercises.

### 5.3.2 *Occupational therapy:*

Not all patients and carers recalled having occupational therapy input into their rehabilitation. More occupational therapy support was experienced by patients in the north of the county than those in the south with no occupational therapy given at DMH. Where participants did

receive occupational therapy, this was mostly at the point of discharge from hospital, as is reported in more detail below. This prompted a number of patients and carers to request occupational therapy at earlier points in their rehabilitation. One patient at BAH felt he would have benefited from help with getting dressed and feeding as: "although it was good to do it myself, it was hard."

#### *5.3.3 Speech and Language Therapy:*

Only a handful of participants reported receiving speech and language therapy during their hospital stay. Support appeared to be more prevalent at UHND with more frequent visits and intense input reported. The use of pictures as a communications tool was deemed to be positive as were explanations given by the therapist: "it was explained what was happening to me for a good hour". Difficulties experienced in BAH were that the therapist came across as a: "a bit condescending" while another carer felt that the professional involved struggled to work with a patient who also had Alzheimer's Disease.

#### *5.3.4 Dietetics:*

Only one participant in the south of the county was aware of receiving dietetics input as part of their rehabilitation. A small number recalled being given diet and exercise as part of their discharge, as detailed below.

#### *5.3.5 Ophthalmology:*

One experience of a visual test being conducted in hospital was reported by a patient in the north of the county.

#### *5.3.6 Emotional support/mental health:*

Two patients in the south of the county experienced mental health and emotional support, reporting being prescribed anti-depressant medication and having support from staff who listened.

## **5.4 Leaving hospital**

All but one participant in the south of the county felt that they were discharged from hospital at the right time. In the north, patients felt that their hospital stay may have been too long whereas carers felt that their loved one's discharge was premature. The latter linked to carers' fears about receiving their relative home. Many carers felt that further support in preparing for this would have been helpful and one suggested that being informed about a carers' support group may have helped. One carer commented that they were not informed about their relative's discharge. A common experience of participants was a lack of notice given of discharge, with patients and carers reporting they were informed 24-hours earlier or the same day. One patient who was given two days' notice of discharge felt that this was sufficient. Inconsistent experiences were voiced about the extent to which individuals were involved in the discharge process. Many felt that choices and options were discussed with them and discharge arranged to suit the needs of the patient and family, while several others would have liked to have been more involved in the process. One positive experience of being discharged to a nursing home was shared, with the individual's family provided with choices and given sufficient time to select one. At BAH, particularly, a number of patients experienced long waits on the day of discharge with no explanation or reasons given.

Around half of participants received occupational therapy input prior to discharge and this was positively received by all. Preparations included discussions about safe driving habits, kitchen assessments, home visits, shopping trips and the provision of literature about potential community occupational therapy input after discharge, as appropriate.

The provision of other patient information was inconsistent across the county with some participants being given information on medication, diet and exercise and others not recalling being given anything at all. One patient in the south found written information and diagrams from the physiotherapist helpful while another in the north valued a contact telephone number for the ward for any 'difficulties' experienced after discharge. The primary focus of patient information appeared



to be medication. At least one participant felt that information on the emotional aspects of rehabilitation may have also helped. Patients and carers in the north, particularly, felt that they left hospital with limited or no information on what to do next: "I felt I was swimming around with no safety net at a time of great vulnerability". Patient transport in the north of the county received positive feedback from participants where this was used.

## 5.5 Community rehabilitation

Experiences of community rehabilitation were varied with two thirds of participants reporting no community rehabilitation input: "After discharge from hospital I felt alone and abandoned". No GP follow-up appointments were experienced by patients in the south with only one report of GP input after discharge in the north. Several patients across the county felt they benefited from further physiotherapy at the local community day hospital, although one request for physiotherapy at home had been denied.

Community occupational therapy was also highly valued by those patients who access these services. In the south, one patient who received occupational therapy support at BAH said: "you could have a laugh and a joke each time I would go....brilliant people and lovely" while patients in the north described the community occupational therapist as 'very knowledgeable' and said: "I knew they were there to talk through any problems and look at ways around things". While sufficient support with everyday tasks was reported by many patients, at least one patient would have valued more cognitive rehabilitation after discharge. Some felt support and advice in getting back into work would have been helpful as would assistance with socialising after a stroke.

Delays in receiving speech and language therapy in the community were also reported by those patients who felt they needed it across the county, with one patient still on a waiting list and a second reporting a wait of four months. In the south, two patients deemed the level of speech and language therapy to be insufficient with discharge from the service coming to soon. In the north, one patient expressed difficulties following speech therapy exercises at home. One patient reported good follow-up from a dietician following weight loss in hospital.

Social services input appeared to be more prevalent in the south of the county, however, delays for home aids such as stair lifts and showers were experienced by a number of participants. One individual also reported to be still awaiting the provision of a wheelchair. Participants in the north, particularly, felt it would have been helpful to know how to contact Social Services or Careline. None of the patients and carers were aware of a community care plan being discussed or agreed. The majority of participants felt that information at the point of or after discharge would have helped them to access further support in the community. Many shared experiences of having to proactively find things out themselves: "Rather than seeking help it would be nice for help to come to you".

Input from the North East Stroke Association's Family and Carer Support Service (FACSS) was highly valued across the county, with many reports of the FACSS fulfilling individual's information and support needs. This was particularly notable in the north of the county where comments included: "FACSS ticked all the boxes but no one else helped", "After discharge the Stroke Association was my lifeline, I felt I had so many questions answered once the Stroke Association visited" and "I felt as if the hospital discharged me and left the Stroke Association to take over from there". While many patients, particularly those in the south, felt that sufficient support was in place to enable them to enjoy life, they conceded that they were unaware of any further support that may have benefited them further. Some support was received by charitable and voluntary organisations such as St Theresa's Hospice, Age Concern and Citizen's Advice. The input of other health professionals such as doctors and community nurses was a reported absence, however, with many participants suggesting that a home visit by such a professional to review and put plans in place to address individuals' needs would be beneficial: "There is not enough understanding of people's circumstances, especially if you live on your own". Specific support for carers was negligible across the county with none aware of being offered or receiving either a carers' needs or a health and social care review. On the rare occasions where carers' needs were discussed, this was instigated by the Stroke Association. Few participants were aware of local carers' organisations and one participant felt that information about a local carers' support group would have helped.

## 5.6 Information & communications

Inconsistent experiences of receiving information were highlighted across the county and at several stages of the patient journey. From the very outset, the FAST television campaign was highlighted as a valuable information source in identifying symptoms. However, participants experienced differing levels of information upon their presentation at hospital. A minority of patients, namely in the south of the county, would have welcomed information about the CT scan, what the process involved and why it was being carried out. Information appeared to be more freely supplied once a patient was admitted to the stroke ward at the respective hospital with some difficulties expressed in knowing what was happening prior to this: "we asked questions of the staff but they did not really tell us all the information about what was happening".

Difficulties were expressed in patients' comprehension of their diagnosis due to their cognitive symptoms. Some felt that the diagnosis was delivered too soon and, while some patients did recall being given information at the time, many felt that further information was required to facilitate individuals' understanding. Participants largely felt that a delicate balance needed to be achieved as in some cases: "much more information and you would not be able to handle it". Professionals appeared to be most proactive in sharing information about medication. Most patients and carers who felt comfortable asking questions felt that they were sufficiently answered, however, many participants felt uncomfortable asking questions of staff. Where medical staff answered questions, several patients in the south felt that the answers were easy to understand and free from jargon. Nursing staff in the north were also described as being very helpful.

A common theme across all three hospitals was the need for more proactive information sharing as: "You don't know what you don't know" and therefore do not know what questions to ask. Patients and carers in the north suggested that information about the 'after-effects' and what to expect from a stroke would be beneficial with many individuals keen for information to validate that what they were feeling and experiencing was normal: "no-one told me how it happened". One participant in the south would have welcomed benefits advice sooner. Participants across the county also reported a lack of information about next steps i.e. where a patient was being admitted to what kind of therapy was to be given and why: "I wish it had been explained". This was most notable at the point of discharge where several participants felt that further information was required about what to expect at home and what agencies were able to offer further support.

Patients in the south valued face to face communications opportunities but a number would have welcomed more of them to enable concerns to be voiced. Their counterparts in the north, however, recommended that verbal information be reinforced with written literature as patients' symptoms meant they often had difficulty absorbing information. The role of relatives in helping their loved ones to interpret and understand information was deemed to be valuable, however, relatives reported being given very little information across the county. One carer in the north felt that relatives' presence often impeded the supply of support and information as professionals assumed that: "He'll be fine because she is looking after him" while a carer in the south resorted to looking at the patients' notes to obtain information. Information supplied by the North East Stroke Association was, again, cited as being extremely helpful, both in hospital and after discharge. Participants in the south recalled an information pack being of particular value: "I was happy that the Stroke Association was there". Occupational therapists were also felt to be a positive source of information, particularly at the point of discharge and in the north of the county. Where written information was supplied, most recipients felt that it was clear and concise and one participant felt that reading difficulties had been accommodated. None of the participants were aware of an educational programme or had heard of self care support such as the expert patient programme. In the south particularly, there was limited awareness of local carers' organisations and, where awareness existed, patients were confused as to whether they could approach them or if they had to wait for the organisation to make contact.

## 5.7 Involvement in own care

The involvement of individuals and/or their carers in their own rehabilitation care appears to have been most prevalent when patients and families were proactive in asking questions and seeking information. Only three participants were aware of having a care plan, one of which pre-existed the individual's admission and a second through the family's request for one. While a handful of patients were aware of rehabilitation goals been set by therapists, namely physiotherapists, the goals were largely felt to be 'given' rather than agreed in partnership with the individuals. Little recollection of being given choices around treatment and therapy was voiced. The majority of participants did feel that they had the opportunity to ask questions, however, and felt that their views and opinions were listened to. Isolated examples of positive experiences were also shared by participants in the south; one family being supported to find a nursing home and given choices and another individual being actively involved in and receiving notes from a social services' case conference. One participant highlighted the challenges they faced in expressing views due to speech problems and another patient requested that choices be extended to include ward moves. Mixed experiences of carers' involvement in the care of their loved ones were reported with some feeling that they were actively involved and others feeling that they had to pro actively seek information.

## 5.8 Travel & transport

Few issues were raised by patients and carers about transport. One patient felt that having a bus stop near to UHND was a positive step while another felt that hospital parking fees made visiting patients a struggle: "I have to go to the bank before I go to the hospital."

## 6.0 Conclusions

The findings of the patient evaluation exercise provide a baseline against which future patient experienced can be compared. As well as identifying areas of existing good practice, they also highlight a number of potential areas for further evaluation and/or improvement. CDDFT, in partnership with other agencies involved in the commissioning and provision of stroke rehabilitation care, will inevitably wish to review these, together with the detailed feedback in section 5.0, to identify priorities requiring action.

### 6.1 Areas of good practice

- FAST campaign successful in helping with symptom identification
- Majority of patients reporting receiving CT scans within 24 hours
- North East Ambulance Service response times and level of care, including delivery of suspected diagnoses
- Confirmed stroke diagnoses given to patients and carers
- Information books about stroke given at the point of diagnosis at BAH
- Positive therapeutic effects of being able to access gardens at BAH
- Flexible visiting times on stroke ward at UHND
- Patients reporting being treated with dignity and respect
- Confidence in professionals' knowledge and skills
- Informative, helpful and jargon-free approach of Stroke Consultant and other medical staff, when seen
- Care and time devoted by nursing staff at BAH stroke ward
- Physiotherapy starting within days of admission to stroke ward
- Positive benefits of both physiotherapy and occupational therapy to individuals' rehabilitation
- Positive benefits of occupational therapy, particularly at the point of discharge
- Positive experiences of speech and language therapy at UHND

- Medication information given at the point of discharge
- Diet and exercise information given at the point of discharge
- Individual and family fully supported in making choices about discharge to a nursing home
- Written diagrams provided by physiotherapist at BAH to enable exercises to continue at home
- Telephone number provided to patient at UHND to enable support to be accessed after discharge
- Patient transport arranged from UHND
- Physiotherapy provided at community day hospitals
- Community occupational therapy
- Good follow-up by dietician after discharge
- Information and support provided by the North East Stroke Association's Family and Carer Support Service, both in hospital and post-discharge
- Information supplied
- Opportunities to ask questions and make comments for those comfortable in doing so

## 6.2 Potential areas for improvement/ further evaluation

- Renewed public communications around the significance of seeking speedy medical attention.
- Improved GP knowledge and skills of stroke symptoms and/or clinical protocols and pathways to prevent delayed admission.
- Reduction in waiting times at A&E at UHND for both treatment and admission.
- More proactive information-sharing with patients and carers about what is happening in the early period of patients' presentation at hospital.
- Process and reason for CT scans to be consistently explained to patients and carers across hospitals.
- Greater information and support to be given to patients and families at the time of diagnosis with such information with support being tailored to suit individual cognitive needs and families given the opportunity to ask questions.
- Awareness raising among A&E and/or medical admissions staff of the emotional impact on and fears of stroke patients and families
- Swallow assessments being carried out, explanations of swallow tests being given to patients and families and/or records of swallow assessments to be given to patients and families.
- Ward moves to take place only as clinically essential and to be fully explained to patients and carers.
- Staffing levels of both therapy and non-therapy staff to be reviewed, particularly at weekends, with particular reference to ensuring continuity of care.
- More visible displaying of name badges and/or renewed efforts to introduce the different people and roles involved in an individuals' care.
- Review of ward 17 experiences.
- Reinforcing need for consent to be obtained for aspects of rehabilitation care, particularly at BAH.
- Consistent medical input to individuals, commensurate with their needs, with greater medical cover, particularly at weekend
- Greater involvement of nurses in rehabilitation team and programme to enable them to be more proactive and responsive in communicating with patients and carers about their care and next steps etc.
- Seven-day therapy service to be provided.
- Greater efforts to help patients understand who their therapists are, what they will do and how the therapy should help them.
- Consistent durations and frequency of physiotherapy input, commensurate with patient needs with more physiotherapy offered and accesses, as appropriate.

- Flexibility and choice in times of physiotherapy provision to be offered, including provision at weekends.
- Opportunities for carers and family to be involved in therapy sessions with individuals' consent.
- Patients to consistently be given follow-up exercises/tasks and activities after therapy sessions with other staff encouraging patients to practice.
- Potential for occupational therapy to be delivered at earlier stage of individuals' care as is clinically appropriate.
- Greater awareness and support for therapy staff in dealing with patients with dementia.
- More notice given to patients and families in particular of impending discharge.
- Appreciation of carers' fears around receiving their loved one home and appropriate steps to support carers' taken
- Holistic, multi-agency approach to discharge to equip patients and carers with consistent information advice and support covering the full spectrum of potential needs, particularly around support available in the community.
- Potential for GP/community nurse follow-up, preferably home visits to fully assess and start to address community rehabilitation needs.
- Greater and more co-ordinated community rehabilitation including cognitive support after discharge, help with getting back to work and socializing.
- Speedier access to speech and language therapy after discharge.
- Earlier social service input to facilitate speedier provision of home aids, particularly stair lifts.
- Specific support for carers after discharge including consistent offer of carers' needs assessment and signposting/referral to carers organisations.
- Specific information on 'after-effects' of stroke and 'what to expect' to validate individuals' own feelings and experiences
- Provision of benefits advice sooner.
- Face-to-face communications opportunities to be consistently offered and reinforced with written information.
- Involvement of carers and families when sharing information.
- Patients & carers to be made aware of educational programmes and self care programme the Expert Patient Programme and how to access them.
- Patients and carers to be consistently informed that they have a care plan.
- Therapy goals to be agreed with individual as part of care plan.

## 7.0 Next steps

### 7.1 Acting upon the findings

Areas of good practice and potential weaknesses requiring further review and/or action have been tentatively highlighted in section 8.0. Further analysis of the findings will be inevitably

required, particularly to prioritise actions. Many of the areas potentially requiring improvement, may have been, are , or are planned to be addressed as a result of Seizing the Future service changes. Others may require new discussions and / or actions. It is recommended that the findings are presented to the Clinical Action Team with a view to a multi-agency action plan be agreed. All major organisations in the provision of stroke rehabilitation care should be made aware of the findings and encouraged to take any relevant action appertaining to their services.

The results will also feed in to the NECVN Stroke Rehabilitation Standards sub-group and all patient views and comments will help in the development of these standards.

### *7.2 Further engagement activity*

CDDFT may wish to explore the benefits of engaging staff, patients and carers in further smaller-scale engagement activities to agree priorities for action and discuss potential solutions. Several patients and carers involved in the phase one evaluation exercise have expressed an interest in being involved in further engagement activities. Many felt that taking part in such opportunities contributed to their rehabilitation. The use of experience based design tools and techniques, as advocated by the NHS Institute for Innovation and Improvement via [http://www.institute.nhs.uk/quality\\_and\\_value/introduction/experience\\_based\\_design.html](http://www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html) would be helpful in engaging staff in understanding patients and carers' feelings and challenges at different stages of the pathway and vice versa.

### *7.3 Feeding back to participants*

It is crucial that the patients and carers who have taken the time to participate in phase one of the service evaluation receive feedback as soon as possible. This should demonstrate how their views have been considered and how they have influenced any planned actions and improvements, together with estimated timescales. It would be good to practice to issue participants with regular development reports to demonstrate how the planned actions are progressing.

## **8.0 Risks**

It is paramount that CDDFT evaluates the effectiveness of the stroke service changes with a view to hopefully evidencing positive outcomes from the patients' perspective. This will be an essential part of being able to evidence the success of the service to both commissioners and critics of the Seizing the Future reconfiguration beyond. Similarly, service commissioners and other agencies involved in the provision of stroke rehabilitation services risk allowing issues in the quality of services to be overlooked. The results of the patient experience evaluation exercise must therefore be taken seriously, fully considered and actions and resources committed to address any emerging issues. Failure to do so potentially jeopardises the Trust's ability to fulfil the above, together with leaving all organisations vulnerable in satisfying legislative and policy requirements highlighted in section 2.2. Furthermore, failure to listen to and feedback to the patients and carers is likely to lead to difficulties in engaging service users in future events, damaging the organisations' public reputation while undermining confidence in local services.

## **9.0 Recommendations**

CDDFT is recommended to:

- acknowledge and take ownership of the content of this report

- engage relevant partner agencies and/or service users in reviewing the feedback from Phase One of the evaluation exercise, agreeing areas for improvement and actions to be taken, potentially via the multi-agency Clinical Action Team
- commit to feed back progress reports to patient and carer participants at regular intervals
- agree the timeline and responsibilities for Phase Two of the evaluation exercise

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17 December, 2009

**Appendices:**

- Appendix A: glossary of terms

## Appendix A: Glossary of terms

A&E	Accident & Emergency
Acute	Aspect of care required when a patient is at his/her most ill
BAH	Bishop Auckland Hospital
CDDFT	County Durham and Darlington NHS Foundation Trust
DCC	Durham County Council
DMH	Darlington Memorial Hospital
FACS	Family and Carer Support
FACSS	Family and Carer Support Service
GP	General Practitioner
NEAS	North East Ambulance Service
NECVN	North of England Cardiovascular Network
NESA	North East Stroke Association
PCPE	Patient, Care and Public Engagement
Rehab	Rehabilitation – care provided to aid a patient in regaining pre-illness quality of life
TIA	Transient Ischaemic Attack – a type of minor stroke
UHND	University Hospital of North Durham