

# Updates and Insights

## November 2019



[www.healthwatchnorthtyneside.co.uk](http://www.healthwatchnorthtyneside.co.uk)

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## Our year so far - April to Sept 2019

It's been a busy six months and we are on course to talk to more people in a year than ever before. We do our best to hear from all sections of the community in North Tyneside.

We are a small staff team currently at 3.2 FTE. We have a fantastic team of volunteers, who have dedicated approximately 1,650 hours of volunteering time between April and September. Our volunteers help us by supporting Engagement events, interviewing people about their experiences of services, administrative support in our office, running focus groups and being our Trustees. Without them we would not achieve what we do.

1236 people told us their experiences of health and social care



1148 people talked to us at 37 events across North Tyneside



We received 1322 pieces of feedback about local services



825 people have completed our first GP access survey so far



We signposted people to 48 organisations for advice and support



Our mental health work was recognised at national awards



## 2. Key areas of work

### 2.1 Mental health



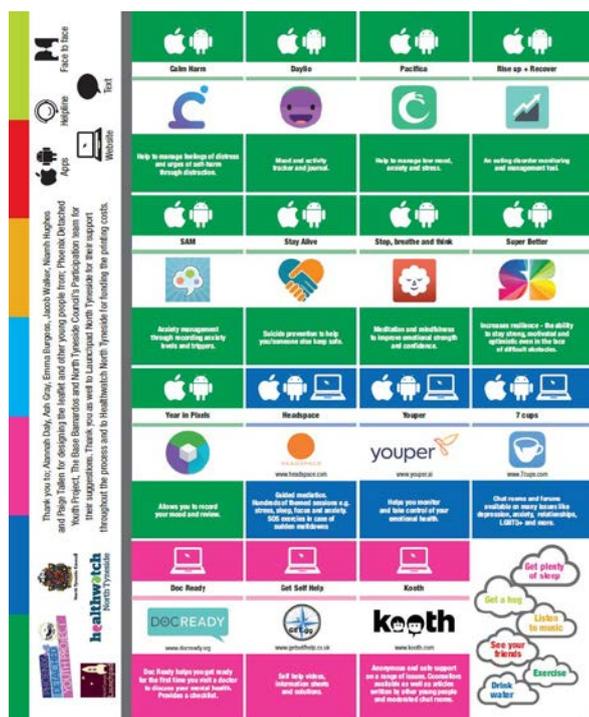
Our work on improving local mental health services was recognised with a highly commended award at the Healthwatch Network Awards in October 2019.

Thanks to local people for sharing their experiences, our voluntary sector partners, particularly Launchpad North Tyneside, and our system partners North Tyneside CCG, Cumbria, Northumberland, Tyne and Wear NHSFT, Northumbria Healthcare NHSFT and North Tyneside Council for their support and willingness to listen and respond to local people's views.

### New mental health resources

We have worked with others to produce two new mental health resources for the people of North Tyneside.

#### Helping young people to 'help yourself'



Young people came together to work on this new resource from Phoenix Detached Youth Project, Barnardos The Base, North Tyneside Council's Participation team, Launchpad North Tyneside, CAMHS and other organisations.

Young people identified the services that they used and they found helpful. The young people helped to design the leaflet so that it would be useful to their peers. The project was led by Phoenix.

Healthwatch North Tyneside funded the printing of 10,000 of these and we are helping to distribute to schools, GP practices, young people's organisations and services.

Please let us know if you would like copies to share.

## Updated Mental Health in North Tyneside leaflet

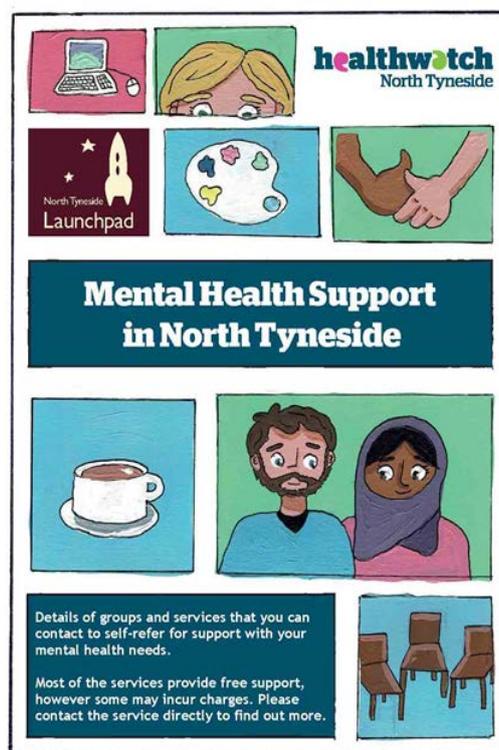
Working with the Service User and Survivors Forum and Launchpad North Tyneside, we have produced a resource for people needing mental health support.

The leaflet provides details of the services that people can self-refer to get the support they need. Most of the sources of support included are free to use but some may charge for some services.

People with lived experiences have been involved in deciding what services are included and choosing the new cover illustration following a competition for North Tyneside residents.

This is the third printed version of this leaflet. So far over 5,000 have been distributed to local services and community venues across the Borough. They have been very well received by professionals and users alike.

Whilst the costs for printing these are small they are still a challenge for our charity. We will be looking for funding to cover the costs of printing the next version - please let us know if you can help with this.



### Mental Health in later life

We are working closely with the Mental Wellbeing in Later Life Board to better understand older people's experience of memory and mental health services. We are currently gathering views of service users and their families and carers. We will identify what's working well and what could be improved. By working with the Mental Wellbeing in Later Life Board we hope that people's experiences will contribute to the planned pathway review and help shape future commissioning activity. We expect this work to be concluded early in the new year.

### Mental health crisis support



Following the publication of our Supporting People in Crisis report in November 2018, there has been some real progress towards the recommended actions we suggested. These actions are overseen by the Working Age Adults Mental Health Board.

In addition to the 'Together in a Crisis' service being commissioned in January 2019, the different service providers have been working towards better coordination and information sharing between services and hope to have a unified referral system in place in the next 12 months. Further updates will come via the Board's reporting.

## 2.2 What people in North Tyneside do when they feel ill

A priority piece of work for us is to get a better understanding of what local people do when they feel ill. We chose this as we heard that people were confused about where to go to get the care they need and some people found getting access to GP services difficult resulting in them needing to go elsewhere for support.

This research project is expected to take a total of 18 months to complete, we expect to finish this in April 2020. It involves:

- Engaging with people in the waiting area in the **Emergency Department at NSECH** - completed November 2018 and report below.
- Engaging with people at the **Urgent Treatment Centre at North Tyneside General Hospital** - completed in February and report being reviewed by Northumbria Healthcare NHSFT and North Tyneside CCG.
- Engaging with people at the **Emergency Department at the Royal Victoria Infirmary** - planned before Christmas in partnership with the RVI, Newcastle CCG and Healthwatch Newcastle.
- Surveying local residents about their experiences of accessing **GP practices** and use of **NHS111**- ongoing. In addition, interviewing services users in GP practices waiting areas - ongoing. We expect to begin reporting back to practices before Christmas and produce an overarching report in March 2020.

We will produce separate reports about each phase of this work and then an overarching report pulling together the key themes, issues and recommendations.

## 2.3 Experiences of the Emergency Department at NSECH



Annex 1 includes the recently published report. Working in partnership with Healthwatch Northumberland and Northumbria NHSFT, we heard from 309 people over 14 three-hour sessions in the waiting area in the Emergency Department and Paediatrics Emergency Department in November 2018. People told us why they were attending the Emergency Department, what other services they had/tried to access and what they thought could make their experiences of accessing care better.

Based on what we heard from people who were attending the Emergency Department independently, we produced a number of recommendations that focus on the following:

Key issues	Next steps
System wide opportunities to better support people to get the care they need through communications and helping people to navigate themselves through the system.	We suggest that a system wide approach is needed to review the information and advice for local people. We would recommend that this review is undertaken once Healthwatch have complete their engagement work around the other urgent and emergency care and GP services North Tyneside residents use - likely to be in April 2020.
Transport issues - particularly public transport access to The Northumbria Hospital, Cramlington.	We suggest that a system wide approach is needed to review the transport issues people have highlighted. This should be led by Northumbria Healthcare NHSFT but will require the input of North Tyneside Council and others.
Changes to the waiting room environment to improve experience and accessibility	Mainly for Northumbria Healthcare NHSFT to review and address.

The key issues identified have been reviewed and considered by Northumbria Healthcare NHSFT, North Tyneside and Northumberland CCGs and NEAS. Northumbria Healthcare NHSFT are working through these actions and have developed an action plan as indicated in their formal response.

## 2.4 People's experiences of stroke support

We are beginning to produce focused issues papers based on local people's experiences of particular themes, issues or services. The first of these focuses on the experiences of people who have had a stroke and their carers and is attached in Annex 2.

The paper makes six key recommendations and makes reference to NICE guidelines, identifying apparent gaps between the guidelines and what people have told us about their experiences. The recommendations focus on:

- Communications and the need for all service providers to be aware of communications needs.
- The provision of person centered follow up support.
- Mental health and emotional support for the individual experiencing stroke and their family/carers.
- Access to social activities - better information about what's available and transport provision to activities.

This report was circulated to North Tyneside CCG, North Tyneside Council and Northumbria Healthcare NHSFT at the end of October 2019 for consideration. We look forward to hearing their reflections and responses.

## 2.5 NHS Long Term Plan

NHS England and NHS Improvement funded the Healthwatch network to work with communities across the country to establish how the NHS Long Term Plan should be implemented locally. More than 30,000 people from across England shared their views about how the NHS can better support their overall health and how it can improve care for specific conditions too.

Staff and volunteers from all 151 Healthwatch also ran more than 500 focus groups across England, bringing together people from all sections of the community to share how they would improve local NHS services.

Healthwatch North Tyneside's engagement fed into the combined **Northumberland, Tyne and Wear and Durham report**. **Read the full report at <https://healthwatchnorthtyneside.co.uk/nhs-long-term-plan/>**

In North Tyneside, we heard from over 150 people through our surveys and focus groups. They told us about:

- Access to services when needed being a key area of concern, particularly in relation to access to GP appointments.
- The importance of joint decision making processes when receiving health treatment and care.
- Positive experiences of quality of care when using cancer health and care services.
- Difficulties in accessing appropriate services when using NHS mental health services.

We are shared a more detailed version of this report which focused on the views of North Tyneside residents with the CCG.

## 3. Emerging issues

### 3.1 Transport

We are increasingly hearing about issues with transport to health and social care services. This is a wide ranging issue and we have heard people having difficulties in:

- Getting to their medical appointments or having multiple medical appointments that require transport.
- People needing care getting to the support services that have been identified as beneficial to them.
- Families and carers struggling to get transport to accompany someone receiving care.
- Families, friends and carers experiencing transport issues when visiting people. There are particularly issues with both public transport and hospitals.
- Older people, many of whom have limited budgets, relying heavily on private taxis to attend multiple appointments resulting in potential financial hardship.
- NHS commissioned patient transport services.
- The lack of community transport solutions and volunteer schemes in North Tyneside.

Transport issues have been highlighted in both our NSECH and Stroke papers attached. Healthwatch England have recently highlighted this issue at a national level. We plan to

continue to investigate and report transport issues relating to different services and would welcome a discussion at a strategic level about improving public transport access in particular.

### **3.2 Prescriptions**

We are beginning to hear more about people's experiences of getting prescriptions. Whilst people are generally very pleased with the support and range of services provided by pharmacists, we are hearing that some people are having issues with the electronic prescription system, particularly:

- delays in prescriptions being sent from the GP practice to pharmacy
- not knowing when prescriptions have been sent/are ready resulting in multiple visits to collect.
- In a very small number of cases we hear of the wrong medicines being given - either the GP prescription being incorrect (identified by pharmacy or individual) or the Pharmacy giving the wrong medicine.
- a sense from some that the individual has to resolve issues themselves.

We are gathering more information about this issue in our GP practice interviews and will analyse people's views once all data has been collected and have a better idea of the scale of the issue.

### **3.3 Hearing loss**

Through our work when talking to older people, we have picked up some dissatisfaction with the support available for hearing loss. People have told us how they feel increasingly isolated as they lose their hearing and this has a wider impact on the people they live with and their families. This is particularly an issue for people with other health conditions such as cognitive impairments or dementia. We continue to gather evidence on this issue through our current work.

### **3.4 Working together on engagement**

There is a need and opportunity for members of the Health and Wellbeing Board to better coordinate the different engagement activities around Health and Social Care issues they are doing. This will enable all partners to understand: what other partners are doing; the impact that is intended; and will prevent duplication and maximise the opportunities for local people to have their voices heard.

This opportunity has emerged through discussions with the CCG and Northumbria Healthcare NHSFT and would welcome the Health and Wellbeing Board's support in better coordinating involvement and engagement activities.

## **4. What else is coming up**

### **4.1 New Healthwatch North Tyneside information**

We are distributing our new publicity information, posters and feedback forms across services and community facilities in the Borough. We encourage all members of the Health and Wellbeing Board to support our work by displaying these and encouraging their services to do so. At the same time we will be delivering the new mental health resources.

### **4.2 Healthwatch North Tyneside Annual Survey**

We launched our 2<sup>nd</sup> Annual Survey at the end of October. Our aim is to gather the views and experiences of as many people from across North Tyneside as possible. We use this information to shape our priorities for the coming year and as a key source of feedback for services. Please encourage as many people as possible to complete this survey and they will be entered into our prize draw. The survey will close in December.

### **4.3 Young voices fund**

In May 2019, we awarded a total of £5,420 in small grants to local voluntary sector organisations to gather and/or respond to the health and wellbeing needs of young people in North Tyneside. The following projects are currently being delivered and we will update the board on the outcome of this work.

- Phoenix Detached Youth Project to: 1) work with others to create a young people's mental health resource similar to Support Groups leaflet (complete, see above) 2) Work with young people to produce a film for GPs and other healthcare professionals about talking to young people about their mental health.
- North Tyneside Carer's Centre to complete an action research project with young carers about their experiences of health and social care.
- DePaul to deliver a mental health event with young homeless people to understand their health issues and support services.
- Barnardo's The Base to work with LGBTQ+ young people to create resources and a campaign about mental health and self-acceptance.

These projects will be delivered over the next 12 months.

### **4.4 Customer experience in Adult Social Care**

North Tyneside Council have commissioned us to help better understand people's experiences of adult social care service, focusing particularly on customer service. This is in addition to our Healthwatch contract. Our work on this will begin shortly and we have recruited a new member of the team, Helen Bedford, to deliver this work.

### **4.5 Residential and nursing care**

Our volunteers will be visiting care homes to provide a lay person's view of having a meaningful daily life within each care home. This is part of a separately contracted piece of work for North Tyneside Council.

## Understanding people's experiences of attending the Emergency Department at the Northumbria Specialist Emergency Care Hospital

### What we did

During November 2018 the Healthwatch teams from Northumberland and North Tyneside heard from 309 people attending the Northumbria Specialist Emergency Care Hospital (NSECH) in Cramlington. We asked people to complete a questionnaire with us about their experience whilst in the waiting area of The Northumbria. 75% of the people we spoke to were attending the Adult Emergency Department and 25% were parents or carers visiting the Paediatric Emergency Department with their child. The people we spoke to were those who independently visited the emergency department and therefore views from those who arrived by ambulance are not included within this report.

We talked to people over 14 three-hour sessions between 9am to 9pm, covering both weekdays and weekends, over various times of the day to understand any common themes in experience.

We wanted to know about people's treatment journey not just their experiences of using NSECH, therefore, findings and actions often relate to system-wide issues which need to be addressed through a multi-agency approach. Considering the responses, we recommended actions for consideration by Northumbria Healthcare NHS Foundation Trust (NHFT) and Northumberland and North Tyneside Clinical Commissioning Groups (CCGs) either separately or jointly according to each organisation's responsibilities.

### Key issues identified

#### Access to, and understanding of other services

A key reason people gave for their use of The Northumbria was the availability of other services.

Access to GP services were heightened as an issue, particularly at weekends and evenings. 35% of people told us they had contact with their GP practice and been advised to attend, only 3% told us they had tried to contact their practice but were unable to access. People told us that they did not try to contact their GP because they either thought the practice was closed when they needed it or felt they 'wouldn't have got a GP appointment'.

NHS 111 was used by 20% of the respondents from North Tyneside and 18% in Northumberland. Most considered their experience to be positive.

People told us they were often **uncertain about where to go for treatment**. This included:

- What services are available at different sites e.g. **'I'm not sure if Rake Lane has an x-ray so came here for my sprained ankle'** or
- Unsure what services are where - e.g. **'maybe a walk-in centre if I knew where there were'** and **'I thought this was a walk-in centre'**
- Thought they would be referred here anyway - e.g. **'I could have been treated at Wansbeck (General Hospital), but I thought they would send me here anyway so coming here 'cuts out the middle man'**.
- Some people told us that they had been to other UTC or Walk -In services but they were given the option to come to the Emergency department due to waiting times or felt it likely they would be referred here anyway.

When people talked to us, they also indicated that they didn't understand language used for different services including **'Urgent Treatment Centre'**.

We also identified that it was common for people to make their decision on the choice of going to their GP or going to hospital rather than seeing a range of different services based on levels of need.

### **Paediatric care**

We spoke to 76 parents and families attending Paediatric Emergency Department at the Northumbria with a child. People discussed positive experiences of using the services including, friendly staff approach and past experiences of quality care. There was a consensus that The Northumbria was the appropriate place for care for children. It appeared that other services often referred children to The Northumbria by default, this seems to include NHS 111, primary and urgent care services. Services sometimes signposted people directly or following being seen by their service initially, which meant people had to wait for both services.

### **Use by the local community**

We identified that some patients using The Northumbria were visiting due to it being the closest hospital and not necessarily the one most suited to their health needs. Local people indicated that they have **'a great hospital on their doorstep'** and they would **'be draft to drive past this place to go somewhere else'**.

### **Alternative place of treatment**

50% of respondents told us they would have preferred to be treated elsewhere. This including 19% say they thought they could have been treated at their GPs.

If they were advised by GP, NHS111 or other, to go to the Emergency Department, some people felt they should have been able to be treated more locally or given a choice of where to attend.

## Getting to The Northumbria Hospital

80% of the people we spoke to had arrived at The Northumbria by car, the second highest mode of transport used was taxis (7%). People spoke to us about significant issues relating to getting to and from the hospital. The key concerns identified related to:

- The lack of public transport available, particularly overnight and issues around connectivity from certain areas (especially from Northumberland and the southern parts of North Tyneside)
- Poor signage for both public transport services and the hospital often meant people were unsure of when and where to get off buses
- The lack of public transport meant that often people relied on a friend or family member to drive, if people were unable to do so they often had to get a taxi which was costly
- Car parking at The Northumbria was commented on both positively and negatively, this often depended on busyness of the car park when people attended. People were happy with the low costs (at the time it was fixed at £1) but also discussed issues around capacity

## Our reflections on access and the waiting environment

We also made the observations below about opportunities to improve the service user experience of the Emergency Department waiting area. We have shared this information with Northumbria FHT, and they have begun to address several of the recommended actions.

Overall, our team found the area very clean, well maintained, pleasant and calm, and identified the following issues:

- Potential accessibility issues for people with physical impairments
- Accessibility issues for people with hearing impairments.
- Limited access to refreshments after 7pm
- Lack of facilities for people needing to charge phones to keep in contact
- Regular updating of triage times to keep patients informed
- Transaction charges for the charge machine being a barrier for those who need to travel by taxi/public transport, or those people who have long waits and need to purchase refreshments
- Regular updating of the bus timetable and availability of bus info when the reception has closed
- Lack of signage and directions to and from the bus stops
- Lack of car parking capacity at busy times

## Overview of recommended actions

We have recommended a number of actions for consideration by Northumbria Healthcare NHS Foundation Trust (NHFT), North East Ambulance Service (NEAS) and Northumberland and North Tyneside Clinical Commissioning Groups (CCGs) either separately or jointly according to each organisation's responsibilities.

## **1. Communications and navigating services**

- a) CCGs and Northumbria FHT to work with NHS111, GPs and service providers to ensure messages about pathways and what services are available where are clearly communicated based to the public. This should also involve increasing awareness about GP appointment availability and out-of-hours support. Healthwatch and Patient Participation Groups/Patient Forums should be involved in this.
- b) Review messages from staff to patients across the system to ensure people are receiving the best advice for them.
- c) Talk to local people to better understand the language they use about services so that future communications can be tailored to be accessible and make sense to those who use services.
- d) Review communications about paediatrics services so that staff, other services (GPs & NHS 111) and the public better understand what services are available where.
- e) Northumbria FHT and Northumberland CCG review how best to manage patients who live locally rather than trying to stop them from coming.

## **2. Transport**

- a) Further explore what public transport is currently available from different local areas to The Northumbria Hospital and consider working with bus companies to increase the number of services from across the catchment.
- b) Work with bus companies to pull into the hospital grounds (rather than passing by) and review messages on buses and bus stop signage so people know when they are close to The Northumbria Hospital.
- c) Review current provision of public transport information within hospital. This should include ensuring bus timetables and information is available 24 hours a day in entrance lobby.
- d) Review car parking strategy at peak times and explore the potential to extend to make additional spaces available.

## **3. Facilities and environment**

- a) Conduct a full access audit of the Emergency Department conducted by experienced team and follow up actions implemented.
- b) Provide a water fountain in the waiting area or similar so that people can access drink when shop/café is closed.

- c) Provide vending machines or similar so that people waiting in the evening can access food. Alternatively, identify a way that people will not miss their appointment when using the facilities downstairs.
- d) Consider providing a charging station or similar for mobile phones.
- e) Update waiting times regularly to keep users informed.
- f) Investigate a free or lower charging cash machine.

## Next Steps

Healthwatch North Tyneside is using this, along with similar research at the Urgent Treatment Centre, GP practices and the RVI to understand what people in North Tyneside do when they feel ill.

Healthwatch Northumberland is continuing to gather experiences of people using primary and urgent care services in the county as these services continue to develop.

## Stakeholder responses

### Northumbria Healthcare NHS Foundation Trust

We would like to thank both Healthwatch Northumberland and North Tyneside for undertaking this important piece of research - in the waiting areas of the emergency department at The Northumbria hospital, Cramlington - where they spoke to those people who had attended independently.

At Northumbria, we value the views of our patients and their experience and this, alongside providing high quality, safe and caring services, is integral to our values and vision and helps us to continually improve.

We have welcomed this feedback by Healthwatch and their suggested actions, which have been discussed at executive level and with our partners across the health system. Some of which have already been actioned such as ensuring the bus timetable screen is always on 24/7, regularly updating waiting time information and implementing changes to the car park.

We are in the process of commissioning an independent charity to conduct a full access audit of the emergency department and looking at access and signage of our facilities. Our staff are fully supportive if anyone attends the department that has carer needs or requires any extra support or assistance and will always provide that extra help.

We have looked to see how we can further improve the environment of the waiting area and whilst we can't provide a free cash machine or install food and drink vending machines, we are looking at installing a water cooler, a charging station for phones and iPad and introducing a vibrating alert if people need to get food from the restaurant downstairs, which is open 24/7.

We will continue to work with our partners to improve communication and to ensure there are clear messages about the services available at The Northumbria especially about when you should attend the emergency department or where contacting another service is more appropriate.

#### **North East Ambulance Service NHS Foundation Trust**

We use the same system, and in many cases the same people, to assess 111 and 999 calls. NHS 111 will only direct a patient to a service which is clinically appropriate for their symptoms. When the outcome is to send an ambulance or advise the patient to attend an emergency department, this is because we cannot rule out a clinical need without them being seen by an ambulance or hospital clinician.

Where it is appropriate, patients calling 111 are offered appointments in their own GP practice or appointments in a nearby extended hours GP practice. All these health services are listed on a directory which is kept up-to-date by the clinicians and operational management working in the service itself. So, if a patient is asked to attend a service further away than they expected, it may be that their nearer healthcare centre is unable to provide the care they need at that time.

#### **North Tyneside Clinical Commissioning Group**

The paper has been discussed and reviewed by North Tyneside CCG and its formal response will be published in due course

#### **Northumberland Clinical Commissioning Group**

The paper has been discussed and reviewed by Northumberland CCG and its formal response will be published in due course.

# Issues Paper: Stroke survivors' experiences of using health and social care services in North Tyneside

## Summary

We spoke to 19 people who had experienced stroke or supported someone who had. People told us about their experiences of using health and social care services during and following stroke.

People shared positive experiences of the equipment service and some good examples of care received by hospital staff, their GP and social care staff. People highlighted areas for improvement in relation to the follow-up support post hospital discharge, the consideration of mental wellbeing as well as physical and the use of accessible communication by healthcare staff. People also noted the importance of support groups and social activities but noted several barriers to accessing such support.

We have also highlighted gaps between what people told us about their experience and the National Institute for Health and Care Excellence (NICE) guidelines.

## Background

Healthwatch North Tyneside is the independent champion for local people using health and social care services. We gather feedback about services from the general public and through targeted engagement with specific groups of people.

We understand that people who experience long-term health conditions will have unique experiences of using health and social care services. We are talking to groups of people who have different long-term conditions and common experiences to understand the issues they face.

There are more than 1.2 million stroke survivors in the UK and stroke is one of the leading causes for disability for those leaving hospital (Stroke Association, 2017). As part of the NHS Long Term Plan stroke has been identified as a key clinical priority. In North Tyneside, we have higher prevalence of stroke on average in comparison to the national average.

### 1. What we did

In August 2019, we spoke to 14 people who had experienced stroke and 5 carers or family members. 11 of the people we spoke to were male and 8 were female. Of those we spoke to some people had experienced stroke within the last year and for some it was several years prior.

### 2. Key issues

People talked to us about a range of good experiences of using services and several areas where their experiences could be improved. The key issues we heard about are outlined below.

## What worked well?

- a. The timeliness of **aids and adaptations** being put in their home to support them to live independently following their stroke. A number of people told us that the appropriate equipment, such as stair banisters and bath seats, were arranged quickly and put in place before they came home from hospital which they found very useful.
- b. Care given when they were first in **hospital**. They were often initially treated at Northumbria Specialist Emergency Care Hospital (NSECH) before being transferred to North Tyneside General Hospital (NTGH). People felt they were happy with the care received at NTGH commenting positively about staff and the food.
- c. Quality of care received from **care staff** once they had left hospital. A person described having had 3 visits a day for 10 weeks after their first stroke, another said they were given a care worker for 6 weeks and they were "brilliant". One person described their GP organising Care Plus who they found "pretty good". Generally they described the care support being gradually reduced over a period of time which helped to ease the process of discharge from services.
- d. Positive experience of some of the services they had encountered for their **other health needs**. One person told us about having easy access to GP appointments and that their GP would often come to do house visits which was very useful. Another noted an experience whereby their GP referred them to NTGH and on arrival were seen straight away - "didn't have time to sit down" - they felt the treatment and staff approach was very good. However, people's experiences were varied, and people felt that some services were challenging to access because of poor information and transport issues.
- e. Overall, the people we spoke to who had more recent experiences of stroke tended to have more positive experiences of using health and social care services, which highlights improvements in the way services support people who experience stroke.

## What could be improved?

### Stroke services:

- a. **Follow up care** - A key issue people discussed was the inconsistency and limited nature of follow-up support provided when they left hospital. People felt suddenly on their own with no contact from different services such as their physio and their district nurse team. One person discussed only having two visits by their speech therapist. Another person said that their contact was infrequent and unpredictable and has now ended. Of those we spoke to, no one mentioned being offered or receiving either a mental wellbeing or carer's assessment following discharge. Experiences post-discharge were often variable, and many people felt isolated and abandoned - "It was like falling off the edge of a cliff".

People who had experience of other long term conditions, including diabetes and heart conditions, described the follow up support for these conditions as much better than what they had received following their stroke. The lack of follow-up support was particularly notable in relation to the support offered through their GPs. The majority of people we spoke to reported limited experiences of support from their GP practice (even annually) unless they had another health condition.

- b. **Psychological and emotional support** - When considering the support offered for people's recovery, most people discussed receiving some level of support for their physical recovery such as their speech and mobility, however no support was offered for their mental wellbeing following stroke. One person discussed experiencing poor mental health when coming to terms with the impact on their mobility: they were given the number for talking therapies to ring but no further information.
- c. **Access to social activities** and sessions to support both people's physical and emotional wellbeing was deemed as important, but often challenging. This was due to both limited information being given about what activities are available and issues relating to transport to activities. Transport difficulties meant that sometimes activities and support was missed out on. For example, one person told us that they were offered access to a hydro-pool for a year but were unable to find a way that they could get transport there. Another person relied on their family to transport them to exercise classes or experienced long waits to get transport to supported activities.
- d. **Communication** - The majority of those we spoke to had communication difficulties following stroke. One carer told us about having to repeatedly advocate on their family member's behalf in order to ensure they were showered and cared for when they went into hospital following a fall. Another person described being verbally asked what they wanted for lunch when they were an in-patient at hospital. The staff then complained that they couldn't understand what the person had requested. To ensure people can meaningfully engage in decisions about their care and preferences other communication methods need to be available. In this case, a visual menu would have enabled the person to independently communicate their preference.
- e. **Need for support when accessing services** - A key concern for a family member we spoke to was the lack of basic care received in hospital and the constant struggle to advocate for their family member's care to be addressed, often due to a person not being able to express or communicate their needs. A support worker echoed these concerns when stating that they felt the people they supported were treated better when the support worker was present. Family members felt that due to their family member's communication difficulties, their needs were not adequately addressed without the input of the family member.

## Other services

When people were engaged with their GP, they discussed experiencing long waiting times, such as waiting a month for an appointment.

Podiatry services were highlighted as an area for improvement. One person had a District Nurse visit to cut toenails, which was later discontinued. Another person experienced delays due to it being really busy and this meant that toenails had been catching on bed sheets.

People's experiences of using dentists were mixed. One person who had recently been to dentist said they were "in and out" quickly. Although they also noted that the practice had removed the magazines and TV screen which was not helpful as they got anxious whilst awaiting an appointment.

Although people told us about some positive experiences of treatment at hospital, there were also concerns raised about the care they received when going to hospital for other health issues.

### 3. Suggestions for providers and commissioners

This issues paper presented an overview of experiences from 19 stroke survivors and carers. Although the number of people we spoke to was limited there were a number of common issues that service providers and commissioners should consider to best support people recovering from stroke.

NICE Stroke rehabilitation in adults guidelines have been included to reflect how such suggestions relate to national good practice.

#### A. Communication

NICE Guideline 1.8.12 states "Help and enable people with communication difficulties after stroke to communicate their everyday needs and wishes, and support them to understand and participate in both everyday and major life decisions".

**Suggested action 1:** All health and social care services should work to ensure all staff are trained in accessible methods of communicating for those who need to communicate non-verbally. Particularly in emergency settings or services which people don't have regular contact with. Staff should also be aware that they need to be more proactive in establishing communication as often the person may be unable request support when they need it.

#### B. Follow-up support

NICE Guideline 1.11.5 states "Review the health and social care needs of people after stroke and the needs of their carers at 6 months and annually thereafter. These reviews should cover participation and community roles to ensure that people's goals are addressed".

**Suggested action 2:** Follow-up support for people experiencing stroke is a key issue as often people experience it as limited and inconsistent. Providers and commissioners should look at ways to holistically improve follow up support across the system. GPs play a key role in this and should ensure that NICE guidelines are followed as a minimum.

**Suggested action 3:** Patients and carers should be offered both a mental health assessment and a carer's assessment prior to leaving hospital, as part of their discharge plan.

### C. Mental and emotional support

NICE Guidelines 1.5.2 and 1.5.3 state "Support and educate people after stroke and their families and carers, in relation to emotional adjustment to stroke, recognising that psychological needs may change over time and in different settings.

When new or persisting emotional difficulties are identified at the person's 6-month or annual stroke reviews, refer them to appropriate services for detailed assessment and treatment".

**Suggested action 4:** Follow-up support often only focuses on a person's physical recovery; however people's mental health and wellbeing can also be significantly impacted. Services and pathways should be reviewed to ensure psychological support needs are identified and met.

### D. Access to social activities

NICE Guideline 1.11.3 states "Encourage people to focus on life after stroke and help them to achieve their goals. This may include:

- facilitating their participation in community activities, such as shopping, civic engagement, sports and leisure pursuits, visiting their place of worship and stroke support groups
- supporting their social roles, for example, work, education, volunteering, leisure, family and sexual relationships
- providing information about transport and driving"

**Suggested action 5:** Work with local support groups and the statutory services to identify what support services and activities are available and improve how people are informed about the support that is available. People told us that access to both information about what activities are available and access to such activities was very important in supporting their wellbeing.

**Suggested action 6:** Ensure travel and access issues are discussed when a referral to a support service is made. Support individuals to understand what transport support there is to access other services and action is taken so that users can access the services they need.