



November 2015 listening event Report

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1. Healthwatch Newcastle

Healthwatch Newcastle is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012. We have a dual role to champion the rights of users of publicly funded health and social care services for both adults and children, and to hold the system to account for how well it engages with the public.

We collect feedback on services from people of all ages and from all communities. We do this through our network of voluntary and community sector organisations (VCS), comments cards at events, regular drop-in sessions and listening events at a range of venues across the city, online through the feedback centre on our website, through social media and from callers to our 'Just ask' helpline. As part of the remit to gather views we also have the power to 'enter and view' services and conduct announced and unannounced visits.

2. Introduction

We organised a listening event during November 2015 because we wanted to provide an opportunity for engagement between the people of Newcastle and the organisations that plan and provide social care and health services for the city.



3. Methodology

Listening events are one of a range of techniques that we use to engage with the public and gather their views about health and social care services. When service providers and planners are involved, these events also provide an opportunity for people to raise issues directly with these planners and providers in a neutral and accessible environment.

This listening event was held in the Sir Bobby Robson Suite at St James' Park on 11 November 2015. It was publicised extensively across Newcastle as a free tea-time event for everyone to meet and share their views with a range of service providers and planners. People were asked to book a place, however they could also turn up on the night, and light refreshments were provided.

To encourage attendance from seldom-heard groups, we asked local VCS organisations to bring along their members and service users. A number of organisations took up the offer: 32 people booked onto

the event and 47 attended on the night. We also provided help with transport and childcare costs where this was needed. A range of service providers and planners attended including:

- Newcastle Gateshead Clinical Commissioning Group
- Newcastle City Council - Adult Social Care and Support
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Northumberland, Tyne and Wear NHS Foundation Trust
- The North East Ambulance Service NHS Foundation Trust
- Vocare (Northern Doctors Urgent Care)
- Newcastle GP Services
- Freeman Clinics
- Newcastle Primary Care Co-operative

4. The format for the event

At registration people were asked to sign up for two of eight possible tables. Tables were themed around specific service areas and included:

- Emergency and urgent care
- Primary care
- Social care
- Hospital services
- Mental health (two tables due to demand)
- Newcastle Gateshead Clinical Commissioning Group - future plans
- 'Deciding together' (mental health service consultation)

Each table had representatives from the relevant organisations and a facilitator/note taker. The role of the facilitator was to encourage a broad and inclusive discussion and to note key points. The role of the organisational representatives was to respond to the points raised, either immediately or, where appropriate, to note issues and ensure that the person concerned received a response at a later date

Discussions were held in two 45 minutes sessions.

5. Issues raised

Below is a summary of the table discussions, the points raised by members of the public and the responses provided by the organisations.

Emergency and urgent care table

Issues were raised in relation to the following services:

NHS 111 service

Issues

- The number of questions asked during triage
- The number of people you have to speak to (up to three) all asking the same questions
- The time it can take to actually speak to a doctor

Response: The system is as it is to ensure the safety of the patient but NHS 111 acknowledge that it can be frustrating and are looking at ways of reducing the number of people patients have to speak to, thereby speeding up the system

North East Ambulance Service

Issue:

- Patient transport vehicles are very cold
- A very uncomfortable ride

Response: Ambulances now have to carry a lot of very heavy equipment and as a result have to have very hard suspension. Patient transport vehicles are often older and may therefore have less effective heating systems. The person raising the issue was invited to be involved in the redesign of vehicles the next time this takes place.

Question: Where are ambulances based, are they kept at particular hospitals and does this affect where people are taken?

Answer: Ambulances are not kept at hospitals but at the ambulance stations. Where patients are taken to is entirely dependent upon the nature of their illness.

Issue: Child with a neck problem, ambulance service offered to send a taxi rather than an ambulance to take child to hospital. Parent thought this was inappropriate.

Response: When we have spikes in demand we prioritise life threatening calls and may offer alternative methods of transport to others, however this should only be after a clinical assessment as to suitability has taken place.

Accident and emergency

Issue: Three year old with ongoing asthma problems often needs to be admitted to hospital. Parent unhappy that each time they attend hospital reception staff question his decision to bring child to A&E

Response: Sometimes there is confusion about where to go and to ensure that people are in the right place, reception staff ask these questions. However, for a child with an ongoing condition this should be highlighted in the 'special patients notes' avoiding the need for such questions.

Issue: Patient sent home after attending A&E with a shoulder injury. Following morning staff got in touch to say it was fractured and he had to be readmitted. Patient filled out a complaint form but this wasn't followed up. The same person was kept waiting for four hours in A&E with a stomach complaint, staff only responded when he collapsed.

Response: Neither of these things should have happened and ambulance staff should always share their assessments with A&E. However as both incidents concern hospitals outside the area (South Tyneside and Sunderland hospitals) providers were unable to advise further.

General

Issue: We need a simple, compact guide explaining which emergency service people should access and when - one does not appear to exist?

Response: All providers agreed it was needed; someone thought NHS England had produced something. Mention was made about the information provided by the Northumbria Trust. Providers agreed to speak to commissioners about this.

Primary care table

Access issues:

- There is uncertainty about the pathways for primary care; more publicity is needed
- People don't understand the changes since 2010
- Online information is very useful but people need to know that it's out there
- Students who also work have no time for appointments

Response: There are telephone consultations available for students. A lot of practices also have online booking appointments for students. There are forums for patients to find out what's happening.

Information

Issues:

- When and who are the best people to educate patients? Is it GPs? Will I listen when I'm anxious?
- I have difficulty reading technical words and understanding English, I need face to face information

Response: GPs in the West End are getting involved in community outreach. Prospect Medical Group worked with the first generation BME population but this was time limited due to funding. Education is vital, as vital as medicine. Information is also available online

Issue: Many people don't understand why receptionists ask so many questions.

Response: Receptionists have to go through a triage system in order to make sure the patient sees the right person.

Consultations

Issue: The Babylon app is a private online consultation where you pay an annual registration fee and then pay per consultation. It is an exceptionally good service.

Response: Potential for future NHS development.



Appointment systems

Issue: How much consultation is there about changes to appointment systems?

Response: Many practices now have online systems which work better for the younger generation but not so well for those who find it hard to access. Each practice may have a different appointment system.

Issue: There are difficulties accessing appointments.

Response: GP appointments are ten minutes which usually end up being 15 and this causes delays. People's opinions are sometimes based on one bad experience or because they don't understand the system.

Social care table

The following issues and questions were raised:

Specialist support services for Deaf people

Question: What specialist support services do you have for deaf people?

Answer: At present Deaflink provides some support, although social workers do tell us that there is a need for more. We are concerned about it but are finding it hard to find a provider who can supply what Newcastle needs. We are looking at what other local authorities do to see if we can learn from them.

Barriers to communication

Issues:

- There are language barriers - where services can help, older people can't always access them
- There is often not enough support out there to help Chinese people get what they need from adult social care services
- Why don't you put information on the Newcastle City Council website?



Response: We fund organisations to provide information and advice and are hoping to expand/remodel this. There are many organisations working within the voluntary and community sector that can provide information to people such as Search, Skills for People, the Alzheimer's Society and Newcastle Carers but perhaps there is an information gap for the Chinese community. The Health and Social Care Direct website is the council's main contact point for information and signposting and can provide information in other languages on request.

Social care workforce

Question: When you go out to tender for a new service do you evaluate for quality?

Answer: At the local authority our normal approach is to decide on the cost of the contract and go out to tender with that figure stated. We would then evaluate the bids we receive on 80% quality and 20% price.

Question: How do you ensure that social care services recruit good workers?

Answer: When tendering for providers we look for organisations that have robust processes in place to ensure recruitment of good quality workers. Finding a way to keep workers when the pay is so low is a challenge, but the introduction of the national living wage will hopefully boost recruitment and retention.

Employment

Question: How can I get experience to be a care worker?

Answer: The best route would be volunteering to gain that experience. There is also a possibility of training and development and there are apprenticeships and intern schemes in care homes.

The future

Question: There are big cuts within social care, especially around services for older people. Will this have an impact on services?

Answer: The local authority has some tough choices to make and it is not getting easier. It will be difficult to protect some services.

General comments

“Social workers do a good job but if you don’t have a social worker your voice is often not heard.”

“Sometimes social workers want you to get letters from the GP to provide as evidence for benefit claims but GPs can charge for this. This makes it hard to claim benefits for people with little money.”

“People are finding it hard to pay for services they are entitled to so don’t take them up despite the charges being capped.”

“People sometimes do not use social care services due to stigma. People worry that their children may be taken away. If this stigma was removed people might use services and benefit from what they are entitled to.”

Some of the people on this table were supported by the North of England Refugee Service. They described very poor conditions in the housing provided. The social care representative took this information away with her and will find out who is responsible at the local authority so the issue can be addressed.

Hospital services table

The following issues were raised:

Waiting times

Issue: When I go to hospital I have a long wait to be seen. If I then need to be admitted I have to wait a long time on a trolley before I get to a ward.

Issue: I had an eight month wait for an MRI scan.

Communication

Issue: It is difficult to complain or give feedback if don’t speak English.

Response: Interpreter services mean this is now much better. The Trust has a comprehensive interpreter service and continues to provide the use of telephone and face to face interpreting services. Over 90% of requests for interpreters are able to be fulfilled.

Issue: After Hepatitis C infection I was told that I would get a letter every six months to go back for blood test but this hasn’t happened.

Response: Advised to visit their GP and ask them to check with the hospital.

Issue: I made complaint but got no response or feedback.

Response: It is standard practice for all formal complaints to be acknowledged in writing within 3 days by the Chief Executive and a response deadline agreed with the complainant. The Trust consistently achieves this target with 90% or more complaints. All formal complaints receive a written response from the Trust.

Issue: Medical personnel don’t always work as a team.

Issue: I had problems with my medical records being kept at separate hospitals and then not being shared when I attended a different hospital.

Operations

Issue: My consultant listed so many negative aspects of having an operation that I then felt I couldn’t go ahead with the operation.

Response: It is important that consultants make patients and their families aware of any possible risks associated with proposed procedures so that they can make fully informed decisions together. However, we apologise if the balance of the discussion was not right on this occasion.

Issue: When I was referred for an operation the process was not explained by my doctor i.e. what it would involve; consequently I was not psychologically prepared for the operation.

Question: Why does everyone have to attend at 7am for an operation that day? Some then have to wait for hours if operation isn't scheduled until late afternoon.

Response: Staff do not indicate when an operation will be done because it causes great disappointment if it is then put back, and the Anaesthetist often needs to meet patients before he goes to theatre for the start of the days operations

Consultant holidays

Question: How long ahead do consultants need to submit holiday plans?

Answer: Minimum six weeks.

Response: Questioner thinks it should be longer because it is very frustrating when you wait a long time to see a consultant and then don't get to see them.

Appointment systems

Issue: Problems occur when appointment A is needed before appointment B as administrators often have difficulties arranging this.

Response: Offer was made to look into this problem for this particular patient.

Discharge

Issues

- A patient was told they would be discharged at lunchtime but it didn't happen until 9pm
- Another patient had to wait 6 hours for the pharmacy to send up medication that was needed before patient could be discharged
- There was problem when an elderly person was discharged from hospital but the family not informed

Response: Hospitals are working with its dispensing pharmacy to increase response times and trialling a new procedure for dispensing medication from local pharmacies for some prescriptions. Discharge planning is complex and there is ongoing work to improve this and try to ensure complex discharges happen before lunchtime with all involved fully informed.

Additional comments

Care of children at RVI is very good.

Mental health tables

Issues were raised in relation to the following services:

Services for people with autism

- Autism and especially Asperger's should be separate from psychological services
- There are issues around stress, anxiety, medication and autism
- It often feels like the family knows more but is not listened to
- For those with high functioning autism, where there is no learning disability diagnosis this leads to a lack of support
- There needs to be a better link between other services and the Autism Strategy
- After diagnosis you are left alone

IAPT (Improving Access to Psychological Therapies) Services

- I attended IAPT and was not happy with the treatment - the counsellor seemed more interested in the paper work; I asked for other support but was passed from pillar to post
- Can you get a mental health worker through IAPT?

Issue: You are taken off treatment then put back on when you hit a crisis - why not have constant low level support, small support packages would make a huge difference and avoid people hitting crisis point

Response: The Care Act and assessment process was explained.

General mental health services

Issues:

- Mental health receives the lowest amount of money and a lot of people suffer from it. I attended a day centre for two years, due to reduced finances, staffing and activities were cut back and transport delayed. If you complained you were called silly or they blamed it on your illness or your situation.
- They try to fit people into boxes for treatment; there needs to be more integration

Response: We are trying to be more specific with the intervention we provide.

Issue: What can you do if a member of your family is ill and taking drugs? I have tried talking to someone but it doesn't seem to help.

Response: We can provide support and there are local organisations such as PROPS.

Issue: How can you help someone like this who is unwilling to accept help?

Response: Mental health has a big impact but in most cases you can't force them, when they want help then you can seek help. However whilst we can't force people to accept help, if there was a feeling that this person could be a danger to themselves or others, then a different conversation would be needed and a different response required.



Advocacy

Issue: The hospital arranged an advocate for my brother. I can tell when he's not stable but the advocate did not seem to focus on the family who support him, they only focused on him.

Response: Sometimes it's difficult if the patient chooses not to share information.

Decision-making

Issue: How can you tell if the patient is in the right frame of mind, if they can make an informed decision?

Response: There would be a capacity assessment.

Discharge

Issue: My relative attended a day care for two years, the service was excellent but the discharge was rushed. She was just told one afternoon that she wouldn't be back. I thought she would have a care plan in place before she was discharged.

Response: Ideally it should be a collaborative plan helping you be aware of any relevant indicators and it should have been handed to you on discharge.

Asylum seekers/refugees

Reasons why asylum seekers and refugees may develop mental health issues:

- Isolation - no extended family or friends
- Pressure from asylum process
- No access to social prescribing
- Financial - can't work
- Homesickness
- Education issues
- Language barriers - use of interpreters breaches confidentiality
- Cultural barriers and stigma towards people with mental health issues
- These are not 'normal' issues and they mean that asylum seekers and refugees are more susceptible to mental health problems

Response: Recommended Newcastle Talking Therapies.

Newcastle Gateshead Clinical Commissioning Group (CCG) - future plans table

The following issues were raised:

Ageing population

Issue: Dementia is now starting in early your 50s and leading to increased social isolation and loneliness.

Response: CCG is working with the voluntary sector to combat this. Event is being held next March for all ages to see how they can connect people better and create awareness of organisations that can help.

Hearing loss

Issue: Deaf loops are available but nobody knows how to use them.

Response: CCG are working with DeafLink and are aware of this issue.

Sight loss

Issues:

- The pressure on eye services is getting worse
- Do over 65s that live in Newcastle get a free eye test?
- What are the CCG's future plans regarding sight loss?

Response: The CCG is currently looking at using different services i.e. optometrists rather than hospital. They are working with the Royal National Institute for the Blind, together they have visited the new RVI eye department and found issues such as unreadable signs, furniture difficulties and the need for speaking clocks.

Autism

Issues:

- Is there anything regarding autism mentioned in Plan?
- There is a big issue with transitional; children with autism are catered for but when they become adults it is more difficult
- When redesigning the autism services you need to visit autism groups

Response: The CCG has been advised by the government to focus on autism and are currently looking at how services can be integrated to avoid any overlap or gaps between transitions. It is consulting with people to understand on what is working well and what improvements are needed.

Personal health budget

Issues:

- How do you access it?
- Can asylum seekers access it?
- Do you have to pay it back?

Response: Access via your social worker would be the quickest route. For an asylum seeker it would be via your GP. You would see no cash as it goes straight to the service you would be using.

Asylum seekers

Issues:

- Asylum seekers are an isolated community who want social activities, connections and relationships
- A lot of asylum seekers are diagnosed with mental illnesses and given medication when really they just need social prescribing

Response: Recommended wellness programmes.



General comments and experiences shared

Positive:

- I had a hand operation at RVI, it was a good service
- Newcastle Hospitals consider the needs of Muslims - i.e. female doctor and diet requirements and they listen when you also suggest improvements
- Palliative care at Marie Curie is good, it is well organised and has robust systems in Gateshead, but it's not so good in Newcastle

Negative:

- My husband had an angina attack and was admitted to hospital on the Friday; on the Saturday he received invoice of £2000 to pay for the treatment - the hospital made a mistake of thinking he was a visitor to the country rather an asylum seeker
- At the Eye Centre in the RVI reception staff point to where to go but when you have sight problems you can't see where they are pointing
- The interpreters GPs use don't understand all languages well; mobile interpreters are useless
- Staff at the hearing clinic call out people's names but some people miss their turn because they can't hear!

'Deciding together' (mental health service consultation)

The following issues were raised:

- There was recognition that whatever system is established, early response is vital and ongoing support; the VCS is best placed to provide this but is underused and under resourced
- The stigma of mental health often prevents people from engaging with statutory organisations; again the VCS provides a solution to this issue
- There was concern about the reduction of inpatient beds in all the options that have been developed as part of the service review; however participants did recognise that for the community model to work, resources need to come out of acute care
- There was general recognition of the very difficult financial position
- Asylum seekers are not always able to access mental health services as it can take years for their asylum application to be processed
- There are 100-150 people in Newcastle who have been refused asylum yet cannot be taken back to their country of origin because it would not be safe; these people have no access to any services and their mental health is a huge issue
- There needs to be cultural competency training for practitioners

Cross-cutting themes

From an analysis of the points raised during the table discussions a number of cross cutting themes have emerged. These include:

Access to and discharge from treatment

A number of issues were raised relating to access and discharge including:

- Uncertainty about which service to access and how
- Difficulties in accessing urgent care
- Waiting times
- Access to certain services denied to certain group (people refused asylum status)
- 'Merry go round' nature of access to talking therapies
- Discharge delays and discharge at inappropriate times of day

The quality of service provided

Quality of care was raised as an issue in relation to a number of service areas including:

- Mental health services
- Social care
- Reception staff at A&E



Isolation

Problems of isolation and the impact this has on people's general wellbeing was raised in relation to a number of different groups:

- Older people
- Asylum seekers
- People with mental health issues
- People with autism

Communication

Poor communication was highlighted as an issue by many people and in many ways:

- Poor quality written information
- Problems with interpreters
- Families of service users not being consulted/involved
- Too little or too much information being provided
- Complaints procedures are too difficult

Lack of services

A lack of services was highlighted as an issue for certain groups:

- Deaf people
- Relatives of drug users
- High functioning autistic people
- Asylum seekers

Concerns about the future

Many people expressed concerns about what would happen in the future but this was particularly an issue in relation to:

- Social care services
- Mental health services

6. Next steps

It is our intention that service planners and providers will use the information gathered at the event and contained within this report to inform and improve their planning and delivery decisions. The information will also help to further develop our understanding of the social care and health needs of the citizens of Newcastle. It will be used to help set our priorities for next year and inform our decision-making about which areas we will look at in greater detail.

This was the first event of its kind for us. In the past we have held smaller listening events focusing on the issues faced by particular groups or communities, but this was the first event open to all Newcastle service users and residents.

Given the very positive feedback from the listening event, we have decided to make this an annual occurrence. However, in retrospect November is probably not the best time of year to expect people to leave their homes and come into the city to attend an event. In light of this we have decided that a summer event will be more accessible and the next listening event will take place on Wednesday 6 July from 2.30pm to 5pm at St James' Park.

This was very much a learning experience for us. Having fully reviewed all the feedback we received, for future events we plan to improve both the operational flow of the event and the facilitation of table discussions.

We wish to thank the service planners and providers who were open to listening and gave up their time to attend the event. We also thank our Healthwatch Champions who worked so hard alongside Healthwatch staff to help make the event a success.

Finally we would like to thank all the members of the public who attended the event for sharing their experiences and concerns so fully and candidly. Some of those who attended shared very powerful or difficult experiences and we thank them for the openness.

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