



# Deciding Together Listening Exercise: Analysis of Findings Executive Summary

March 2015

# CONTENTS

<b>1</b>	<b>Introduction</b> .....	<b>1</b>
1.1	Overseeing the Listening Exercise (Governance and Accountability) .....	3
1.2	Responses to the Listening Exercise .....	4
1.3	References.....	4
<b>2</b>	<b>Summary of Findings</b> .....	<b>5</b>
2.1	Accessing Services .....	5
2.2	Treatment in the Community.....	6
2.3	Transition from Children’s to Adults’ Services .....	8
2.4	Inpatient Care.....	9
2.5	Transport and Travel.....	11
2.6	Section 136 Place of Safety .....	12
2.7	Specialist Mental Health Care Services .....	13
2.8	Services for Older People Including Memory Services (Newcastle Only) ...	14

# 1 Introduction

This short report provides a summary of the findings of the listening exercise.

Kenyon Fraser is an independent marketing, communications and PR agency based in Liverpool. Following a competitive bid process the team was commissioned by NHS North of England Commissioning Support Team to undertake an objective and independent review of the feedback from the public “*Deciding Together: Developing a new vision for mental health services for Gateshead and Newcastle*” pre-consultation listening exercise conducted between November 2014 to February 2015. The exercise was focussed on discussions around specialist mental health services. The definition given throughout the exercise was:

*The sort of services you might get from a community psychiatric nurse (CPN) treating you at home, through to the more serious, but thankfully, much rarer cases when people might need to spend time in hospital.*

*It’s really important to remember that we are not talking about the sort of mental health problems for which you get care from your GP or primary care counsellor or therapist. These are more common mental health issues, such as anxiety or depression, and they are well treated by your GP with talking therapies and sometimes medication.*

*The specialist services that we are talking about in this document are the much more complex mental health issues like severe depression, schizophrenia, psychosis and personality disorders.*

This exercise sought the views and shared experiences of specialist mental health services from people who:

- Receive or have received care;
- Care for someone who uses or has used the services; or
- Have a special interest in this area of service delivery.

The overall objective of this exercise is to collate the feedback gathered into a cohesive set of emerging themes and observations, which will then be used to help inform the development of a set of scenarios for the future of specialist mental health services.

These scenarios - alongside other data - will then be tested in a rigorous formal consultation, which will build on the lessons learnt in the pre-consultation listening exercise.

The Kenyon Fraser team was provided with the materials for review from the following sources:

- The “Deciding Together” survey;
- Focus group discussions, convened and moderated by Community, Faith and Voluntary (Third) Sector partners;

- Market stalls, held in convenient public locations, providing the opportunity for drop in comment;
- Participant feedback from all events.

The Mental Health Pound exercise and the in-depth consultations by Northumbria University are stand alone reports, produced by independent organisations and as such are outside the scope of consideration of this report.

The listening exercise sought views around a structured set of questions or key lines of enquiry, which were:

- Access to services and getting care urgently
- Specialist community health services (services outside of hospital)
- Adult inpatient units in Gateshead and Newcastle
- Ensuring a place of safety – section 136 suites
- Services for people with especially complex mental health needs
- Services for older people including memory services (Newcastle only)
- Transport and travel.

There was also a specific interest in the issues surrounding:

- The transition from children's to adult services.

## 1.1 Overseeing the Listening Exercise (Governance and Accountability)

The listening and wider ‘deciding together’ exercise is directed by an advisory group, which is a partnership made up of:

- HealthWatch Newcastle<sup>1</sup>
- HealthWatch Gateshead
- Service user, carer, MHVCS representatives from Gateshead and Newcastle
- CCG mental health commissioning lead
- CCG patient, public and carer involvement officer
- NECS mental health provider manager
- NECS senior communications and engagement manager
- NECS senior communications officer
- NTW deputy director of partnerships
- Other key partners invited to join the group as indicated by the group’s work. This is known as the “*Deciding Together Communications and Engagement Advisory Group*” providing advice, guidance and intelligence on the engagement activity and insights gained to the Mental Health Programme Board.

The advisory group is responsible for developing and co-ordinating communications and engagement activity around all stages of the deciding together public engagement consultation process. The overall objectives of the group are to:

- Ensure a co-productive consultation process;
- Provide a forum which allows two way communications and discussions between commissioners, NTW FT and key third sector and scrutiny partners; and
- Ensure in particular the process is carried out in a positive and non-stigmatising way, which reflects the social model of disability.

It should also ensure that views expressed outside of the deciding together process are captured and fed into appropriate organisations for quality and general service improvement purpose.

---

<sup>1</sup> N.B Healthwatch retain their scrutiny role

## 1.2 Responses to the Listening Exercise

- The listening exercise gathered opinion from 164 people through either attendance at a focus group/market stall event or completing the survey.
- A total of ten focus groups were conducted community and voluntary sector organisations.
- In total, 61 participants attended the focus groups and market stalls. Seven organisations and individuals provided their response by letter. For anonymity, the names of these organisations have not been provided.
- A total of 103 respondents completed the survey, however not all respondents completed every question.

## 1.3 References

A copy of the information sources and feedback notes can be found on the following webpage: [www.newcastlegatesheadccgalliance.nhs.uk](http://www.newcastlegatesheadccgalliance.nhs.uk)

The details of the listening exercise are included in “*Deciding Together. Developing a new vision for mental health services for Gateshead and Newcastle*” published by the NHS Newcastle and Gateshead CCG in November 2014, available to view at:

<http://newcastlegatesheadccgalliance.nhs.uk/wp-content/uploads/2014/10/Deciding-together-consultation-FINAL1.pdf>

## 2 Summary of Findings

### 2.1 Accessing Services

The focus groups and market stall responses tell us that you feel:

- The mechanisms in place to respond to people's needs should be changed
- The healthcare professionals we see to access support need to understand issues around mental health and to know the services that are available
- We want support to discuss mental health issues and address the stigma
- We need help to address cultural issues
- We want personal contact with a primary healthcare professional who can help us access the services we need
- We want to know who we can talk to and we want help to do this in our local community
- We want to talk to the people that can help us in a way we are comfortable and familiar with
- We want a crisis team that responds to us, simply and consistently. We need appropriate support at the time we know we are having a crisis.

The responses from the survey tell us that you think:

- The most important aspects of contacting local specialist mental health services identified by participants was 'being able to speak to someone quickly' and 'being able to make an appointment straight away' (87% and 88% rating these as extremely or very important respectively)
- A larger proportion of participants felt it was important that there was a single phone available 24/7 for individuals to contact the service, as opposed to a phone number only available during office hours (71% and 50% rating these as extremely or very important respectively). However, a quarter felt having multiple points of entry across different providers was extremely important (25%), and a further 31% as very important
- The need for the service to be more responsive to patient needs was repeatedly emphasised, as well as the importance of having clear and effective pathways for referrals and access, to ensure that both health professionals and individuals are able to access the service quickly and easily
- The majority of participants indicated that they would access mental health services occasionally/sometimes during evening or weekend opening hours (53%). However, a quarter indicated that they would frequently access services during these hours, and a further 11% stating that almost all of their service access would be during these hours.

## 2.2 Treatment in the Community

The focus groups and market stall responses tell us that you feel:

- It is important to be confident that you will get support through psychological therapies in time
- There is frustration with the lack of clarity around
- More support is needed, as is confidence in the process from the people providing psychological therapies
- The third sector has an important role to play
- The role of carers in the wellbeing of people receiving care needs to be recognised more widely
- Carers provide better care with better information
- Recognised good practice is often ignored or not known about.

The responses from the survey tell us that:

- Among those who had received treatment from the CMHT (approximately 41 participants), there was a mixed agreement as to whether participants felt they had been involved in the planning of their care and treatment (50% agreed, 35% disagreed)
- Over half of these participants indicated that they had not been offered a choice of psychological therapies (61%)
- Similar levels of agreement and disagreement was found in terms of whether participants had only been offered one choice of psychological therapy (44% agree and 47% disagreed) and whether participants had, or had not, experienced a situation in which there were no psychological therapies available after being told that they would benefit from receiving one (40% agreed, 43% disagreed)
- Half of participants indicated that they were satisfied with the quality of care they have received (49%), with a quarter rating their experience as very good or excellent (35%)
- Dis-satisfaction among service users related to individuals being turned away by the crisis team although they genuinely needed/wanted support, staff shortages leading to a lack of consistency in care and frequent changes, a lack of cohesion between services, patients and carers and lack of specialist support available for specific conditions (e.g. treatment for eating and compulsive disorders)



- Respondents gave mixed feedback with regard to their involvement in and understanding of their care plans (37% felt involved in their care plan and treatment whilst 41% stated that they understood their care plan) as well as the ease at which they are able to contact their care co-ordinator or somebody else if their care co-ordinator was not available (28% and 29% agreeing to these statements respectively)
- Half of respondents were satisfied with the amount of information they had been given about their care and treatment options (46%), however fewer respondents felt that this information enabled them to make better and more informed decisions about their care and treatment (33%). Participants suggested that more detailed up-to-date information about the service should be made available to patients, as well as information about community activities, projects and volunteering opportunities, and fact sheets with different drug and therapy options
- Half of respondents felt that the people in their care team have a good level of understanding with regard to their recovery (51%), whilst 44% felt that they received help to achieve their recovery goals
- In terms of how the service can improve the support offered to patients it was emphasised that services need to be more responsive to patients' needs, GPs should be more aware of how the CMHT operates so that they can signpost accordingly, as well as developing peer support programmes to facilitate service users and ex-service users to share experiences
- A variety of suggestions for improvements to specialist mental health services were made. These included more staff and reduced caseloads, offering interim support whilst individuals are waiting for their first appointment, better communication and administration, clarity in the role and responsibilities of CPNs and other health professionals, better connections with the community sector and more support for family and carers
- A number of healthcare professionals provided suggestions which specifically related to the service reconfiguration: ensuring that staff are empowered in the process of service re-design to improve morale, ensuring better connections are made with the police and ambulance service via schemes such as 'street triage' and ensuring that there is an adequate provision of individualised, integrative formulation-based psychological therapies.

## 2.3 Transition from Children's to Adults' Services

The focus groups and market stall responses tell us that you:

- Find the current service confusing and struggle to see how young people make the transition to support under adult services
- Feel all the people involved can work together more effectively to support the transition
- Feel the service is based on barriers and inflexibility
- Feel there needs to be more support available
- Feel there is a need to support the places young people go to, to help them in the transition
- Overall, you feel there is a gap in the provision of mental health support to young people, aged 16-18, which needs addressing in the future.

The responses from the survey tell us that you think:

- Only a small minority of participants had experience of moving from children's to adults' mental health services (six participants)
- The experiences encountered by these individuals were mixed; while three participants felt involved in decisions about their transition, only two indicated that they felt supported
- Improvements to the transition were felt imperative with suggestions focusing upon better liaison between the children's and young person's service (CYPS) and adult services with regards to facilitating a smoother, more gradual transition and by addressing the 'age-gap barrier' for those aged between 16-18 years.

## 2.4 Inpatient Care

The focus groups and market stall responses tell us that you:

- Think people need to feel part of their community to support recovery
- Feel travelling is a major issue for families and carers
- Think that moving services outside of the immediate area is a backwards step
- Feel distance will impact on service
- Feel it should be service quality before building
- Want to know that the people are safe
- Want to know that if inpatient service is the best course of action that it will be a pleasant place to stay
- Want to see great facilities and services that respond flexibly to the needs of all
- Overall, you prefer the home/community environment preferred over hospital care where possible.

The responses from the survey tell us that you think:

- 34% of participants indicated that they had experience of inpatient mental health care, approximately half of which were satisfied with the service received (53%) and rated their experience as very good or good (57%)
- The majority received their inpatient treatment at The Hadrian Clinic, Newcastle or at The Tranwell Unit, Queen Elizabeth Hospital (48% and 36% respectively), with 64% rating the physical environment and surroundings as fair or poor. (77% of these experiences occurred two years ago or more)
- Having bedroom facilities with privacy, having access to visiting areas for relatives and friends and having access to fresh air were perceived to be the most important environmental aspects of inpatient care (83%, 82% and 80% rating these as extremely or very important respectively)
- The majority agreed on the importance of being able to keep in contact with family whilst in hospital, that they would like to spend the shortest possible time in hospital and that the physical environment is very important to them (93%, 86% and 86% strongly agreeing or agreeing to these statements respectively)
- To help patients to stay out of hospital or to be discharged sooner, a number of suggestions were put forth including frequent community care follow-ups, medication reviews and prompts, 'half-way' houses/day centres, a support line

for individuals to speak to someone when they feel they need to and most importantly ensuring that an adequate level of support is in place immediately following discharge whether this be from family, support workers or carers

- Suggested improvements to inpatient services included more peer-led groups and male/female orientated activities, reducing the workload of staff to enable them to spend more quality time with patients, whilst also having time to update relatives, improving patient safety and providing a variety of food options for service users
- A number of participants repeatedly expressed strong objections to the proposals to relocate and reduce the number of inpatient beds in terms of the detrimental effect it will have on the individual as well as friends and family who will have to travel further to see their loved one.

## 2.5 Transport and Travel

The focus groups and market stall responses tell us that you feel:

- We feel travel and transport is mostly a negative experience
- We feel the NHS could help us with travel and transport to enhance the patient experience and recovery

The responses from the survey tell us that you think:

- The main modes of transport used by patients and their families to travel to inpatient services was their own car (29%), public transport (25%) or a friend or relative's car (20%)
- The majority favoured only travelling short distances to receive care (75% stated that it was perfectly acceptable or acceptable to travel 0-7 miles and 40% 8-15 miles). However, ratings of acceptability for longer distances improved when offered transport by the NHS. While 34% had found it totally unacceptable to travel 16-24 miles and 55% to travel more than 25 miles by their own means, this figure decreased to 22% for 16-24 miles and 33% if provided with NHS transport
- Those who had experience of travelling long distances to receive inpatient care or to visit a relative/friend indicated that it was stressful, costly and time-consuming and therefore made it difficult for family and friends to visit their loved ones, especially for those on a low income or those without a car. A small number of relatives stated that they have had to reduce the frequency with which they visit their loved one due to the cost of travelling
- To help mitigate transportation issues, respondents suggested that some form of funding, re-imburement, or free transport provision, such as a shuttle bus, should be put in place. It was also deemed essential to ensure that there were good transport links in place. Other suggestions included a mental-health ambulance to provide secure and discrete transport for patients or using taxis to transport low risk patients, reducing the demand on A&E ambulances.

## 2.6 Section 136 Place of Safety

The focus groups and market stall responses tell us that you feel:

- The section 136 suite is vital but it could work better and most importantly people in crisis need to feel safe
- The section 136 suite is only part of the process and the support that “wraps around” it is as important, if not more important, in making people in crisis feel safe.

The responses from the survey tell us that you think:

- Only a small minority of participants had experience of using the Section 136 suite in Gateshead or Newcastle
- Suggestions to improve the service, offered by a health professional, included securing funding for a specific vehicle to transport individuals when issued with a section 136, improving accessibility of the suites and expanding the ‘street triage’ process to enable the ambulance service to specifically request the specialised mental health vehicle
- 79% agreed that mental health services and the police should work more closely together. However, it was felt imperative to ensure that police officials have an awareness and appreciation of different mental health conditions to ensure that individuals are treated appropriately.

## 2.7 Specialist Mental Health Care Services

The focus groups and market stall responses tell us that you:

- Feel the moving on and rehabilitation units should be in the communities where people live
- Want to see support for family and carers
- Think the valuable learning, experience and different approaches, as well as reach into marginalised communities, needs to be recognised more widely.

The responses from the survey tell us that you think:

- 17% of participants indicated that they had experience of psychiatric intensive care services, approximately half of which were satisfied with the care received and described their experience as very good or good. The majority of these experiences had occurred two years ago or more
- The small number of suggestions to improve this service related to providing more opportunities to patients to be taken off the ward, more structured activities for service users and giving relatives/carers more opportunities to input upon the patient's care, by encouraging them to take part in review meetings
- A small number stated that they had experience of rehabilitation services for people with complex mental health needs (11 participants), seven of which were satisfied with the care received and half rating their experience as very good or good. The majority of these experiences had occurred two years ago or more
- It was suggested that it would be more effective if rehabilitation services were offered in community settings, whilst also giving service users the opportunity to leave the ward together.

## 2.8 Services for Older People Including Memory Services (Newcastle Only)

The focus groups and market stall responses tell us that you feel:

- There is a need for a simple system of support and older peoples' services will benefit from:
  - Having a single key person to help navigate through the care system who is able to provide frequent updates to the family;
  - Supporting dietary needs particularly in cases of a diagnosis of Alzheimer's; and
  - Having more dementia experience amongst the staff in hospitals.

The survey tells us that:

- A small number of respondents stated that they had experience of older people's services in Newcastle, just over half of which were satisfied with their experience, describing their experience as very good or good
- It would be beneficial for patients and their families if there were more leaflets to explain how the service operates, whilst relatives requested a preference to be kept more up-to-date about the patient's prognosis and possible treatments.





**For more information, please contact:**

**Caroline Latta**

Senior communications and engagement locality manager

**Email: [caroline.latta1@nhs.net](mailto:caroline.latta1@nhs.net)**

**Tel: 07900 626 549**