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**In-depth Analysis of**

**Qualitative Interviews for the**

**Deciding Together Consultation**

**Final Report**

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**1.0 Introduction**

**1.1 Background:**

Deciding Together is a **public consultation by the** NHS Newcastle Gateshead Clinical Commissioning Group (CCG) which **sought the views of local mental health services users and carers on the different ways specialist mental health services could be arranged.** The CCG also gathered feedback from mental health professionals and service providers around the best ways to arrange services in the future. The variety of approaches used in this wider work included surveys, focus groups, in-depth interviews and the presentation of a series of scenarios to service users and carers. On behalf of Newcastle Gateshead CCG Northumbria University undertook work to design a tool and use it to conduct in-depth interviews. This report focusses on these in-depth interviews which captured the lived experience of both mental health service users and carers.

**1.2 Methodology:**

This work has been led by service users and carers in partnership with academics from Northumbria University. This approach to evaluation holds the benefit of generating relevant and rich data because the interview tool is designed and delivered by people who have first-hand experience of services. It is an approach which has been successfully utilised in previous research conducted by the evaluation team undertaking this work.

Four mental health service users and carers who were trained as evaluators, co designed an evaluation tool with university staff and the funders (see appendix 5.2). These evaluation tools explored service users and carer views of using mental health services in Newcastle and Gateshead, including a set of scenarios (see appendix 5.1) based around potential configurations of services.

The participants were all residents of Gateshead or Newcastle and either used adult mental health services in the last 3 to 5 years or were unpaid carers, family members or supporters of people who used adult mental health services in the last 3 to 5 years. Participants were recruited by the NHS North of England Commissioning Support Unit, from events delivered in relation to the wider consultation. Having expressed an interest in the evaluation, they were followed up by a phone call from the NHS North of England Commissioning Support Group and sent information sheets about the in-depth interviews. The aim was to recruit 25 participants of which 17 were to be service users and 8 carers and family members.

Interviews took place either at Launchpad in Newcastle or the Clubhouse in Gateshead, both of which are service user led organisations. The evaluators conducted a total of 18 interviews in January and February of 2016. Written consent was gained prior to the interviews which were approximately one hour in length and were digitally recorded. Participants were paid £20 for their time and expertise. Basic demographic information was requested from the participant prior to the start of the interview. Participants were encouraged to talk about experiences of mental health services that had occurred in the last 3-5 years. Documentation generated from the interview was kept in a secure place.

Academics (Dr Toby Brandon and Helen Atkin) from Northumbria University arranged the transcription of the data, which was then managed and analysed using NVivo 10. The early themes were checked for their trustworthiness at a group meeting with the four service user and carer evaluators, leading to the production of this report.

**1.3 Aims:**

The work has two main aims:

* To produce a final report presenting the findings supported by evidence, giving themes/summary findings.
* Verbal presentation of findings to stakeholder group.

1. **Demographics of sample**

Due to the small sample size (n=18), the data merely gives an indication of the broad demographics of the participants in this evaluation. It should be noted that there is not an even split in the numbers of Newcastle and Gateshead residents who took part. Two thirds of the 18 participants who took part lived in Newcastle, it should also be noted that of the 7 service users from Newcastle who took part, 4 of them were currently using inpatient services on the same ward in Gosforth, Newcastle and therefore draw on their experiences in these services to answer the questions. Almost two thirds of the participants had used services for more than 15 years or had supported people using services for that length of time.

**2.1 Number of people who took part in relation to area of residence:**

* 18 people took part in this qualitative consultation, 9 of whom were male and 9 were female.
* Of the 18 participants, 12 lived in Newcastle and 6 lived in Gateshead.
* Of the 12 people who lived in Newcastle 7 were service users and 5 were carers.
* Of the 6 people who lived in Gateshead, 4 were service users and 2 were carers.

|  |  |  |
| --- | --- | --- |
|  | Newcastle | Gateshead |
| Service Users | 7 | 4 |
| Carers | 5 | 2 |

**Table 1: Numbers of service user and carers living in Newcastle or Gateshead**

**2.2 Age range:**

The participants were adults with ages ranging from 25 years to 70+.

**2.3 Time in services:**

The length of time service users had been in service ranged from 1 to 15+ years. 11 out of the 18 people interviewed had been in services for 15+ years. The table (2) below shows the number of people who lived in Gateshead or Newcastle in relation to the length of time they had used services.

|  |  |  |
| --- | --- | --- |
| Time using services | Gateshead | Newcastle |
| 1-4 years | 3 | 1 |
| 5-9 years | 0 | 1 |
| 10-14 years | 0 | 2 |
| 15+ years | 3 | 8 |

**Table 2: Time using services and place of residence**

**2.4 Choice of scenario in relation to area of residence:**

Three scenarios were presented to the participants in accordance with the choices set out in the consultation (Appendix 5.1). Due to the small numbers it is not feasible to draw any conclusions about specific preferences that would be generalisable across Newcastle and Gateshead mental health services. However, the main theme from this data indicates that the option of services being delivered from Morpeth received little support and that participants generally wanted to have services delivered close to their place of residence.

**Scenario T:** 15 people from across Newcastle and Gateshead said “no” to this scenario. 2 people said “maybe” and 1 person said there was not enough information on which to base their decision.

**Scenario N:** 10 people from Newcastle and 2 people from Gateshead said “yes” to this scenario. I person from Newcastle and 1 person from Gateshead said “no”. 1 person from Newcastle and 2 people from Gateshead said “maybe”. 1 person said there was not enough information on which to base their decision.

**Scenario G:** I person from Newcastle and 4 people from Gateshead said “yes” to this scenario. 7 people from Newcastle said “no”. 4 people from Newcastle and 1 person from Gateshead said “maybe”. I person said there was not enough information on which to base their decision.

**Scenario 1:** 5 people across Newcastle and Gateshead said “yes” to this scenario. 9 people stated that they had “no preference”. 3 people said “no”. I person said there was not enough information on which to base their decision.

**Scenario 2:** 3 peopleacross Newcastle and Gateshead said “yes” to this scenario. 5 people said “no”. I person said “maybe” and 7 expressed “no preference”. I person said there was not enough information on which to base their decision.

|  |  |  |
| --- | --- | --- |
|  | **Newcastle** | **Gateshead** |
| **Scenario T = Yes** | 0 | 0 |
| **Scenario T = No** | 11 | 4 |
| **Scenario T = Maybe** | 1 | 1 |
| **Scenario T = Not enough information** | 0 | 1 |
| **Scenario N = Yes** | 10 | 2 |
| **Scenario N = No** | 1 | 1 |
| **Scenario N = Maybe** | 1 | 2 |
| **Scenario N = Not enough information** | 0 | 1 |
| **Scenario G = Yes** | 1 | 4 |
| **Scenario G = No** | 7 | 0 |
| **Scenario G = Maybe** | 4 | 1 |
| **Scenario G = Not enough information** | 0 | 1 |
| **Scenario 1 = Yes** | 2 | 3 |
| **Scenario 1 = No** | 2 | 1 |
| **Scenario 1 = Not enough information** | 0 | 1 |
| **Scenario 1 = No preference** | 8 | 1 |
| **Scenario 2 = Yes** | 2 | 1 |
| **Scenario 2 = No** | 2 | 3 |
| **Scenario 2 = Maybe** | 1 | 0 |
| **Scenario 2 = Not enough information** | 0 | 1 |
| **Scenario 2 = No preference** | 7 | 1 |

**Table 3: Choice of scenario and place of residence**

1. **Findings**

As a consequence of a project meeting with service user and carer evaluators the main themes of right support, right place, right time and right values were generated. In this section each of these will be broken down and explored in more detail. All settings and services mentioned have been given an ID code in brackets.

**3.1 Right Support**

The right kind and level of mental health support was a key main theme generated from the qualitative data. The right support was broken down into sub themes of communication, information, housing, examples of negative support and positive support, the role of the police is then explored along with the influence of social support. The influence of conversations in mental health recovery and finally transport issues lead into the next main theme.

**3.1.1 Communication:**

The importance and quality of communication between professionals/services and service users/carers was a key sub theme. In terms of practicalities; the availability, ease and response of communication systems such as contact telephone numbers was highlighted:

*‘Well, I think I would provide more than one telephone number, which is all the (T1) has. I think it has a second number. Which I think somebody kindly gave me [laughs]. But in theory they only have one. There was an assumption that I was just going to do as I… As they wanted. That I was just going to fit in with their requirements. They ended up by leaving a message saying I can phone anytime I can… And I was thinking “On one phone line? I’ll not bother.”*  (Carer C)

Effective communication between different mental health teams was also indicated as a challenge to effective running of services, this was exacerbated by staff going on the sick and issues not being followed up:

*‘Erm, the main physical issues that we’ve had is around self-harming, so… They’ve been dealt with separately by separate staff and in fact, you’re often in a situation where you’ve got two medical teams, not competing, but working in parallel and not speaking to each other. For example, one of the times, he was in Hospital (H1) with a paracetamol overdose and he was obviously in a really, really poor state of mental health; such a state that at that time, we were saying that he shouldn’t be released back into where he was staying, because he was in assisted accommodation with no support. The support was supposed to be there, but the guy was on the sick, so, erm, this was two days before Christmas or something… He’d took an overdose and then went into (H1).’* (Carer D)

Consistent quality communication with professionals was a vital issue for service users:

*‘Well, she’s (professional) not very good at communicating. She’ll say, “You’ll have to have an appointment with the doctor at the clinic, in outpatients. But she never got back to me what day or what time. And I’ve got to have that done before Monday coming. So I’ve been on the phone, which I shouldn’t have to do. It takes me three times to try and catch her. And she’s never in the office. And even if she’s out, they’re not passing messages on.’*

(Service User N)

In contrast really good communication with one named individual was seen as significant, this was characterised by an openness and wiliness to engage with the carer:

*‘I also find if there’s problem, or I’m worried about anything, there’s this nurse who I really got on with at the (H2). And they’ve travelled to (H3), all the staff. And she says to me, “If there’s any problem at all, just come to me. Or phone me anytime.” And that gives you confidence’.* (Carer O)

**3.1.2 Information:**

The importance of pursuing quality information was stressed, particularly at transition points and early discussions on mental health recovery:

*‘Really. I would say that advice to anyone who is moving from child, well adolescent to adult (services), its, it’s getting as much information as you can. Especially about recovery. Because I think that something that I just didn’t have at that point in* *time’* (Carer E).

The lack of information was emphasised both in the community for carers but also in inpatient settings for services users, the need for them to continually ask about what was going etc. was stressed:

*‘When I was on the ward I wasn’t given any indication of what was expected of me, I wasn’t told oh just rest or try and have a normal day as possible with getting up out of bed, I wasn’t given any information. I wasn’t told if there were any therapeutic activities on, I was not told whether this voluntary position would become, you know, obligatory or whatever. I wasn’t told what I was allowed to bring in my little overnight bag. I wasn’t given any information; it was up to me to ask.’* (Service User H)

The lack of information was also a sticking point for some carers, linking to 3.1.1 around the occasional lack of effective communication by staff:

*‘Well like I was saying, no one… No one tells you anything. You knaa? When someone is first admitted into hospital, no one sits there with the family or carer. Not once has anyone said: “alright, we’d like to meet up with you and this is what will entail when your brother’s in hospital and what would you like to help you? And are you on benefits? And can you claim this…?” Never… I’ve never ever had any such meeting in my life. It’s hard enough getting to meet the psychiatrist on the ward, you know?’* (Carer F)

**3.1.3 Housing:**

Housing was the next key sub theme and in particular the importance of the role of someone to troubleshoot around navigate housing issues:

*‘But within the NHS and within the ‘spending the mental health pound’, that’s one of the suggestions, to introduce navigators, so… So it is important, because you can get the medical stuff right, but it’s no good on its own. You can get the housing right, but that’s no good on its own. It’s even worse. In fact, that’s what’s happened with [my son]. He’s had several housing options, but they’ve come at a time when he’s not able to take advantage of them because of his emotional instability and the behaviour that comes from that.’* (Carer D)

The same carer also stressed their concerns around service users being discharged into the community without appropriate housing being put in place:

*‘So they’re going to be in touch with him daily, I think. Just to check if he’s alright. But we’ve had that support before and it quickly dies off. Because what I’ve said to them is: you can’t release a vulnerable adult into a homeless situation*.’ (Carer D)

Finally another carer describes what constitutes good housing options and the stress they experienced when housing breaks down:

*‘He needs, like, supported living. But of course, at the same time, he walked out. He was there for a month’s trial. And he loved it. And there was other people there and he got on with them and the woman that ran it – she said, “I like your [Name]. He’s got a lovely nature.” He has. And then after the month – his month was up – and she said, “Well, [Name], are you going to live here?” And we kept his flat on. And he said, “I don’t know. I don’t know.” She said, “I’ll do with you… I’ve never done this with anybody else. I’ll give you another month’s trail.” He was there ten days and he walked out. And he just came to me and knocked on the door and he said, “I’m not going back there. Give me my keys.” And he said, “You can get a van and go and pick all my stuff up.” And he went back to the flat.’* (Carer M)

**3.1.4 Negative Support:**

Concerns were expressed by a participant over the support available and provided to carers:

*‘The consultants and staff do not engage enough with family members or carers. For example, the triangle of care, within the first 72 hours of someone admitted in hospital, they’re supposed to sit down with family and carers and the service user etc., and take into account the whole bigger picture, the impact it has on the family; what support the family needs as well as the service user, etc. and they don’t do it. They’re supposed to fill in a ‘get to know you’ form, which never gets done……..Well, I would have loved a carer’s assessment. I would have also liked written care plans, because for example, I’ve never had anything in writing explaining: if this happens, this is what I should do. You know what I mean? An action plan. I presume that’s part of a care plan. I’ve never seen one. Erm, and I would presume that’s part of a carer’s assessment as well, but I’ve never seen one.’* (Carer F)

The first point of contact with receptionist was seen as vital to giving people a positive experience of services, but examples were given of it coming up short:

*‘but the fact that even the receptionist in a GP’s surgery is the first port of call and a lot of them are not very nice, and if you’ve got PD you’ve got a terror of receptionists anyway, and if they have PD training, or just help with understanding about anxiety generally or just basic stuff like making eye contact when a patient enters the room, if you’re on the phone let them know that you’ve seen them.’* (Service User H)

The (T1) came in for some criticism and in particular their relationships with other services:

*‘And then he was declared medically fit and then the (T1) came and assessed him for his mental health and the two didn’t work together at all. In fact, I’ve seen some actually… Quite a lot of evidence of antagonism between the two teams. The last time that I was in there, which was about two weeks ago, the (T1) were very, very arrogant towards the nursing staff.’* (Carer C)

**3.1.5 Positive Support:**

In contrast some services and professionals were described in very positive ways.

*‘We’ve had support from (S1). They’ve been good. Well, my son was allocated a mental health social worker and she was absolutely brilliant, and she helped my son out of rehabilitation, wards that he seemed to get kind of stuck on. She made it possible through housing, for him to live independently; she then tried to support him using other members of the community team.’* (Carer D)

(S1) and (S2) were both praised by service users:

*‘With (S2) – absolutely brilliant, yes. I couldn’t knock any one person that I’ve met. [Name], [Name], [Name], [Name] – absolutely amazing.’* (Service User J)

Inpatient services also came in for praise from service users:

*‘I can’t speak more highly of the staff. The early discharge coordinator, [Name] And individuals in acute day services. Particularly [Name], who’s the psychologist there. They’re just wonderful to have.’* (Service User B)

The (S3) role in supporting people to get engaged was also favourably reported:

*‘They are based at (H4) but they cover all areas of Newcastle and Northumberland. And they are very good; I have been involved with a support worker called [Name] who has got me out and walking around the estate. And she introduced herself at the hospital when I was first there, when I was first at (H3) the first time around. A very nice lady, and they are based upstairs from my consultant. And they have got a good [Name] who are in a good team.’*

(Service User Q)

A number of participants commented positively on Willow View:

*‘No I will concentrate on (H3) because I don’t want that to get moved. For people there after me as well. The staff have always got a smile on their face, I know they have got two lives, they have got their home life, and they have got their professional life, but you knock on the staff, on the office door and the, there is not once I have encountered a bad tempered member of staff for knocking on the door.’* (Service User Q)

**3.1.6 Police:**

The different roles of the Police were also commented upon by participants. Their 24 hour availability being seen as vital in compensating for the lack of availability of the triage service. In addition the importance of training for the police around mental health issues was highlighted:

*‘I think he has, yes. I think that day when he went out to the (H5), I think he was… But there’s issues with the (T2) as well, because the police are always available, ‘cos they work 24/7, but the rest of the (T2) isn’t.’ So even though it was holding a knife to his own throat, there were other people in fear of their own safety, the police officers, basically, thought they were going to get stabbed and that was basically because their perception was that they were coming out to a knife fight; not that there was a vulnerable person self-harming. Now that makes a heck of a difference and that’s why I mentioned the police before, because they have to have the correct training to know how to deal with vulnerable adults.’* (Carer D)

One carer also described how the police end up picking up the pieces when the services fall short:

*‘You know? And the following day is the day he wound up on the streets with a rifle, a knife and a bat and surrounded by armed police, threatening his neighbours. You couldn’t make it up. And then the psychiatrist failed to section him, failed to put him on a secure ward, put him on a non-secure ward and he tried to escape every day and despite the fact that he was trying to kick the doors through every day, they failed to monitor him adequately and he did escape five days later and he had the police chasing him again. You know? It’s pathetic. It really is’.* (Carer F)

**3.1.7 Social Support:**

The importance of support systems that are wider than statutory services were stressed by a number of participants. This included family and friends:

*‘Considering how ill my son was, I wouldn’t have managed without the support and the intervention of two members of my family. My sister-in-law on one side, who was a social worker. And my brother-in-law on the other side, who was a GP.’* (Carer C)

In addition the role of a supportive employer and other voluntary organisations for the carer was mentioned:

*‘But fortunately I do work for Gateshead council, and they are a carer friendly council, and my manager was very, very supportive. So at times that helped but I think that it was getting harder to do that. I knew that, it is that you know you can only do these things for a certain length of time and then you are going to, you know, absolutely go under. I suppose that is why I was heading towards my summer holiday knowing that I could just, you know . ……(S4), and what we did was we managed to get my son 9 hours of support from a personal assistant. Now that was interesting because it was actually my son and I who would actually interview the people. And I think that was really, really empowering for my son, and I always left it to him to actually make the final choice. And the first PA that he had was actually an occupational therapy student, and he was absolutely brilliant.’* (Carer D)

Other groups also played a part in supporting service users:

*‘I go to the men’s group. And I help out and, like… We go and pick, like, food parcels up for the homeless and stuff like that. So it’s, like, all volunteer work. And we go to allotments and stuff like that, and just dig the garden and plant loads of veg and stuff like that. And then at the end of the…’* (Service User J)

**3.1.8 Recovery:**

The concept and potential application of issues surrounding mental health recovery were discussed by both service users and carers. For some this discussion was very heartening:

*‘Well, I was… Actually, I was at a meeting this morning. And they discussed everything. Was he was like when he came into hospital, what he’s doing now, all about his medication. And they think that he is on the way, you know, to better than what he used to be. And it’ll take a while for him to recover, but he will recover. And they’re just trying to get the right medication.’* (Carer M)

The recovery centre was also seen as a positive route:

*‘The (S7), I attended a bit when it first started up and I liked it, but the travelling there was too much of an issue psychologically, so I’ve had to wait until they’ve just opened a branch in the centre of Newcastle, [Name] now, now I’m going to start attending there. So it’ll be really good for me’* (Service User B)

Recovery was defined well by one service user as a reflective journey:

*‘The… recovery isn’t something that means complete… Completely losing your voices and losing your… Losing your symptoms. And recovering that way. Recovery can also mean that you learn to cope and get everything working well and you can… You can sustain that or…Yeah, I think I haven’t got a choice, really, nowadays. Because I’ve got like… I understand that I’ll have these symptoms for the rest of my life. Less so, with being able to cope with them. But that’s what the other thing was – recovery doesn’t mean a complete loss of symptoms. It means coping with their symptoms. Leading a life that’s worthwhile and sustaining it. The stability.’* (Service User U)

However for two carers’ recovery seemed far away, firstly as there was no time within a series of crisis to tackle it:

*‘I: Has the idea of recovery been discussed with you and with your son?*

*P: No. Not really.*

*P: No. It’s always just dealing with the next crisis. Sometimes we are… We’re back to getting… Sometimes we’re in a situation where we’re just trying to get through that day and we’ve been in that situation a lot of times in the last four years.’* (Carer D)

Secondly recovery was just seen as unobtainable for the carer:

*‘Recovery? Not really. Because I don’t think he’ll ever recover. I think if you’ve got schizophrenia, you don’t get out of it. You’ve got to deal with it the best way you can. Take your medication and continue with your life as best you can.’* (Carer M)

**3.1.9 Transport:**

The challenges of using transport both to and from services was a significant sub theme. Travelling to the outlining services was seen as troublesome in terms of both time and cost:

*‘They’re in these obscure sites because traditionally, they were asylums that were out of the way of like normal people and therefore they are remote. You know? I guess [the towns] growing up… Ryhope, (H6)… But it’s safety, but it’s vast expense. You know? It’s…You simply would be stopped from going because it would take you so long. I mean, it took me three hours to get to (H7) and back; it would probably be longer to get to (H6)… Now people don’t all have… I don’t have the money; I probably have the time, but it would make you less likely to go and therefore I think his recovery would be hindered more, so he would be more likely to stay in their longer and all this crap about best clinical practice is just rubbish. You know?’ And like I say, irrespective of that, other people would not be able to go as often, even if they were millionaires, because they work, so they would simply not have… I mean even I’m less likely to go somewhere that might be four hours there and back to (H6), including walking up some hill that I’ve never been on, especially in the winter when it’s dark – Same in (H7) – I’m just less likely to go, because you just are. But if I was working, which, you know, again, I might be’* (Carer A)

For those without cars in seemed to be difficult to get to services especially if the service user was being regularly moved around between services:

*‘I thought the process was abysmal. I… I was amazed at, really, how much it changed. If I hadn’t had a car, to help him, to pick him up and to take him places and so on, I don’t know how we would have managed. Because the previous time I didn’t have a car. So that was getting to know all the bus services and things. But certainly… We were moving between the (H8) and the (H9). And waiting for the (T1) for hours. I was appalled at the current provision. And it’s there.’* (Carer C)

**3.2 Right Place**

Getting support in the right place whether inpatient services, or in the community was the next main theme. Sub themes of localness, the facilities offered, the available activities, where to invest and the staff involved will be explored in turn.

**3.2.1 Localness:**

A significant number of people advocated the importance of having local mental health services:

*‘The most…I wouldn’t call it a change, but ‘anti-change’... It is imperative that the beds are kept local and that there are enough of them so that I and his other family and friends can go and see him more often and make him feel supported and it’s been proven that that in itself aids recovery.* (Carer A)

The following is an example of the challenges faced in services based in various locations. A couple of participants report problem behaviours on inpatient wards made them feel intimidated and one carer described the paradoxical need for inpatient care:

*‘I think that would be very difficult, I think that you still need acute services in the Newcastle area. And even for Gateshead, I think for someone who lives out in Chopwell to, or Rowlands Gill, to expect then to travel down to Ryhope is just too big an ask, especially for families, when you have already got that huge stress of your relative actually going in to hospital, it is all very stressful to start with. So for me, when my son went in to Ryhope, because he had never been there before I had to, sort of, wait until the weekend and to actually go and see him. And then, I then asked if could speak with the psychiatrist, and arrange meeting, and I ended up ringing every day, for about 5 days before a member of staff actually said oh yes, we will, the psychiatrist will meet you, and they just gave me a date, there was no erm, what do you call it. . .’* (Carer E)

Age of service users also played a factor in the potential location of services:

*‘Well, it would depend where they lived, wouldn’t it? If they lived in Newcastle, (H4) would be the best one, wouldn’t it? Because a lot of old people – if they’ve got a partner, they would never get to (H6). If it’s the man going in and the woman has got to go and see him – or the other way round – they would never get there. I mean, I’m 75 but I’m quite fit and I can walk all over the place. So it wasn't a problem for me. Once I found out where it was. But it would be for a lot of old people. So (H4) would be the best. Because you can get the bus right there.’* (Carer M)

Participants showed clear territoriality about where they live and where services should be:

*‘“I live in Gateshead, I’m a Gateshead man, why would I need to go to Sunderland for something? Just traveling there is going to stress me out, I’m not going”. So he was just denying himself the treatment he needed cos accessing the treatment was just too painful.’* (Service User H)

**3.2.2 Facilities:**

In terms of inpatient care the facilities on offer were reordered as important, in particular where you could sit and talk with the service user was significant:

*‘Well some things had been done; when he was at the high dependency unit, we weren’t allowed in his room, but now they’ve moved it off to this bungalow thing that they have there at (H12) at the new hospital; you are allowed in his rooms. And I found that very difficult, because… I mean, they’ll have a visiting room like this with hard chairs and it’s ridiculous, because if that had have been another family there, it would have been even worse, but he couldn’t relax, you couldn’t relax… You weren’t allowed to… The people in the high dependency unit weren’t; allowed to make themselves tea. It was very strict, it was all… It seems to be everywhere… uniforms. They answer the phone; I wasn’t allowed… I didn’t feel welcome, ‘cos I know there’s issues of confidentiality,’* (Carer A)

Another important issue was having en-suite bathrooms in services:

*‘Change…? An en-suite room would have been nice. And I think that meant a lot to me because apparently I sort of was right next to the showers and asked them to unlock them. You know, to increasingly earlier times in the morning, to have a shower. And it would have been nice to have been able to just do that ordinarily, without having to have people unlock things.’*

(Service User B)

It was indicated that any locations also have relevant surrounding facilities and the carer stressed that they would rather travel and have the service user safe than just have him local:

*‘And then the one in (H6), well there’s nothing to be rehabbed into there, because… You know? Whereas (H10) is ideal, it’s got everything, it’s got Gateshead, it’s got the leisure centre, library, Newcastle… But it’s now also got this, so I put it to them that in fact, it’s probably a rehab that is in the most ideal situation in the country, ‘cos it’s a four minute walk away form a self-run service user hub that is fantastic and getting awards and all this; it’s brilliant. And I think they may get that point; they thought: Ooh. Because putting a rehab unit at (H6) is nonsensical, because there’s not even a bus there…..Well; I’ve got a car, so yes. But it’s more round the time. Even if I… I mean, I would say it is out the way, (H6), but we’re grateful to have him in there. Because he’s safe. If it was a choice between having to travel a long distance, just because it’s inconvenient for us, or having him safe, I know which one we’d choose and we’d choose to have him safe.’* (Carer D)

Participants commented on a desire for inpatient settings to be more like homes and less like hospitals as this would aid recovery:

*‘How would you make it more homely? And not like a ward? Yeah, that’s something they haven’t flagged up. The main… What was it? When you’re in a hospital, or in a hospital environment, it’s clinical. Sterile. And uniform. Whereas what I’ve liked the further out I get is that I get to… The bit where everyone gets to gain a bit of character to where you live, and the older stuff. And it’s a bit of a mismatch. But that’s one of the main things I’ve said before – is that I can’t stand the clinical, sterile, uniform approach. You just…’*

(Service User U)

One carer presented an overall rational and view of where services should be based:

*‘The two options where you can save the most money and therefore put the most money into community services, which is where it’s needed, to stop them using the inpatient services in the longer run, is the two which are the hardest to travel to; Sunderland and Morpeth. So I understand the issue. I understand the frustrations of families who are having to travel. But on balance, I think it’s more important to have somebody in a place where they’re being cared for and struggle with the transport than the other way around, so… I don’t… Not everyone shares that view, but I would happily make that compromise.’*

(Carer D)

**3.2.3 Activities:**

One carer indicated that any place to stay also needs to have relevant activities so service users do not get deskilled during their stays:

*‘Because of this lengthy stay from, you know, from (H8), to (H3) that was the rehab place at (H4) at the time, to then (H11), so all that time it was this really lengthy stay in hospital, so he was really deskilled. So the way that it was set up, where he had his own bungalow, but there was staff, who would come in and work with him, to support him to do that, and they would walk in to Morpeth to do the shopping. He likes swimming, a member of staff would go down to the pool with him, to the point of where he would do those things on his own. And it was all of that, starting from having all of the support there, in all of the things you want to achieve, to be able to look after yourself, but actually not just look after yourself, you know not just do shopping, and cooking, and cleaning, but to actually, you know, be a part of the community, having some work skills and some leisure time. So it was a good model.’* (Carer E)

Activities can also lead to social interactions of value:

*‘Well there’s quite a few activities on the ward like they play, they go outside though you know what I mean? Into the community, play like, I don’t know, like bowls and go to the cinema, I mean they’ve got a lot of activities on the ward for males and females, they’ve got like women’s group as they call it, put make up on do their nails and the lads just play pool or you know, and they also have coffee mornings where you can all sit together, you know. There’s not many of them come but you can come if you want, they get like biscuits and stuff, bits and bobs and we all sit and have a coffee together and chat about the day you know, and they get their newspapers, buy their newspapers you know some of them just read the newspapers.’* (Service User T)

**3.2.4 Staff:**

The role of staff is vital over a building or a place:

*‘Yeah, it’s down to the staff. It’s not down to where the building is, right? I mean, you could have the best building in the world right on your bloody doorstep, right? But if the staff aren’t doing the job, it’s not going to work. They’re the cogs in the machine. And it’s the staff who need educating. I mean some staff are…You could say they’re naturally good at the job. ‘Cos they’re naturally concerned and they’re naturally… Some people have got their own incentives to engage with people, but others haven’t.’* (Carer F)

**3.3 Right Time**

Services need to be provided at the right times to support people appropriately. Sub themes here included the significance of continuity in care, what happens at transition points and the vital role of the GP.

**3.3.1 Continuity:**

The importance of having services that mesh well together with one care coordinator was stressed by one carer:

*‘That’s very shoddy. Whereas obviously if they’re all local to the hospital, then your own named care coordinator can go and visit you in hospital and to all the meetings. I mean, the care coordinator, if you’ve got a tribunal in hospital, they’re the ones who organise it; they do everything. That’s why we’re complaining that this fella didn’t… You know? He went on holiday and they have to give a report, ‘cos they’re the ones who know you in depth. To have any old case worker doing it is highly inappropriate and you know, if you didn’t see your care coordinator that you see in the community while you’re in hospital would be bad practice, so if she’s suggesting that they will not do that because it would be too expensive and time consuming, the petrol and staff money, that is very bad clinical practice in my view. Very bad.’* (Carer A)

The stress here is on joined up services:

*‘we need to have much more joined up services and recognize that people are complex and so you know, I’ve yeah, I’ve accessed charities for like housing, my child’s young carer, my mental health all this stuff it all comes together.’* (Service User H)

Having a positive ongoing relationship with one staff member was seen as helpful:

*‘So it’s about continuity as well. Always being… Yeah. It’s difficult if people keep changing, isn’t it? Or if they don’t keep in touch. Are there any treatments in the community that you would like or would have liked that you haven’t managed to get?’* (Service User N)

Integrated social and health workers was also highlighted:

*‘Well yeah, it is. And you talk about the right time, so… I think the medical support has lagged behind the housing support and you need everything to work together. That’s where you need care coordinators and I’m not just talking about medically; I’m talking about the service which is being talked about, which is navigators. But they need to come from the NHS. So [my son] had a navigator at the moment, but it’s from (S8), but it’s patchy, the support, to be honest.’ (*Carer D)

**3.3.2 GP:**

The significance of having a good GP was also stressed:

*‘A good experience was a GP. A GP out of hours service in the (H9). That particular GP had worked with psychiatric services elsewhere. And she was scathing about the provision in Newcastle. That helped me feel that this was somebody who was saying… Whom I could trust.’* (Carer C)

The key role of the GP as the conduit to mental health services was indicated by one carer:

*‘Your single point of entry onto the NHS is your GP, really. That’s… And the whole system is built on having a GP. If you don’t have a GP – and lots of people in this situation, vulnerable adults with chaotic lifestyles, who are moving around all the time – they don’t have an anchor point and a route into the NHS. So how on earth you’re ever going to get…’* (Carer D)

**3.3.3 Transition:**

Two service users commented on what advice they would like to share with people moving people between child and adult services:

*‘I would tell the child that if they feel that there is something wrong with them, there probably is, if they feel that something’s not right, even if they don’t have the terminology to explain it or even if they are really ashamed to broach the subject, if they deep down think something’s not right then they need to speak up! Because I didn’t and I suffered in silence for years and I wasted my life.’* (Service User H)

Overall service users advised younger people to seek support:

*‘I would give advice to a young person to get the help that they think whatever it is they need, to get support and not to try and deal with it on their own, you know cos now there is there’s help now but there wasn’t you know, way back. And I’d advise them that if they felt whatever low or whatever to go and seek help.* .’ (Service User T)

**3.4 Right Values**

Services and professionals need to operate with a clearly articulated set of values. Key to this was the sub themes of being listened to, empathy and respect.

**3.4.1 Being Listened To:**

The first key sub theme in terms of values was ‘being listened to’ and the concerns of being ignored by services:

*‘I also felt that my concerns were being actually ignored, especially when my son is on a dual medication, one of them being clozapine, and of course when you stop taking clozapine for a couple of days it is really dangerous to just start again yourself on the same dose’.* (Carer E)

Another example of not being listened to:

*‘To me… To me they just didn’t help [Name]. In (H8), he was in for two years. And I used to go to meetings and I felt I was banging my head against a brick wall. They just didn’t want to know. They did what they wanted to do. And he was there for two years, you know, and it’s a long, long time. And he got frustrated and it didn’t help*.’ (Carer 0)

In contrast when participants are listened to the service works really well:

*‘I’ve spoke to the staff quite a lot and they’ve always been there for me, you know and they are a really good bunch. Because not one of them will say get away I’m busy, they will not say that to you they will always make time and space for you*.’ (Service User T)

**3.4.2 Empathy:**

Sharing compassion and empathy was seen as vital to quality mental health care:

*‘He was in the room and they wanted the room and they were getting him ready to move him into the room, ‘cos he was going up to (H6) and they came and went “are you ready?” And they went “We are busy having an interview. Get out” and it was really like that and then they went “We have been asked to come here…” And this is their attitude “…By the nursing staff to do an assessment and we’re doing our job”. So there was no working together’.* (Carer D)

One service user ended up going to the (S6) for empathy:

*‘I tried to kill myself on Christmas Day. I went and had ten pints, eight cans of thingee. And I don’t even like vodka – two half bottles of vodka. And I woke up in the middle of the night and I had a paracetamol bottle with all the thingees and everything on the floor, so… But apart from that just ring them up. And I rang the (S5) hotline up on Christmas Day. And they said, “Oh, would you mind not please swearing.” And I thought, “Ah, well, stuff you.” So the boss rang me up and that was it. And I just told her. And she said… The she said… She said… We got cut off, but she disconnected. And then she rang me up again, and I just said, “Here, pet, just… Off with yourselves.” And that was it. But that was it. And there was no… So I rang up the other night and I said, “Excuse me, can you give me the number of the (S6)?” So they gave me the new number for the (S6). So I rang them up and had a chat with them the other night.’* (Service User L)

**3.4.3 Respect:**

Respect was also seen as a key factor in constituting quality care:

*‘They talk to you. It’s simple little things like… They ask you how you’re doing and they… You know, so they’ve got the caring approach.’* (Carer D)

**4.0 Summary**

The in-depth interviews provided the following points for consideration within the wider Deciding Together consultation.

**4.1 Right Support:**

* Participants wanted better facilities in inpatient settings, including en-suite toilets and private areas for service users and carers to meet.
* They wanted inpatient settings where activities reflected the diversity of their needs including reading, art, games and opportunities to be outdoors.
* The availability of quality information particularly around transition points such as moving in and out of services or between children and adult services was reported as important.
* Targeted support over maintaining quality housing was also stressed by participants. This would help avoid service users being discharged from hospital into unsuitable housing arrangements or becoming homeless.
* Ongoing conversations over mental health ‘recovery’ were reported as important in developing hope for both carers and service users.

**4.2 Right Place:**

* When considering the three presented scenarios the general theme from this qualitative data indicates that the option of services being delivered from Morpeth received little support and that participants generally wanted to have services delivered close to their place of residence.
* Participants overall wanted an increase in investment in community mental health services. Where this worked well intervention was ‘recovery’ orientated.
* A recognition is needed of the time and cost implications for travelling to and from services. This was seen as having a direct effect on the frequency and length of visits that carers could make to service users.

**4.3 Right Time:**

* Continuity of care and the benefit of having one professional who steers people through the service was important to achieving joined up services.
* The importance of having a good GP particularly from the outset of becoming unwell was also stressed.
* At transition points such as moving between children and adult services extra support and information was valued.

**4.4 Right Values:**

* One of the biggest concerns of both service users and carers was not being listened to by services.
* The different mental health teams and inpatient services need to communicate effectively with each other. Participants reported different services not informing each other of changes to service users’ care and even services being in conflict.
* Continuity of care provided by both staff and services was also important to participants.
* The values of staff were seen as key, in particular clearly articulated respect and empathy.

**4.5 Limitations of Work:**

The sample of 18 participants is relatively small given the locality and population and cannot be considered to represent adequately all the localities and groups of carers and service users. Four participants have been sampled from the same inpatient service which may have skewed some of the responses.

1. **Appendix**

**5.1 Scenarios:**



**Scenario N**

**NTW Trust Wide Acute Patient Services Based At:**

**St Nicholas’ Hospital Newcastle**

**Rehabilitation Services Based At St Nicholas’ Hospital Newcastle**

**And Elm House Gateshead**

* The adult acute assessment and treatment service (three wards) for Newcastle and Gateshead residents being provided from St Nicholas Hospital, Newcastle.
* The rehabilitation ward at St Nicholas Hospital, Newcastle would provide complex care and Elm House in Gateshead would be retained as a moving on rehabilitation unit.

**Comments:**



**Scenario G**

**NTW Trust Wide Acute Patient Services Based At:**

**Gateshead**

**Rehabilitation Services Based At Elm House Gateshead**

* The adult acute assessment and treatment service (three wards) for Newcastle and Gateshead residents being provided from a location to be identified in Gateshead.
* A complex care rehabilitation ward would also be provided at the same location. Elm House in Gateshead would be retained as a moving on rehabilitation unit.

**Comments:**

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**Scenario T**

**NTW Trust Wide Acute Patient Services Based At:**

**St George’s Park Morpeth**

**and**

**Hopewood Park Sunderland**

**Plus**

**Rehabilitation Services at Gateshead**

* The adult acute assessment and treatment service for Newcastle and Gateshead residents being provided from NTW’s hospital at St George’s Park, Morpeth (two additional wards to be provided there) and from NTW’s hospital at Hopewood Park, Sunderland (one additional ward to be provided there).
* The rehabilitation service currently at St Nicholas Hospital, Newcastle being provided from St George’s Park; Elm House in Gateshead would be retained as a moving on rehabilitation unit.

**Comments:**



**Scenario 1**

**Older Peoples Services Provided from St Nicholas’**

**Hospital Newcastle**

**Comments:**



**Scenario 2**

**Older Peoples Services Provided from St George’s Park Morpeth**

**Comments:**

**5.2 Interview tools:**

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***Deciding Together Evaluation***

**Carer Version**

**Interview Topic Guide**

**Preamble:**

Deciding Together is about getting your views on what’s important in local mental health services, how they can be delivered in a better, more effective way to help people **recover sooner**. The Newcastle and Gateshead Clinical Commissioning Group who manage the area are aware that services need to change. In particular the improvement to both the environment and accommodation that is required by service users and carers. In addition they want to **invest more in community services** and need help in creating better ways to offer support. We work for Northumbria University and plan to carry out 25 in depth interviews with service users and carers like yourself. These interviews will provide a source of evidence for recommendations for improvements in the final report by the Commissioning Support Group.

**What’s happened so far?**

* Work started back in July 2014
* They listened to the public, service users, carers, NHS and social care professionals, the voluntary and community sector, elected members and members of the public
* Specialist services were discussed including those for more complex mental health conditions like severe depression, schizophrenia, psychosis and personality disorder
* A dedicated listening exercise ‘Deciding Together’ ran from November 2014 to February 2015
* Introduced a new way to engage local people in these complex issues by giving them the opportunity to step in the shoes of health commissioners through two participatory budgeting events called “how to spend the mental health pound”
* Feedback was published in March 2015 (on the Deciding Together website).
* This feedback combined with clinical evidence and best practice information will inform different ways that in-patient and community mental health services could be arranged in the future – these are called scenarios and are set out on the **accompanying material** which we will show you later.

*Some of the following questions may be difficult to answer either because you haven’t thought about them before or you have just forgotten what happened. Don’t worry about this, please just tell us if you either don’t understand or are feeling confused by the question. If there are any questions you can’t or don’t want to answer, just say so. If you want to stop the interview for a break at any time, please let us know. There is a lot of ground to cover and we have a lot of information to get through and you may have a lot to say about some questions. We are also only interested in your experience of supporting someone using services in the last 3-5 years. We don’t want to take up too much of your time so please don’t be offended if we interrupt you at any point. Your questions will probably come up later in the interview.*

*Are you happy to give us/me a little bit of information about your experiences?*

*Some of the questions are open questions and some just require a yes /no answer.*

1. **Personal history of supporting someone using mental health services**

* How long ago did you the person you care for start using services?
* 1-4 years 5-9 years 10-14 years 15+ years
* Which services have they used in the last 3-5 years?
  + Name of services
* Do you feel their physical health has been taken care of within mental health services? Yes No
* Do you feel that the service has been respectful of their religious and or cultural beliefs? Yes No
* Have they used community services including the voluntary sector e.g.

MIND; voluntary support groups, Tyneside Women’s Health as well as NHS services e.g. Care Coordination; CPN; CMHT?

* + Names of services

1. **Community services - these are services outside hospital e.g. CMHT or voluntary services (Relevant only if the service user has used community services).**

We’d like to ask you about your experiences of the person you care for using community services and what your views are of these services.

You have told us that they have used……………….. [Name of community services]:

1. In your opinion, could you briefly tell me a bit more about how using these services affected/affects the life of the service user?

Prompts:

* + Which professionals has the person you care for seen?
  + What treatment options were they given?
  + What treatments did they receive?/ are they receiving?
  + Do you think professionals spent too much or too little time with them?
  + Do you think that professionals were involved at the right time or do you think the person you care for should have been provided with support earlier or later?
  + Did these treatments help them - how?
  + Was there anything this treatment helped them do that they couldn’t do before?
  + Would they have liked to have access to treatments that they weren’t offered?

b) Could you briefly tell me how your life was affected while the person you care for was using these services?

* Were there implications for other members of the family?
* Were there things that you stopped doing or needed to start doing?
* What support were you offered?
  + What support would you like to have been offered?

What is particularly important to you about the services in the community the person you care for has received?

In terms of ‘community services’ how do you think things could be done better in the future?

Can you pick one of the community services you have mentioned and tell us about **communication between staff and the person you care for**. We will talk about how people communicated with you later in the interview.

Prompts:

* If this was a good experience - why did it work well?
* If it was a difficult experience - why did it not work well?
* Do you think the person you care for felt in control of their care and the planning of their future?
* Did everything that was happening in their care make sense to them and to you?
* Do you think people explained things to them in a way that they could understand?
* How easy was it for them to access help and support when they needed it? What means of communication works/would work best for them? (e.g. texting, email, phone etc.)
* Has the idea of ‘recovery’ been discussed with both the person you care for and yourself? If so what was talked about?

Did the person you care for have similar experiences when they used other community services, or were their experiences different? If so, in what way were they different?

**2) Transition between child and adult services**

a) Does the person you care for have any experience of the move between children and adult services in the last 3-5 years?

Yes please go to next questions

No please go to question (b i)

**If yes**, what was it like?

i) Reflecting on their experience of requiring mental health support or services during adolescent years, how do you feel we could improve services?

* + What would have helped them in moving into adult care?
  + What would have helped them to manage their condition and support their recovery?
  + What advice would you give to a carer of a young person who is moving into adult services?
  + Is there anything about the location of services that works well or not?

ii) Did you feel that the person you care for needed help as a young person and didn’t receive it?

b) **If no**

i) What advice would you give to the carer of a young person who is moving into adult services?

ii) Did you feel that the person you care for did need help as a young person and didn’t receive it?

1. **Adult inpatient services (Gateshead and Newcastle)**

(This is a question both about the geographical location and also the model of care that works best)

Has the person you care for used any (one or all) of the following inpatients services? YES

1. The Tranwell Unit, Queen Elizabeth Hospital Gateshead
2. The Hadrian Clinic, Newcastle General Hospital
3. St Georges Park in Morpeth
4. Hopewood Park in Sunderland
5. Have they ever had to use services outside the North East in the past 5 years? Yes No

Prompts:

In choosing the service where you felt the person you care for was the most comfortable, in your opinion:

* What was it that worked particularly well? e.g. relationships, communication, process, opportunities, environment, access to staff and therapy, privacy, safety etc.

If we look at the service where they were least comfortable:

* What could have made it better?
* Were the services in the right location for you, other family members and friends?

What was your experience of the continuity of care e.g. between inpatient units; inpatient and community services?

What is the most important change you would like to make to in-patient services?

1. **Places of safety**

Has the person you care for ever become unwell in public? Have they ever been under a 136 section (taken to a place of safety?) Where were they taken?

Prompts:

* From your perspective, what was their experience of those services e.g. Section 136 suite at the Tranwell Unit in Gateshead and St Nicholas’ Hospital in Newcastle or another setting?
* When they have become unwell in public, what would have helped?

Has the person you care for had any experience of feeling ‘vulnerable’ in public and needed help from the police or ‘street triage’ services?

* What did help or would have been more help to them and to you in this situation?

At these times, what is particularly important to you as a carer about care and services?

1. **Speciality services**

Has the person you care for used any of the following services?

* The Psychiatric Intensive Care Unit (PICU)
  + If so, what worked well for them when they used this service and what could be improved?
* Have they used the rehabilitation service for people with complex mental health needs including:
  + Male and female high dependency units.
  + Longer term complex care rehabilitation units.
  + Moving on units.
  + Community rehabilitation services.
  + Other rehabilitation service …………………..
  + Have they had any experiences of moving between working age adult services and specialist services? When was this?

How can things be done differently in these services in the future?

1. **Transport and travel**

(These are questions about transport and travel in relation to the person you care for and yourself/other family members/ friends.)

* How does/ did the person you care for travel to services?
* Did they need to travel during their time as an inpatient?
* As a carer were you, other family members and friends able to visit easily?
* How did you travel?
* How can people be better supported if they need to travel to an in-patient service? (this includes both service user and family/other supporters)
* How did the person you care for travel home at the end of their stay in hospital - what worked well/what could have been done differently?
* Have you as a carer been given information about claiming your travel expenses back, have there been any particular issues for you, other family members and friends? If so what?
* What if any was the impact of travelcostson you/ family/friends/other supporter’s being able to visit you?

Is there anything else that is particularly important to you about transport and travel?

Prompts: issues of visiting, arranging leave and discharge.

How can things be done differently in future as far as transport is concerned?

1. **Keeping in touch with the person you care for**

How easy was it for you/family /friends and the person you care for to spend time together when you visited?

* What facilities were provided?
* What facilities would you have liked?
* Why are these important to you? e.g. how the availability of facilities affected the relationship

How easy has it been to keep in touch with the person you care for whilst they have used services?

* Was it difficult or easy for you to visit?
* What would have made it easier?

How easy has it been for you/ family and friends to contact staff?

* How happy were you with the way that staff communicated with you/ family/friends?

Did the person you care for feel included in discussions with family and friends? Also, did they feel included when family or friends talked to professionals? If not, what were the reasons for this?

1. **Final question - bringing it all together**

*Evaluator summary:*

Could we briefly summarise what we have talked about before:

It sounds like the important issues for you in caring for someone who is using services have been……….and what didn’t work well for you at that time was …………and would have been helpful for you at that time was ………….

Is there anything important that we haven’t talked about that you think would help improve future mental health services in Newcastle and Gateshead? Such as

* The sharing of information?
* Helping the person you care for get back into community life?
* Helping the person you care for get into employment?

Bringing it all together, could you tell us in just a few words what a ‘good service’ would look like for you and what needs to remain and what needs to change in local services?

**Scenarios**

The commissioners in Gateshead and Newcastle are proposing some scenarios for the future of mental health services in Gateshead and Newcastle. They would like to know your views on which scenarios you would prefer and why?

(Refer here to the scenarios T, N and G plus scenarios 1 and 2 as prompts)

**Is there anything else you would like to add?**

**Thank you for your time.**

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***Deciding Together Evaluation***

**Service User Version**

**Interview Topic Guide**

**Preamble:**

Deciding Together is about getting your views on what’s important in local mental health services, how they can be delivered in a better, more effective way to help people **recover sooner**. The Newcastle and Gateshead Clinical Commissioning Group who manage the area are aware that services need to change. In particular improvement to both environment and accommodation is required by service users and carers. In addition they want to **invest more in community services** and need help in creating better ways to offer support. We work for Northumbria University and plan to carry out 25 in depth interviews with service users and carers like yourself. These interviews will provide a source of evidence for recommendations for improvements in the final report by the Commissioning Support Group.

**What’s happened so far?**

* Work started back in July 2014
* They listened to the public, service users, carers, NHS and social care professionals, the voluntary and community sector, elected members and members of the public
* Specialist services were discussed including those for more complex mental health conditions like severe depression, schizophrenia, psychosis and personality disorder
* A dedicated listening exercise ‘Deciding Together’ ran from November 2014 to February 2015
* Introduced a new way to engage local people in these complex issues by giving them the opportunity to step in the shoes of health commissioners through two participatory budgeting events called “how to spend the mental health pound”
* Feedback was published in March 2015 (on the Deciding Together website).
* This feedback combined with clinical evidence and best practice information will inform different ways that in-patient and community mental health services could be arranged in the future – these are called scenarios and are set out on the **accompanying cards** which we will show you later.

*Some of the following questions may be difficult to answer either because you haven’t thought about them before or you have just forgotten what happened. Don’t worry about this, please just tell us if you either don’t understand or are feeling confused by the question. If there are any questions you can’t or don’t want to answer, just say so. If you want to stop the interview for a break at any time, please let us know. There is a lot of ground to cover and we have a lot of information to get through and you may have a lot to say about some questions. We are also only interested in your experience of using services in the last 3-5 years. We don’t want to take up too much of your time so please don’t be offended if we interrupt you at any point. Your questions will probably come up later in the interview.*

*Are you happy to give us/me a little bit of information about your experiences?*

1. **Personal history of using mental health services**

* When did you start using services?
* 1-4 years 5-9 years 10-14 years 15+ years
* Which services have you used in the last 3-5 years?
  + Name of services
* Have you used community services including the voluntary sector e.g. Mind; voluntary support groups, Tyneside Women’s Health as well as NHS services e.g. Care Coordination; CPN; CMHT?
  + Names of services
* Do you feel your physical health has been taken care of? Yes No
* Do you feel that the service has been respectful of your religious and or cultural beliefs? Yes No

1. **Community services - these are services outside hospital e.g. CMHT or voluntary services (Relevant only if the person has used community services).**

We’d like to ask you about your experiences of using community services and what your views are of these services.

You have told us that you have used……………….. [Name of community services]:

a) Could you briefly tell me a bit more about your experiences of using these services?

Prompts:

* + What information were you given?
  + Which professionals have you seen?
  + What treatment options were you given?
  + What treatments did you receive?
  + Do you think professionals spent too much or too little time with you?
  + Were they provided at the right time or do you think they should have been provided earlier or later?
  + Did these treatments help you - how?
  + What were you able to do that you couldn’t do before?
  + Would you have liked to have access to treatments that you weren’t offered?

What is particularly important to you about the services in the community you received?

In terms of ‘community services’ how do you think things could be done better in the future?

Can you pick one of the community services you have mentioned and tell us about your experiences around **communication with staff**?

Prompts:

* If this was a good experience - why did it work well?
* If it was a difficult experience - why did it not work well?
* Did you feel in control of your care and the planning of your future?
* Did everything that was happening in your care make sense to you?
* Did people explain things to you in a way that you could understand?
* How easy is it for you to access help and support when you need it? What means of communication works/would work best for you? (e.g. texting, email, phone etc.)
* Has the idea of ‘recovery’ been discussed with you? If so what did you talk about?

Did you have similar experiences when you used other community services, or were your experiences different? If so, in what way were they different?

**2) Transition between child and adult services**

a) Do you have any experience of the move between children and adult services in the last 3-5 years?

Yes please go to next questions

No please go to question (b i)

**If yes**, what was it like?

i) Reflecting on your experience of requiring mental health support or services in your adolescent years, how do you feel we could improve services?

* + What would have helped you in moving into adult care?
  + What would have helped you to manage your condition and support your recovery?
  + What advice would you give to a young person moving into adult services to ensure they have a good experience?
  + Is there anything about the location of services that works well or not?

ii) Did you feel that you did need help as a young person and didn’t receive it?

b) **If no**

i) What advice would you give to a young person moving into adult services to ensure they have a good experience?

ii) Did you feel that you did need help as a young person and didn’t receive it?

1. **Adult inpatient services (Gateshead and Newcastle)**

(This is a question both about the geographical location and also the model of care that works best)

Have you used any (one or all) of the following inpatients services?

1. The Tranwell Unit, Queen Elizabeth Hospital Gateshead
2. The Hadrian Clinic, Newcastle General Hospital
3. St Georges Park in Morpeth
4. Hopewood Park in Sunderland
5. Have you ever had to use services outside the North East in the past 5 years? Yes No

Prompts:

In choosing the service where you were the most comfortable:

* What was it that worked particularly well? e.g. relationships, communication, process, opportunities, environment, access to staff and therapy, privacy, safety etc.

In choosing the service where you were least comfortable:

* What could have made it better?
* Were the services in the right location for you and your family?

What is the most important change you would like to make to in-patient services?

1. **Places of safety**

Have you ever become unwell in public? Have you ever been under a 136 section (taken to a place of safety?) Where were you taken?

Prompts:

* What was your experience of those services e.g. Section 136 suite at the Tranwell Unit in Gateshead and St Nicholas’ Hospital in Newcastle or another setting?
* When you have become unwell in public, what would have helped?

Have you had any experience of feeling ‘vulnerable’ in public and have needed help from the police or street triage services?

* What did help or would have been more help to you in this situation?

At these times, what is particularly important to you about care and services?

1. **Speciality services**

Have you used any of the following services?

* The Psychiatric Intensive Care Unit (PICU)
  + If so, what worked well for you when you used this service and what could be improved?
* Have you used the rehabilitation service for people with complex mental health needs including:
  + Male and female high dependency units.
  + Longer term complex care rehabilitation units.
  + Moving on units.
  + Community rehabilitation services.
  + Other rehabilitation service …………………..
  + Have you had any experiences of moving between working age adult services and specialist services? When was this?

How can things be done differently in these services in the future?

1. **Transport and travel**

(These are questions about transport and travel, but we are also interested in how this impacts on being able to keep in touch with your family/friends/other supporters. All participants should have used inpatient services).

* How do you/did you travel to services?
* Did you need to travel during your time as an inpatient?
* Did your family or friends manage to visit you easily? How did they travel?
* How can people be better supported if they need to travel to an in-patient service? (this includes both service user and family/other supporters)
* How did you travel home at the end of your stay in hospital - what worked well/what could have been done differently.
* Have you been given information about claiming your travel expenses back, have there been any particular issues for you or your family and friends? If so what?
* What if any was the impact of travelcostson family/friends/other supporter’s being able to visit you?

Is there anything else that is particularly important to you about transport and travel?

Prompts: issues of visiting, arranging leave and discharge.

How can things be done differently in future as far as transport is concerned?

1. **Keeping in touch with family and friends**

How easy has it been to keep in touch with family and friends whilst you have used services?

* Was it difficult or easy for your family and friends to visit you?
* What would have made it easier?

How easy has it been it for your family and friends to contact staff – have there been any other issues your family and friends have commented on?

* Have you been happy with the way that staff communicated with your family - if this was your choice?

Have you felt included when staff and family have been communicating with each other about you?

1. **Final question - bringing it all together**

*Evaluator summary:*

It sounds like the important issues for you in using services have been……….and what didn’t work well for you at that time was …………and would have been helpful for you at that time was ………….

Is there anything important that we haven’t talked about that you think would help improve future mental health services in Newcastle and Gateshead? Such as

* The sharing of information?
* Helping you get back into community life?
* Helping you get into employment?

Bringing it all together, could you tell us in just a few words what a ‘good service’ would look like for you and what needs to remain and what needs to change in local services?

**Scenarios**

The commissioners in Gateshead and Newcastle are proposing some scenarios for the future of mental health services in Gateshead and Newcastle. They would like to know your views on which scenarios you would prefer and why?

(Refer here to the scenarios T, N and G plus scenarios 1 and 2 on cards as prompts)

**Is there anything else you would like to add?**

**Thank you for your time.**