



# Experiences of mental health services in Newcastle and Gateshead

## About Healthwatch Newcastle and Healthwatch Gateshead

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

We collect feedback on services from people of all ages and from all communities. We do this through our network of voluntary and community sector organisations; during events, drop-in sessions and listening events; online through the feedback centre on our websites; via social media and from callers to our information and signposting phonenumber. As part of the remit to gather views, we also have the power to 'enter and view' services and conduct announced and unannounced visits.

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Publication date: April 2019

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# Contents

1. Introduction.....	1
2. Methodology .....	2
3. Findings.....	4
4. Conclusion and recommendations.....	13
General recommendations .....	13
Specific recommendations.....	14
5. Acknowledgements .....	15
Contact .....	16

# 1. Introduction

Healthwatch Newcastle and Healthwatch Gateshead shortlisted mental health as a potential priority area for 2018–19 for the following reasons:

1. When we consult on our priorities for the coming year, mental health always scores very highly.
2. We believe our research in this area will complement the information already gathered as part of the ongoing review of mental health services.
3. It provides an opportunity for Healthwatch to be further involved in that review.
4. Our key remit is to ensure that all service users and the public are involved in the ongoing development of health and care services, especially those who may struggle to have a voice or to get involved.

A prioritisation exercise took place during spring 2018, consisting of a public survey and a prioritisation activity at our annual conference in April 2018. Members of the public and our stakeholders considered this subject to be the top priority for both Healthwatch.

We decided to concentrate on gathering the views and experiences of groups or communities who had not been involved, or had only had limited involvement, in recent reviews of local mental health services ('Deciding Together, Delivering Together' and 'Expanding Minds, Improving Lives'). Following consultation with partner organisations and mental health specialists, it became apparent that we could have chosen many different groups. However, we wanted to get a good spread of views from different types of communities and the groups we decided to focus on were:

- Lesbian, Bisexual, Gay and Transgender (LBGT) community
- Veterans
- African/Caribbean community
- Students in higher education
- People who are homeless/living in insecure accommodation
- People in receipt of Universal Credit

We chose these particular groups because we knew through our own involvement in the mental health consultations, and through talking to colleagues in the public and voluntary and community sectors, that these groups had been under represented in the engagement and consultations so far. Also, they are groups of people who can struggle to have their voice heard more generally.

We undertook some of the research ourselves but also offered local organisations the opportunity to apply for a small grant of up to £1,000 to enable them to carry out work on our behalf. This allowed us to hear the views of people and groups that Healthwatch would otherwise have struggled to engage with within the limited time scale of this project.

The organisations that worked with us as partners on this project were:

- Changing Lives, through the Fulfilling Lives Newcastle Gateshead programme, which focussed on people who are homeless or living in insecure accommodation.
- Forward Assist, which focussed on veterans.
- Citizens Advice Gateshead, which looked at people claiming Universal Credit.

Consultations with the LGBT community and the African/Caribbean community were carried out by Healthwatch Newcastle. A third-year student on placement from Northumbria University carried out a consultation with students in higher education.

For comparative purposes, we decided to ask all participants in the research the same series of short open questions. Answers to these questions were gathered through a variety of methods including focus groups, structured one-to-one interviews, online surveys, creative data capture and peer research. All participants were asked:

1. What are your experiences of trying to get help with your mental health?
2. If you managed to get help, what sort of help did you get and how effective was it?
3. What could have made things easier or better for you?
4. Choose three words that describe what a first-class mental health service would look like to you.

We hope that this qualitative approach, focusing on service user experience, will provide constructive insights into any emerging issues across communities or specific to certain groups and that these, plus our resulting recommendations, will feed into the ongoing review of Newcastle and Gateshead mental health services.

## 2. Methodology

Because we were quite prescriptive about the questions that we wanted to ask, we were keen that the organisations carrying out research on our behalf chose their own methodologies, which were appropriate to their client group and their circumstances. This was something we asked about in the grant application process and discussed with shortlisted applicants when they later presented their ideas to us. Consequently, we were satisfied that a wide variety of research methods were used to gather the information. Details on the research methods can be viewed in the individual ‘mini project’ reports from each organisation<sup>1</sup>. However, in brief:

- The Fulfilling Lives Newcastle Gateshead ‘Experts by Experience’ group carried out peer research with people who were homeless/living in insecure accommodation. A number of different techniques were used, including one-to-one interviews, focus groups and creative data capture, where art-based methods were used to secure visual responses to the questions.

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<sup>1</sup> [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports)

- We decided that the most effective way to consult with a large, diverse and dispersed LGBT community would be via an online survey. We sent the survey, plus an explanatory email, to 14 different organisations, networks and key individuals, asking them to circulate and promote it.
- Forward Assist chose to run two focus groups split by gender. This was because many of the female veterans stated that they felt vulnerable around their male counterparts. The focus groups incorporated creative data capture techniques including a ‘views tree’ and a ‘recommendations light bulb’.
- We worked with a voluntary organisation called ACANE (African Community Advice North East) and, with their support, offered a focus group for members of the African/Caribbean community. Healthwatch staff also carried out a further small group discussion and two home visits where one-to-one interviews took place.
- Students in higher education were offered an online survey and invited to attend a focus group. As expected, the online survey proved to be the most effective way of gathering information from this group of mostly young people. No students took up the offer of the focus group.
- Citizens Advice Gateshead chose to ask the survey questions during their one-to-one advice sessions with clients. Clients had previously been identified as facing challenges associated with Universal Credit and had responded positively to enquiries about their mental health.

Each piece of work aimed to consult with 20 individuals. However, because of the different methods chosen, the different sizes of the populations concerned, and the differing capacities of the organisations and individuals involved, the numbers of responses gathered varied quite widely across the groups.

Group	Numbers of responses
Homeless/insecure accommodation	23
LGBT	32
Veterans	30
African/Caribbean	14
Students	13
Universal Credit	27
<b>Total number of responses</b>	<b>139</b>

While the total of 139 responses is significantly above our target of 120 across the six mini projects, we acknowledge that this is still a very small sample size. Therefore, we cannot say that findings are a true reflection of the experiences of all the people from these particular communities who have accessed local mental health services. What we can say are they are the views, experiences and issues identified by the 139 people involved.

The partner organisations were asked to produce a short report detailing their findings<sup>2</sup>. All the information contained in the reports and shared with Healthwatch is anonymous and non-identifiable.

The purpose of this particular report is to provide an overview of the whole research project, to pull together the findings from the six mini projects and identify any issues, either across all communities or specific to certain groups, and to make recommendations for improvements.

Everyone who completed surveys or who was involved in the research was also asked to complete a Healthwatch monitoring form. Not all participants chose to do this but where information is available it has been included in the project reports. From the information available it is possible to say that most of the mini projects recorded a good gender mix, that the most common age banding of respondents was 25–49, and that there was a good range of Newcastle and Gateshead residents for those projects where this was relevant. There were also people who, while they were involved because they identified as representative of a particular group, also identified as representative of other groups included in this work, for example, an LGBT student.

The project as a whole was co-ordinated by a project manager who developed and promoted the small grants scheme, and engaged with and supported successful applicants. She also project managed the work carried out internally, supervised the student on placement, and was responsible for the production of this final report.

### 3. Findings

We reviewed and collated the results from all six mini projects and looked for common themes. Where significant, we also identified issues specific to particular groups. For a more detailed analysis of the findings of each of the mini projects, please look at the individual project reports at [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports).

As mentioned above, participants across all the projects were asked the same four questions:

1. What are your experiences of trying to get help with your mental health?
2. If you managed to get help, what sort of help did you get and how effective was it?
3. What could have made things easier or better for you?
4. Choose three words that describe what a first class mental health service would look like to you?

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<sup>2</sup> See [www.healthwatchnewcastle.org.uk/about-us/reports](http://www.healthwatchnewcastle.org.uk/about-us/reports)

### 3.1 What are your experiences of trying to get help with your mental health?

This question asked participants to tell us about their experiences of trying to access help. A number of issues were identified by several of the groups participating in the research.

#### Internal barriers

These included people's reluctance or inability to acknowledge or understand that they had a problem, to ask for help with that problem and then to accept the help offered. It also covered people avoiding asking for help because they felt stigmatised or prejudged due to their circumstances or characteristics. It was identified as an issue by four of the groups<sup>3</sup>. People told us:

**“It was very difficult to ask for help in first place due to not recognising I had a mental health issue... didn't want to take up doctor's precious time and my own pride and stigmatising myself. Easy to get appointment at doctors, not so easy for me to accept help/referral/medication, etc.”**

**“Asking for help was extremely difficult, it took me two, nearly three, years.”**

#### Lack of information

This covered a lack of knowledge about what help might be available, how to access it and who might support people to do this. It also covered the quality, accessibility or appropriateness of information provided. It was raised as an issue by four of the groups<sup>4</sup> and for some it was identified as compounding internal barriers:

**“I think that the first step is admitting to oneself, that one needs help, and that can only be helped by knowledge of what support and services are available, and to be honest, finding information on these is not easy.”**

#### Waiting times

Long waiting times were identified as an issue by four groups<sup>5</sup>. People had mixed experiences of trying to access their GP, some very positive, others not so good. Of particular concern was the wait for specialist services which, for some, led to further deterioration in their health or meant that the original treatment plan was no longer appropriate. As one person told us:

**“Usually by the time I am seen it is too late, the damage has been done.”**

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<sup>3</sup> African/Caribbean community, LGBT, students, veterans

<sup>4</sup> African/Caribbean community, LGBT, students, Universal Credit

<sup>5</sup> LGBT, students, Universal Credit, veterans

Another explained:

“I waited six months for counselling therapy sessions to be set up for me, however at this point I was in an entirely different place.”

### Staff attitudes

This included both medical and non-medical staff and covered lack of compassion and understanding, lack of awareness of the participants’ issues, stigmatising people because of their circumstances and a general lack of respect. It was raised as an issue by three of the groups<sup>6</sup>. Two respondents told us:

“GP does not know what to say to me, I don’t go now.”

“They make you feel like a number in the system rather than a human being – they made me feel like a freak.”

The mini projects also identified issues that were specific to their client groups<sup>7</sup>. Some of the more noteworthy issues highlighted include:

- **Cultural barriers** – this was a particular issue for the African/Caribbean community. All participants felt that in their culture mental health was a taboo subject. No-one admitted to having a mental health problem due to the stigma attached to this. It was seen as a sign of weakness especially among the male population. Furthermore, a person with mental health issues is perceived by other people in the community as lacking support from their family, thereby giving that family a negative reputation. All of this led to a ‘grin and bear it’ approach to mental health.
- **Too complex** – both veterans and those who were homeless or living in insecure housing felt that their issues were ‘too complex’ and that frontline services in particular didn’t know how to deal with them and consequently avoided doing so:

“I told a health professional I was raped ten year ago, I was told it was too complex for her to deal with, they gave me a number to ring instead, I never did.”

People felt stigmatised because of their multiple issues or the complexity of their needs. This was a particular issue for those with a dual diagnosis. As one person told us:

“I sat for an hour... told him about my issues, that I self-harm when I get depressed... they said come back when your treatment’s finished for alcohol use. I felt let down, I haven’t been back to mental health support.”

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<sup>6</sup> Homeless, LGBT, veterans

<sup>7</sup> See [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports) for details.

- **Need to escalate** – for those who were homeless or living in insecure housing, the need to escalate their problem in order to access help was identified as a major issue. People explained how they had to increase the chaos in their lives through self-harm, criminal behaviour or violence in order to get the help they needed.
- **Transport issues** – for people in receipt of Universal Credit, and those who were homeless or living in insecure housing, the cost and/or the difficulties associated with travelling to their GP surgery was another particular issue. People wanted to remain with the GP they felt comfortable with, but a transient and/or cash-strapped lifestyle made this very difficult and meant some people were unable to access help when they needed it. As one respondent told us:

**“I don’t want to change doctors... having to bring it all up again. Sometimes I’d take the tablets cos talking about it all again, like explaining what’s happened to me to get to this, is a big trigger.”**

### **3.2 If you managed to get help, what sort of help did you get and how effective was it?**

With this question we were interested to know what type of help people were getting and also how effective they found it. The most common form of treatment across all participant groups was medication and most, but not all, described their experience of taking medication as positive, especially once any initial dosage problems were resolved. This was followed by talking therapies. However, people’s experiences of talking therapies was much more mixed, with some people describing the experience as very positive, others as much more negative.

A wide range of other treatments, including alternative therapies, were mentioned<sup>8</sup>. For some treatments people generally reported positive results (counselling) while other treatments elicited a more mixed response (group therapy and CBT). Interestingly, several people from different groups stated that self-medication (usually alcohol and/or drugs) was the way they best managed their problems. Others chose more positive types of self-help or paid for private treatment. However, while all who paid for private treatment found this a positive experience, it was clearly not an option available to all respondents.

Compared to the other questions, this question received the most positive responses with a significant minority of people, once they managed to access help, being very happy with the help they received. As one person told us:

**“I accessed counselling a number of times, the help I received was amazing.”**

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<sup>8</sup> See [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports) for details.

Another said:

**“I’m taking part in talking therapy and it’s very beneficial.”**

However, this wasn’t universal and again a number of issues were identified by participants from several of the participating groups.

### **Organisational issues**

These were identified by four of the groups<sup>9</sup> and covered a wide range of issues, such as problems transitioning between services, having to retell their story, people not sharing information or passing on notes and problems accessing effective medication. As one respondent said:

**“I changed surgeries... when I was up the surgery they took us off me pregabalin completely... there was no conversation about why there wasn’t a reduction and the medication was removed.”**

Another respondent told us:

**“I don’t trust seeing a different person each time, no-one reads each other’s notes properly.”**

Within this category, long waiting times were also identified as a significant issue, as one person described it:

**“The waiting times are literally beyond the joke.”**

Another told us:

**“I was referred to another organisation, not NHS, with a huge waiting list. All I wanted was a CPN.”**

### **Staff attitudes**

These were also identified as an issue by four of the groups<sup>10</sup>, while some people spoke very highly of the care and attention they received. As one respondent told us:

**“I am incredibly impressed with the care and attention the GPs took with my husband when he was actively suicidal. The surgery has supported him (and me) through this.”**

Others found staff to be impersonal and difficult to talk to. Some people felt pre-judged because of their past history, others that staff were almost fearful of them because of the complexity of their needs.

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<sup>9</sup> Homeless, LGBT, students, veterans

<sup>10</sup> Homeless, LGBT, students, Universal Credit

Two veterans told us:

“I want to be seen by someone not scared of war and death.”

“Accessing community mental health support in Gateshead was the worst experience of my life... they told me I’m out of their league.”

### Lack of service/choice

Many people had concerns about the lack of choice or lack of an appropriate service. For some this meant only being presented with one option that wasn’t effective; sometimes because it wasn’t appropriate or because there wasn’t enough of it:

“Referred to talking therapies – very difficult for me to attend, it takes courage to do that kind of thing and I didn't have the courage.”

One student told us they received five counselling sessions and felt that they ‘didn’t get to the root of the problem’. Another respondent explained:

“Six to eight hours for a lifetime of trauma and then shut that door, and that’s scary.”

Other people referred to the lack of services with the expertise to deal with their particular issues. A veteran told us:

“I get easily frustrated trying to get people to understand me, more so when they have no training in veterans’ issues.”

One respondent mentioned that there was no specialist NHS help available for LGBT people, and someone else felt that there was a lack of awareness of transgender issues among GPs. The mini projects also identified issues that were specific to their client groups<sup>11</sup>. Some of the more noteworthy issues highlighted include:

- **Language barriers** – this was a particular issue for the African/Caribbean community and resulted in people not accessing the help they needed. One man talked of being offered counselling but did not go because he was not confident with the English language and it would be embarrassing for him. Language barriers also compounded feelings of isolation and ‘not belonging’ experienced by this group, which in turn deterred them from accessing or maintaining treatment and support.
- **Unmet expectations** – people who were homeless or living in insecure housing told us that their experience of talking therapies often did not meet their expectations, which were high because of how the treatment was explained to them. They told us:

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<sup>11</sup> See [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports) for details.

“I got six weeks, maybe eight weeks, I’ve spent a lifetime with this problem, I thought brilliant, someone’s going to sort this out in a matter of weeks!”

“I thought I was going to get cured, this person was going to wave a magic wand, talking therapies, you’ve fought that hard to get help and I had no idea what that even was.”

The experience of being let down when talking therapies failed to meet expectations may have contributed to the feelings of despair and desperation that were particularly highlighted in this group.

- **Handover issues** – for veterans there were significant issues relating to the sharing or handover of information from military to civilian health services. This resulted in GPs being unaware of the patient’s history and circumstances, and veterans having to retell (or not tell) what could be very difficult stories. For some it also led to delayed access to treatment. As we were told:

“No hand over by the MOD has resulted in delayed treatment for me by the NHS.”

“I am sick of being rejected because nothing has been passed over.”

### 3.3 What could have made things easier or better for you?

We were particularly interested to hear what could have made things easier or better for people, both when they tried to access help and when they received treatment. Participants identified the following themes.

#### **Better information**

Knowing what help is available and how to access it would have helped several of the groups. In particular, the African/Caribbean group identified this as a significant issue. As did the LGBT community, which highlighted the need for more LGBT-specific information and support. As one young respondent told us:

“I think more needs to be done to raise awareness of how to get help for mental health issues, preferably in a way that wouldn’t scare off young people identifying as LGBTQ.”

#### **Greater understanding and awareness**

This was identified by all of the groups involved in the research. Within this general heading, the need for more awareness of and openness about, mental health issues was highlighted, and it was recognised that this was needed at a societal level, within health services and within schools.

Greater understanding of people’s particular issues was also raised and was linked to the need for better training:

**“How can you talk to someone who you know has no training?”**

### Shorter waiting times

The need for shorter waiting times was mentioned by four of the groups<sup>12</sup> and while many acknowledged the high demand for services, they felt that waiting times were still too long and were having a detrimental effect on people’s health. As a student told us:

**“Waiting times should be faster for people with self-harm and suicide ideation.”**

Another respondent said:

**“Waiting time has been key this time – it’s really difficult to access the right support at the right time.”**

### Improved systems

Another common theme was the need for improved systems and this was linked to waiting times. There were a number of different suggestions:

- Easier to access, more flexible appointments were mentioned and referred to both primary and secondary services.
- Being able to see a GP or a specialist that people felt comfortable with, or at least someone of their preferred gender, was mentioned by several respondents.
- A more person-driven approach was also raised, as one person told us:

**“Someone coming to the house I think would have helped me sooner. Because I couldn’t leave the house... my mental health got worse and worse.”**

### Someone to talk to

Several of the groups stated that someone to talk to while they waited to access treatment, while treatment was ongoing or as an alternative to more formal treatment, would be of huge benefit. As a member of the African/Caribbean community told us:

**“Just an opportunity to talk to someone and let off steam.”**

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<sup>12</sup> LGBT, students, Universal Credit, veterans

Another respondent stated it didn't need to be in person:

**“There should be a free number, so you don't annoy the 999 people... we don't want to sit in waiting rooms, we want to speak to someone, the right professional – there should be an emergency line for mental health.”**

### **3.4 Choose three words that describe what a first-class mental health service would look like to you?**

Finally, we asked all respondents to identify three words that would describe a first-class mental health service. As well as hearing what specifically would have made things better or easier for people, we were keen to understand what people thought overall about how a first class mental health service should be. We felt that asking people to describe such a service in just three words would give a good overview. The responses reflected the findings described earlier in the report.

Of course, the 139 respondents chose many, many different words. However, three words were mentioned more than any others:

**Understanding**

**Accessible**

**Fast (timely)**

The prevalence of these particular words is perhaps unsurprising considering they have been chosen by communities, many of whom have long experienced both a lack of access and of understanding in their lives.

The next set of words, which were mentioned less often but were still of significance for more than one of the groups were:

**Non-judgemental**

**Listening**

**Person centred**

**Caring/supportive**

We acknowledge that this was a very simplistic approach. Words mean different things to different people at different times, and alone they provide little detail about what people need and want from their local mental health services. However, we hope they give a sense of what the people who were involved in our research believe to be of importance in their mental health services and that this insight is of value to the commissioners and providers of local mental health services.

## 4. Conclusion and recommendations

It is worth mentioning first that a significant minority of respondents reported positive experiences when accessing mental health services and receiving treatment and support. Just under a third of all the responses we received from the LGBT community were positive, and other groups also reported positive experiences. As one respondent told us at the end of their survey:

**'I think the NHS is a fantastic service and they are doing their absolute best, they just need more support and funding from central government. I would happily pay a higher tax rate to make sure the NHS remains accessible.'**

However, a number of key issues emerged from the surveys and we have based our recommendations around them. The four main recommendations are relevant for all of the groups that were involved in the research. We have also included some specific recommendations for particular groups, taken from the reports of the relevant mini projects. Not all of the mini project reports included recommendations as this was not required in the specification, however, you can read recommendations where they were provided at [www.healthwatchnewcastle.org.uk/mental-health-mini-reports](http://www.healthwatchnewcastle.org.uk/mental-health-mini-reports).

### General recommendations

We recommend that providers and commissioners of local mental health services work with the local community and, in particular, the groups who took part in this research to:

1. Provide accessible and inclusive information about what constitutes mental wellbeing and about the mental health services that can help people attain it. This information should be available in a variety of languages, formats and in a wide range of community locations, including schools. Where appropriate, group-specific information should also be available.
2. Ensure that all staff receive the training they need to guarantee that patients are treated appropriately for their condition and circumstances, and with respect and understanding. In particular, GPs and mental health specialists need to be aware of the specific issues and needs of the different communities that took part in this research.
3. Investigate ways to reduce waiting times and/or to reduce the negative impact of long waiting times on service users. This should include providing more flexible appointments in more accessible venues/locations and at times which better suit people's needs.
4. Develop a service that can ensure that people have someone to talk to informally while they wait to access treatment, while treatment is ongoing, and after treatment; or as an alternative to more formal treatments.

## Specific recommendations

We recommend that providers and commissioners of local mental health services work:

With people who are homeless or living in insecure accommodation:

- And their colleagues in drug and alcohol services, to ensure that services are inclusive for people with trauma histories and coexisting mental health and substance use issues. This inclusivity should include opportunities for joint staff training and cover timeliness of support, accessible information and support, information which appropriately prepares people for treatment, and the widening of service thresholds to support people with multiple and complex needs.

With the African/Caribbean community to:

- Ensure that steps are taken to support this community to recognise the triggers and early signs of mental health issues. This should include practical advice, opening up the lines of communication and working towards breaking down the stigma attached to mental ill-health. In particular, there is a need to work with the community to help provide safe spaces for men to talk through their issues.

With the LGBT community to:

- Ensure that people can always choose whether they see a male or female professional and can have access to specialist services where this is appropriate.

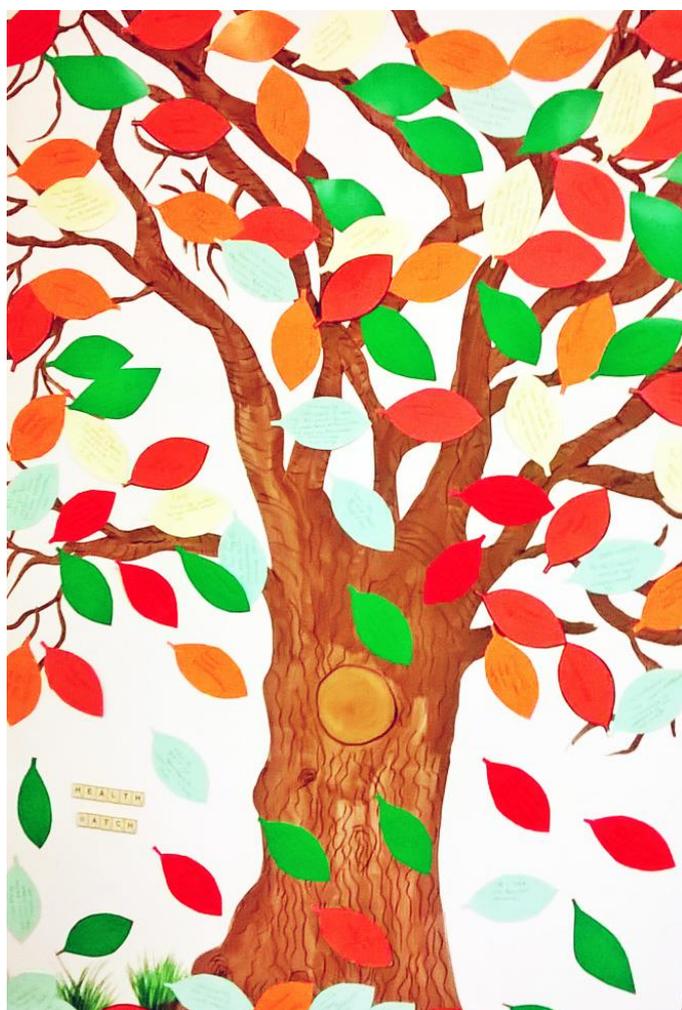
With veterans to:

- Provide for the mandatory inclusion of a question about previous military service at the assessment stage of any treatment. This will allow civilian health and social care organisations to better understand the issues veterans face. It will ensure a more effective assessment of veterans needs by 'flagging up' the possibility that the presenting behaviour or issues may be directly related to past military service or the transition from it.

## 5. Acknowledgements

Healthwatch Newcastle and Healthwatch Gateshead would like to thank all those individuals who took the time to share their experiences of and views about local mental health services. We would also like to thank Forward Assist, Citizens Advice Gateshead and Fulfilling Lives Newcastle Gateshead<sup>13</sup>, who carried out the research on our behalf and encouraged people to take part. Their involvement has brought Healthwatch an unprecedented depth and breadth of knowledge and understanding.

Finally, we extend particular thanks to Leigh Jones, our student on placement, who carried out the research with university students, and Sheila Blatchford, the 'Expert by Experience' from Fulfilling Lives Newcastle Gateshead, who co-led that piece of work. You both did a wonderful job in challenging circumstances.



Forward Assist's 'views tree', used to research veterans' views

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<sup>13</sup> Forward Assist [www.forward-assist.com](http://www.forward-assist.com)

Citizens Advice Gateshead [www.citizensadvicegateshead.org.uk](http://www.citizensadvicegateshead.org.uk)

Fulfilling Lives Newcastle Gateshead <http://fulfillinglives-ng.org.uk>

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