



Investigating Patient Experiences of Accessing Mental Health Services

August 2016

Background Information

Patients frequently see their GP as the starting point to getting help with a mental health problem. To access a number of mental health services, patients often require a referral from a health or social care professional. Referrals between services often involves long waiting times from the time of referral to an initial assessment and then an additional wait to begin treatment. This can often be frustrating for all involved. Some services allow for self-referral, which means that the patient can contact them directly without needing to speak to their GP. In the Tees area there are currently a number of voluntary services allowing both GP and self-referral.

It has been brought to the attention of Healthwatch that the number of referrals made via GP's in the Middlesbrough, Stockton and Redcar & Cleveland area are declining, causing concern for patients who are requiring these services. In addition to this, there have been a number of changes to mental health services in the area with Tees, Esk and Wear Valley no longer providing Improving Access to Psychological Therapies (IAPT) services in the Tees area. This is believed to be causing an increase in waiting times for the other IAPT service providers as they take the strain of the changes.

Rationale for Investigation

Following Healthwatch's 'Shaping Mental Health Services Together' event, a range of comments and concerns were received from those who attended regarding current mental health service provision.

Long waiting times to access services was found to be a major concern. There is the feeling that there are some gaps between services which need bridging with a sharing of information with regards to what's available and where the services can be found, in particular with GP's as this is usually a patient's first point of contact. In addition to this, it was felt that some doctors are not listening to their patients and find it is 'too easy to just give medication'. There is a need to improve inter-departmental communication to prevent patients having to repeat 'their story' more than once.

It was felt that there is no awareness and little promotion of mental health services for those in the community, which should not just be targeted to those who have a mental health condition. There appears to be a lack of choice and information available with barriers to accessing services e.g. the language used.

Concerns were expressed by those who have accessed mental health services in all three areas regarding the lack of prevention services due to limited resources. There are also barriers to accessing services especially for patients who have sensory or learning disabilities e.g. autism and those who find it difficult to interpret information.

Following this feedback, Healthwatch decided to carry out further research into these particular highlighted issues.

Methods

A qualitative research project was carried out which involved a questionnaire being created from prior research investigating mental health services. An online link was generated and advertised on the Healthwatch website, Facebook and Twitter pages. In addition to this, paper copies were sent to various mental health organisations and the local hospitals. After participants had completed and returned the questionnaire a thematic analysis was undertaken to discover emerging patterns. Any themes or gaps found in the data formed the basis of the questions for some focus groups.

Participants were recruited for a focus group through various methods, such as being invited through the Healthwatch social media pages, the Healthwatch newsletter, Healthwatch annual event and through other organisations who attended the event such as Saltburn Well-being Centre, IAPT services and Healthwatch volunteers. Participants had the choice of focus groups in two locations and were asked to attend one. The focus groups lasted approximately two hours each, after this the data obtained was then analysed.

Questionnaire Results

A total of 44 participants completed the questionnaire, five male, 37 female and one who wished not to disclose gender. They were aged at least 16 years, the median being 45 to 59 (34%). Local authority areas of residence were Middlesbrough (32%), Stockton (25%), Redcar and Cleveland (25%) and other North Eastern LA areas (18%). Most participants completed the questionnaire themselves (86%), while a further 14% completed it on behalf of a family member.

Results from the questionnaire, which aimed to investigate patient experience of accessing mental health services, found that the majority of participants were currently accessing mental health services. The remaining participants had previously accessed mental health services. Participant comments suggested that barriers such as waiting times, awareness and the length of sessions affected their accessibility to the relevant services.

GP referrals were revealed to be the most popular amongst participants. It is clear from results that GP's serve an important role in a patient's awareness of mental health services, as some participants stated they had made a self-referral after contact with their GP. However, other professionals are equally as likely to impact on a person's access to mental health services. Various participants suggested that employers, the crisis team and hospital staff had all aided their referral to the appropriate services.

The largest service accessed most by patients was MIND, which was accessed significantly more often than Alliance and Starfish. None of the participants completing the questionnaire had accessed any services or treatments provided by Insight.

Upon accessing mental health services most participants felt pleased with the information provided to them, although it was stated that on occasions information could have been made clearer with regard to waiting times and the length of sessions. Although a high percentage of participants did receive an initial assessment call, some did not and others were unsure.

A large number of participants suggested that the referral process was good, however very few would rate it as being excellent. Many felt that there could be further improvements.

The average number of sessions available to patients is between six and 10, although a quarter of participants received less than six and a quarter received more than 10. It is clear that patients would like to see a more person centred approach to sessions and treatments, with possible improvements to the length of time available per session.

It is clear there are issues with consistency and communication with counsellor appointments. Commonly patients would be left without a counsellor for weeks, due to holiday or sick leave. This issue was also apparent by other comments, patients suggesting the need for greater consistency and confidence in seeing the same healthcare professional throughout treatment.

Just under half of participants waited one month before attending their first appointment with services, a small number were seen within a week and others waited between three and six months before receiving support. Although over half of patients felt that the waiting times had not affected their mental health, a significant number did feel that the lengthy wait had an impact. A decrease in waiting times was a factor most participants agreed is necessary in order to reduce barriers in accessing services.

Patients emphasised their need in having someone supportive to talk to about their conditions. One way to increase this could be through social prescribing, patients agreed on the benefits of this and were keen to learn more. Many agreed this could reduce isolation and create a community of shared experience.

Other improvements patients wished to see was more compassionate care and greater listening skills from GP's, which would ensure the development of rapport and trust. Patients also identified this as barrier to accessing mental health services. Patient remarks in the 'comment section' supported this and raised issues about the poor attitude some healthcare professionals showed and, the lack of a person centred approach.

Patients identified stigma as a fundamental barrier in accessing mental health services, which was particularly the case for the elder generation with mental health conditions. Patients perceived a lack of awareness of mental health services in the local area, particularly for specific age groups and organisations.

Focus Groups Results

A total of five participants, three female and two male, took part in a focus group meeting at Saltburn Wellbeing Centre, with two staff members acting as facilitators. Another seven females and one male participants, with one staff member acting as facilitator, attended an arranged coffee morning focus group at the Arc in Stockton. Overall a total of 13 participants took part in the focus group meetings and were invited to attend via the use of social media and leaflets. All participation was voluntary. Participants resided in the North East of England and were aged 16 and over.

From the research of the focus groups discussions, three main themes were found, they were; barriers, preliminary care and the development of aftercare services.

Theme 1: Barriers

Results of the analysis revealed that those with poor mental health found a variety of barriers which affected both their initial attempt of accessing mental health services and also with their self-perceptions of their individual conditions. From these findings it is clear that patients felt that barriers in accessing mental health treatment such as, the point of referral, stigma, GP relations and their personal feelings towards mental health, could be reduced significantly by greater awareness of both mental health in general and available treatment or services.

Access/Point of referral:

“Trying to get help was a nightmare.”

“Things had to get a lot worse before they would do anything.”

“The long waiting times and criteria. You have to be at a very low point to access these services.”

Participants at both focus groups raised issues about their attempt to access mental health services and, the point at which they were considered eligible to fit the specific criteria in order to receive any help or support from a mental health professional. This seems to be a common experience for those who suffer with mild to moderate mental health conditions, a view which was widely supported during focus group meetings.

Waiting times in accessing mental health services can be a negative experience for those with less severe mental health. Focus groups revealed a common consensus in how long waiting times can increase mental health symptoms, create barriers to receiving necessary care and reduce confidence in services. Many participants reported that significant waiting times made them feel as though they were ‘one amongst many’, or ‘just a number’. During focus groups it became apparent that some participants felt they had to use the ‘right words’ to gain a referral and there is a belief that services try to ‘catch out’ those who don’t meet the criteria.

Focus group participants highlighted the need for a ‘middle of the road’ service, which they believe would be helpful in preventing mental health from declining. A ‘middle of the road’ service could reduce the feeling that help and support is only available for those at a ‘very low point’.

GP Relations:

“You feel like you’re wasting their time and then you’re out hanging with an open wound.”

“They opened a file and looked me up and down. They asked ‘what is really wrong with your life?’ I wasn’t strong enough to contend with that.”

“People hold on to bad experiences.”

General Practitioner and patient relationships were found to have a significant impact on patient’s experiences of accessing mental health services. A good relationship between GP and patient is central to delivering high standards of care and is equally important in the diagnostic and treatment periods. A good relationship between both parties allows for better communication, which is key to identifying symptoms of mental health and selecting the appropriate treatment for an individual, based on their individual needs.

During focus group discussions, it became apparent that some struggle to form strong, trusting relationships with their local GP. Negative experience was suggested as a barrier preventing patients from attempting to access mental health services through a GP referral.

Not all experiences discussed were negative. One individual commented on the fact that ‘there are some good GP’s’, it was clear that others within the focus group had also received excellent support from their local GP service. A combination of trust and continuity is essential in the formation of good GP relations and also to support the recovery of those experiencing mental health symptoms.

Awareness:

“Your find out from each other, by accident. It’s sad it’s not in neon lights because it’s important information, if not for yourself, for a family member now or in the future. It’s all word of mouth.”

“I think campaigns are helping, advertising and putting things on TV, it’s getting people to recognise symptoms and asking for help.”

“There is a net people fall through”

Results from focus group analysis revealed issues concerning awareness in both the participants local community and of mental health symptoms in general. Many agreed that although media campaigns and publicity around mental health exist, more could be done to improve awareness, with specific emphasis around sign-posting and reaching out to specific populations who may not access the internet.

Concerns were raised with regards to the current awareness of mental health services and treatment options. Continuing to promote awareness of both mental health symptoms and conditions will improve recognition and, reduce the stigma which remains apparent in current society. Better awareness in this generation could build a good foundation for improved awareness in future generations.

However, not all symptoms are obvious in some individuals with mental health conditions. Those with mild to moderate mental health conditions may continue functioning in everyday life, present themselves as society expects them to behave and feel in some cases their condition is not severe enough to seek advice. During the focus group discussions, it was common consensus that due to the waiting times for those with mild to moderate mental health conditions, people often withdraw and try to continue their everyday life without the support they require. The agreed solution to this issue was to create a 'middle of the road' service, which could provide immediate access to those who are faced with long waiting times.

Stigma:

“Mental health is depicted in a negative way. Culture makes it harder. It’s debasing, not taken seriously.”

“Men are supposed to be the stronger sex, supposed to be there for their families.”

“Men are expected to hold the fort, whereas women can be more open and honest.”

The general feeling amongst focus group participants was that stigma of mental health remains prevalent within current society. Based on this perception, many commented on the effect stigma can have on feelings, resulting in a sense of both isolation and separation from the rest of the community. As mental health can affect anyone at any time, the perception that stigma is still present can be extremely detrimental to those experiencing mental health symptoms.

Although participants identified the efforts of advertisements and campaigns to address this issue, it was agreed that stigma can often be a result of deeply culturally ingrained perceptions within society. These suggested cultural issues are generally related to the traditional social perceptions of men and male behaviour, Women were reported feeling more comfortable communicating about personal issues, in comparison to males.

Attitudes:

“It makes you feel isolated, separated, lonely, fear.”

“Happiness is a journey not a destination. You need to find things that make you happy along the way.”

“It’s like she thinks I’m a statistic. I feel I am one amongst many. I’m just a number.”

“I kept asking, I don’t belong here, that’s how I felt. I don’t feel I can relate to them.”

Mental health for some can seem isolating, separating and debasing. A sense of separation can often cause barriers in communication and facilitate withdrawal from community and social events. Some focus group participants felt that mental illness to some extent defined their identity that they felt like a number or statistic, rather than an individual. Feelings of separation also produced feelings of being unable to relate to others, both with and without on-going mental health conditions.

Understanding, awareness and education are essential in reducing negative attitudes towards mental health. An increase of person-centred therapy could be key in decreasing isolation and improving relationships between patients and mental health professionals. Larger volumes of staff or volunteers would be of great benefit to improving patient experience of accessing mental health facilities and possibly help in the reduction of pressure on organisations.

Theme 2 - Preliminary Care

When patients need to access services, if they have been to their GP or self-referred, obstacles can make it difficult for them to receive support from services, as they do not communicate with other services or the family. With regards to healthcare professionals there is a lack of consistency, so patients will keep seeing different professionals for most appointments. However, if patients do manage to see professionals, there can be a long waiting list. Also patients feel that there is a time restriction per session and that the number of sessions they receive are too few.

Communication:

Patients felt there was a lack of communications between healthcare professionals. They wanted more joined up services so each service had up to date information on the patient’s condition. However, professionals simply do not have time to contact all the services involved with the patient.

“There need to be more joined up services from GP to mental health service, from the beginning. All the services are separate from each other, they all need to singing from the same hymn sheet”

“Well twice the police took her in to hospital. When her name pops up, I think it’ll be flagged. There is a lack of communication. We were only contacted by the crisis team once. The system wants changing, not the people, the system”

“I work between both of them for different reasons. They have to notify each other. I agree people need to communicate. People are under pressure”

As there is no system in place which flags up when there is an issue, healthcare professionals are unable to track or be alerted when a serious issue occurs. This could have serious consequences to patients, especially those who are severely ill. Due to certain guidelines and specific criteria, which requires large amounts of

paperwork, they do not have time to communicate with other services as they are currently under too much pressure.

Consistency:

Patients find there is a lack of consistency in being able to see the same GP, counsellor, community nurse and other healthcare professionals. This is due to the large waiting lists the NHS has to see professionals. If a patient has an appointment with a different healthcare professional each time then this can be difficult as then there is no rapport between the patient and the healthcare professional.

“I can’t do with seeing different people. I don’t want to start this again. I’ve started with you and now you’re passing the book. I can’t drag the past 15 years of my life up again and again. “

“He was at lifeline getting counselling then he came to the end of his contract with his counsellor and had to move him on. He was offered a new counsellor but he didn’t see the point as then he would have to explain his story again and then start again”

“You need continuity and trust so you can get better or else you are starting over again. You get sick of saying your story”

Due to the lack of consistency when a patient sees a healthcare professional, it means every time they see someone with regards to their mental health they need to explain their whole story and mental health history. However, it can be very distressing for some patients to relive their history by sharing it because when they think and talk about their mental health it becomes very real. Due to the lack of continuity, there is no trust created between the patient and the professionals.

Some people may avoid trying to get help because they have to keep bringing up the past and it is painful to revisit. Whereas if the patient had someone they could approach who knew their story and history they would not need to bring up the past over and over again. The patient would therefore feel more confident and comfortable talking about their mental health.

Waiting Lists:

Due to the long waiting lists it can take patients up to six months to be seen by a professional. However, some people need help immediately but are unable to get it as lists are so long, which can make some patient’s mental health even poorer.

“I accessed counselling sessions through my GP but I was told that I would only have 16 sessions. However what if at the end of the 16 sessions I did not feel ready, I was offered more sessions but that took between 16-32 weeks. Due to the referral time then I went back to the drugs and counselling.”

“Going to the GP to tell him, the waiting time between treatments, you go in ready, all fired up, you haven’t slept, you throw up and feel ill. You then hear yourself say it and it’s then double the pain, you will get a letter through the door and it may take up to 4 weeks. You wouldn’t wait that long with a broken leg.

Then by the time of the 4 weeks the wound is starting to close up and as it closing up you are dealing with it.”

“Hard as waiting lists, I was on for 6 months and then I accidentally found this place. I had a counselling session within one week. This place saved my life. You are only supposed to have 6-8 but you can have more if you need it. Talking can be really helpful as they have groups where you can talk but you aren’t judged if you miss a week. Also as the GP waiting list is so long this can help in the meantime”

For those with mental health problems, it can be an issue to try and get help from GP’s or admit you need help. Mental health can be fragile, so patients may need to quickly access services. To be told it can take four weeks will be too long for some patients. Due to long waiting times, a patient’s mental health can decline. One individual made this connection between mental health and physical health issues: “like a broken bone would not be left as it would get worse, this should be the same for mental health.”

Length of Sessions:

When patients access counselling through their GP, they are offered a varying length and number of sessions. However, patients become aware of the little time they have and can panic when they are about to complete their last few sessions. This can often leave patients feeling they need more help.

“I had to sort that out before I could use services. I was offered counselling through GP services. You can only have 16 sessions - ‘I can only help you from here to here.’ It made me panic. I get to the end and just be getting to the point of the problem and then she would say there was nothing I can do and you need to re-refer”

“The NHS are better because they have to be. But you can feel like you’re a case load rather than an individual. The last person had an alarm on their phone for 45min. Right ok. You feel like a number, trying to force things out. Not natural.”

“Sometimes sessions aren’t long enough or not enough. I was only allowed 8, but managed to get 10. But it was only at session 6 that things started to click. I had only had a few sessions left. His hands were tied. After the last 2, well, what do I do now? It was like ‘thank you very much, there is the door.’ It wasn’t his fault, but some people, a lot of people need that extra support.”

When patients are finally seen by a healthcare professional, it can take a while to build up a rapport. However, once this is built up and patients are finally getting somewhere to resolve the issues or are finding strategies to help with their problems, the sessions are at an end. Patients get close to the end and start to panic as the support is nearly finished and often they are not ready for it to end. Patients are then recommended to re-refer to start the whole process all over again.

There are further issues with re-referral which link to consistency and waiting times. Once a patient is re-referred, there are the lengthy waiting lists to endure

which can take up to six months to see someone. This can be difficult as patients have complex issues which they relive when they tell their story again, making the feelings very raw. Cutting off sessions when a patient has reached the point of addressing their personal issues, leaves the patient in a very vulnerable state. Also once a patient has been re-referred the likely chance is that they will end up seeing a completely different person, so they will have to start again sharing their story and building rapport for it all to come to standstill and a stop once the sessions have finished again. In the end it just becomes a continuous cycle.

Theme 3- The Development of Aftercare Services

The analysis found that after preliminary care, those who have mental health would like more support and feel there are no services in the middle to support people when they are feeling low. Also, patients do not know how to access resources, they admitted they tend to accidentally find them. Patients said that one way to help maintain and increase patients mental health is by talking and listening to other people who have a similar experience as themselves.

Middle of the Road Services:

Those who have experienced poor mental health will often experience high and low points and need someone to speak to when their health starts declining. However, as their symptoms are not deemed 'extreme', they cannot receive any immediate treatment from services as there are no intermediate services.

"I'm not swinging off the rafters but I am struggling mentally and sometimes I am in the middle. There needs to be more therapy and treating for person to person with what is currently affecting their mental health now."

"Improvements there need to be middle of the road services. People are only taken seriously if they are extreme but won't deal with middle of the road people"

"The long waiting times and criteria. You have to be at a very low point to access these services. There should be a medium."

Everyone's mental health shifts, this is especially apparent for those who have existing mental health conditions and sometimes when their mental health changes it can make them feel low, though not as low as when they are a danger to themselves or others. When a patient hits this low point they want to be seen as quickly as possible, without having to go through the hassle of going to see a GP and being put on a waiting list. This is why it would be beneficial to have intermediate services which patients can easily access when they need to.

Wellbeing Centres and Support Groups:

One method that patients identified as a way to help maintain and improve their mental health is through support groups. Here they can talk to other patients who have had a similar experience to themselves so as not to feel alone.

"I think that is happening. Places like this (well-being centre) is not regimented, you feel free to and open to share experiences. I have done a lot of work doing

focus groups with addiction - sharing altogether. I think this is a big help, if not bigger.”

“Self referral is helping like places such as place like this [Saltburn Wellbeing Centre] as it isn’t regular, it is free and open to share your feelings. I have done a lot of work with focus group and sharing feelings in focus groups, through the power of sharing can be a bigger help than anything working together and knowing you are not alone.”

“Talking can be really helpful as they have groups where you can talk but you aren’t judged if you miss a week”

Patients sharing their experience of mental health is one of the most helpful methods of maintaining and improving their mental health. Sometimes with mental health it can be a challenge to do everyday tasks, even leaving the house can be difficult. Having a service someone has to commit to every week can be off-putting. If a patient misses one session they may not go again as they feel they might be judged. The patients want something flexible, where they are free to come and go as they please.

Resources:

“The sad thing is that some of the best services have gone.”

“We try, but we are limited.”

“We need more support workers.”

“There should be someone there to have a conversation with, there seems to be a lack of resources.”

Analysis from both focus groups revealed that a lack of resources such as funding, mental health professionals and available service options, is creating issues for patients attempting to access potential mental health services and treatment. Due to a lack of consistent funding, courses or classes provided by various organisations are pulled and those who previously benefitted are left to search for other therapeutic options.

Funding and voluntary opportunities are vital for services in order to deliver courses or classes which create a community of shared experience and learning. Without sufficient funding or volunteers, services have to limit the options they provide to those with mental health conditions.

It is essential that funding is granted to services in order to train new staff members and extend the amount of available support workers. Suggestions of a service which provides free, around the clock support and advice was strongly insisted upon during focus group meetings. Participants agreed that having instant access to speaking to someone directly, would help patients with mental health conditions ranging from mild to severe.

Recommendations

Healthwatch would like to propose the following recommendations:

1. There is a need for improvement in both consistency and continuity during sessions and appointments with GP's and the relevant services, for patients with mental health conditions. It is recommended that patients are assigned an elected member of staff to deal with their issues. In the event this is not possible, improved communication must be achieved so patients do not need to keep repeating their story numerous times. Patients must also be made aware in as much advance as possible of any changes to their care e.g. change of counsellor.
2. Waiting times need to be reduced to prevent the adverse effect this has on people's mental health. As reported in the current study, many have stated that lengthy waiting times can cause a decline in mental health, as patients are unable to access services quickly and their condition often increases in severity. In 2014 the Government published a plan and guidelines to achieve better access to mental health services by 2020.
3. Local support groups and classes/courses need to be promoted as they are vital in encouraging those with mental health to engage with others and provide a safe environment to share experiences and learning. This could be achieved through social prescribing services in which GP's are able to refer people or there could be a self-refer option. Social prescribing has been found to have positive benefits such as self-esteem, improved mood, opportunities for social contact, various transferable skills, weight loss, healthier lifestyles and greater confidence.
4. A "middle of the road" service, similar to a drop-in needs to be implemented across each area in the local community. This will aid those who are experiencing long delays before their first appointment with somewhere to go. Healthwatch have received feedback from individuals who have previously used the MIND drop-in service in Middlesbrough, however, this has since closed and individuals have expressed the need for this or something similar to be brought back to the community.
5. An effective system needs to be put in place so that the family/carer of someone with a mental health condition are informed of their treatment and recovery. It is also important that there is an option for services to access information from a family member via consent as they often see individuals on a regular basis and so could provide vital information which services would otherwise not know about.
6. There needs to be a system which carries essential information about the individual, so they do not need to keep repeating their distressing story,

which can then be accessed by all the professionals who work or are involved with that individual.

7. A more person centred approach to both counselling and appointments needs to be adapted. Treatment should be tailored to the individual, rather than the condition. It is hoped that by adopting a more tailored approach, patients will be able to reach a stable point in their mental health, reducing the risk of re-referral. This approach also needs to be considered for the number and length of sessions given to each individual. Longer sessions may help those experiencing mental health understand their feelings and move forward with their treatment.

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