

Feedback from people with mental health and anxiety on the Rapid Investigation Service

Background

Wessex Voices arranged to interview six adults who experience mental health issues and anxiety. A Rapid Investigation Service leaflet was sent in advance to allow time for consideration and feedback. Each interview was carried out virtually. Some people had a mental health condition with anxiety. The others were on the autistic spectrum. This is a record of the interviews and resulting recommendations.

Recommendations

- Treat people with dignity and respect, anticipating the support needs of people with anxiety and autism
- Acknowledge the effort and difficulty to attend appointments
- Demonstrate an awareness of the patients' anxiety with reassurance, understanding, calmness and empathy
- Those with autism require an organised, business-like approach to receiving information
- Give clear plan of what is going to happen; outlining where, why and when. GP referrals do not always this make clear to patient from outset.
- Give clear explanations about what tests are required, entail, and are for
- Provide clear timelines for results, giving these concise and accurate explanations of these
- Give clear, precise and uncomplicated information about results and next steps

People's experiences of using health services

“I was in such a state of heightened anxiety. I was not in a position to describe what was going on. In fact, I bolted from hospital twice.”

“It took me two years to even go to the GP”.

People had poor experiences of recent visits to the hospital, highlighting lack of information about the appointments and clarity about what tests were for and what would happen at the appointment. Anxiety about health outcomes and prognosis are heightened further by a sense of not knowing what is going to happen next.

The waiting times to find out about the results of tests and how to access the results was highlighted as an issue, causing additional distress and anxiety. Poor communication was described in many answers relating to bad experiences before and after hospital visits. The (in)ability to manage their anxiety before a visit to hospital was highlighted as a factor in attendance or non-attendance. Having support to attend appointments is important.

One person is still waiting for a four month call back from a hospital about results from a procedure, but Covid arrived, the follow up appointment was cancelled and no follow up call has been made since.

Feedback about the Rapid Investigation Service

When asked about the Rapid Investigation Service most people were positive about it and positive about a team being there specifically to support the process and the individual.

Most people welcomed and commented positively on the 28-day turnaround time for results.

The word ‘cancer’ brought about a level of anxiety and distress for one person who was unable to continue with a conversation about the service. One person lost a parent at a young age to cancer and feels strongly that this service will save lives. This experience is still a contributing factor to their poor mental health now.

Speaking with people with mental health and anxiety

“The first thing would be a well done for getting this far. To say it that is the biggest encouragement. It has taken such a big push to get your voice heard. The acknowledgement that you have been so much to get to that stage. The time as well to have with you as sometimes the pressure is there for only a few minutes.

So the call that listens to you in a person centred way. I think that’s a good relationship I just think you want someone to be human.”

“Yes don’t go around the bushes, be direct and factual, don’t put opinions into it because opinions can sway people. your opinion might be different from mine and I’m stressing that I might have cancer, I might blow up at you, I might never come back again.

It needs to be focused factual; this is the situation. And for me personally it would have to be a little bit stern, obviously caring and empathetic and things but a little bit stern like you need to keep to this, this is your journey.”

Being spoken to with respect is important, as is not being hurried and giving enough time for people to absorb what is being said. Anxiety at appointments can often lead to feelings of panic and a strong desire to flee before getting there. Being kind and calm and showing empathy without a sense of urgency helps.

Taking in and retaining information can be difficult. Anxiety and stress of the appointment can stop someone being able to take any information in or hear what is being said. Being clear about test results is important. When giving details the content needs to be accurate, relevant and concise.

Support for people with mental health and anxiety

“But he has come along to that with me and had to do all the talking because all the way there I wasn’t speaking , I was getting into a proper panicking getting all anxious and he kept me distracted and talking and looking at different things always thought when we got in there it was more the fact that he was keeping me there like him being there meant I couldn’t leave you know what I mean like my mind is a fight or flight so I’ll get over panicked I end up crying and then I’ll end up leaving. So he was there just to have someone there just as I know that if he’s there on I can’t just walk off. That’s how he would help me anyway.”

“Talk to me like an adult. I want someone to be friendly I want them to be organised, I’d like I’d like them to reassure me I want to know what the process and procedure is. Explain the process Define what their role is and ask me if I have got any questions. Or how I’m feeling even. To ask if I have anyone with me for support. Have I told anybody. Some people might be fretting on their own.”

Some people would choose to take someone with them to appointments and meetings for support. They can help calm and distract the person; navigate getting to the appointment; and prompt questions if the person has stopped listening, or taking in details or instructions about what will happen next. Having someone to listen to what is said is important.

How the RIS contacts people

Voice notes via Whatsapp was suggested by one person for the following reasons: “Having options, it might be an idea to have WhatsApp. If you don’t have credit, most places have Wi fi and if you don’t have credit, you can still get access to talking to someone as long as you can find Wi-Fi somewhere, so it gives more options. But also, with WhatsApp you can do voice notes, I think that would be useful because it’s still having a conversation and it’s still like a conversation but some people get really panicky on the phone as well ... it might just give another option. You don’t have to spend time typing etc. You can still talk but you don’t have to record your voice straight away back to that person you can give yourself five minutes think about what you want to respond with and then do your recording. It gives people a bit more leeway.”

Finding out about the right time of day to arrange contact is important for some people due to medication and best time of day. One person said they were not keen to be seen on Zoom type calls. Asking people about their specific needs will need to be part of the welcome call and considered by the service.

Having tests and what you need to know

One person asked about being provided with a road map from the beginning of the process that outlines a personal pathway for the individual in a very visual way.

“This is the journey that we're going to face, obviously we might differ from this journey as everyone else is different ... these are the main points we are going to hit ... So we are going to do a welcome today and ... (then another to) go through your symptoms, let's go through this next step on that journey ... and have it all planned out so that they know exactly what they are going to get ... its more the anxiety of I don't know what's going to happen. So give me options ... tell me this is what we are going to do how we are going to do it and even ask questions in the middle of so we can tailor to each person's experience.”

How information should be provided and formatted

Results should be given in as clear and concise way as possible. Providing links to relevant websites and information would be useful to save reading too much.

“So ... this is what happened, this is going to happen and this is going to happen, this is what we're going to do, this is when you'll find out, we'll go from there.

I would want them to be armed with information regardless of the outcome. I would want the evidence. I want someone to talk with if a consultant had given bad news. Take someone with me”.

How information about results should be shared

Most people wanted to know their GP had been sent a copy of the same information they had received, produced in easy-to-understand language.

“I would want to see a copy of what is said as I don't take things in, especially if it is bad news and I would want to see what went to GP. I want to know, or I will make it up! It is different for other people. I am likely not to take it in if I am in heightened state. I would want to know what is next... I want to know what's going on. I might not want to know all the details ... Follow up phone call would help”.

For more information

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