

# Feedback from people with learning disabilities and their carers on the Rapid Investigation Service

## Interview process

Wessex Voices arranged to interview three adults with a learning disability and four carers of people with a learning disability. No carer or cared for person interviewed were related to each other.

An Easy Read leaflet for the Rapid Investigation Service was sent in advance of each interview to allow time for consideration and feedback. Each interview was carried out either using Teams or Zoom or telephone. One carer provided their written response. This is a record of the recommendations and interviews undertaken.

## Recommendations

- Both the person with learning disabilities and their carer should be provided with information in advance of accessing the service (e.g. in Plain English and Easy read). This should start from the GP referral, onwards
- There needs to be a personalised approach around communication preferences and the needs of the person with learning disabilities
- Not assume online appointments and information will work for everyone
- People and carers should be given time to prepare for appointments
- It would be helpful to have clear, bullet point information for carers to prepare those they care so they know what each of the calls with the RIS will cover
- Going for tests, it would be helpful to have pictorial/photo aids of directions and what the tests involve in advance. Do not use cartoons
- The RIS should ensure the services they refer the people on to are made aware of individual communication preferences and needs in a proactive way. This should include going back to the GP.

## People's experiences of using health services

Most people had positive experiences of recent visits to the hospital. The use of Easy Read and pictorial literature before and after a hospital visit is helpful. They highlighted where the importance of positive staff attitudes saying they liked it when staff are 'friendly', 'courteous', 'patient' and show 'respect'. A good service was reported to be one where people are polite and take their time with patients so they do not feel hurried.

*“A patient manner with time to listen, time to explain and use of Plain English makes experiences good.”*

In reverse, poor communication was described in many answers relating to bad experiences. [Diagnostic overshadowing](#) was also mentioned in some cases. One person recently experienced a two-year delay in receiving a diagnosis for Parkinson's from the first sign of symptoms because of diagnostic overshadowing. They described poor follow up and coordination of care from their GP the causal factor.

## Feedback about the Rapid Investigation Service

When asked about the Rapid Investigation Service people were positive about it and the potential for shorter turnarounds for results. People and carers welcomed the idea that phone contact with the service would save time in terms of travel and appointments that could be undertaken at home (rather than going to hospital).

Carers especially said the service would enable them to communicate with a dedicated team and this would help coordinate visits and appointments, allowing preparation lead in time to prepare for appointments, phone calls etc. Carers said it is important to keep a GP informed and involved throughout the process.

Carer's comments about the RIS leaflet included that it should clearly state and encourage carers to be involved; people with a learning disability do not always know what a 'working day is' so clarify this; and one did not like the use of the wording 'might be cancer' and said it should be at the end of the information, if at all.

## Enabling people to use the RIS

People said that they need support to know what to expect from the service and it is important to have time to prepare and absorb what is going to happen. Having a supporter /relative/careworker or carer help before using the service and during the service would help. Part of this would include having information from the GP at referral in Easy Read or Plain English.

*“Having extra time for an appointment is helpful.”*

*“Knowing what to expect helps me to prepare xxx in a way that I can help him with appointments.”*

*“Asking me what time of day is best would be very helpful because I know that xxx is better in certain parts of the day than others.”*

*“Being friendly and nice to me is good.”*

## Speaking with people with a learning disability

Taking time with patients and being clear to check for understanding is important. Being polite, kind, and respectful is also highlighted. Having an understanding of how individuals might communicate according to their cognitive ability or executive functions is often discussed as key to knowing how to communicate. An example is one parent carer said that it is important when asking her son a question to give him a lot of time to respond. Asking the question again in another way because he does not respond immediately would affect his thinking process and add confusion and most likely not elicit an answer at all. One carer said that clinical staff should keep chatter light and about the likes and dislikes of the person before asking any questions.

*“Keep to 15 minutes and then suggest he goes for a coffee with a relative/carers before getting to detail that he cant understand.”*

*“Ask him if he has understood what has just been said.  
Or can you repeat what I just said.”*

*“.. he has been so institutionalized he won't say no to anyone.”*

*“If I can't understand you, I will ask you to write it down and if you can't understand me, I will write it down for you.”*

## Support for people with a learning disability

Each person needed support of another person to enable them to use the service. Carers and support workers are needed to assist with preparation, arranging appointment times and attending appointments. One person mentioned that it should not be assumed that family members are always welcome as supporters as some people may prefer to attend or be supported by someone else. This is worth checking. One person said she needs a female worker to attend appointments with her. If she cannot have a supporter to attend, she would not go to the appointments. All parent carers interviewed said their relative would not be able to use the service without support. One parent thinks she acts as a broker.

*“Having my mum support me means she can help manage my anxiety.”*

*“I need support to get there and have help to find the right place, find the toilet and things like that.”*

## How the RIS contacts people

Three people with learning disability said they would need help in advance of joining a video meeting and would welcome a trial run beforehand if a video meeting was to be set up. One carer said her son would not want to be in shot on a video or screen and would be unlikely to use the phone on his own but with her in situ they could manage. Being punctual and having a defined appointment time (e.g. 2 pm on Tuesday 4<sup>th</sup> May rather than random contact) for telephone or video calls was important to all participants. Individuals may have preference for timing of calls depending on when they function best in the day.

*“Condensed bullet points helps us to get ready with information. I don’t have time for reams of details in advance. To get him to look at the screen is really quite something. So it would be getting the service to understand that the same call is difficult. There are ways around it if you can pre plan,..”*

*“I’ve just put it on loud speak. Yeah, so that enables everyone to have a conversation because he’s probably the only teenager I know that does not like mobile phones.”*

## Having tests and what you need to know

Advance information using photographs, including of those doing the tests, and clear directions would be welcomed. Material in photographs makes it easier for people with learning disabilities to relate to rather than cartoonised images. Be clear in appointment letters about what people should expect and experience. Reducing anxiety for some is important.

*“... the first thing that I was stressed about, especially if it was in the hospital or in a practice I have not been to before was oh my god where would we park... next thing where on earth is it in this great huge, enormous hospital. We usually go to QA, that’s not too bad ... but Southampton General they’ve got like footsteps you follow then A does that and he is way happy. Okay, coloured footsteps is good. Well, it says for example ‘diagnostics’ but you find yourself going through the ‘Screening Unit’... you actually go to the X ray unit to have a test like an ultrasound or something, or MRI or whatever but there is not mention of X ray unit in the letter. I think it would be helpful to know in advance because you know, come with an autism head on, they*

*will take everything very literally.”*

*“First question always is, what’s the cafe like, they like positivity”*

*“Would rather see things during the waiting room time, is there some sort of play or a laptop, waiting, waiting is quite a big thing. “*

*“We got a leaflet, explaining what this test was and illustrations of exactly what was going to happen. And, very simple terminology. So, very low jargon, I think, I think, a language has to be friendly. It has to be straightforward, and it can't have double meanings. So you have to open your mouth to let a tube go down or up your bottom. And it's not going to be pleasant, but it'll be as quick as possible. Somebody will help you get through this, somebody will be with you, and you'll be given a tablet to make you feel okay. It's got to be an honest, straightforward good language, leaflets, because for me as, as his mum. I would then be able to show him that, and I would be able to talk with him about stages, and I would be able to then measure and gauge his anxiety level, and to see if he would be able to cope with that. Yeah. And if that test is done without me there then, I wouldn't be able to explain to him. Somebody will be there, it might not be me. We'll meet that nurse on the day. You know it's enabling a very comfortable conversation outside of clinical anxiety. So keeping it friendly keeping it honest and straightforward.”*

*“I have to say, hospital (Poole) is fantastic, because I was able to take him up to the date of the scan. Go to the department and see the machine. Go through the door that he will be going through in a couple of days' time. The only thing that I would comment on is that time lapse. It can't be done. One week later, a month before it actually, it's got to be within a short time scale, so that it doesn't show that*

*information and store it, and then it becomes irrelevant. So, but at the time, I couldn't fault them they were fantastic about opening up and doing everything that would make him feel. It was great in the end they were brilliant. And the same with the endoscopy, when we went to the department. I asked for specific nurse to meet him at the desk. So I could say so and so. And they did that it was good she gave a nice little interview beforehand. There was continuity, and there was that little feeling of someone special. There wasn't that feel of somebody is going to suddenly appear down this long corridor to whisk me off.”*

## How information should be provided and formatted

Information should be clear, simplistic but not to the point of babyteach. Do not use abbreviations or jargon. Plain English and Easy Read would be preferred. Some people said that sending a letter to the patient directly would be of no help as it could remain unopened or hidden.

Participants said that if the service has learned how to engage and communicate well with a patient with learning disabilities a certain style, the same should be applied to follow on correspondence to GP's and or other departments. Sharing the knowledge gained would mean that the patient would have better continuity of service and experience. If a GP receives the same correspondence in Plain English, they too can be encouraged to use the same plain English in talking to the patient.

*“especially if we are moving towards open access for patients’ records...”*

*“If we had even, even 20% of what we discussed about, you know, having things in advance and calling it an easy language, it would be a much better experience.”*

## How information about results should be shared

Results and next steps should be clear and to the point about a condition or findings. They should be presented in a very basic language. e.g. ‘We found X and you will need to do this to get better/ Y will happen next’.

*“Yes, it’s about recognising an individual pace of understanding and absorbing information the family will do a lot of that extra input.”*

*“You know, once that interview, once those, those things are done. The family is managing the fallout from it.”*

*“They’re the ones that are putting it in perspective, helping that person to not dwell on it, or to see the positives to lift that person in a way that hopefully they know how it’s all going to be done very informally, away from the service providers.”*

## For more information

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