



**Learning disability annual health
checks and covid - 19 vaccine
experiences
August to December 2023**

Background

- ▶ Carried out in partnership with Herefordshire General Practice
- ▶ There are 150 people with a learning disability who were either not attending health checks or covid vaccines or both.
- ▶ Gathered views of 40 people with a learning disability.



What we did

We asked people to tell us:

- ▶ Experiences of learning disability health checks and covid vaccines in Herefordshire if they attend.
- ▶ Why they go or don't go.
- ▶ What could have been better? What medical centres could do to encourage people to go?



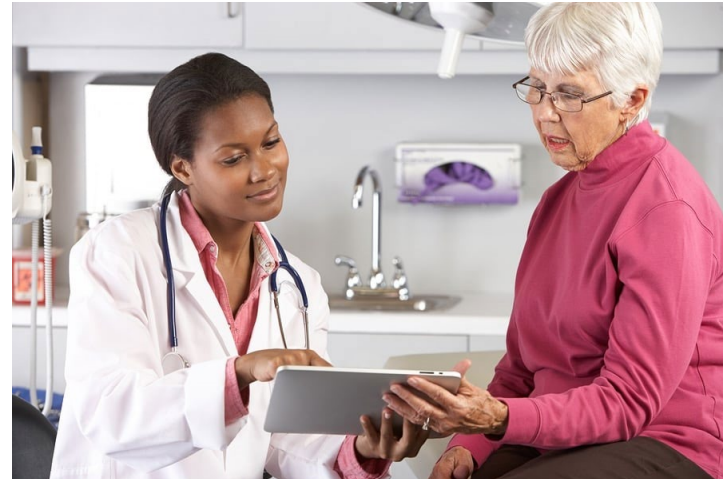
Who we spoke with



- ▶ 40 people. 37 face to face, 3 via carers.
- ▶ All over 14. Between 18 and 70 years old. Most in 40's and 50's.
- ▶ They were a mix of male (19) and female (21).
- ▶ All were white British.
- ▶ 8 lived independently, 17 lived with a parent or carer, 13 lived in a group home with other people with a learning disability, and 2 unknowns.
- ▶ People were registered in medical practices distributed across Herefordshire a total of 14 different practices (Listed in Appendix 5).
- ▶ 15 mentioned a long-term condition other than learning disability including autism, dyslexia, epilepsy, heart condition, joint or spine issues

Have you had health checks or not?

- ▶ After viewing the film 30 (75%) people thought that they had attended an annual learning disability health check, 7 (17.5%) thought not and 3 (7.5%) were not sure.
- ▶ Overall Sentiment (view of health checks). Overall, 24 (60%) people thought the learning disability health checks are good, 4 (10%) Neither good nor bad, 4 (10%) bad and 8 (20%) didn't know.



What did you think of your health check? Positive experiences

Comments collected indicated that many people had a positive experience of having an annual health check because:

- ▶ Kind staff
- ▶ Good communication.
- ▶ A support worker came with them.
- ▶ No waits once there
- ▶ A good plan afterwards



What did you think of your health check? Negative experiences

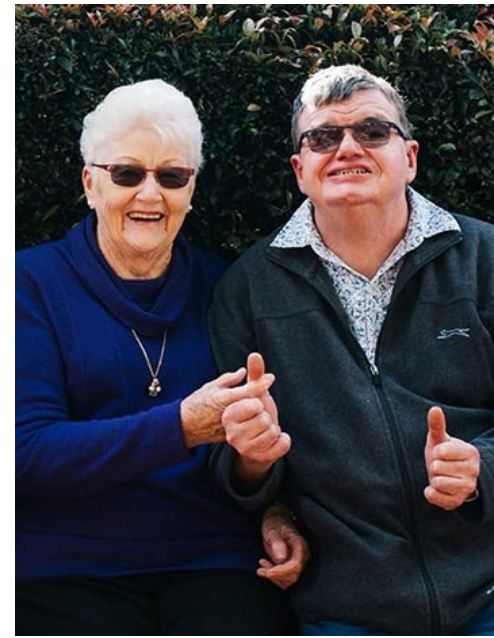
Comments collected indicated that many people had a less positive or a negative experience of having an annual health check because:

- ▶ Difficult communication e.g. speaking to carer, long medical terms, too quiet, too fast, unclear, needing longer to process for a reply, lots of questions.
- ▶ The experience was stressful and worrying and many didn't like the idea of blood tests.
- ▶ Explicit sexual questions were embarrassing or upsetting.
- ▶ Waiting a long time. Difficulties getting an appointment.
- ▶ Not understanding letters before or paperwork afterwards.



Why do you go?

- ▶ The vast majority of people said they go to their health check because their parent or carer says so and arranges it for them.
- ▶ Most people who said they liked the annual reviews said they thought they were a good idea, they helped them to plan and to give them advice, and that it was good to have a check-up to stay healthy.



Why don't you go?

For people that did not go the reasons given were that they:

- ▶ Don't need to go because they feel well.
- ▶ Don't see the point in going every year.
- ▶ Don't understand the letters.
- ▶ Don't like the surgery environment.
- ▶ Find it scary.
- ▶ Have many other health issues and other priorities and don't feel it necessary to have another appointment.
- ▶ Don't know.



What would make health checks better/easier for you? Ideas to improve them included:



Better communication - Listen. Talk to me not my carer. Speak slower. Fewer medical terms. Less critical. Tell me what I do well too. Give me time to think.

Give the questions before but allow us to answer on the day so we have a chance to prepare and understand.

Check my records before so that you don't ask the same questions all the time.

Please don't ask me again if I'm pregnant.

Don't have them so often.

A choice to have a female doctor if you wish.

Be on time or I get nervous.

Make the plan in easy read. Make letters easier to understand.

Explain why annual health checks are a good thing.

Could we have health checks in different places that might make us feel more relaxed



Have you had a covid vaccine?

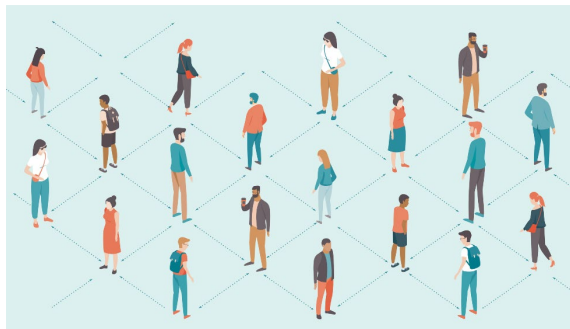
- ▶ 34 (85%) of the people interviewed had received covid vaccines,
- ▶ 4 had not (10%)
- ▶ and 2 didn't know (5%)



What do you think about covid vaccines - the good and the difficult?



- ▶ Some people felt that the covid vaccine was a bit painful and some people felt it was just a scratch. For some this bothered them and for most it didn't.
- ▶ A few people said it made them very anxious and they hated it and feared it.
- ▶ Some people had aftereffects like feeling wheezy or having aches and many felt it had been different each time they had gone.
- ▶ One person said that they didn't like being with lots of people and crowds but because of social distancing, it had been OK and very fast. They would like it to continue being delivered that way.



Why do you go or don't go to have a vaccine?



- ▶ Most people went because the appointment was arranged for them, and they were told it was a good idea.
- ▶ Many people thought that the vaccine would prevent them from getting covid. Others knew it might not prevent it, but it would be less severe for them. Some people knew that they might be more likely to have complications if they caught covid and the vaccine would help it to be a milder infection. Some people suggested that it was to protect other people and to stop the spread of covid.
- ▶ One suggested that it helped them not to worry about covid as much.
- ▶ One person commented that they had read a lot of people who were against the vaccine but that they had ignored what people were saying partly because they had said vaccines cause autism. As an autistic person, they found this false and offensive.
- ▶ One person who didn't go initially said that they couldn't stand needles and only had a vaccine when they had to in order to travel.
- ▶ One person who didn't have a vaccine said that their parent had said that it was not a good idea and their parent had not had one either.



What would make covid vaccine experience better/ easier for you? Ideas to improve them included:

Make them hurt less. Explain that they don't hurt. Try distraction.

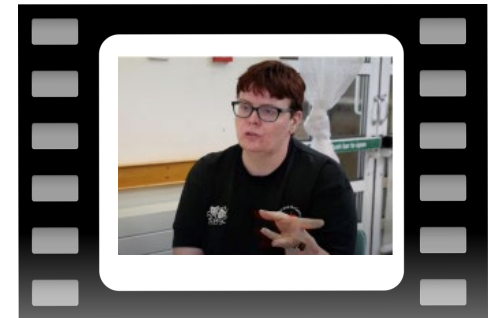
Stop the waiting times once you are there. Make it easy to get an appointment.

Perhaps show a film so people are less scared the first time they go, and they know what to expect. Encouragement from other people with a learning disability. Have a telly advert. Don't listen to scare stories.

Have a home visit.

Do something about the side effects.


One person who did not get a vaccine said there was nothing that could be done to persuade them they just don't like needles





Recommendations

We made recommendations drawing from people's comments under these headings:

- ▶ Communication improvements 
- ▶ Use of films and the voice of people with a learning disability
- ▶ Targeting younger people
- ▶ Targeting parent/ carer/ support organisations
- ▶ Targeting people that live independently





What next

Sharing the learning:

- ▶ Learning has been shared with PCNs (Primary Care Networks) and GP Leadership Team
- ▶ Learning to be shared at the GP Practice Nurse forum
- ▶ Improving letters and communications to patients
- ▶ Shared learning with the ICB (Integrated Care Board) to be considered within future commissioning of services
- ▶ Consider how this learning can be used to provide future services through Talk Wellbeing

