

**healthwatch**

# Learning disability annual health checks and Covid-19 vaccine experiences

August 2023



**healthwatch**  
Herefordshire

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# Context, appreciations

## Context

Healthwatch Herefordshire carried out this project in partnership with Taurus Healthcare and WBC (Wargrave, Cantilupe and Belmont) and gathered the views and experiences of 40 people with that have experienced annual learning disability health checks and covid vaccines in Herefordshire.

We aimed to learn why people attend or do not attend, what the barriers are, what works well, and how to improve the experience.

Each Medical Practice wrote to any adults with a learning disability over 14 who had not attended either an annual health check or a covid vaccine or both.

We composed a friendly and accessible letter with pictures and a link to a video to explain the project. We asked people to contact us to meet or to drop into 8 venues across Herefordshire (Kington, Bromyard, Ledbury, Leominster, Hereford, Ross on Wye) at set times.

We were informed that there are 150 people with a learning disability who were either not attending health checks of covid vaccines or both.

This approach gave rise to 4 of the experiences recorded. 1 in person and 3 choosing to fill an online survey rather than meet.

In addition to this, we arranged to meet adults with a learning disability who attend day activities across Herefordshire (Leominster, Hereford, Ross on Wye) with the help of Aspire, ECHO and Horizon. We showed the film and asked individuals their views. By this approach we collected 36 experiences.

We asked people to tell us:

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

A few people were non-verbal but were able to indicate sentiments and yes and no given options.

Some suggestions were inferred as individuals found it difficult to make suggestions e.g. If someone said waiting was annoying, I inferred that fewer delays would improve the experience.

Thank you to the participants in the survey for sharing your stories and to the organisations that allowed us to undertake interviews in their services.



Thank you to the members of Our News Our Views for helping to make a film at short notice about health checks to encourage people to speak to us.



# Summary of results

## Demographics.

40 people with a learning Disability shared their experiences of learning Disability health checks and covid vaccines. 3 were relayed by carers/ parents and 1 was a person on holiday in Herefordshire.

Responses were from people over 14 aged between 18 and 70 with the majority in their 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.

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?

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

There were many comments to indicate that staff were kind that they were spoken to in person or that the health practitioner talked to their carer or parents and them.

There were just a few comments to say that they felt sometimes they were not talked to directly and wanted to be talked to as an adult.

Most people felt that they understood what the health practitioner was saying. A few people said that they did not always understand but that was why they bought a support worker with them who explained it to them afterwards and they were OK with this.

A couple said medical terms could be difficult to understand and a couple felt medical practitioners could speak more clearly, slowly, and loud enough for somebody with hearing difficulties. (In a later question people suggested better listening and giving people time to process and reply).

Most people indicated that they took a support worker or carer or parent with them to help them in their health check and that this was very important to them.

Some people said that they met the same doctor or health practitioner each time others said they didn't but would like to and others said that they didn't mind who they saw as long as they were nice.

Some people found the experience worrying and difficult and said that they got a bit scared and anxious going to the health check. Reasons varied:

- because they didn't like having a blood test which they felt was painful.
- the questions asked were felt to be a lot.
- three people pointed out that they found the sexual questions upsetting for example being shown explicit diagrams, being asked repeatedly if they were pregnant.

A number of people pointed out the difficulty getting an appointment and the long queues on the phone.

A number pointed out the waits that you have sometimes on the day. Some people found these waits annoying, and others were quite happy to wait with their carer.

Many people knew there was a plan produced but fewer had actually seen it and some said it took a while to come. Some suggested it would be good if it were in easy read so they could use it and others said their staff supported them with the plan. Many people said they did not know about the plan or had not seen it.

## Why do you go? Why do you not go? (To have a health check).

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.

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

- don't need to go because they feel well.
- 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 see the point in going every year.
- don't know.

## What would make health checks better/easier for you?

Ideas to improve them included:

- Talk to me not my carer.
- Listen.
- 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.
- Better communication.
- 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?

## Anything you would like to know?

There were only two comments and difficulty understanding this (unclear) question.

### Comments:

- The plan can take a long time to come.
- When I have a rough night and my body is telling me you need to go back to sleep. What should I do?

## 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.
- 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.
- Try distraction.
- Have a telly advert.
- Have a home visit.
- Don't listen to scare stories.
- 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.

## Anything you would like to know about covid vaccines?

A couple of people asked:

Why are people with a learning disability in more danger?

Will we keep having them forever?

Are they going to be a regular yearly thing like the flu vaccine?

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# Conclusions and Recommendations

In appendix 1 are the results in full. Please read them as well as this summary to gain a proper flavour of what people said and to draw out any other reflections we may have missed.

## Explaining the importance of health checks and covid vaccines

The film was very useful introducing ourselves and health checks. We found that it engaged people and nearly all of the participants watched it all the way through with interest.

Making a series of short films about health checks and covid vaccines is recommended.

Any films about health checks and vaccines will need to be short and clear and it is good to have people with a learning disability featured and ideally, speaking.

Films will need to explain what to expect and address or challenge some of people's fears without introducing fears to those that don't have them!

(Also see Appendix 3 to see WBC clinical suggestions for videos).

In addition, we recommend considering what might be helpful for those that cannot access film links. There are a number of Easy Read guides about health checks and vaccines. Consider how these, or adjusted ones, can be made available to people that do not access IT based resources.

During this project we were contacted by an individual about a project called "Supercharged Me" and was run by Kingfisher Treasure Seekers who had carried out similar research in Gloucestershire. They subsequently created a campaign called 'Super Charge Me' which is worth checking out. They told us that:

*"the number of health checks taken in Gloucestershire has gone up each year since we started the Supercharged Me campaign, but it is really difficult to define the causal link".*

There's more information at <https://www.kftseekers.org.uk/superchargedme>.

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## Communication.

It is recommended that actions are taken to improve communication in these areas:

- **Letters of invitation** while mainly read by parents and carers need to be accessible for people with a learning disability too. Perhaps a standard letter and an Easy Read one can be included. Links to films and the offer of reasonable adjustments would be recommended. Questions that are likely on the day could be sent beforehand in easy read but with a clear indication that they can be answered with help on the day.
- **Making appointments** – any improvements that could be made to help carers/ parents/ people with a learning disability to easily arrange a health check and covid vaccine would be welcome.
- **Content** – During the annual health check it is recommended that practitioners:
  - Speak slowly and clearly explaining or simplifying any complex medical terms checking for understanding by active listening giving time for the individual to respond.
  - Speak to the person with a learning disability while including the parent/carer.
  - Give positive feedback as well as advice to improve health so that the individual does not feel criticised.
  - Read notes beforehand so that there is less repetition.
  - Take care when discussing sexual issues and sensitivity to patient reactions to explicit content.
  - Seek feedback about the plan they received last time and what worked and didn't and whether they found it easy to understand and action. Apply learning.
  - Make any reasonable adjustments requested and if no requests are made make adjustments appropriate to a person with a learning disability taking account of any additional adjustment needs e.g., autism, physical disabilities, anxiety, hearing impairment.
- **After and plan** – Plan to be in an easier-to-read format so that the person with a learning disability can look at it. Aim to send it back promptly and indicate that the person should see it and be able to refer to it during the year. Perhaps add some tick lists/checklists/ other resources they could use during the year. E.g., Exercise chart, drink chart, diet sheet, Stool chart.

## Targeting younger people.

Frequency – It is important to get younger people into the habit/ culture of health checks however, some will feel they are not a priority and feel fit and healthy. Target younger people with the rationale and consider spacing them out if once a year is considered too frequent.

For young people with lots of Health issues consider how to answer the question of why they should come to a health check on top of that.

### **Targeting Parent/ Carer/ Support Organisations.**

Most people with a learning disability rely on support from a parent or carer/s so it is important to give information to inform them about the importance of annual health checks, how they are different than the ones they have and of vaccines.

Perhaps an additional film could target parents and carers as well as organisations/ services that provide support.

Another time it would be useful to hear their views too.

### **Targeting people that live independently.**

There were 7 people who lived independently. All had a support network of paid carers or family.

We didn't find a pattern to suggest this category was less likely to wish to be treated differently as with the Gloucester project but the individuals we met were mainly well connected into day services with the exception of 2 that still held a preference for Easy Read or Easier read letters and plans.

All had experienced health checks and thought they were good.

However, it feels important to note that our sample is small and there are likely to be many people with a mild learning disability for whom the Gloucester approach might be worth considering.

### **WBC Clinical Feedback.**

In Appendix 3 are more suggestions which all tally well as proactive beneficial actions and responses to the above.

# Appendices

## Appendix 1: Results in full with participant comments.

### 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 .

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?

#### Good.

Comments included:

It is good. I sometimes get a bit anxious, but they understand. They explain in a way I understand. I am able to take someone to support me.

Good. Like it.

Very good. Talking, helping me eat better e.g., fruit. I talk to them and make friends. They are kind and helpful. I go with mum and dad.

I go regularly to the hospital and surgery next to ASDA. We talk about my diet and how I am doing with my exercise. Mum does the talking. I don't ignore the Doctor's advice. Mum supports me with my eating habits and exercise.

Good. I go with Mum. They mostly talk to Mum, and this is OK.

Good. They are kind. I have a plan. Mum or dad take me. I have a lady doctor. She is good. I have the same one all the time. Dr. X. She is wonderful and nice.

Good. I go with mum.

OK went straight in.

I feel OK when I go. I am not sure if they give me advice. I make a plan myself. Not sure if they gave one to mum. They are kind. I just think they are very nice and friendly no matter where I go.

Hampton Dene I like. I don't remember seeing a plan. We may get it in the post. Perhaps the staff have it. I just don't understand some of the words. I just give it to X and she does it right. X is pretty OK. They mostly speak to X but they do speak to us both. Sometimes they speak in a way I understand it. The surgery keeps on putting things in letters that I don't understand. It would be better if in Easy Read. I like Hampton Dene I don't like that one by Morrisons I am not going it is just annoying.

Good. Sometimes quick sometimes wait a long time. My doctor retired I have a new doctor who I have not seen yet. I don't mind seeing different doctors. I can't hear what they are saying as I am a bit deaf. They probably share my plan with others and my support workers I don't know.

It's a good thing. I walk to the surgery with my key worker. I see Dr. X. I think they give me notes afterwards on notepaper which is then in my house. I think it is in Easy Read. Seeing some doctors is good. Dr. X is good.

Ok. I don't remember a plan. Mum takes me. The surgery is nice. You only wait a few minutes. It is OK. I understand what they say. I don't like tablets I take medicine.

It's good going to find out things. They ask you how have things been. They give you a blood test and blood pressure unless you've just had one recently. None of this worries me because I have had many of them. If I don't understand what they say the support worker explains and also, they can remember it for me. Sometimes they speak too fast. It is all OK occasionally I have to wait no longer than 30 minutes.

Good and kind. Not sure about the written thing. They may give it to my carer. I have had one, but I don't think I go every year. I go quite a lot for other stuff. I can hear and understand what they say although they could speak a bit more slowly and clearly.

Very good. Informative. Useful. Nice to speak face to face with the GP and have blood tests etc. done by a nurse at a separate appointment before the GP. Fownhope surgery are excellent and very accommodating & provide a very good service & caring & friendly.

I go with my mum but I ask lots of questions too. I have it every year. I like Dr Amy very much. She tells me things in a way I can understand them. It's very important I have a check up every year as I like to stay healthy. I like the doctor taking care of me. I feel important and I feel grown up.

I used to go every year. Mom took me you get a blood test and a wee pot and drink more. It's exciting but not exciting. Scared but not scared. Hard to swallow. It stings when they take blood. It's good they give you medicines. People are brilliant they wear nurse costumes and T-shirts and make people feel better they talked to both mum and me. I have different doctors doctor X in Hereford and doctors in my surgery. X as well, they measure your wee pots. You can wait a long time it is a bit boring, but I chat with mum.

Feel better. Different doctors is ok. They don't take blood it is not nice. No waiting they are on time. They talk to my parents and that is ok. I understand mostly. I like exercising.

Good. X takes me. My boss and carer. I don't mind the wait. I understand nurse and doctor. I go with my shared lives carer.

Alright. The doctor speaks to mum which is ok. I understand. I wait a long time and that is ok with mum.

Good. I understand. They talk to you. You wait a long time, and it is boring.

Good. I understand what they say. I have the same person each time. It is good. I have the plan and it goes to my group home.

I see the doctor a lot. They are usually good. It is very difficult now as my parent died and I moved to live a long way from my surgery. Even if I travel to Hereford, I then have to get to surgery (out of central Hereford city). My other parent can't drive and is ill after strokes. My sibling can help but it is not easy as they live far away too. (Person advised how to register in new market town if wished). When I go my parent and I understand what is said. I remember a plan. I don't have it but just remember it. Once they forgot us and we waited ages - that was bad.

## Neither Good nor bad.

Comments included:

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I find it difficult. It feels like they are being nosey and critical about my life. They showed me rude pictures of my parts, which I thought were porn and disliked. It is good to have a check-up and have support with me. It is a lot of questions. I look after myself and feel they told me I don't. They don't listen that well.

Alright. You wait a long time it is annoying. I see the same person. She is alright. I talk to her and understand what she says.

I don't go every year now, but I used to. I go with a support worker when I go to the doctor. The staff talk to both of us, and I knew what they were saying. I found waiting a long time annoying.

OK. The doctor talks to both the support worker and me. I understand. No plan I remember.

## Bad.

Comments included:

When I go to the doctor X goes with me. It is scary. (Does not go for a health check)

A bit scary. If I need to go to the doctor I go with my carers. They are sort of kind. I don't like going. I don't like needles. (Does not go for a health check)

I get scared. I find it difficult. I go with staff. The doctor talks to both of us and I understand. The plan is useful. It is on paper but not easy read.

Thumbs down. Worried. Crowded. Long wait.

## Don't Know.

Comments included:

I don't go. (Does not go for a health check)

Don't know.

Surgery generally does a good job. Can be difficult to get an appointment. Long queue on phone! They do look after my diabetes.

## Why do you go? Why do you not go? (To have a health check).

Those who go for a health check gave these reasons why they go:

It helps me think about my health and what I can do to look after it.

Because my parents think it is important and I understand.

Like it. Medical centre.

It helps me to eat well. Mum or dad take me. Talk and listen to what they say.

Good to talk about my diet and exercise.

Mum tells me to go.

Mum thinks it is good.

Don't know.

Mum arranges.

Staff arrange, I think.

Someone arranges and takes me.

Good for doctors to see you again.

Mum arranges.

You get advice on what to do or eat or not to eat. They do write it down and you get a printout the support worker can check it. I keep it in the house. It is written in a way that I can understand.

Because mum, X books it for us. Important to look after our health & have regular check-ups & blood tests. Good chance to speak to a GP face to face in a relaxed way before we are ill.

They are good to make sure I stay healthy. I need my thyroid checked every year and I need a blood test. If I don't have it, I could get very ill.

Why? When poorly my mum rings up.

Get you better. I receive plan later. With staff I can plan, and I understand it.

Parents said to.

Carers said it was a good idea.

Mum tells me to go.

Good to check.

Arranged for me.

Important to look after your health. My parents always made sure I went.

## Those who do not go for a health check gave these reasons why they do not go:

I don't go. I am well. I don't need it.

I wouldn't want to go for a health check. It is scary. My teacher passed away years ago so I am scared going to the doctor. I don't like the idea.

I don't think I go. Not for that amount of time. I don't understand letters from the surgery. When I go to the surgery I think they are rude. It is crowded. You wait a long time. Hours. It puts you off. A long time to get an appointment too. Not kind. Don't speak to you or your carer.

I don't go because I am 20, young and fit. It is not an emergency. I feel fit.

Don't know but I have had other health issues and a major operation so pre-ops only. I have had so many medical appointments. I thought I had but talking it through those were to prepare me for operations. They can take that long. I have also had medical reviews which can take a long time.

I don't know it looks useful. In my surgery, it looks nice they are kind and I have not had to wait long.

I do like the doctor sometimes, but I didn't see the point in going every year. I don't go every year now, but I used to. I found waiting a long time annoying.

I have Diabetes and have regular checkups. I don't consider myself to have a learning disability.

## What would make health checks better/easier for you?

### Ideas to improve them.

People found this a very hard question and some answers were inferred from their previous comments about things they found difficult. Some of the comments may also be not specific to a learning disability health check but to Medical Centre appointments generally.

#### Comments from those that go:

Sometimes I got asked twice!

Ask questions more slowly and listen to the answers. Be careful not to sound like you are criticising. Give me time to think. Speak slowly. I like the easy-read health action plan, but the other letter (Widgets) Mary showed me was so full and muddled – I have dyslexia and didn't like it. Give me plenty of warning about the date. Let me have the questions before so I know what to expect. I still want to answer them on the day but be prepared so I don't get anxious and can think about my answers with my support. Don't show me rude (explicit) pictures.

Nothing I like it.

I sometimes don't understand what they say but mum or dad do. Sometimes they talk more to mum and dad than me.

I find it hard if it is a new person. Couldn't understand plan. Pictures would be better.

If running late can wait but if on time it is ok. I could see plan for myself but happy that mum tells me.

I like having the same doctor as I do now.

Easy Read would be good for the plan. Maybe offer health checks in different places.

Speak slowly and clearly in my direction and make sure I can hear.

Tell people it is good for doctors to see you again. It is a good thing.

Speak a bit slower (if they speak fast).

I get anxious. I am comfy going to a doctor on my own with a lady doctor. I can't wait a long time which makes me more nervous. The last time I saw a doctor for medical checks I wasn't anxious. I have different doctors all the time. I don't mind that as long as they have checked my records before they start asking all the same questions.

Do the plan in Easy Read.

Some doctors do not talk to me as they think I don't understand so they talk to my mum instead. I don't like that. If I don't understand I will say I don't. The doctor must talk to me because I am the patient, not my mum. I am not stupid just because I have Downs Syndrome and I am not a little girl anymore I am a young lady now. Dr. X talked to me and made me feel good about everything. I like her.

Wait less time.

Wait less time.

A film might help to explain it to people who don't go.

Not waiting.

No needles. Less scary.

**Comments from those that don't go:**

I don't need one I am healthy. Maybe when I am older.

I don't like it when they ask are you pregnant every time. They know I live with parents and have no boyfriend. They can speak a little fast and use medical terms. They sometimes talk to my parents, and I prefer direct to me. Before one of my operations, it was a long wait. It is difficult if you get there late and miss an appointment. Sometimes people prefer a female doctor I don't mind myself.

Nothing I feel well.

A film might help if somebody scared.

On time. Go not so often.

## Anything you would like to know?

There were only two comments and difficulty understanding this question.

### Comments:

The plan can take a long time to come.

When I have a rough night and my body is telling me you need to go back to sleep.  
What should I do?

## 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?

### Comments:

Fine. I don't like needles, but it was quick and didn't hurt.

All fine. I don't like a lot of people and crowds but because of social distancing and the fast way they were done I was ok.

Didn't like it. Don't like needles. Staff kind. Appointments can be bad times. Too early or interfere with my routine. I didn't like it. Wouldn't go again.

Alright. Didn't hurt.

Stings a bit.

Didn't feel painful. I did feel a bit wheezy afterwards.

Not too bad. (x2)

Good

OK

I was OK. It did make my arm a bit achy, but it didn't last that long. They were kind. They asked if this was a booster vaccine. Very nice.

I hate injections. Didn't fancy it. Eventually, I did have one. In the end, it was alright.

I have covid vaccine and flu every year. Sometimes alright sometimes makes you poorly. My sore arm feels heavier.

All clear with the doctors.

Once I had two injections every day. They are nothing to me just like someone pinching for a second. Someone always comes with me for my covid vaccine because you have to sit down afterward just in case you get a bad reaction. Usually, if I'm just going to get a blood test I will go on my own.

Ok, and I had Flu at the same time. The Flu arm was more sore but Covid one was OK. It is all quite quick.

The first two were not too bad but the third (boosters) were absolutely rough because I had surgery and had high blood pressure at the time. I felt achy and rough.

I got a headache. Before I had it I thought it is going to hurt, how is it going to be? My carer held my hand.

I didn't like my first one as I had side effects.

I don't like the pinch when it gets in and you can feel weird after.

It was OK. I felt very tired afterwards & my arm was sore & swollen.

I think they are good to have. They do not hurt you and they help you stay well. I don't want to get sick.

Bit nervous. It's good better in the end. With the booster, I felt a bit yucky. My arm was swollen. I went to the toilet because I was nervous. The needle hurt.

Hurt but ok.

Good. Scary but doctor explained what would happen.

Fine. Scary. Later ones I was sore for longer. Sore arm. Sometimes could be better. People are kind.

OK, alright. It hurts a bit. It alright.

Good. Does not hurt. No achy arm. Not sure if I have had flu vaccine.

Alright

I have had all and boosters. They are alright not too painful. I also had flu and shingles vaccines.

Ok but I did get a bad sinus headache after it and arm ached. But I was not sick.

Not painful.

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

### Comments from people that had a covid vaccine:

I don't want covid to harm me. I heard it would help to not make it so bad if I caught it. My parents said it was a good idea and they had theirs. I had covid after the vaccine and it wasn't too bad.

To protect me so covid isn't too bad if I get it. My parents said it was a good idea.

Had Covid twice not nice. Told will be worse.

People said it was a good idea.

Can't remember.

To stop getting covid. To stop the spread of the virus to my family. I had lots of lateral flow tests that make you sneeze, but I never got Covid.

Mum arranged.

I had Covid. My parents and I got vaccines. I was told it is a good idea.

Someone said it is a good idea. I would go again. Just one little prick.

I went because it was the right thing to do, and I knew loads were going to get it done at the time and I needed to get it done. I would go again.

Arranged for me.

Mum arranged it in our house, I think. It is to stop us getting too poorly.

I have a Flu jab but not covid. Mum got a covid injection, but I didn't. I think injections are scary.

Covid vaccine. I go because I have been advised to go and I have heard the news and thought I certainly do need one. Having a covid vaccine helps you not to worry about covid as much.

To stop me from getting covid or the Flu.

It protected me but more important protected my grandparents that live with us.

It came in a letter, and I just agreed to it. They said I needed it, so I went.

I didn't want to catch it. The school was opening up and I didn't want to pass it on to my friends. I am scared of needles. Still am a bit scared.

I know it is good for my health, so it is good to go. There is a high chance you'll die if you don't get it.

We were invited and was the right thing to do.

I have had covid injections as it's important I don't get very poorly. I am more likely to get complications from COVID because of my Down syndrome.

I don't know why I went Mum said to go.

To make you better.

The staff said a good idea. I had no side effects.

---

Carer said a good idea.

Someone told me it is OK.

I am not too worried about injections. I had a lot before. I thought it was the best thing to do. I thought I better have it. I know a lot are against it. There always will be people against things and they are not always right. I thought it was to protect myself and others.

The family said good idea and I agreed.

Good idea.

**Comments from people who had not had a covid vaccine:**

Mum said not a good idea. Mum didn't get one either. I have not had flu one either.

I really didn't want to go. I can't stand needles. Everyone tried to persuade me but I refused. Eventually, I did have one because I had to have one or I couldn't go abroad on holiday. In the end, it was alright. I might go again but it depends on what support staff go with me. Also, some surgeries I am not keen on.

## **What would make covid vaccine experience better/easier for you? Ideas to improve them.**

### **Comments:**

Tell people that they don't hurt. Explain why they are important in Easy Read.

In the future keep up social distancing for people with autism.

Waiting is not nice at surgery.

2 people said: Don't know.

Maybe a film might help before you have your vaccine to show you what to expect. It is that first thought of it. A film might help. Healthwatch asked if I would like to help by saying my experience on film. I'd give it a go! It might help.

I don't want to go. Don't like needles.

You could do nothing; I just don't want one. When I went to the hospital and had a scan, they showed me a film on the laptop first to see what to expect. That was good.

Tell people not to be scared.

Say it is completely normal to have the vaccine. It may hurt. Be able to make your own appointments as an adult.

It is a good idea to go with somebody. Also, good to be distracted. A telly advert would be good showing it and what is going to happen.

Have someone to distract you. Perhaps a home visit somewhere familiar. Explain it in a film.

Don't get news from Fox News! Don't listen to patriarchal leaders who don't read and drink paint! They say it causes autism to have a vaccine. Firstly, that is not true. 2ndly there is nothing wrong with autism. 3rdly I'd prefer that and prefer autism than being dead! The test that said that was wrong.

It would be better if you didn't wait so long and if it didn't hurt.

A film before you go the first time would be good.

Don't pick up needles from the floor.

Have to wait a long time and fill a form while you wait.

Not painful.

Reduce wait times to get appointments. Make it easier. Ringing up is very difficult.

No side effects! A film might be good and encouragement from other people with a learning disability.

## Anything you would like to know about covid vaccines?

### Comments:

Why are people with a learning disability in more danger?

Will we keep having them forever?

Are they going to be a regular yearly thing like the flu vaccine?

Help me with different types of pills.

.

## Appendix 2: Letters

The following two letters were sent to patients to request they participate in the research.

### Health Checks and COVID vaccinations

Please tell us your views and make a difference



We are working with Healthwatch to gather the views of people with a learning disability. We want to know what you think about annual health checks and COVID vaccinations.



We want to listen to your views about health checks and COVID vaccinations whether you've had them or if you haven't had them.



Please have your say by talking to Mary from Healthwatch.

It will take less than 30 minutes.



You can give your views in different ways:

- You can visit Mary at the places listed in the flyer.
- You can talk to Mary on the phone.
- You can contact Mary by email.
- You can fill in an online form.



All you say will be private and confidential. Mary will combine everybody's comments into one report. Individual names will not be in the report.



Your views are important to us.

Thank you for helping to make a difference.

## Health Checks and COVID Vaccinations

Please tell us your views and make a difference



Hello, I'm Mary. Please tell me what you think about annual health checks and COVID vaccinations.

Watch a video of me talking about annual health checks and how you can help improve them. To watch the video, type in the link or use the QR code.



<https://tinyurl.com/HealthwatchHC>

Just turn up at these venues. There is no need to book.

Hereford. Tesco Superstore café, Abbotsmead Rd, Belmont, Hereford HR2 7XS	Monday 7 <sup>th</sup> August	2.00- 3.00
Bromyard. Bromyard Centre Hub, Halo, Cruxwell Street, Bromyard, HR7 4EB	Tuesday 8 <sup>th</sup> August	11.00 - 12.00
Hereford. The Courtyard café, Edgar St, Hereford HR4 9JR	Tuesday 8 <sup>th</sup> August	2.00 - 3.00
Kington. Lion Café, 52 Bridge Street, Kington	Wednesday 9 <sup>th</sup> August	10.00 - 11.00
Leominster, Tourist Information Centre, Corn Square	Wednesday 9 <sup>th</sup> August	1.30 -3.30
Ledbury, The New Market House Café, 1The Homend, Ledbury HR8 1BN	Tuesday 22 <sup>nd</sup> August	10.00 - 12.00
Ross on Wye. Morrisons café, 1 station St, Ross-on-Wye HR97AG	Wednesday 23 <sup>rd</sup> August	10.00 - 12.00

Or



We can talk about health checks and COVID vaccinations on the phone or we can meet at a time and place which is easiest for you.

Please contact me in any of these ways:

1. By phone: 07925 882537
2. By email: [mary@healthwatchherefordshire.co.uk](mailto:mary@healthwatchherefordshire.co.uk)
3. Fill the form which you can find here: <https://tinyurl.com/HealthCheckHW>

*Healthwatch Herefordshire listens to your views about health and Council social services; we speak up on your behalf to help the NHS and Local Authority to plan and deliver services that meet your needs. For more information about Healthwatch visit [www.healthwatchherefordshire.co.uk](http://www.healthwatchherefordshire.co.uk)*

## Appendix 3: WBC clinical feedback.

WBC practitioners have been considering this issue simultaneously and have suggested these potential changes to increase take up of health checks.

- Involving the paperwork could be useful as patients can see what they need to fill out and bring with them.
- Including what we do in the video: height, weight, pulse, ears, eyes, dental, swallow, some questions about health, discussion about their life, blood test and the need for a urine sample.
- Explaining that the appointment is with a nurse / HCA and what colour uniform they can look out for.
- Video/photo of the outside of the building.
- “Through the door” experience – where Reception is & staff providing a friendly welcome.
- Explain reasonable adjustments that can be made e.g., a quiet waiting room, earlier in the morning/quieter time of day, waiting in the car rather than the waiting room, if preferred, a tour of the surgery to alleviate anxiety.
- Advising that it all takes place in one appointment, but bloods can be taken on a different day, if preferred.
- Longer appointments always offered to give people time to talk/ask questions.
- Surgery staff are available all year round – you don’t need to wait until AHC to make an appointment/discuss concerns.
- Possibly including input from the Wellbeing Team to describe the support they are able to offer.

## Appendix 4: Gloucester Study and subsequent campaign.

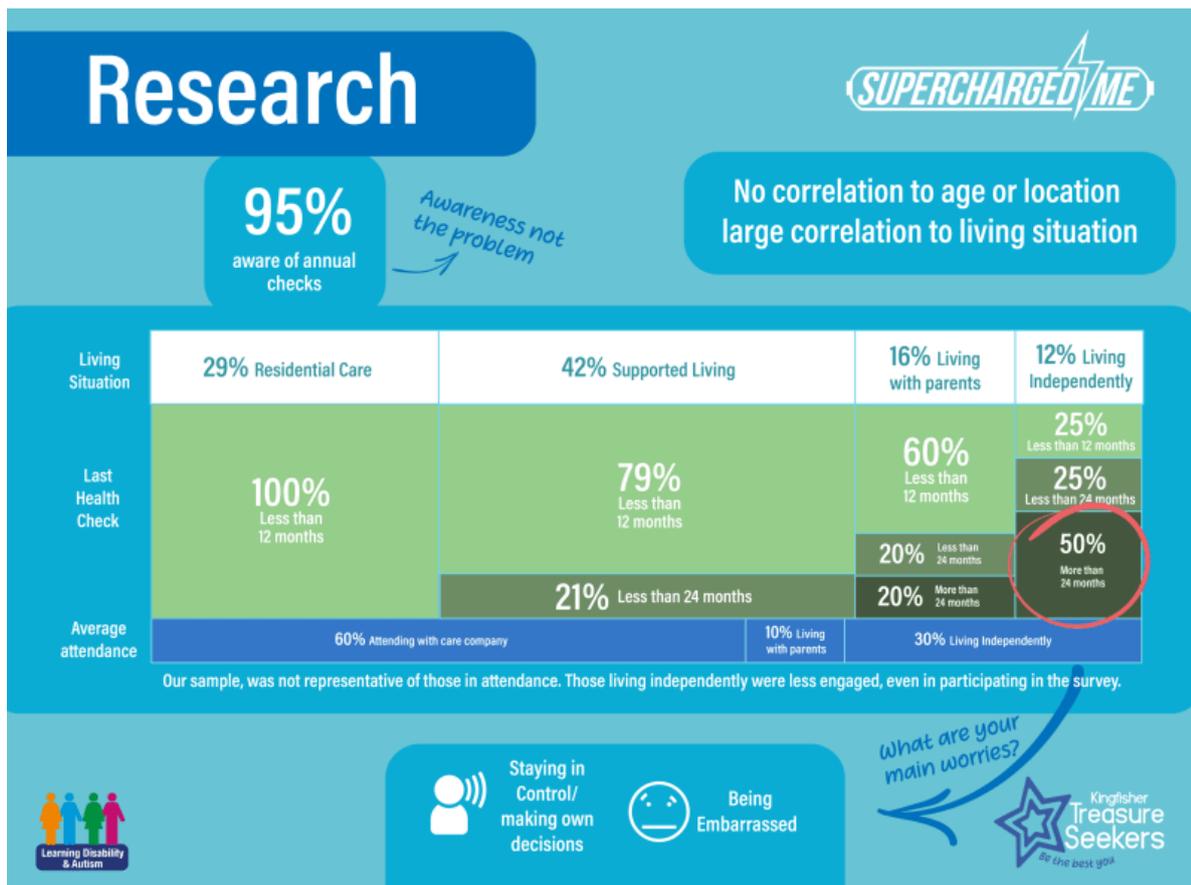
“Supercharged Me” was run by Kingfisher Treasure Seekers who had carried out similar research in Gloucestershire. They subsequently created a campaign called ‘Super Charge Me’ which is worth checking out. They told us that:

“The number of health checks taken in Gloucestershire has gone up each year since we started the Supercharged Me campaign, but that it is really difficult to define the causal link”.

There’s more information at <https://www.kftseekers.org.uk/superchargedme>. and if you email [info@kftseekers.org.uk](mailto:info@kftseekers.org.uk) they’ll be happy to put you in touch with the team or share details. There follows an excerpt from the website:

### Supercharged.Me

Supercharged.Me is a co-produced campaign following research, to support adults and young people with learning disabilities to engage with having an annual health check.



In 2018 Treasure Seekers conducted some research around annual health checks and discovered some interesting trends.

We found a trend of those living independently were far less likely to have had an annual health check in the past 2 years and were less engaged in the consultation. Upon a deeper dive into this group, control was a major barrier.

We formed a small coproduction group to gather ideas as to how to solve this issue. The group wanted to create something which didn't look like standard NHS/Local Authority materials. They didn't feel represented by usual marketing materials as they had less obvious physical disabilities and so wanted to represent inclusion through the use of non-human characters and they didn't want to use easy read. This group felt 'in between two worlds'; that of Learning Disabilities and mainstream community.



Supercharged.Me is a campaign targeting this particular group. It consists of social media messaging, a website and print material all focused on taking control of your own life by looking after your health.

In 2020 Supercharged.Me was shared regionally across the Southwest as with funding from Health Education England.

There is only one question - have you been Supercharged by having your annual health check?

Visit [www.superchargedme.uk](http://www.superchargedme.uk) to find out more!

## Appendix 5: List of Surgeries and Medical Practices.

3. What Surgery or Medical Practice do you go to?				
Answer Choices			Response Percent	Response Total
1	Alton Street Surgery		9.68%	3
2	Belmont Medical Centre		6.45%	2
3	Cantilupe and Hampton Dene Surgery		3.23%	1
4	Colwall Surgery		0.00%	0
5	Cradley Surgery		0.00%	0
6	Fownhope Surgery		9.68%	3
7	Golden Valley Practice		0.00%	0
8	Hereford Medical Group		16.13%	5
9	Kingstone Surgery		0.00%	0
10	Kington medical Practice		0.00%	0
11	Ledbury Health Partnership		0.00%	0
12	Mortimer Medical Practice		3.23%	1
13	Much Birch Surgery		3.23%	1
14	Nunwell Surgery		3.23%	1
15	Pendeen Surgery		16.13%	5
16	Ryeland		9.68%	3
17	Tenbury Wells Surgery		0.00%	0
18	Wargrave House Surgery		6.45%	2
19	Weobley Surgery		3.23%	1
20	Don't Know		6.45%	2
21	Prefer not to say		0.00%	0
22	Other (please specify):		3.23%	1
			answered	31
			skipped	9
Other (please specify): (1)				
1	21/08/2023 11:33 AM ID: 224836668	Birmingham - on respite in Herefordshire Surgery Great Barr?		



# healthwatch

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