

# **Supporting Vaccine Confidence**

COVID-19 Vaccinations: Views and experiences

Interim Report

(Responses from 3 - 8 March 2021)

I suffer from anxiety and hadn't been out in a year nearly. So was really anxious and had lots of questions and vaccinator was so patient and reassuring.







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#### Introduction

During this interim period **over 1800 surveys were completed** (and a further 269 partially completed.) The survey is due to close on 31 March 2021.

The purpose of the survey is to understand from people how to improve the vaccine service and vaccine confidence and thereby uptake through feedback (both what is working well and what could be changed).

We are also asking people who have not yet had the vaccine about their thoughts to see what further information is needed to support people to make informed decisions.

#### For regular updates on the local vaccine programme please visit:

https://www.sussexhealthandcare.uk/keepsussexsafe/sussex-covid-19-vaccination-programme/

#### New text message service for COVID-19 vaccination invitations

As the COVID-19 Vaccination programme moves on to new age groups, (as of 10 March 55+ year olds are being invited for the vaccine) the National Booking Service will shortly begin carefully trialling a text message service for COVID-19 vaccination invitations and reminders, in addition to the letters that are currently sent to eligible people. It is hoped that this approach will help the NHS issue invites to eligible groups more quickly and be more convenient for lots of people, particularly those in younger age groups.

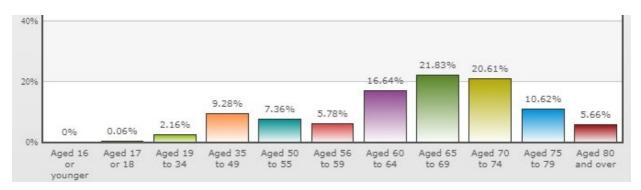
People receiving these text messages will be invited to book online at <a href="mailto:nhs.uk/covidvaccine">nhs.uk/covidvaccine</a> or by calling 119, for an appointment at a local Vaccination Centre or pharmacy-led site. The text message will be sent using the Government's secure Notify service. They will appear as being sent from NHSvaccine. These text messages are in addition to those which are currently being used by some hospitals and local GP-led vaccination services.



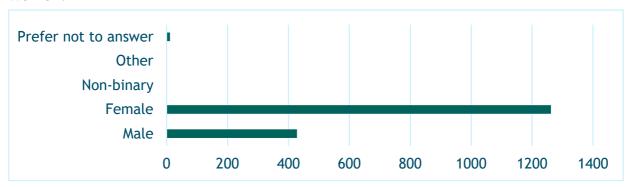


## About the respondents

There has been a useful spread of ages and locations.



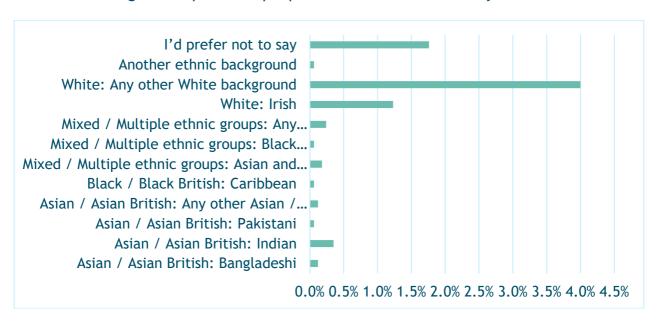
**Gender identitgy -** There was a much larger response from people who identify as women.



4.33% (73 respondents) stated their gender was different to the sex that was assigned at birth, with 16 people preferring not to say.

**Ethnicity** - 91.77% of respondents selected White: British / English / Northern Irish / Scottish / Welsh.

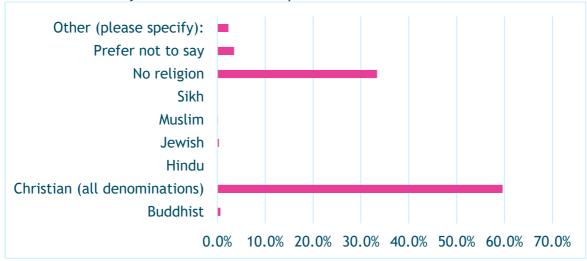
Of the remaining 140 respondents people identified their ethnicity as:





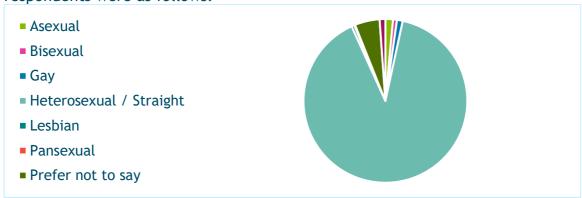


The breakdown by faith or belief of respondents was as follows:



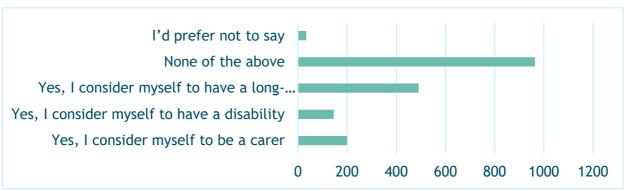
I do not understand why these questions are deemed necessary for an essentially emergency medical programme.

In line with most surveys, we asked people about their sexual orientation. The respondents were as follows:



There were some interesting comments to reflect on the relevance and appropriateness of the above questions for future surveys.

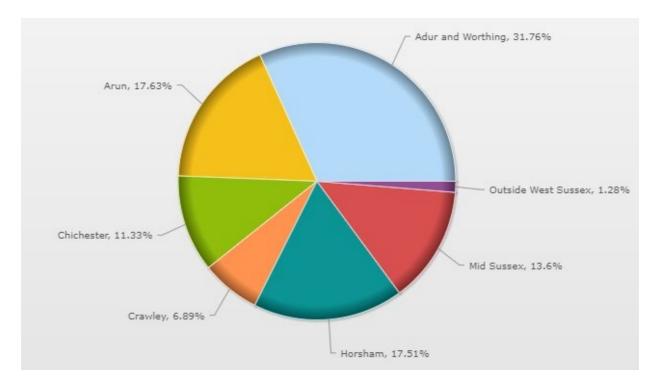
We asked people if they considered themselves to be a carer, have a disability or a long-term health condition? (Ticking all that applied).







#### The location breakdown of responses was as follows:



183 people classified themselves as being a frontline health or social care workers or key worker.

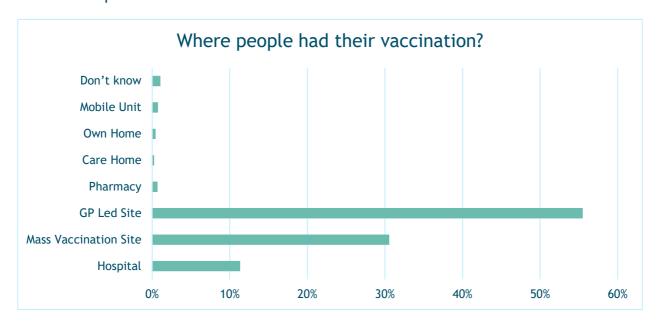
189 people classified themselves as *Clinically Extremely Vulnerable*, with a further 350 as having an underlying health condition (including anaphylaxis).





### Vaccine experienced

92.5% of respondents have received a vaccine and some have had two doses.



Most people have detailed exactly where they received the vaccine, and we will include this in the final report. Similarly, there is some useful narrative around the vaccine received and this will also be included.

Just over half the respondents had been invited to receive a vaccination and was given a time, date and location to attend, with 22% responding the national letter.

Nearly 65% said they did not receive more than one invitation.

Where people had commented on why they selected a particular option, there was an equal balance between the speed to get the vaccine (often going with what came first) and staying local/known location. Others chose location as able to book day/time and second dose or ease of booking.

After booking, we had very bad weather (snow and ice) making it unsafe to travel. I was able to rebook easily online. There was a note on the website saying that because of the bad weather, it was understood that people would need to cancel and rebook.

As a wheelchair user I could not go to Brighton and my Dr has not made contact so had to wait for Westgate centre to come online for access

.. the NHS LETTER way of arranging the appointment was ridiculous and mainly useless, because the vaccination centres were miles away from my location.

After one week of attempts to find a local centre, I notified my GP and arranged a local attendance centre!



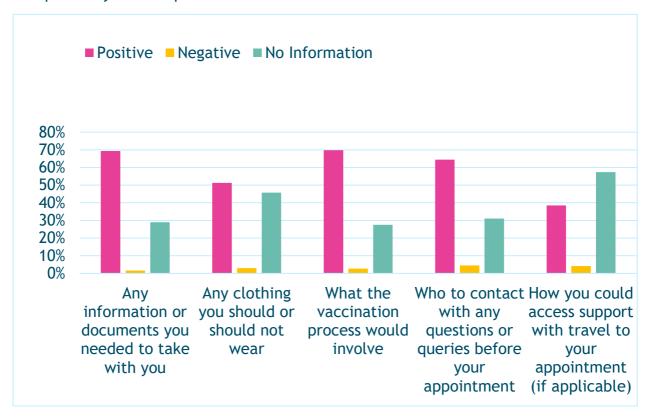


#### **SECTION ONE**

## Vaccine preparedness

96% of respondents had a positive reaction to information on when and where they would/could receive the vaccine, with 90% clear on how to confirm attendance or non-attendance.

The positivity rate drops for other information needs:



We suggest this may become more of an issue as the vaccine programme rolls out to people who are less familiar with processes for having a vaccination.

This is something that can be easily addressed through for example sending a confirmation text with a link to information on how to prepare yourself for the vaccine.

Over 8 in 10 respondents were happy with the amount of time between the invitation and vaccination appointment. 71% stated they were able to book at a time/date that suited them.

It would be nice to have an idea of when I'll get 2nd jab

Person on phone booking appointment was very helpful. She made all our appointments at the same time.





#### Some areas for communication learning are shown below.

Unable to find correct information regarding safe length of time between positive Covid result and vaccination. Nobody knew!!

Not at all happy that the NHS website told me to wait until the GP contacted me for a local injection (group 5), but the GPs were told to do group 6 and not contact group 5. I had to find out from a post on Facebook that if I phoned the surgery I could go to the local GP led site.

I originally booked to go to a London Hospital, and I tried several times a day over 2 or 3 days to cancel that appointment so it would be available to someone else, and I could never get through to anyone.

Unable to attend by myself had to get son to take me who is my carer, but quite short notice. I also have dementia so found any instructions hard to remember.

It would have been helpful to be warned that I was likely to need a clear 48 hours afterwards to allow for side effects - it seems these are more likely than not, including for much younger people.

My husband was invited and as his carer I had to go with him. Although I was the right age to receive I was told I couldn't be done at the same time - but I was!

But NOT locally which I would have preferred - concerned now for second jab in case my nausea happens on train during return journey home.

Hub not keyed up to provide care for those with needle phobia like me who need to lay down flat, in a private room and to be left laying down for 20 minutes or so afterwards. I have received a dreadful service in trying to book the first appointment and the manager of my GP practice, who was clearly overwhelmed, has asked me to complain to our local MP which I will do. Had to wait 2 weeks for someone to phone me after initial text asking me to book appointment. I made 11 phone calls in all to get my appointment. A very stressful experience on top of being needle phobic.





## Experience of vaccine services

Challenges in accessing first vaccines:

- 86% of respondents reported no problems in attending the first vaccination appointment. Some additional comments demonstrate peoples gratitude and how small changes are important:
  - Suspending parking charges
  - Volunteer was very helpful arranging for my husband to get me in front of queue as I'm unable to stand for long as disabled.
  - Not sure about bus stop nearest to centre slightly problematic due to partial sight but bus driver on the day was very helpful.
  - Only challenge was mum's mobility in and out of car. Excellent help from volunteers at Tangmere with wheelchair assistance.
- Parking for 6% had been an issue, for example those with mobility issues.

Disappointed to be charged for parking at Crawley Hospital having traveled there when not offered a vaccination at Haywards Heath...

• Whilst statistically only 2% of respondents reported an impact on their caring responsibilities, this was still 17 families.

Had to queue 40 mins outside having left husband who has dementia at home on his own. Although I told the lady on the door no notice was taken of this. I was extremely unhappy that I had to join this queue and did not know if husband would still be inhouse on my return.

• Travel (costs, time, and lack of public transport) affected 85 people.

Didn't know where the centre was, so had to do test journey day before to check time was adequate to do journey between wife's vaccination in (location given) and get to (Other vaccine site given).

We had a cab for jab taxi but the cost is £9. So, £18 there and back. Paid by charitable donations but should not be necessary. Appointments should be daytime at the hospital which is on a main bus route with a frequent service.

Couldn't travel by public transport - would be 2 buses and nearly 2 hours travel each way. So, had to get taxi each way.

Very long waits outside on a very cold day and I was eventually seen almost an hour after my appointment time.





Am disabled and went to Lancing on my mobility scooter. This is further than I usually travel as my back and left leg go into spasm. Was also told I could drive my scooter straight into the hall, but this was not the case, however the support staff brought out a wheelchair and pushed me around in it.

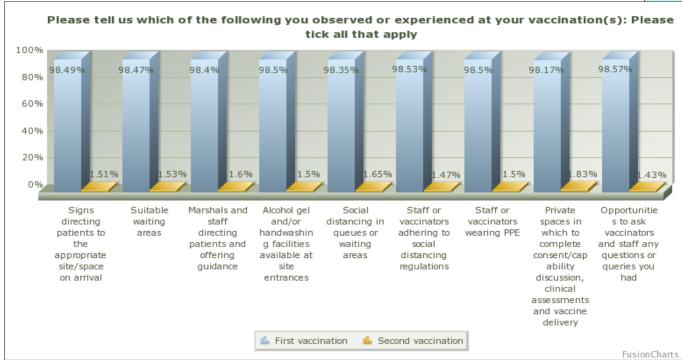
#### There were a few signage issues identified:

- Could have done with street signs for the Westgate Centre in Chichester.
- Signage from the entrance to the hospital only signed from the front entrance to hospital where it was crowded. Signs from road outside were the wrong way round.
- Initially couldn't find the location, and then wasn't aware that there was parking just behind the entrance, so parked in sport centres car park, arrows were there but they were not saying what they were for.
- Car parking arrangements at the leisure center very unclear was concerned I would need cash and haven't had any for about a year!! Could do with being clarified, but not a vaccination issue per se.
- Only issue I had was in not knowing where at Chichester Hospital I was supposed to go. I was given the name of the building, but nothing to indicate where it was at the hospital or any signs when I arrived at the hospital. I think parking would have been an issue if we had not been in a lockdown.
- I felt the signs at Crawley Hospital needed to be more prominent as initially I missed the sign on driving into the car park.
- The Centre itself was poorly signposted as a vaccination centre i.e. from 200 yards away nothing until right up to the building. But after that all good.
- Very poor external signage. Were expected to know where to enter the building. Not having visited the Bognor Regis medical centre, I had to try a number of entrances. A poor old lady had an awful job finding where to go. Not good enough.





#### Respondents report highly positively on the set-up of vaccine sites:



Please note the following comments, which are helpful to check service provision against:

- I felt that it was not very private when I actually received my vaccination, because the people at desks with computers were within 5 feet of me and facing on to the place where I had to sit and receive my jab. I would have preferred a bit more privacy. But I was just happy to be getting the vaccine! I arrived early because of bus times so waited away from site.
- Joined queue 5 minutes before appointment time (as requested when I booked appointment). Queued for 30 minutes outside (thankfully a dry day) but found others had arrived for later appointment times. Would have been good to prioritise by appointment times. It also meant I missed next bus home!
- The chairs were cleaned in the pre vaccine waiting area, but not in the post vaccine waiting area. I find that very surprising and poor as this shows lack of protection for the people receiving the vaccine.
- Waiting post vaccination and booking next appointment slightly chaotic. There
  was no system in place, just left to whomever got up quickest as the
  administrators became available.
- Appointment booked for 8.30 but vaccination centre did not open until 9.00.
   Was not notified of change.





- I was told to sit in car for 15 minutes after jab. Exactly how I would have got help if I had suffered reaction I do not know as was in public car park and there was still that queue to get into the health centre. NO ADVICE GIVEN ON POSS SIDE EFFECTS. NO LEAFLET. Jab given in corridor, standing behind a screen.
- The pamphlets referred to a record card of the vaccine given but I was not
  offered one and on enquiry was told they were not being given, yet subsequent
  people have received one with a date for the 2nd dose- I didn't receive a date
  for a second dose either.
- Very poor arrangements. No hand gel. Initially no social distancing so I complained. Five waiting areas to move through! Inadequate infection control in final waiting/booking room so complained again. No hand gel at exit. I was amongst a crowd of people for over one and a quarter hours any of whom could have been infected having kept myself safe for months by not going to supermarkets. It was chaotic and s ridiculous amount of time spent in the building. Every other venue is less than twenty minutes.
- In a leaflet given after was given the vaccination I was told I should mention that I was on Immune Suppressant drugs too late then!!!!!!
  - <u>Note:</u> This is necessary to ensure appropriate timing of second dose but without this explanation it would look odd to people as to why this is being asked at the end of the process.
- Was only given a tiny drop of sanitizing gel at the door. Not enough to cover your hands.
- The staff inside were not wearing masks. (Mentioned by a couple of people).
- No consideration or opportunity to ask for help given to me as a disabled person who has issues standing, even though the aids I use would suggest that.
- I think the post-vaccine waiting area at Bognor was too crowded and not ventilated by opening window/s.
- The volunteers marshals got very close to me. Which wasn't necessary.
- Booking in staff (member) was rude and no time or provision for questions.
- too many people to help !!!!!! there were 5 X as many staff as people being Vaccinated and a lot of staff standing around doing nothing as there was nothing to do?
- I thought we had to sit somewhere for 15. It was jabbed and out the door!
   Note: People are not aware, necessarily of the differences between the vaccines for waiting times, as this has also come up in other conversations.

Lots of people spoke of cleanliness of facilities and this suggests that it is important aspect of installing confidence in the programme. One person said (Name of site) is in a very poor state of repair and didn't look particularly clean.





Over 80% of respondent felt they were given enough time to read and understand the information provided before consenting to have the vaccine. 6% felt there was not enough time given.

98% of respondents felt safe or very safe at the vaccination site(s).

Had to change all masks for surgical masks.

I felt this was a very good thing.

Of the remainder ventilation and lack of social distancing (in queues which is harder to control but may be something marshals can be more alert to but also in the post-vaccine waiting areas) were detailed more often.

Anaphylactic shock came up quite a few times and this may be an area where more booking attention/information is needed.

#### Other concerns were:

- As I have been shielding it was a bit unnerving to be in a closed environment with other people.
  - <u>Note:</u> This was mentioned a number of times, an issue raised was marshals not distancing adequately.
- There was no clear separate entrance for vaccinations. Everyone was asked to press a button on the intercom and talk into the speaker. Shocking. Not sure who thought this was a good idea!
- I felt there was a lot of people in one area and felt unsafe waiting for 15 minutes in a room full of people after the jab.
- Waiting queue was not socially distanced and signing paperwork didn't feel safe enough. (This may feel the case because in other cases people are no longer asked to sign, e.g. for prescriptions, parcels, etc.)
- The person giving the jab was rubbing their hands together so can only presume they had sanitised.
  - Was not aware of any sanitiser. There did not appear to be any sanitising of touch points.
  - Had I any allergies, tried to answer this but interrupted and asked if I had any reactions to previous vaccines.
  - Arm was not cleaned,
  - Persons put their finger over injection site, no gloves, removed finger then put back on for a few seconds, no cotton swab.
  - Asked if I had driven there, I had not, so told I could go.
  - This was all done standing, at no time offered a seat. Felt dizzy after leaving on my way home, decided to get home and if I needed help I would ring someone.





- Sent straight out to my car. So extremely unsafe.
- I had to queue outside for 45 minutes with no shelter from the rain. Inside there were far too many people in the room and poor ventilation. It was the worst experience in the last year when I had been very careful about social distancing. This was unacceptable.
- Too many people and I was asked to wear a visor even though I am exempt from wearing a face covering on medical grounds. This made me very hot, breathless and anxious. I was glad to have the vaccine but I was glad to leave too.
- My ICE details were not taken and I was not given the opportunity to sit down after the injection.

Vaccination was given in an open hall in front of several others also receiving the vaccination with no privacy or dignity afforded. No individual cubicles/screens. Brief and what felt a rushed conversation with doctor/nurse of any concerns regarding vaccination, medical conditions, allergies - again in open room full of people awaiting vaccination - no privacy afforded to individuals and did not feel I was able to discuss my concerns fully.

No card given as record of vaccination and batch number - told not available.

Told after vaccination that could not drive for 15 minutes (not made aware of this beforehand) and told to wait in my car. No checks made on those waiting in cars in car park and little means of getting medical help if needed

Whole process felt rushed - a conveyor belt. Felt like we were herded like cattle to make the whole process expedient.

Accessibility of location/building was largely suitable for most people who responded (over 87%).

Issue that have not already been raised were in regard to lack of access to toilet facilities.





#### Post-vaccine information

**98%+** of respondents had written confirmation of the vaccines, information on possible side-effects and information on who to contact if they had any adverse reactions. The same of keep safe measures for after the vaccine.

A chance to know who to write to in order to say thank you so I am doing it now!

The information was not for the clinically extremely vulnerable. I got the "older adult" leaflet. Patronising and not detailed enough.

87% also received information with a time, date and location of the second dose appointment.

68 people had not received any of the above information.

There was absolutely no time to read the 3 sides of A4 I was given on the way in. Whilst this is down to the super-efficient flow of people (and therefore avoiding the need to stay indoors any longer than necessary, perhaps the information could be placed online so that people can read it beforehand thus preparing any questions they may have for the clinician

#### A few people commented:

• they would have liked more information about the vaccines and more about side-effects, as what they were given was very basic.

It was also suggested that it would be useful to be able to feedback on sideeffects.

Where to notify adverse reactions not listed on the paperwork if unable to use the Yellow Card system.

• Their names were not on the card given to them. Others reported not getting a cards or written information that they had received the vaccine.

Most comments related to the lack of date/information about the second dose.

A couple of people mentioned consuming any alcohol before or after the vaccine and the impact of doing this? Perhaps this can be added to the FAQs?





We asked people if they had any outstanding concerns after receiving their vaccination. 149 answered, yes - they did have outstanding concerns.

I have to travel to Midhurst for my second vaccine there is now a vaccination centre in Chichester, but it appears absolutely impossible to change my venue. I have two small children and am a lone parent. Midhurst is very far.

Most comments related to the second dosage appointment and repeat of the sideeffects they experienced (with narrative of a wide range of effects). Other mentioned:

- Issues in identifying parent carers effectively.
- Poor administration with first vaccine call-up and getting forgotten.

People also expressed concern over new variants and the length of time of immunity the vaccine provides.

Next time I will take a plaster with me to prevent the blood staining my clothing. Also have paracetamol ready before the pain takes hold.

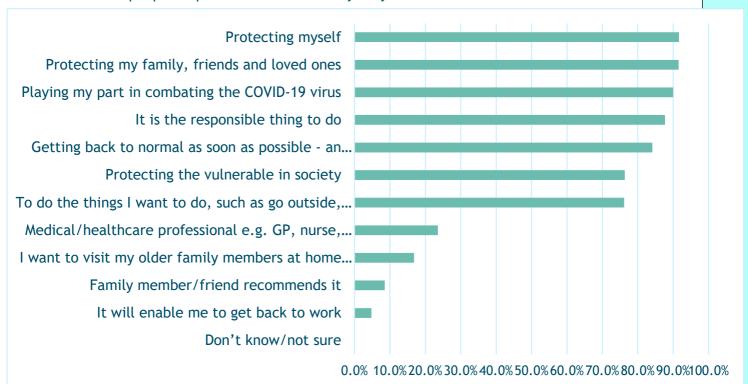
The fact that the vaccinations are referred to as 'jabs' when I only felt a slight scratch (like the flu vaccination) and wondered if it had been done properly. I didn't feel anything being injected into my arm as I did when I had the anti-pneumonia vaccination a few years ago, and could feel the needle going in and liquid being injected. Calling them jabs may put off people who are afraid of needles, as has occurred with a friend of mine.





## Why people opted for the vaccine?

We asked people to pick all the reasons why they decided to have the vaccine.



Most people shared information relating to protecting them and others. People wrote of global safety and avoid more variants.

Some were resigned to having it.

Resigned myself to being a 'guinea pig' so that more data can be collected.

Overall, based on experience over 99% of respondents were likely to encourage family and friends to accept a COVID-19 vaccination.





## How can the vaccine programme be improved?

Many people responded to say there was nothing to improve. Here is what people have suggested needs to change.

#### **Prioritising**

- Please sort out the way parent carers are acknowledged and recognised not all unpaid carers receive carers allowance. This means there needs to be a focus going forwards on how unpaid carers and parent carers who have vulnerable children who depend on them cam be identified.
- An appointment time, rather than a slot, so people like me with a needle
  phobia can avoid waiting in a queue, which, if they're like me, they may have
  done a runner before getting to the front of the queue! I was lucky, and
  deliberately (and successfully) booked into the last 10 minute session to
  minimise the risk of having to wait.
- Really would like couples to be vaccinated at the same time as my husband is very vulnerable and I was really worried that I had to wait awhile before I had my vaccination.
- IPC are somewhat behind the other two local surgeries and do not as yet appear to be following up hesitant patients. Some standardisation of roll out between surgeries would have allayed some anxieties in our community.
- Where one elderly frail immobile person was having a vaccination done at home that the partner of that person could also have been done at home at the same time.
- Please vaccinate all teachers.
- If seems very random when you are called and GPS ask not to call them, so no way of getting info I had been instructed to shield the first time, so was expecting to have the jab before 15 Feb, but was called later than this and at very short notice.

#### Information

We recognise that much of the programme is being determined nationally, but one of the things we can do locally is to use all communication methods available to GP-led Services (such as social media, practice websites, local magazines etc.) to let local people know how they will be contacting when it is their turn to have the vaccine.

Talking to one of the volunteers I mentioned what happened to those who
could not communicate their needs but wished to be independent and as I work
with AAC users we discussed use of symbols and easy to read info - we have
made free examples that can be created by anyone thanks to a grant and
support from UNICEF <a href="https://globalsymbols.com/about/featured-board-sets">https://globalsymbols.com/about/featured-board-sets</a>





Personally, I think even if it's way down the line Communication that one WILL receive the vaccine in, i.e. June then you know you're in the system. Also, whether to expect a phone call or text or email. I carried my phone everywhere until I'd heard.

Making sure patients have sufficient info of the procedure of the vaccination at all stages. Poor info causes stress and lack of confidence.

Maybe not say "jab" for those people who are needle averse.

- Clear signposting at site. Details of transport options. I am a carer for my husband who is disabled and it was an expensive taxi fare.
- Don't send letters inviting people to travel way out of their area when they can have the vaccine much nearer home worried a lot of people I know.
  - Note: We understand this to be outside the control of our local NHS.
- Clearer information regarding the risks to themselves and others if they refuse the vaccine.
- Give vaccine info and side effect details before not after the vaccination.
- The booking link made it easy but more info ought to be readily available if you have issues that may make having the vaccination a problem.
- Having a dedicated phone number to ask questions before the appointment or before you make the decision.
- To be given time to read the information leaflet before going in to the room for my jab. As it was a busy site, all patients were being ushered in and out as quickly as possible with not much time to read the vaccine pamphlet in case it triggered any questions a patient may subsequently have had about the vaccination.
- As a health care worker involved with the vaccination programme, I would love for there to be more clarity re vaccination deliveries and therefore more certainty as to when and how the clinics can be run. Also I would love for there to have some kind of collaboration between the IPC and the SCFT in Chichester. After all, this is a national programme, working together is essential and expected.
- To be told to wear a short sleeved prior to the vaccine.
- Do not show the vaccination process e.g. needle going in on every TV news. That can put off a lot of people, including close friends I have spoken to.
- Make it uniform I e either we all receive a card with date, dose etc. and a date for the second dose or no one does.





- I think people especially younger people should be warned that they may have a severe reaction to the jab and need a day or two off work.
- More information on side-effects.
  - On the flip side, someone wrote: There's a lot of emphasis in the Press on expected side effects. But I had none at all. Nor did one of the two people managing the vaccinations.
- To remove misinformation from all social media and continue to encourage everyone to accept their invitation to be vaccinated.

Local Facebook postings about the efficiency of The Glebe Team - how delighted/relieved people were. These spontaneous comments are useful to calm any fears e.g. coming together of too many people - to then be told by users that it is so well controlled! etc.

- Don't get me started. Found those in Bognor very dour. No smiles and no one to ask re my personal concerns about my husband at home. Completely unavailable.
- The two options of travelling to a mass vaccination centre or waiting for a GP were not clearly explained. Many of our friends (and we) had to ring the GP to find out which option was advisable.
- All retired residents such as myself, should be offered locally and have access to information if there is a delay. For instance, via your surgery's website.
- More positive PR on the AZ Oxford vaccine please!!
- Letting the public know that scientists and doctors have been working on a vaccine since the first SARS outbreak not just since the outbreak of COVID-19.
- Keep getting a good cross section of the public to talk openly about their experience.
- More information of symptoms to look for if have had COVID especially like myself, as i was in intensive care and had full CPAP helmet, steroid and oxygen plus other medications -

I was told to arrive as close to my appointment time (15.14) as possible, yet there were people in the queue ahead of me who were almost half an hour early. I was therefore late for my appointment, but nobody seemed to be bothered by any of this. Next time I'll arrive half an hour early too!!

 Yes! Please could GP surgeries keep their patients informed! Even if it's a universal text saying local centre is skipping a group! I am in Group 5 but





- yesterday realised, I am in Group 6 so could have gone to local centre. There will be a lot of people ""waiting"" for GP surgery to get in touch (Park View).
- Have a set telephone number for people who have additional or special requirements to call and discuss what they need.

#### **Booking method**

People have referenced poor links between the NHS national system and GPs suggesting it is 'fragmented' and 'confusing', so needs looking at.

- Book the second vaccine with the first.
- Allow booking at local centres.
- The invitation text looked like a scam, I had to verify it. Can it be made clearer that it is genuine especially as it doesn't come from the NHS or my GP surgery? Nearly ignored it.

I missed the MSDH text, because I thought any text would come from my surgery (via econsult) and EVERYONE in my area had received a letter, including my husband and brother.

- Fill up any unused slots with any people willing to turn up at short notice rather than letting any vaccine go to waste. And use low dead space syringes if they aren't already.
  - <u>Note:</u> the system has notified us that there is mutual aid going between GP Practices to avoid vaccine wastage and to help cover the earlier priority groups.
- There is no way of cancelling or changing dates. In my invitation there was a number but when called no one answered. There is no one to ask questions to beforehand.
- I am uncertain as to how the GP surgery would have contacted me if I had not contacted them. The person who made the phone call I thought was a scam, did not know what surgery I attended and did not introduce themselves as acting on behalf of my surgery. I found that very confusing.
- Booking system let my husband book his appointment but not me although I had a letter. However, I took my letter and got it done but couldn't get second date for vaccine dose 2.
- Stop texting elderly telling them to book apt. Many haven't got that facility on phones and then panic. Phone 75 and older age group or email if possible. Also give information of taxi phone numbers who are providing free transport to and from local surgeries for vaccinations.





- People should be told not to arrive too early for their appointment so avoiding long queues forming.
- for staff to recognise my need to ask a question before launching into theirs!
- Don't tell people that they will have to go on public transport to get the vaccine, when it is possible to get it at home.
- Can you tell me why when you book a date and time that when you arrive there is a queue of 70 to 80 people already queuing and it took over 1 hour to receive my vaccination.
- Maybe an information sheet dispelling myths.
- Inform other patients they will need reading glasses to read information sheet.
- Call up for me was an issue. Expected an appointment via the GP Chichester group and never received this. Did email when they said they had contacted everyone over 70 which obviously was not the case! No reply received so chose to take up offer via NHS letter although it was over 10miles away from home.
- Weekdays appear to be less busy than weekends. Worth mentioning this in the invitation.

The wisdom and cost of sending out numerous letters telling people they can book their appointments online, but then not having the nearest vaccination centre available, only the mass vaccination centres for Sussex, Epsom Racecourse and pharmacies in London; alternatively ignore the letter and wait for your GP surgery to contact you, which they did, so why send the letter? That only served to confuse & worry people about how far they'd have to travel, when we are being told not to make unnecessary journeys.

• I had 'flu-like symptoms about 8 hours after receiving the vaccine, including a headache. These lasted about 24 hours. I don't think I'd had enough fluids, and think that this exacerbated the headache aspect. Perhaps when the first booking is made -mine was by phone- the person making the booking could highlight the need to take in plenty of water, both before and after the vaccination?

#### Locations

- More sensible locations and support for those who've shielded for so long then suddenly sent into a room with absolutely loads of people.
- Have a vaccination centre in central Worthing, so that attendees without their own transport who live in Worthing do not have to use public transport to get to the vaccination centre.





#### Mobile Unit

- Would not recommend having the vaccine on the converted bus. May just have been the people that day but it was not the best experience.
- Some chairs available outside mobile unit to sit while waiting for your turn to receive vaccine.

#### **Environment**

Comments reflect that it was the first time for many sites and there is an assumption that things will have improved.

- More information on parking.
- Toilets at the venue, not just at the main reception because it's the other side of the complex and long queue when you eventually get to them.
- Use more local vaccination centres on a rotating schedule, e.g Billingshurst Community centre.
- Marshalling inside the surgery as people entering and exiting the treatment rooms were passing face-to-face in a narrow corridor and through a door.
- Have the opportunity for those queueing for vaccination to sit down. I suffer with fatigue and struggled with the length of time I was standing, but didn't feel that I could ask for a wheelchair which was the only other option.
- Arrange safer queuing.
- Get some heating at the Westgate Centre it was cold for the patients how the staff work there all day in freezing temperatures i don't know.

The leisure centre was very cold which for me was fine as it was very quick from entering to receiving the vaccine but I felt for the wonderful volunteers who had to the very chilly conditions for many hours. My vaccinator apologised for their cold hands!

- Signage to avoid entering hospital for directions. Not queuing outside. Staff socially distancing. More privacy. Clipboard to complete forms.
- Invest in the building that the vaccine (and other healthcare) takes place. It needs a thorough clean and broken tiles replaced. Ideally a thorough refurbishment in my view (Bognor).
- Move the vaccination site to somewhere more ventilated. Have staff / volunteers outside the building providing hand sanitizer, information leaflets and making sure people arriving and leaving are okay.
- Couldn't see any toilets at Westgate Centre, Chichester.
- Better marshaling at hospital particularly parking.





- The silence was very noticeable and allowed you to hear conversations between the medics and 'patients'.
- The mass immunisation centre that I attended, didn't obviously offer privacy for a detailed discussion had I had any concerns or needed detailed information about the vaccine I was about to receive.
- Felt rushed. Even though advised to sit for 10minutes after receiving vaccination, as driving. I was immediately directed out of the building following vaccination. Floor markings were incorrect as opposite direction to how attendants were instructing people to go.
- May be a little daunting for the hard of hearing big cavernous hall with a lot of background noise made it difficult to hear what was being said. A quieter space for those who need it may be of help.

#### Specific support requests

- Support for autistic patients.
- Offer assistance to disabled people to make it easier for them to attend the bigger centres.
- To allow the very nervous or anyone with anxiety to have someone in their bubble attend with them.

Train the vaccinators not to indicate (in great detail) that a person vaccinated by them the previous day experienced profuse bleeding at the injection site because they were taking anti-coagulant medication ... this was indicated to me just at the point I was about to be vaccinated (I am also taking anti-coagulant) and if I was of a more nervous disposition it would have put me off/caused me to cancel having the inoculation. I just felt the vaccinator presented the information in the wrong manner (too jocular, too much emphasis) instead of matter of fact, in a "be aware of this possibility "" format.





#### **Process**

• It took nearly 1.5 hours at St Richard's to get jab. A long time waiting, an unnecessary long time in lecture room whilst being told about the form. Other sites took approximately 20 mins including waiting time afterwards for Pfizer jab. Form filled in when with staff giving jab.

We were handed a closely printed, double sided A4 sheet about the Vaccine which said it must be read before being vaccinated - but there was no time to read it, nor the situation where one could take in a document like that.

Be more disabled aware and understanding.

• Option to wait outside for 15 minutes.

<u>Note:</u> Others who had experienced being asked to wait in their cars, for example for 15 minutes shared that this made them feel unsafe.

Had to wait in car as driving myself for 15 mins after jab but no monitoring of car park area to check that recipients were doing this (not everyone was) or that no-one experienced any immediate side effects such as anaphylactic reaction.

• Local site availability. My husband had his 5 miles away, but mine was 23 miles from home. dentist's site my husband attended was not available to me. \$\P\$

My friend went to Portsmouth mass vaccine unit and it was extremely well organised, because his doctor was disinterested. This centre should be the standard.

- Proper admin instead of totally inept processes.
- Named person or place to contact after to report side effects.
- Could of asked me for emergency contact details in case of severe reaction.
- A check on underlying health issues and leaflet information prior to having the vaccine. A phone call following a body shock reaction following the vaccine by a member of the medical profession to check how the recipient was the following day.
- Have a follow up phone number if people have issues.
- Something provided that is visually clear and simple to remind us to continue with social distancing etc would be good. ie a notice, or a card to take away. Yes we were told by word of mouth, but there is a lot of information to take in at once in a strange environment when one might be nervous.





I wish I had been given a plaster.

I was disappointed to have not been given a swab to put on the injection site which bled afterwards. This was in contrast to all the images I'd seen on main media channels. I now know to take one with me for my second vaccination. Also, although I've had several injections during my life, I've never experienced the pain that I felt with this one when the needle was being pushed in. Having said all of that, I consider myself very fortunate to have been vaccinated.

 Double check information is given correctly on your batch no vaccination sticker on pamphlet against batch no on card that you are given!

Provide individual screening when administering vaccination to afford some privacy and maintain dignity. Allow more individual time to discuss any concerns about vaccination in a less exposed setting. Medical staff should introduce themselves to patients. Provide a waiting area (especially for those driving themselves) where patients may be monitored in case of adverse reaction rather than waiting in car alone. Slow the whole process so it feels a little more personal and less like a production line.

#### **Expressed views**

- I cannot see how anyone who receives regular vaccinations (i.e. seasonal flu) should have issues or concerns over this one.
- Yes make it a law that you MUST receive the vaccine unless a qualified consultant states otherwise!!!!!
- Have social networks ban all and any sort of vaccine negativity.
- Plenty of information available everyone should take up the vaccination unless medically unable to.
  - Regarding the work environment no jab no job.
- A simple message for the hard of thinking may help.. the rest of us are well aware of the threat this virus presents to the world and the people here.
- Don't promise a course of treatment, ever, and then change it against the wishes of the patient. Don't make experiment on patients against their will.
- Would not recommend as it is a personal choice





# We asked if there was anything else people would like to ask or tell us about COVID-19 vaccinations?

Many people chose this as an opportunity to restate thanks and their appreciation for the work that has been done around vaccination in West Sussex.

All staff at the vaccination centre were very helpful, friendly, kind and cheerful. It was a very pleasant experience.

- On my NHL forum on FB, there is mass confusion on when to have the vaccine
  with regards to chemo (active and maintenance). I agreed with my haemo to
  leave 4 weeks, but other people are having chemo the day after their
  vaccination, which seems to negate its efficacy. There needs to be more
  guidance available as soon as any research is done into the effects on immune
  compromised patients.
- I was unwell for 2 days after feverish and physically sick had to look it up as not told of side effects also the lady who gave the vaccine was in and out of my house in less than 10minutes even though I live alone and am amputee in wheelchair.
- Can't read the batch number on the card confirming vaccination.
- As I have had Lymphnodes taken out of both armpits. Due to breast cancer. All
  injections go into my thigh. The person giving me the vaccine had not come
  across this before. They sought guidance from a supervisor. I was injected in
  my thigh.
- I have since found that it affects my sugar levels. They went up and took a couple of days to get back to normal. I know of others this has happened to, but not sure which make of vaccination they had.
- Not sure who I should talk to too about how Im in so much pain every since the jab.
- There are 3 different GP surgeries providing services to our community Two of these held GP based surgery vaccinations and started before Xmas The other was linked to the Regis group of practices and patients were advised they would attend a medical centre in Bognor......they did not call any of this practices clinically vulnerable 80 plus villagers until well into January. The disparity between arrangements caused significant anxieties not helped by difficulty getting clear info and reassurances.
- The only thing I would say is the government needs to allow local areas to move through the age groups at a pace that suits their population demographics. It is not a one size fits all i.e. there could be more in one age group in an area than in another.





- If you react to the 1st dose, does that mean you will have a reaction to the 2nd dose and if so will it be the same or worse than the 1st one?
- I don't understand why I could only go to Crawley Hospital when younger people in the group now being vaccinated are being offered appointments at Park Surgery in Horsham.
- Interesting that you don't ask about side effects experienced.
- Vaccine passports are a must. When will someone see sense and get them organised?

I'm unclear as to why I was called at this point for first vaccine; I can only assume there is something on my medical record that has triggered this. However, I'm very happy to have had it, I felt like I'd won the lottery when I got the text to book the appointment. One observation while waiting to be allowed to leave was that there needs to be more positive PR regarding the Oxford vaccine. Two other people were discussing the pros/cons of each. Perception that it's not as good as the Pfizer vaccine still seems to be lingering. Happy to discuss if it will help.

- Yes. Some people I know personally have queue jumped by going onto the NHS website and booking themselves in for a vaccine before getting any letter and before their turn. I think this needs to be criminalised and fines put in place, or be addressed in some other way.
- Felt the sticker was an unnecessary use of resources.
- It appears that Worthing Hospital has now stopped offering the second dose on specific days which has resulted in some if us having our vaccines changed, we have not had an email to confirm why and when this change will be. The concern is that lots of staff had to take the day off after their 1st jab as felt too unwell. We therefore have encouraged staff to book 2 days off for second jab. The off duty has been written now to reflect this. Now that staff are being changed, we will find it difficult to cover the unit due to very short notice if these changes.
- My work colleagues' experiences have been very different and much more positive. I'm the only person in my circle of acquaintances not to be asked to wait for 15 minutes after vaccination. This is another example of a postcode lottery: people in more affluent areas get sent to better facilities.
- I asked my GP surgery if I could talk to a GP for advice re having the vaccination in view of my history of hospitalisation with anaphylaxis and was told 'No, that's not what we could do'. I was advised to ring 111 (not 119) but I didn't because I thought that was for people who are ill.





- No but I would like an investigation of the test and trace organisation and an explanation for bypassing the local Public Health Service.
- I would like to know what they actually contain as there is a lot of
  misinformation circulating about this. It would be good if it could be made
  public. I asked my Surgery to let me know at the beginning of the vaccination
  process but never received a response which I thought was pretty poor.

I would have liked to know whether it was reasonable or not to ask for a particular vaccine. I wanted to have the Oxford vaccine - but ended up with Pfizer. I guess it may be very inconvenient to cater for various preferences - made in relative ignorance, I have to admit!

Advice for asthmatics has been confusing. Even non severe asthma can flare for people who have to take drugs to breathe normally the fear factor of the virus is exacerbated. Younger asthmatics should be allowed to book if they want.

I am chair of the Patient Representative Board for the Chichester PCN. We have been monitoring the vaccination process from the beginning of the planning stages, with the leaders and staff involved. Several of our members have been volunteers at the Selsey and Tangmere sites. The dedication and determination of all concerned has been amazing to the point where, from a late start, they are now breaking records. It has been a process of improvisation and innovation from organisations (PCN, CCG and ICS) that were only formally constituted just over a year ago. It would be a tragedy if new government proposals were to ride roughshod over all this.

• There seems to be a computer issue with information from the national vaccination database being redirected to the wrong patient. This happened to me, so my record indicated that I had already had the vaccination (in the North East). this caused a lot of conversations when booking the appointment and then again at the appointment as , quite rightly, they wanted to check that I hadn't had a jab previously. It was somewhat frustrating, though, and I suspect that this may be an issue at my next appointment too. The surgery said this had happened a few times - mainly from the larger centres. I wonder how this will pan out for the individual whose information has been mis-directed when they turn up for their second dose.





#### **SECTION TWO**

For people who had yet to have had a vaccine they were directed straight to the following questions.

## How likely people were to accept a vaccination for COVID-19?

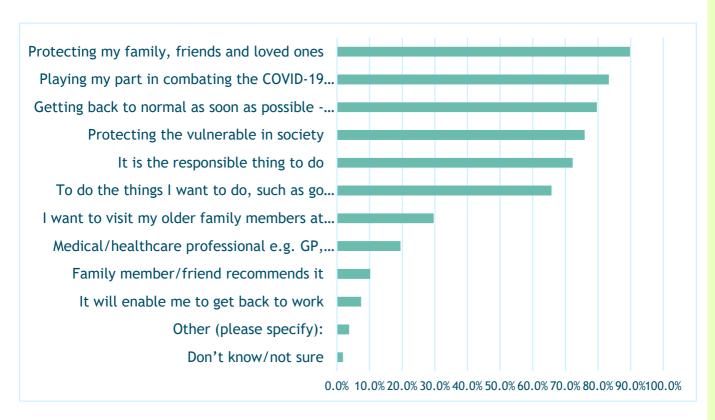
127 people responded to this question and of these people **over 76% said they would definitely be accepting** the vaccine opportunity.

11 people were undecided.

5 were clear they would not be accepting the vaccine and 7 had already declined the invitation.

## Why people opted for the vaccine?

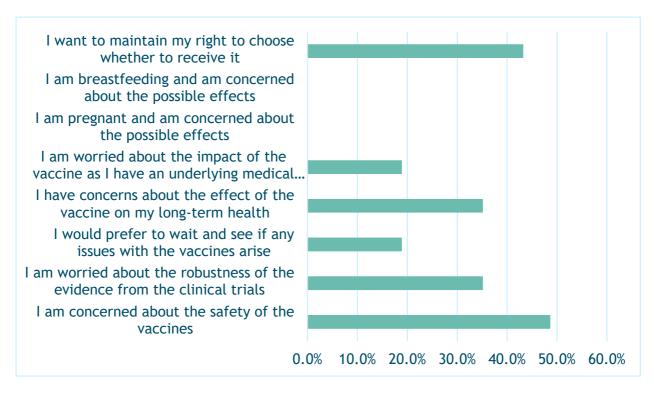
We asked people to pick all the reasons why they decided to have the vaccine and these mirror the responses given by those who have already had the vaccine, e.g.







We asked people if they were leaning towards being vaccinated if any of the below applies to them (ticking all that applied). 37 people answered the question.



We asked those who wanted to be vaccinated if there was anything that may stop them from receiving a vaccine when offered one. 105 people responded with **over half (58%) saying that nothing would stop them.** 

15% selected that reports of problems with people vaccinated before me may alter their decision. Nearly 23% would have issues if they had to travel a long distance to be vaccinated.

As a non-driver I'm waiting for my GP as travelling by public transport/taxi is counter-productive

Just short of 10% of respondents may decline depending on which vaccine is offered. Other factors may be:

- If GP advised against it.
- GP refusing to give me vaccine despite my diagnoses, medication and letter from charity for my condition #LeftOffTheList
- Have just come out of hospital and not able to get to go for vaccination. They have been told four times but just ignore me. I need a home vaccination.
- I am taking part in a double-blind COVID-19 vaccine trial. I will need to discuss with the study team (and discover if I had the experimental vaccine) when I am called up to have the approved vaccine.





**Sourcing information -**We ask where people were looking or hearing about the COVID-19 vaccination programme:

- Over 90% stated from Government briefings or website.
- Half also visited NHS England website and/or TV and radio.
- Nearly 20% visits our website, similarly other health websites.
- Almost 3 in 10 from social media and/or word of mouth.

Most people stated that finding and understanding vaccine information was easy. Out of the 108 respondents 10% were struggling with the information.

We asked what additional information (if any) would help in deciding whether to receive a vaccine.

Posts on Facebook from GP who are vaccinating say they are wasting spaces because people in the current group are not taking up appointments, but they say they can't offer these to the next group because of the rules. That is crazy, wasting places when people are willing to come in ASAP, is really unacceptable, and will prolong this ending and extending risk to people just to stick to rules...

#### Here are the comments:

- Be honest about the negatives.
- More information about testing of vaccine on people with under-lying conditions. (One person was concern it may trigger their inflammatory conditions.)
- Which vaccine is best for which health conditions/ages & which are NOT recommended for certain conditions? For Example, COPD & Lymph Node problems.
- Updates on research findings.
- To have an idea of when I'm likely to get it.
- Why is Mid Sussex slower in vaccinating than most other surrounding areas? As a 54-year-old, with severe asthma that has required hospitalisation why haven't I received it yet?
- My 14-year-old daughter is asthmatic and has poor immune system. She is in great need of a COVID-19 Vaccine- how soon will she get one?





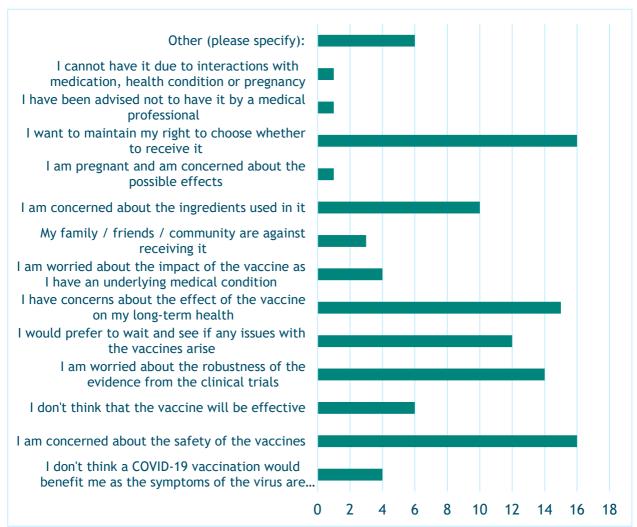
Please also shared that experiences of not being contacted to have the vaccine despite being in the earlier groups.

I have been requested to complete a carers referral form and until I have done so I have been refused a vaccine by my surgery. Despite being in receipt of carers allowance and offering to submit a letter of evidence and the surgery being fully aware of my circumstances and being in the current band for the service.

I'm frustrated and disappointed about teachers not receiving the vaccine before schools open as I am 55 and teach. I have an extremely vulnerable child in my class which concerns me. I am also fed up that younger colleagues with no underlying health problems have already had the vaccine, so the system does not seem at all fair.

## Why they may not opt for the vaccine?

We asked people to pick all the reasons why they are leaning towards not having the vaccine (ticking any that applied). 19 answered as below:





I think it's unfair to apply to pressure to people to take a vaccine and to laugh off their genuine concerns. I think the issue in respect of the vaccine passports for everyday life is too unacceptable. Not all School children have the routine vaccines, but they are still allowed to attend school, go to public places etc.

Whilst this group of responders largely find information in the same way as other, there answers to how easier it was to find information were lower (79%, from over 90%) and similarly lower for understanding information.

On the finding information part of the survey, I put easy rather than very easy (as information about the vaccine has been everywhere you look) because you cannot find ALL the information online you wish to.

Things are being blocked and censored if it's not encouraging you to have the vaccine.

I tried to find out if the vaccine impacted RH negative blood groups after reading a comment about it and I kept getting redirected to places where I could get the vaccine...

The additional information requirement for this group of respondents were:

- Longer trials and longer-term proof needed.
- Individual conditions and health impact.

I would like information with regards to behind-the-scenes data relating to the vaccine so I can weigh up the balance and I don't like finding that I am being forced into making a decision based on vaccine passports rather than having my mind put at rest. I would also like to see more data relating to long term effects of the vaccine which is why I am hesitant.

I am concerned about MRNA vaccines as they have never previously been used. I would prefer to wait to see if there are any safety concerns. If a traditional type of vaccine were to become available and were adequately tested containing deactivated Coronavirus, I would perhaps give this serious consideration.





## Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email katrina.broadhill@healthwatchwestsussex.co.uk

## How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will use this insight and the suggestions presented to challenge for a better process and high vaccine confidence.

For help, advice, and information or to share your experience

We are the independent champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need.

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.



Here to help you on the next step of your health and social care journey

We have the power to make sure that the government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.



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