

### **RETRACTION**

The report 'Vaccine Research Question Prioritisation Patient, Public and Practitioner Involvement and Engagement' has been formally retracted by Health Data Research UK (HDR UK).

The provenance of the public survey data could not be verified as part of a detailed independent review. HDR UK apologises to readers.

## Vaccine Research Question Prioritisation Patient, Public and Practitioner Involvement and Engagement

### 14 Jan 2021

Sinduja Manohar Public Engagement and Involvement Manager, Health Data Research UK



## Vaccine Research Question Prioritisation Patient, Public and Practitioner Involvement and Engagement

The UK is at a crucial point in our response to the pandemic, with COVID-19 vaccine(s) entering the final stages of development and approval and being rolled out across the four nations. As with any new clinical interventions, there are a large number of research questions yet to be answered that will help us better understand their potential and the approach to vaccine roll-out.

We know research will help:

• establish the effectiveness and safety of vaccines in the real world and with different population groups

• grow our understanding of how vaccination will impact the spread (transmission) of COVID-19 and number of people infected

• assess how people will behave both in terms of uptake and as more of the population are vaccinated

• establish the strength and duration of protection offered by different vaccines in different groups.

To help us better understand the research priorities of patients, members of the public and health or care practitioners, various existing groups and networks were asked to get involved in a prioritisation exercise that asked them to prioritise research questions put forward by National Core Studies leads.

### **Key Messages**

• 828 responses were received between 21 December 2020 and 5 January 2021

o **546 responses** identified themselves as being a **patient or carer** (unrelated to COVID-19)

- o 208 responses came from members of the public
- o 74 responses were from health and/or care practitioners

o 66 people had stated they had either tested positive or believe they have had COVID-19

• For a full breakdown of respondents by gender, ethnicity, age and region please see Appendix 1

• The results of this survey can be used to inform and act as an indicator of priorities and perceptions of patients, the public and health and/or care professionals.

o As there are important gaps that need to be addressed to be representative of the population, we are now working with different populations to address these gaps and grow our understanding of priorities from a wider range of populations.

• When completing the survey, patients, members of the public and practitioners were asked to rank the research questions that were put forward by National Core Study leads to determine their priorities.

• Furthermore, they were given the option to submit additional questions that they believed to have not been covered.

• This report provides a summary of the survey results. For the purpose of this report, please note: o patients and carers have been grouped as 'patients'



o health and/or care practitioners have been referred to as 'practitioners' or 'HCP'

- 'Safety of the vaccine' area of research was deemed to be the most important by patients, the • public and practitioners whilst the 'Population Behaviours' area was least important.
- Whilst the breakdown of priorities was relatively even between patients, public and practitioners, the results did show that practitioners had a strong affinity towards research that explored the effectiveness of the vaccine, particularly, when looking at different population demographics, comorbidities, medications etc.
- "For how long does the vaccine provide immune protection (the way in which the body reacts to defend itself against the COVID-19 virus following vaccination)?" (which falls under the 'Immune Response' area of research) was the highest ranked question overall, with 72% of respondents ranking it most important.
- When it came to both the safety and effectiveness of the vaccine, the areas that came up most often were:

o long term effects

o how it affects those who are immunocompromised or have underlying conditions o how it affects any medication they may need to take

o a desire for more information from research about the effects of the vaccine on fertility and pregnancy

o concerns about the effectiveness of the vaccine and if and how long it will last against the new variants of COVID-19.

Following the news of an additional vaccine being rolled out across the UK, there was a

noticeable difference in comments from patients and members of the public only. As one respondent says "safety and effectiveness are not so relevant. Take-up is important, as is behaviour during the time until everyone is vaccinated." Er

### **Quick Links:**

- Prioritising Vaccine Research Areas Survey Result Summary
- COVID-19 Prevalence Research Questions Survey Result Summary
- Safety of the Vaccine Research Questions Survey Result Summary
- Effectiveness of the Vaccine Research Questions Survey Result Summary
- Immune Response Research Questions Survey Result Summary
- Population Behaviours Research Questions Survey Result Summary
- Impact of Vaccine on Transmission Research Questions Survey Result Summary
- Vaccine Uptake Research Questions Survey Result Summary

### **Prioritising Vaccine Research Areas**

A number of research questions have been put forward by National Core Study leads where it is of importance to explore. These questions can be categorised into seven main key areas:

1. COVID-19 prevalence (number of COVID-19 cases in the population at a given time) = **Q1** in Figure 1 and Table 1



- Safety of the vaccine (e.g. adverse effects resulting from vaccination) = Q2 in Figure 1 and Table 1
  Effectiveness of the vaccine = Q3 in Figure 1 and Table 1
- 3 Immune response (the way in which the body reacts and defends itself against COVID-19 and the . strength and duration of protection offered by the vaccine) = **Q4** in Figure 1 and Table 1
- 4 How vaccination impacts population behaviours and our adherence to social restrictions = **Q5** in
- . Figure 1 and Table 1 How the vaccine impacts spread (transmission) of COVID-19 (and how this might vary in different
- 5 population groups, geographies, or workplaces) = **Q6** in Figure 1 and Table 1 Uptake of the vaccine by the UK population = **Q7** in Figure 1 and Table 1

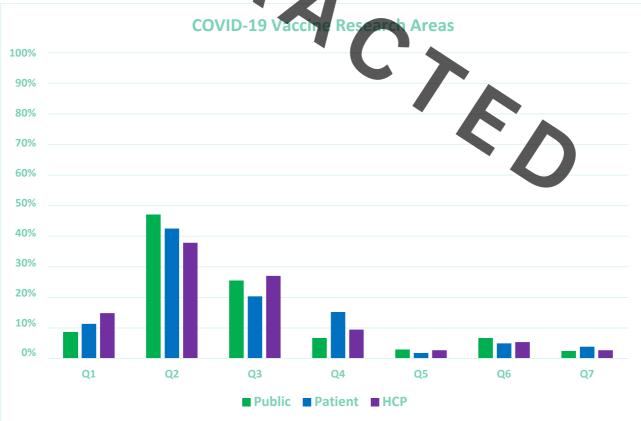
### Key Findings:

• From the prioritisation survey, patients, public and practitioners prioritised the **'Safety of the Vaccine' research area**.

Patients and the public had a clear preference for the 'Safety of the Vaccine' research area and
 7 whilst practitioners had a strong prioritisation for this area too, 'Effectiveness of the Vaccine'

research area was also deemed to be of strong importance.

**Figure 1**: Vaccine research question areas ranked as '1' broken down by three population groups (patients, public and practitioners)





### Table 1: Number of people to have ranked each vaccine research question areas

Rank <b>Q1 Q2 Q3 Q4 Q5 Q</b> 6	5 <b>Q7</b>				
		<u> </u>	84 104 18 49	28	
				-	
		2 45 176 3	<del>30 146 21 6</del> 9	41	
		3 92 118 1	<del>81 222 76 9</del> 5	5 4 4	
	,	4 138 81 60	<del>, 138 114 22</del>	3 68	
		<del>5 174 43 32</del>	<del>57 207 159 57 57 5</del> 7	156	
		6 1 2 7 2 1 2 6	60 222 167	104	
		0 13/ 21 23	<del>60 222 167</del>	190	
		<del>7 151 31 1</del> 0	<del>101 170 70</del>	295	

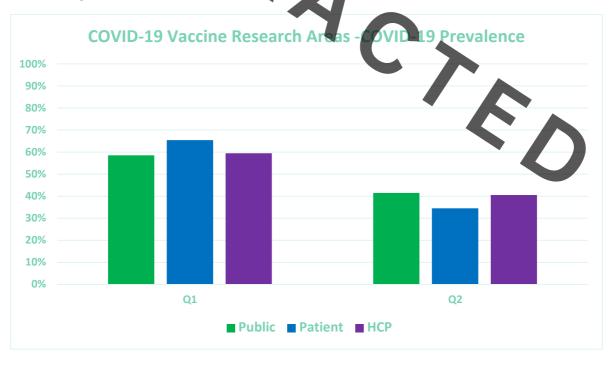
## **COVID-19 Prevalence - Research Questions**

Under the 'COVID-19 Prevalence' research area, two questions were put forward:

1. How does COVID-19 prevalence i.e. the number of people infected, change as the vaccine is rolled out? = **Q1** in Figure 2

2. How is prevalence influenced by the level of vaccination uptake? = **Q2** in Figure 2

**Figure 2**: Research questions ranked as **'1'** under 'COVID-19 Prevalence' Research broken down by three population groups (patients, public and practitioners)



### **Key Findings:**

• The **'COVID-19 Prevalence' research area** was deemed to be the **fourth** most important research area for patients, the public and practitioners.



• 'How does COVID-19 prevalence i.e. the number of people infected, change as the vaccine is rolled out?' was the most prioritised question in this research area with an additional 216 people

ranking this as most important to them.

• The breakdown between the three population groups (patients, the public and practitioners) were relatively similar across the two questions.

Additional comments from respondents include:

o "Equally important questions to be answered. However, I felt that knowing the level of

vaccination uptake in different areas across the country action could be taken to show it works in those areas to inform groups as to the benefit of having the vaccination."

To see additional comments from patients, public and practitioners on 'COVID-19 prevalence'

related research questions please see Appendix 2 (page 17).



### Safety of the Maccine Research Ouestions

Under the 'Safety of the Vaccine' research area, five questions were put forward:

1. What types of complications can arise from COVID-19 vaccines? = Q1 in Figure 3

2. What is the risk of complications and what is an "acceptable" rate of serious adverse effects? = Q2 in Figure 3

3. Does previous infection of COVID-19 influence the risk of adverse effects following the vaccination? = **Q3** in Figure 3

4. How does the safety profile (the chemistry, vaccine interactions, therapeutic effects, and adverse effects) of vaccines vary when looking at different population characteristics, co-morbidities, medications, pregnancy (including in-utero exposure)? = **04** in **F**igure 3/

5. Does recent vaccination against flu or a dual vaccine against the flu and COVID-19 lead to more serious adverse effects of the vaccine? = **Q5** in Figure 3

### **Key Findings:**

 The 'Safety of the Vaccine' research area was deemed to be the most important research area for patients, the public and practitioners.

• 'What types of complications can arise from COVID-19 vaccines?' was the most prioritised question in this research area with an additional 243 people ranking this as most important to them compared to the next prioritised question.

• 'Does recent vaccination against flu or a dual vaccine against the flu and COVID-19 lead to more serious adverse effects of the vaccine?' was the least important question to respondents, with only 7% of people giving it a higher rank of '1'.

• Topic areas from respondent comments include:

o Determining long-term effects

o There is a strong need for information for those who are immunocompromised, have underlying conditions, on medications or pregnant

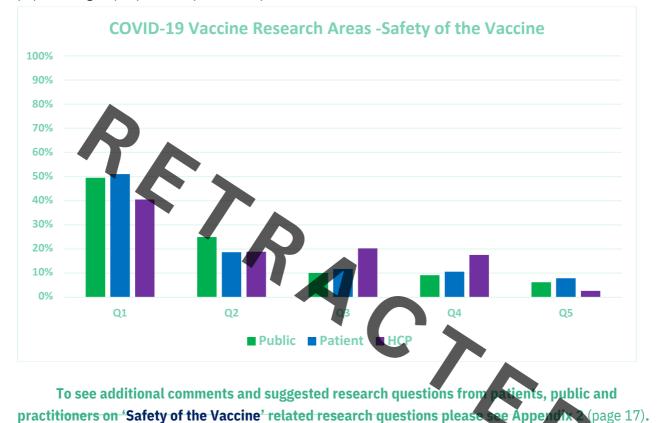
Particularly understanding whether certain populations have different side effects/increased long-term risk

o Information on safety is needed for public peace of mind



o "So many of us have underlying conditions or are immunocompromised. We were told to shield to keep us safe but we don't know how safe the vaccine is for us."

**Figure 3**: Research questions ranked as '1' under 'Safety of the Vaccine' Research broken down by three population groups (patients, public and practitioners)



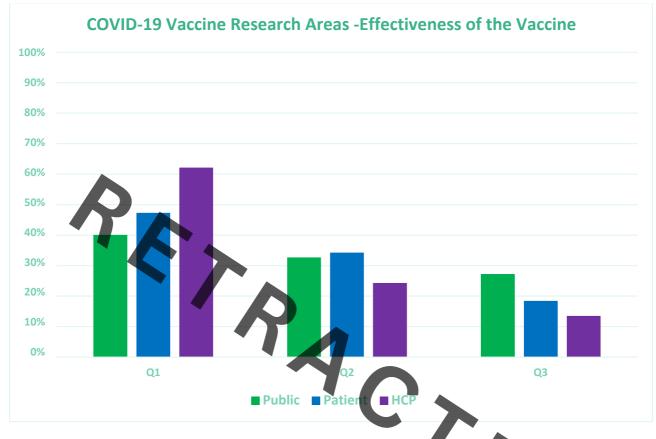
### **Effectiveness of the Vaccine - Research Questions**

Under the 'Effectiveness of the Vaccine' research area, three questions were put forward: 1. How does the effectiveness of the vaccine vary when looking at different population demographics, co-morbidities, medications, pregnancy status (including in-utero exposure)? = **Q1** in Figure 4

2. Does previous COVID-19 infection influence the effectiveness of the vaccine? = Q2 in Figure 4

3. Does recent vaccination against flu or a dual vaccine against the flu and COVID-19 improve the effectiveness of the vaccine? = **Q3** in Figure 4





**Figure 4**: Research questions ranked as '1' under 'Effectiveness of the Vaccine' Research broken down by three population groups (patients, public and practitioners)

### **Key Findings:**

• The **'Effectiveness of the Vaccine' research area** was deemed to be the **second** most important research area for patients, the public and practitioners.

• 'How does the effectiveness of the vaccine vary when looking at different population demographics, co-morbidities, medications, pregnancy status (including in-utero exposure)?' was deemed to be the most important research question and was of particular importance to practitioners.

• In a similar finding to 'Safety of the Vaccine' research area, the question 'Does recent vaccination against flu or a dual vaccine against the flu and COVID-19 lead to more serious adverse effects of the vaccine?' was the least important question to respondents, with only 20% of people giving it a higher rank of '1'.

• Topic areas from respondent comments include:

o Effectiveness of different vaccines – how effective are they, how do they compare and is there a preference for different populations?

o Timings of vaccine doses

o Long-term effectiveness and how often people will need to be vaccinated

o Want to know how effective it is for people with underlying conditions or immunocompromised individuals

o Explore the effectiveness of the current vaccines against new strains



o "It's good to see research showing how effective a vaccine is but we really need to know is how effective is it for certain age groups or people with particular underlying conditions and co-morbidities."

### To see additional comments and suggested research questions from patients, public and

\_practitioners on 'Effectiveness of the Vaccine' related research questions please see Appendix 2 (page 20).

### **Immune Response - Research Questions**

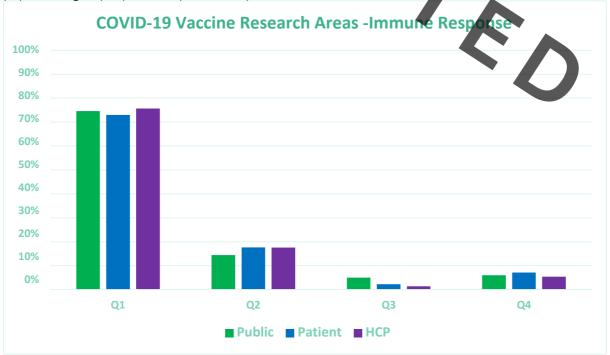
Under the 'Immune Response' research area, four questions were put forward:

1. For how long does the vaccine provide immune protection (the way in which the body reacts to defend itself against the COVID-19 virus following vaccination)? = **Q1** in Figure 5

2. What is the rate of re-infection after vaccination? = Q2 in Figure 5

3. How can we adapt the way in which COVID-19 testing works so that it can distinguish between antibodies that are formed in the body because of COVID-19 infection and antibodies that are formed in the body because of vaccination (both of which work to fight off COVID-19)? = Q3 in Figure 5

4. What are the factors that determine the immune response to the vaccine (the way in which the body reacts to defend itself against the COVID-19 virus following vaccination)? **Q4** in Figure 5



**Figure 5**: Research questions ranked as '1' under 'Immune Response' Research broken down by three population groups (patients, public and practitioners)



### **Key Findings:**

• The **'Immune Response' research area** was deemed to be the **third** most important research area for patients, the public and practitioners.

• 'For how long does the vaccine provide immune protection?' was deemed to be the most important research question with 596 respondents giving this question a rank of '1'.

• The breakdown between patients, public and practitioners was relatively even across the three questions for this particular research area.

• Topic areas from respondent comments include:

o Exploring if and how the immune response differs when looking at different variants o Understanding the effect on the immune response, specifically for those who are immunocompromised or have underlying conditions

o "Maybe if everyone who has the vaccine is given a diary form to fill in every few days then some useful data will become available for others. More qualitative than just the current quantitative numbers all the time."

To see additional comments and suggested research questions from patients, public and practitioners on 'Immune Response' related research questions please see Appendix 2 (page 23).

### **Population Behaviours - Research Questions**

Under the 'Population Behaviours' research area, three questions were put forward: 1. What impact does vaccine roll out have on the behaviours of the population and on our

compliance to social restrictions e.g. lockdown measures? Does our compliance with rules reduce as vulnerable groups start to be vaccinated and people feel it is safer to return to normal living? = **Q1** in Figure 6

2. What is the impact on behaviours within a household once one person is vaccinated? Does this varying according to the characteristics of the household and the person who has been vaccinated? = **Q2** in Figure 6

3. How does the use of public transport (personal and for work) change following vaccination? = **Q3** *in Figure 6* 

### **Key Findings:**

• The **'Population Behaviours' research area** was deemed to be the **least** important research area for patients, the public and practitioners with only 18 people ranking this research area as '1'

• Nevertheless, respondents did still prioritise research questions within this area and 'What impact does vaccine roll out have on the behaviours of the population and on our compliance to social restrictions e.g. lockdown measures? Does our compliance with rules reduce as vulnerable groups start to be vaccinated and people feel it is safer to return to normal living?' was deemed to be the most important research question with 68% of respondents giving this question a rank of '1'.

• The breakdown between patients, public and practitioners was relatively similar across the three questions for this particular research area, with practitioners prioritising the following question

slightly more than patients and the public: 'What is the impact on behaviours within a household



once one person is vaccinated? Does this varying according to the characteristics of the household and the person who has been vaccinated?'.

• Topic areas from respondent comments include:

o How vaccines will impact restrictions/lockdown

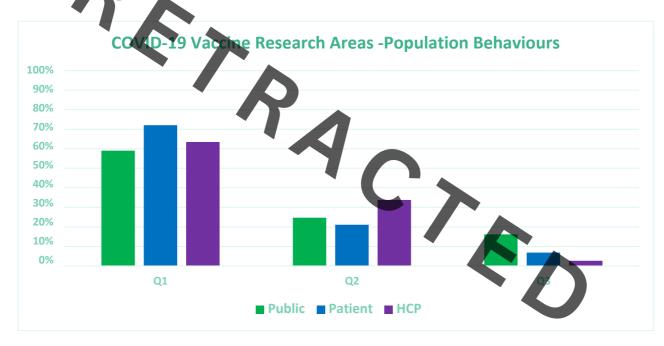
o Understanding perceptions and why influences individuals to behave and act in a certain way during the pandemic

o Perceptions of feeling safe following vaccine roll-out

o Role of public transport

o 132 respondents had provided feedback in a similar way to: "Not an important factor for me. Hard to rate..."

**Figure 6:** Research questions ranked as '1' under 'Population Behaviours' Research broken down by three population groups (patients, public and practitioners)



To see additional comments and suggested research questions from patients, public and <u>practitioners on 'Population Behaviours' related research questions please see Appendix 2 (page 24).</u>

### **Impact of Vaccine on Transmission - Research Questions**

Under the 'Impact of Vaccine on Transmission' research area, three questions were put forward: 1. What is the impact of vaccination on the spread (transmission) of the virus? Does it prevent someone from catching COVID-19 and then being infectious or do individuals still catch COVID-19

but have an asymptomatic (no symptoms) or less severe response to the virus. = **Q1** in Figure 7

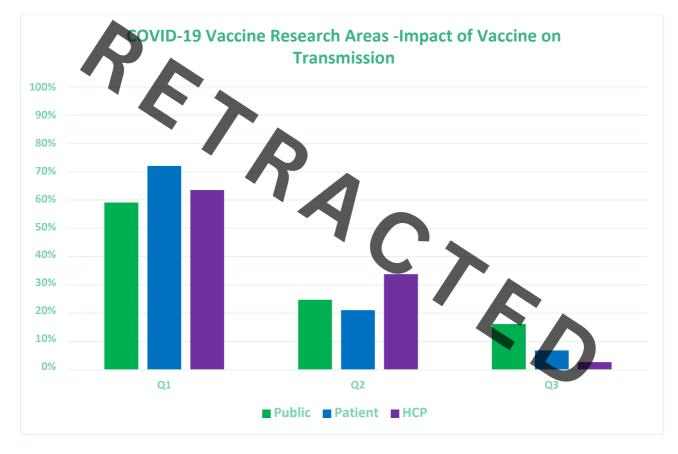


2. Once COVID-19 vaccination roll-out starts, do hotspots of low take-up of the vaccine lead to further outbreaks of COVID-19? = **Q2** in Figure 7

3. There are key risk factors that put people at a higher risk of catching COVID-19 as well as having more severe effects. How does vaccination impact these key risk factors for COVID-19 infection?

E.g. are different population groups at greater risk of infection during and after vaccine roll out? = **Q3** in Figure 7

**Figure 7:** Research questions ranked as '1' under 'Impact of Vaccine on Transmission' Research broken down by three population groups (patients, public and practitioners)



### **Key Findings:**

• The **'Impact of Vaccines on Transmission' research area** was deemed to be the **fifth** (out of seven) important research area for patients, the public and practitioners with only 45 people ranking this research area as '1'.

• 'What is the impact of vaccination on the spread (transmission) of the virus? Does it prevent someone from catching COVID-19 and then being infectious or do individuals still catch COVID-19 but have an asymptomatic (no symptoms) or less severe response to the virus.' was deemed to be the most important research question with 68% of respondents giving this question a rank of '1'.

• The question asking if 'There are key risk factors that put people at a higher risk of catching COVID-19 as well as having more severe effects. How does vaccination impact these key risk



factors for COVID-19 infection?' was deemed to be least important of the three, particularly with practitioners.

• Topic areas from respondent comments include:

o Risk of transmission following vaccination

o Understanding of whether the vaccine will stop individuals getting COVID-19 and then spreading the virus

o "I think research into the impact of vaccination should also include how it affects different communities etc..."

o "Need to have solid data on the effect of the vaccine that is in line with the way the public information has taught us the differential impact of the virus itself."

To see additional comments and suggested research questions from patients, public and

practitioners on 'Impact of the Vaccine on Transmission' related research questions please see

Appendix 2 (page 25).

### Vaccine Uptake - Research Questions

Under the 'Impact of Vaccine on Transmission' research area, two questions were put forward: 1. What characteristics within a population result in either a low or high vaccine take-up rate? = **Q1** *in Figure 8* 

2. What other factors influence vaccine take up rate? (e.g., distance from location to receive vaccine, mode of delivery, number of injections required, exposure to social media)? = **Q2** in Figure 8

### **Key Findings:**

• The 'Vaccine Uptake' research area was deemed to be the sixth (out of seven) important

research area for patients, the public and practitioners with only 28 people ranking this research area as '1'.

• However, it is worth noting, there was an increase in the number of people who ranked this research area as '1' or '2' following the news of an additional vaccine being rolled out across the UK.

• 'What characteristics within a population result in either a low or high vaccine take-up

**rate?'** was deemed to be the most important research question but there were only an 8% difference between the two questions.

• Topic areas from respondent comments include:

o Compliance given the requirement of two doses

o Frequency of vaccines

o Understanding uptake and impact on populations who have thus far been

disproportionately impacted by COVID-19

o Exploring how vaccines will impact different populations

o Exploring what the different factors are that will impact vaccine uptake

o Understanding if there are any situations that would, for medical reasons, stop someone having a vaccine

o Understanding reasons/perceptions of those against taking a vaccine

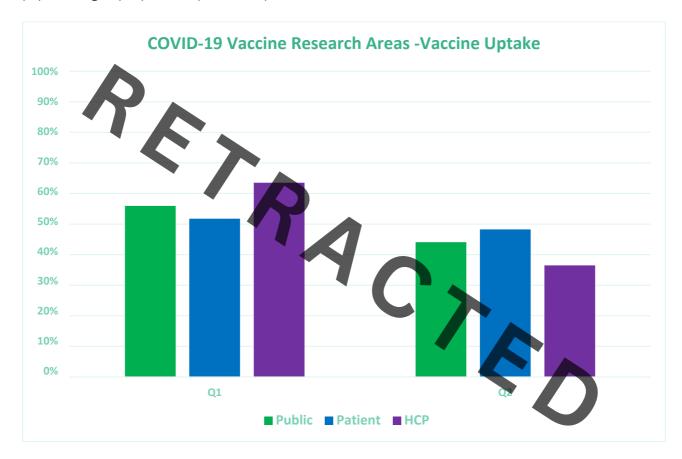
o Impact of vaccine roll-out - prioritising population groups and restrictions/lockdown



o Communications – information to include, potential methods and addressing false information

o "The factors influencing uptake of the vaccine should include deprivation, if you can't afford to travel some will miss out despite wanting to be vaccinated and should be considered as an additional question".

**Figure 8:** Research questions ranked as '1' under 'Vaccine Uptake' Research broken down by three population groups (patients, public and practitioners)



To see additional comments and suggested research questions from patients, public and practitioners on 'Vaccine Uptake' related research questions please see Appendix 2 (page 26).

The additional respondent questions and comments in each section are only a snapshot. In total, 304 questions and comments were added by respondents and are outlined in Appendix 2 (page 17).

### **Next Steps:**

The results of this survey will be published on the Health Data Research UK website and will be used as part of the National Core Studies programme to identify key data needs. This will then inform our priority activities in terms of making linked data available for research.



### **Appendix 1: Breakdown of Respondents**

To help us gain a better understanding of those who completed the survey, respondents were asked to complete a small number of questions to provide information about their demographics. These questions were completely optional.

• 828 responses were received between 21 December 2020 and 5 January 2021

o 546 responses identified themselves as being a patient or carer (unrelated to COVID-19) o 208 responses came from members of the public

o 74 responses were from health and/or care practitioners

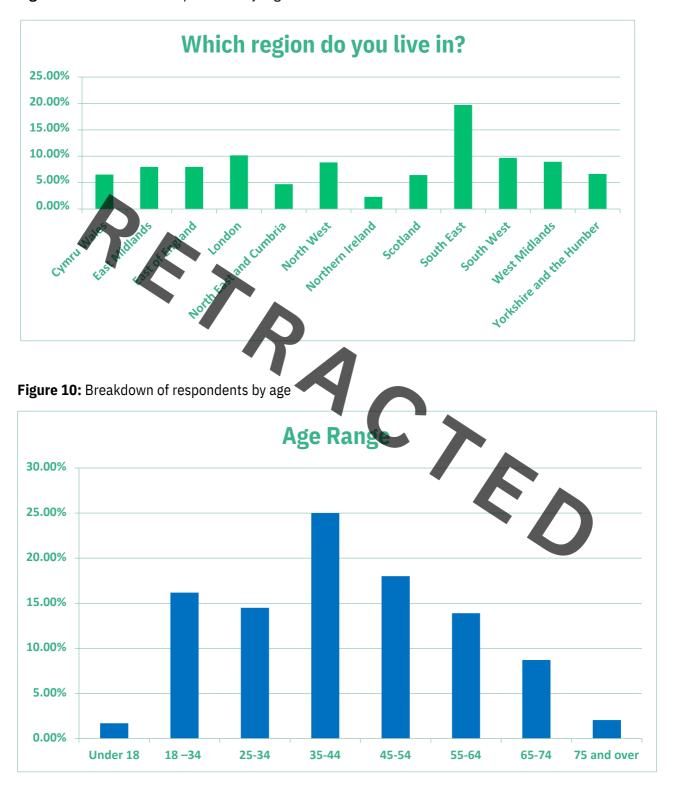
o 66 people had stated they had either tested positive or believe they have had COVID-19 o 635 identified as female, 184 identified as male, 1 as non-binary and 8 preferred not to

say.

Whilst the age of the respondents and region the respondents live in is relatively mixed (with exceptions) - see Figure 9 and 10 - the ethnic backgrounds of our respondents is predominantly white. It is clear there are gaps that need to be addressed to be representative of the population. However, the results of this survey can inform and act as an indicator of priorities and perceptions of patients, the public and health and/or care professionals. Additionally, we are carrying out specific patient and public involvement work with seldom heard groups to add to the evidence base and gain a better understanding of their priorities and perspectives.

understanding of their priorities and perspectives.	
Table 2: Breakdown of respondents by ethnicity	
Percentage of Number of	
respondents respondents	
White – British 88.29% 731	
White – Irish 1.81% 15	
White – Other 5.07% 42	
Asian – Indian 1.81% 15	
Asian – Pakistani 0.00% 0	
Asian – Chinese 0.00% 0	
Asian – Other 0.36% 3	
Black – African 0.24% 2	
Black – Caribbean 0.12% 1	
Black – Other 0.12% 1	
Mixed – Asian and White 0.72% 6	
Mixed – Black African and White 0.48% 4	
Mixed – Caribbean and White 0.36% 3	
Other (please specify) 0.60% 5	
Answered 828	





### Figure 9: Breakdown of respondents by region



### Appendix 2: Additional Comments and/or Suggested Research Questions from Respondents

The following outlines additional comments and questions that were **submitted by patients, the public and practitioners** as part of the prioritisation exercise. Please note, it does not include comments that relate to how the survey was set up or more general comments that are unrelated to COVID-19.

### All comments and questions have been grouped under each research category.

# COVID-19 prevalence (number of COVID-19 cases in the population at a given time)

### Additional Suggested Research Questions:

No additional questions were submitted under this research category

### **Additional Comments:**

- Equally important questions to be answered. However, I felt that knowing the level of vaccination uptake in different areas across the country action could be taken to show it works in those areas to inform groups as to the benefit of having the vaccination.
- The immunity period offered by the vaccine is much more important (spread per population). Knowing that I would be (90%) immune for minimum of 2 months and a maximum of 5 allows me to reduce my risk of infection more than any policy could. What's the point of reducing the prevalence to <1% if in X months, when the immunity runs out, it snowballs back up?
- The %age population required to protect others who can't vaccinate for medical reasons is of the highest concern to me what is the figure needed for herd immunity through vaccination.

### Safety of the vaccine (e.g., adverse effects resulting from vaccination) Additional Suggested Research Questions:

### **Determining long-term effects**

- Are there any long-term side-effects, e.g. 12 months on?
- Long term outcomes
- I'm interested in the adverse reactions and how safe it will be in the long run
- What any long term side effects are (this will just take time to find out) and the incidence/population characteristics of people suffering SAEs
- Long- term effects of vaccination with different vaccines longitudinal follow up with different populations *would* be good.
- I'm interested in the adverse reactions and how safe it will be in the long run, and will it really be more effective than the flu one in terms of virus mutations.

### Exploring whether certain populations have different side effects/increased long-term risk

• Whether certain groups are more at risk of side effects than others.



• What is the impact of the Covid19 Vaccines upon the communities that have already been the most disproportionately impacted from the Covid19 pandemic, i.e. the Elderly, BAME and Disabled People?

• The safety aspect particularly for BAME communities with adverse effects i.e., allergies is important to look at.

• If different types of technologies produce more effective/safer vaccines (e.g. mRNA compared to inactivated)

# Fertility and Pregnancy - Exploring whether certain populations have different side effects/ long-term risk

- What are the long-term effects and does this impact fertility?
- Need more information on pregnancy and the fertility risks!
- I'm seeing more in the news about effects on fertility. Does this mean I have to choose between the two? More information is definitely needed
- Has fertility been charged checked after vaccination?
- Has fertility for both men and women been checked for effects after vaccination?
- If I have to make a choice between fertility and the vaccine I need to have more information on the risk
- There are important questions about the impact of C-19 vaccines on the developing (i.e. foetal and neonatal) brain (and the impact of vaccine derived protection from clinical and sub-clinical C-19 infection)
- We need to know what the effects are on pregnant women and their foetus so that people can make an informed choice about getting the vaccine
- If I'm trying to get pregnant can I still get the vaccine, seen some worrying information about fertility online
- Is it safe for pregnant women to have the vaccine?
- Can people who are pregnant have the vaccine?
- Whether it is safe for pregnant and breastfeeding people to receive the vaccine
- Effects for women who are breastfeeding how much is passed through breastmilk? Will this have

any adverse affects on babies who are breastfeeding? Do the effects differin babies and children of different ages?

### Underlying conditions - Exploring whether certain populations have different side

### effects/increased long-term risk

- So many of us have underlying conditions or are immunocompromised. We were told to shield to keep us safe but we don't know how safe the vaccine is for us.
- Impact on existing medical conditions
- Whether the vaccine results in a flare up of underlying conditions
- Have the vaccines been tested on vulnerable groups and people on differing medications
- If people have bad immune systems and allergies and on lots of medication, would the vaccine effect anything?
- Have the vaccine been tested with immune suppressant drugs for reaction on human?
- Can immunosuppressed take the vaccine?
- Safety of the vaccine for those with suppressed immune systems (taking immunosuppressants)
- The effect & safety of the vaccine for people with autoimmune conditions

• What are the risk of people on autoimmune suppressant? Is this vaccine 'live' or can be obtained in 2 forms i.e., live and non live vaccine?



- How safe are they for people on immunosuppressants?
- Are covid vaccines safe for the immunosuppressed population?
- I would also be interested in whether underlying health conditions/immunosuppression affect the risk of complications from the vaccine.
- I am immune compromised through biological therapies. I would be interested in understanding the implications to the immune system & effects of the vaccine, Covid & other vaccines to the population on biological treatments. I have also had allergic reactions to some medications, but no vaccines, so would like to understand my risk of reaction
- . Does the covid-19 vaccine react to any specific medications?
- . Autoimmunity and allergy need to be investigated more specifically with regard to Covid vaccine.

### **Additional Comments:**

### Information on safety is needed for public peace of mind

• The safety and effect of vaccine is most important I think for public peace of mind and motivation to go and get it. I've already heard so many say that it won't be safe or that "it won't have enough of an effect" and "it's pointless" and have said they won't get it. I think it needs to be hammered home that

it's safe and will work.
From the public perspective the safety of the vaccine to be used is paramount There must be sound evidence that the vaccine is to reviewed for adverse reactions.

• More information on the vaccine of what it contains as safety is paramount in deciding whether you will have the vaccine as there are so many scaremongering information out there like to know the facts

• I am mostly worried about adverse long-term effects we can't know yet if the vaccine and of covid-19 and whether risk outweighs the benefit depending on the individual

• The vaccines have been developed in different ways - might some be better suited to individuals eg those allergic to egg? the fact that the Pfizer vaccine needs to be stored at very low temperatures

makes me worry whether the vaccine will have been 'spoilt' and so less efficacious without my knowing

• There are also clear questions about establishing long-term safety and post-marketing surveillance data collection infrastructure

# There is a need for information for those who are immunocompromised, on medications or pregnant

• I am keen to have the vaccine but worried about side effects as I have multiple drug intolerances and had a bad reaction to the TB vaccine. The only information about side effects seems to be regarding people with severe allergy problems, I haven't seen anything about people with intolerances.

• I personally take a lot of medications and this is a concern of mine. I will still have the vaccine when offered but it is an anxiety.

• As a "rare" patient I get maltreatment and at risk of it, and no help if bad things happens to me, all the time, and medical staff systematically underestimate the risks for me and the possible risks in general, and often don't believe in me before they see the damage done themselves, when it's too late for me - this is not acceptable!

• Many medicines don't work for me, and/or give me serious side effects/adverse reactions. Especially

those meds designed to manipulate the immune system in any way. Medical staff lack understanding and knowledge about this problem and are not ready to handle that in practice in general.



- Not everyone responds healthily or efficiently to vaccination, please don't forget about us the society, from politicians to medical staff need to get educated about that! And we need scientific research that addresses these issues, not just healthy respond in healthy people. My family that I live with respects my fragile health, but not people who don't know me, and even medical staff lack in respecting good hygiene etc.
- . Any data on immunosuppressed people on medication having had the vaccine during trial?
- People should be asked about their medical history e.g., allergies and current medication. Some like me may have just had an infusion so timing of the vaccine when administered may need to be adjusted i.e., not on day of infusion for instance as side effects from that already tiring etc.
- 1 million women are pregnant every year in the UK; these are two (or even three lives in twin pregnancies) lives we are considering safety for in a pandemic. Understanding vaccine efficacy and risk for this particular population is incredibly important.



### **Additional Suggested Research Questions:**

# Effectiveness of different vaccines – how effective are they, how do they compare and is there a preference for different populations?

• Something on whether there is any different effectiveness for different groups from the different vaccines that are now available.

• Several different research teams have each produced vaccines with some fundamental differences: Is one type of vaccine more effective for any one particular group e.g. by ethnicity, age, comorbidities?

• How effective is the vaccine on mixed raced groups? We have been made aware of Black white etc, but not on mixed races whose genetic make up *might* be different

- The effectiveness of the vaccine on specific people i.e. those of Mixed Race with medical conditions, as research is specific to BAME but haven't seen any on mixed race. I would like to know how it affects
- me

• The Pfizer and AstroZeneca vaccines are different. Is there anything to say that some people are better suited to one than the other?

### **Timings of vaccine doses**

• Will it still be effective after a 12 week gap when it was advised it should be 3?

• How can we know for certain that those people who have had the first jab will still be safe after waiting 12 weeks, rather than 3 for the 2nd jab?

• Clarity about the issue of only have one vaccination and delay receiving the second as proposed currently by the government.

• The evidence that supports a longer duration between doses for Pfizer vaccine.

### Need information on long it is effective

• For me and my family, we are most concerned about how long the vaccine lasts once administered, what is the length of immunity, will a booster be needed in the future and how is immunity measured?

• How long a vaccine confers immunity

• This may come later but a lot will want to know how long protection lasts after being vaccinated.



• How long is the vaccine effective for? This probably isn't known but the population may need some reassurance that this is being monitored.

• Duration of protection is very important to understand, but presumably we won't know this for many months, so constant research is needed. And the response to the vaccine may be very different to natural immunity (i.e. better)

• Duration of the immune protection is the critical question, as with this knowledge people will know when they should be getting re-vaccinated and how long they are protected for.

# Want to know how effective it is for people with underlying conditions or immunocompromised individuals

• It's good to see research showing how effective a vaccine is but we really need to know is how effective is it for certain age groups or people with particular underlying conditions and co-morbidities.

• I think research into the impact of vaccination should also include how it affects different communities etc.

• How effective is the vaccine on people taking biologic medicines (monoclonal antibody medicine)?

• Effect on non standard immune systems, specifically over active ones, not just immuno compromised (weakened) how safe is it for people who, for example respond badly to BCG? Or other live vaccines

- Are the vaccines against COVID-19 effective for immunosuppressed or immonodulated patients?
- Just % impact of effectiveness and longevity of effectiveness when on immune suppressants
- Is it effective in patients on immunosuppressant medication?
- The efficacy of vaccines in immunosuppressed people. Those that are taking immunosuppressive drugs for certain conditions.

• For immuno-compromised people, does the immunisation affect current biological medications and effectiveness of the vaccine.

- · How do immunosuppressive medications affect effectiveness of the vaccine
- How effective in patients on immunosuppressant medication?
- The way it works with immunocompromised people or medications
- How effective is the vaccine on people with Crohns taking immunosuppressive medication e.g. azathioprine? Would having multiple vaccines improve this or not as some do the same thing?

• I have IBD and take biological medication. I specifically would want to know what effect the vaccine would have on me and my family...

- Have trials taken place on people with bowel disease and those on immune suppressant medication?
- What about patients undergoing immunotherapy?

• Yes How *does* the vaccine react With other treatment i.e. chemo Is the treatment less effective. *Whether* that is the vaccine or chemo

• How effective is the vaccine on vulnerable groups i.e. diabetes?

• What are the allergies that contraindicate a vaccination so that I don't have a wasted journey? I don't trust my GP notes to be fully filled in.

### Explore the effectiveness of the current vaccines against new strains

• Will it stop new strains of COVID-19?

• There is a new strain of Covid-19, what are the chances of even more strains developing and the vaccine they not working?



• Are the vaccines that are available now effective on the new variant virus/es or will new vaccines be needed to control the new variant virus/es? There have been comments that the current vaccines

will be effective against new variant virus/es but is there evidence that this is so?

- Are all of the different vaccines going to protect against the new variants?
- What is the effectiveness of the vaccines of the new variant compared to the original COVID-19?

• What is the evidence that the vaccine will work as well with the new variant, and particularly with the earlier vaccine that hasn't been 'tweaked'?

- There are new variants, will the vaccine work?
- Vaccines were being worked on before the new strains were known. Is this going to influence the effectiveness?
- Effectiveness of the vaccines against the new strains?
- Is there one vaccine that works stronger against the new variant compared to the other vaccine?
- How effective is the vaccine against the mutations or will we need to look through to new vaccines?
- There are new vaccines but also new variants so how will this work against them?

• Will vaccines work at all as the virus has mutated since they were developed? Has the spike protein changed to the extent the vaccines won't work?

- Will it really be more effective than the flu one in terms of virus mutations.
- I also have concerns over long term effects of the vaccine and I don't trust it will be that effective on the different strains of COVID

### Additional research questions

- Whether it actually stops you getting Covid or does it make it less severe (like flu vaccine)?
- Is the effectiveness of the vaccine reduced by injecting it in to an asymptomatic (infected) person?
- How long will it take to get the virus eliminated?
- Confirmation as to how soon after completing the vaccination course, immunity is established.
- More information regarding the way it will improve the treatment of COVID-19

### **Additional Comments:**

### Long-Term Effectiveness

• The long-term efficacy and effects of the vaccine need to be research but this could take years e.g. for a 20-year old who is vaccinated, what effect will it have in later life, fertility rates, possible birth defects in progeny, and life expectancy. (knocking a year or two off life expectancy would be better than the effects of catching Covid-19!)

### How often people will need to be vaccinated

- Most important for me is to understand how often we will need to get the vaccine or boosters.
- Will the Covid-19 vaccine be similar in spirit to the yearly flu jab, i.e. will it have to change as the virus mutates, or will there come a time when we will look upon this like we look upon the common cold -

annoying if we catch it, but not life-limiting or life-threatening, and nothing for which we really need a vaccine.

• The duration of protection needs to be considered in different groups rather than the population especially for those who are immunocompromised.

• Seems rather premature to think about re-infection, since vaccination roll out seems to be slower than is ideal.



### Vaccine effectiveness and new strains of COVID-19

• If a new variant develops which is resistant to this present vaccine, would we need a full Clinical Trials of the tweaked vaccine?. If so what would be the time frame?.

• There should be communications to tell people who would like to know how Vaccines help to kill the Virus and how to prevent the Virus from coming back in a different strain.

### Immune response (the way in which the body reacts and defends itself against COVID-19 and the strength and duration of protection offered by the vaccine) Additional Suggested Research Questions:

Exploring if and how the immune response differs when looking at different variants

• Response and effectiveness against covid-19, particularly against common variants

# Understanding the effect on the immune response, specifically for those who are immunocompromised or have underlying conditions

- I would be keen to know how people with anaphylaxis in the past and strong immune systems can have which type of vaccine and which type of protocol support to assist them (systemic mastocytosis Mast cell activation syndrome)
- Interactions with other medications is a concern.
- As someone with a pre-existing condition (Crohn's) and on medication (azathioprine

immunosuppressants) I'm mainly concerned about whether studies have been done specifically on

those with chronic conditions and on immunosuppressants as I'd like reassurance about how it may interact with those

- · How is vaccination affected by immuno-suppressant medications?
- What is the impact of immunosuppressants on development of the immune response?
- · How does it react with overactive immune systems?
- · How does the vaccine react with over active immune systems?
- Immune response for people taking immune suppression medication.
- Interaction with immunosuppressive medicines

### Additional research questions

- One area not specifically mentioned was idea of combining different vaccine approaches for a stronger response, but perhaps that was in the suggestion for understanding immune response.
- What long term changes do they cause to the innate adaptive immune systems and why?

• If different types of technologies produce more effective/safer vaccines (e.g. mRNA compared to inactivated)

### **Additional Comments:**

- I have complex immunological problems and know the body and immune system does not respond and react the same way in every person on immunological stimuli from meds and infections - but this is often forgotten about or even ignored in the discussion about the vaccine and the ignorance about it is huge among medical staff. It needs to be addressed, to raise awareness! Not every individual responds *in the way* that the mean group member would in theory!
- Differentiated T-cell responses due to strong immune system



- I don't understand why we would need to know whether antibodies have been formed by infection or vaccination, apart from general scientific interest
- Maybe if everyone who has the vaccine is given a diary form to fill in every few days then some useful data will become available for others. More qualitative than just the current quantitative numbers all the time.

# How vaccination impacts population behaviours and our adherence to social restrictions

### Additional Suggested Research Questions:

### How vaccines will impact restrictions/lockdown

- Do you still have to shield after having the vaccination?
- At what levels of vaccination within the population that restrictions can be removed

• Is there benefit of vaccinating the household of those who are immunocompromised (as with flu vaccination) and should this be prioritised

### **Understanding Perceptions**

• I'd like to see research on how the general public who are ignorant about chronic diseases and disabilities also about young people may change their behaviour - and if there's a risk they'll respect

us medically fragile even less with a vaccine rolling out, thinking it's absolute protection and that everyone can have the vaccine, which is not the case, and how that decrease in respect for us medically fragile people can be prevented.

• It would be very helpful to know about people's understanding of both the virus, its spread and vaccination effectiveness. This is a good opportunity to capture people's understanding of viral

disease - after a year of information, how much has been absorbed, understood, misunderstood. What impact does social media, fake news have on our understanding of the facts. The pandemic is a disease and yet attitudes to policies and our understanding around it are highly politicised within families, communities, age groups, genders etc...What influences these differences in opinion and therefore behaviour?

### Additional research questions

• Research about the impact of vaccination on mental health should be prioritised. The effects of the pandemic on mental health are documented, and it seems important to understand if the vaccination programme improves mental health and alleviates the "ticking time bomb".

• How does compliance with restrictions decline among under 50s - the longer they have to wait for the vaccine and realise they probably won't be getting it.

• Research on behaviour on children with other medical conditions and drugs they take regularly to keep them well.

### **Additional Comments:**

• 132 respondents had provided feedback in a similar way to: "Not an important factor for me. Hard to rate..."



### How vaccines will impact restrictions/lockdown

• I want to know how much vaccine will allow me or my loved one to mix with others and live normally. Or whether the restricted life remains

• Restrictions should be maintained until a safe level of the population is vaccinated and the lag time for effectiveness is reached.

• Restrictions must be maintained throughout the vaccination period to reach optimum 'herd immunity' levels

### Perceptions of feeling safe following vaccine roll-out

• Behaviour will change as people will think all those that were vulnerable are safe and I will just shrug it off like millions of others. the problem with this selfish thinking is that means the virus then has millions of hosts it can be transmitted to. If each host acts as a laboratory the virus can then mutate and target any one group age, gender, race.

• I really believe that people will think all is safe once they have the vaccine. Whereas I believe yes we will have protection and be hopefully less vulnerable but safety measure will still need to be adhered to because I believe COVID can still be transmitted but the vaccine will help us to fight it more readily thus less hospitable admissions.

### Role of public transport

• Any consideration of changed behaviour on public transport should not just be for London tube

travel. If the priority groups for getting the vaccine are older groups then their use of public transport is not the same as work based commuters. Needs clear thinking what experience of vaccinated people is relevant to the bulk of the population.

• Public transport rarely appears as a factor in the spread of the disease but it comes with work as well as socialising. Despite putting it third, it should be included in all research into behaviours.

## How the vaccine impacts spread (transmission) of COVID-19 (and how this might vary in different population groups, geographies, or workplaces) Additional Suggested Research Questions:

### Risk of transmission following vaccination

- Does the vaccination mean that these people can still pass on the virus to unvaccinated people?
- Risk of transmitting virus once had the vaccine
- Can Covid-19 still spread even after vaccination?
- Can vaccinated people still spread the virus? Key question. Also very relevant for potential use of immunity passports, which to my mind probably won't work. Can we rule them out?

# Understanding of whether the vaccine will stop individuals getting COVID-19 and then spreading the virus

• Do the vaccines stop you having COVID19? Or, do you still get it, but less severe? If you can still get it, can you still pass it on?

• Crucial that people know whether the vaccines prevents people from catching it, and therefore possibly spreading it or whether you can still catch it but with less severe results and still spread it.



# Understanding of whether the vaccine will stop individuals getting COVID-19 and then spreading the virus

- What proportion of the population need to be vaccinated in order to curb the spread?
- What happens to people who refuse the vaccines?

### **Additional Comments:**

• Would it not be better to test for antibodies to COVID in confirmed or suspected cases and therefore not waste vaccines on some who have immunity, while vaccines are in short supply?

• I haven't seen or heard discussion of whether or not a vaccinated person might still infect others through viral infection, picked up from others' infected aerosol exhalations, of their epidermis or clothing; if that can occur then it should surely be important to tell the public to continue to socially distance

distance

• How are we supposed to know if vaccinations stop the spread when it even says this is not known after vaccination on the government website?

### Uptake of the vacane by the VK population Additional Suggested Research Questions:

### Compliance given the requirement of two doses

• In the compliance of attending for the second vaccine, are there any population groups shown to have higher levels of non-compliance?

• Need something on this business of having to have 2 jabs. We do not know yet if people will not bother to get the 2nd jab.

### **Frequency of vaccines**

- Will it need to be administered every year?
- How frequently will people need to have a vaccine? Every six months? Every ye

# Understanding uptake and impact on populations who have thus far been disproportionately impacted by COVID-19

• Research into the impact upon the protected characteristics; Race, Disability, Age, Gender is critical to show the population there has been diversity in the testing population for the vaccinations. Otherwise diverse communities will fear that it is only really the usual suspects of being White and Male have been tested.

• Research into communities that have been disproportionately impacted and that have still not been factored into the prioritisation of the vaccination order, e.g. BAME communities. It would be interesting to see how this impacts the take up with these communities.

• We know there is more reluctance within the BAME communities to take the vaccination. This needs to be studied and discussed with the BAME communities, so see how we can achieve proportional representation for the UK population. Otherwise, this will impact upon the communities that have already been the most disproportionately impacted from Covid19 pandemic.

• Interest in difference in cultural and social economics uptake of vaccine

### Exploring what the different factors are that will impact vaccine uptake

• What factors affect vaccine uptake?



• Lockdown has been long and hard for some communities this has affected how they see the roll out of the vaccine

• Factors that can be changed to increase uptake are vital.

• The factors influencing uptake of the vaccine should include deprivation, if you can't afford to travel some will miss out despite wanting to be vaccinated – impact of this should be researched

• Does offering the vaccine while a patient is already in the gp or hospital for other reasons increase the uptake of the vaccine

• Does a particular kind of vaccinator (e.g. GP, community health work, someone else specifically trained for Covid-19 vaccines. programme) influence uptake?

• As more people become vaccinated and prevalence declines this could be a strong motivating factor for the rest of the population. Should we even consider vaccine passports?

• What lessons can be learned from low uptake of other vaccines?

# Understanding if there are any situations that would, for medical reasons, stop someone having a vaccine

- What are the medical conditions that prevent patients from not being included in this?
- Should you be well to take it or it doesn't matter if you have e.g. a temp/copd flu symptoms?
- Another question is how do the flu vaccine and covid vaccine effect works well or not on patients who's have both?
- May we receive COVID 19 vaccine, being with symptoms or with flu, heart disease, allergic to collagen, and so on?
- How long after another live vaccine can you take the Covid vaccine?
- How long after having the vaccine should you wait to try for a baby?

### Exploring how vaccines will impact different populations

• How the roll out is protecting the most vulnerable. E.g., difficulty and frustration in making appointment?

• How far low community vaccination uptake for previous vaccines may influence uptake in particular groups for Covid 19 vaccines?

• People at low risk may well be able to go back to normal live without having received the vaccine - as they are at low risk. This should be explored - i.e. is this safe?

• I think the prevalence among all diverse groups could highlight where and why uptake is different.

### Perceptions

• How people feel about being required to show proof of vaccination - or exemption from it where necessary - in order to pursue various activities

• Include beliefs and attitudes about vaccination and vaccines in this research.

### Understanding reasons/perceptions of those against taking a vaccine

• Should we be considering the societal impact/ judgement against anti vaxxers?

• An understanding of conspiracy theories, fake news and misunderstanding around vaccines - the role of the media in supporting good information or 'fake' news, which news outlets are trusted/used by which populations. The impact of these sources and how to mitigate for misinformation.

• More on factors influencing people's choices re vaccines; i.e. we need to better understand the psychological factors at play.



### **Additional Comments:**

I think we pretty much know the answers to these questions! Additionally they relate to "associations", not causal relationships, so are unlikely to be of help in identifying ways to improve vaccine take-up

### Compliance given the requirement of two doses

• I was keen to have the vaccination but now that only 1 dose is being given, I am annoyed that after all the research and effort of scientists, we are only to be given a partial dose. From my understanding the trials were based on a 3 week gap for efficacy, not 12 weeks. Seems like a half hearted cost

cutting process, with all thought now being given to the Oxford/AZ vaccine as it is cheaper and easier to administer than the PfizerBioNTech. Pfizer had a very short lived glory time and seems to have been dumped in favour of Oxford/AZ.

• People are now (this afternoon on BBC news 31 Dec) being told their second jab will be delayed until 12 weeks. According to earlier reports the AZ one will Apparently work better with a longer delay

between jabs. But it seems very odd for this to apply to the Pfizer vaccine as well. It makes me worry that older people could remain at risk if they only receive one dose as I cannot understand how the research can apply to both 3.

### Vaccine roll-out – prioritising population groups

• Vaccination should come to the community, not the other way round. It benefits all of us to have high take-up.

- What is the time scale of patients will GPs be able to undertake this?
- How the roll out is protecting the most vulnerable. Eg difficulty and frustration in making appointment
- We will have the complication as the elderly are vaccinated first, then the younger member of the household may feel less obliged to follow rule, as the person who was most at risk is now vaccinated. Communication and management of this risk will be key as the vaccination is rolled out to more

households nationally.

- Why is ethnicity not a criterion for early vaccination when it appears to increase severity of the infection?
- Would like to know if Crohn's patients will be one of the first to have the vaccine
- Do we know the number of patients who had adverse effects, will they be able to have the vaccine?
- There is a lot of data on take up levels for flu jabs among different eligible groups eg 12% care home staff but 72 % NHS staff. To get high take up asap the groups that take up flu jab can be brought in first to help build community immunity.

• I have a feeling there will not be a great uptake of the vaccine in young 'healthy' individuals. I'm more interested in the effect that vaccination in vulnerable groups (assuming uptake will be higher here) will affect hospital admissions and mortality.

• As a young woman of child baring age, but also in a high risk category I am torn. I would have 100% had the injection but now talks of it affecting fertility I do not know what to do. A lot of young people are having the same dilemma, however they are not high risk, so if I was then I wouldn't risk it. But in

my high risk position I am really unsure. On the COVID vaccination print out, it says to 'exclude pregnancy before taking vaccine' - what does this mean?! Should we have babies first?! We need more information! Also as high risk and immunosuppressed, we have been informed the vaccine may

only be 50% affective. Is this true?!



• Speed is of the essence, would be better to get all who wish to have vaccination rolled out asap, not waste time looking for anti-vaxer

### Vaccine roll-out and restrictions/lockdowns

• The rules on restrictions have often included demographics e.g., older people, people with certain

long-term conditions, criteria for shielding. So, there would be a consistency in messaging and public understanding if the vaccine impact was communicated on the same basis.

### **Communications – information to include**

• It would be valuable to get the data as the vaccine is rolled out the effectiveness it has on Covid in your particular area. Updates would be greatly welcomed.

• When communicating, would like to know what would the data be based on? Not much of this info from clinical trials and still v little experience of the vaccine with many people.

• Need to have solid data on the effect of the vaccine that is in line with the way the public information has taught us the differential impact of the virus itself.

• Would you need to highlight somewhere that 'previous Covid infection' may include unknown, asymptomatic infection?

• Can't see the link between COVID and flu vaccination, so this would need careful communication to avoid people prioritising one over the other.

• Why the AZ vaccine is believed to achieve greater efficacy at 12 weeks (I assume the protocol was for a set period, but haven't read it)

• Just to be kept updated with the response and effectiveness of the vaccine.

• Uptake of different populations and involvement of communities *is needed* in the education training and rollout *for* influencing and increasing uptake.

### Communications – relating risk to age

• Relate these vaccine risks to age

• Relate vaccination effectiveness to age. Verify dosing level of multiple jabs to optimise effectiveness.

• Relate vaccinations effectiveness to the natural immune response to the covid-19 of healthy persons and their ages

#### Communications – methods and addressing false information

• FAQs are always useful, especially if they include questions so that the answer can be NO e.g., if I have had flu jab this winter will I be prevented from having a COVID vaccination?

• Need to be able to answer question "What do I do now I have got COVID? I feel awful, is this normal?"

• What is the effect on vaccine take-up of different forms of publicly-disseminated information / data / propaganda?

• All possible public media sponsored by government and relevant medical professionals nationally & locally should encourage & demonstrate to our population the need and value of receiving antipandemic vaccinations

• Announcements made to the public should be consistent and clear - for example there were mixed messages over how much time should pass between the first and second shots of the vaccine.

• I believe more people would respond positively to the vaccine if all the information was out there about each vaccine, its name and manufacturer, its ingredients and their action on the body.

• I think the spread of misinformation is the biggest threat to uptake of the vaccine...



• Urgent and honest post mortem findings need to be broadcast to the public to prevent false news. I am thinking of the healthcare worker in Porta that had the Pfizer vaccine and two days later dies. News outlets need to only share facts no assumptions or face fines. This will help with how many people take the vaccine.

• How can you promote this to people who are speaking out against the vaccines?

### **General Comments:**

### **Understanding priorities**

• I would be interested to understand whether the current prioritisation needs to be revised once we know more about the vaccine. For example, in the future, would there be a greater impact by vaccinating younger people with underlying health conditions ahead of the elderly who might otherwise be in good health?

• These *are* very difficult questions to answer. I think there is quite a conflict in many people between what is logical and emotional/gut response. It has been suggested that it's like an iceberg only the 10% (logical thought) is visible above the waterline, while 90% (emotional/gut feel) is invisible below.

• Several of the options are all worthy of priority. However the safety and effectiveness of the vaccine is the only way to end the pandemic so has to have priority

### Change in prioritisations following additional vaccines coming to the UK

• The Oxford vaccine has been approved today, so safety and effectiveness are not so relevant. Takeup is important, as is behaviour during the time until everyone is vaccinated.

• If there are more and more vaccines it gives us choice so less concerned about effectiveness and more about how the people of the UK will behave

• I've just seen in the news we have a new vaccine from Oxford? I still think safety is important and is my most important in your ranking system but now we need to look at how many people will take the vaccine

• Effectiveness and then very closely followed by safety of the vaccine were the two things that instantly came to my mind before I even saw your survey but now that the AZ vaccine is around, should we actually be thinking about how many people take the vaccine?

• News today is making me question what I think is most important. I think I'll stick with vaccine safety but you need to work to make sure people are sticking to the restrictions or as you say 'population behaviours'

• I'd originally said safety but I'm beginning to think that if we have more vaccines it will probably be covered so perhaps how many people take the vaccine?!?!?!

• Safety is extremely important and that shouldn't be diminished but now that we've got the Oxford vaccine, let's put time into what that would people take the vaccine and how will they be influenced

• I always say safety safety safety but this is a strange time and with new vaccines here and in the US you should think about focusing on how to get people to stick to restrictions and lockdowns

• I think effectiveness is key. But with the news in the background as I complete this survey and hearing from the experts, I think time needs to spent on how the UK population reacts once some people get vaccinated and whether they think they'd just be safe

• I like your phrasing of population behaviours. I stand by my decision to say safety is my top priority but I think more people will change how they behave once vaccines start to be given so you should

think about researching that



• If you look at my previous answers I spoke a lot about how safe is the vaccine. However, you need people to take it and with more vaccines coming on board it's important to know who will take the vaccine

• We need to know how safe the vaccine is but if there are other vaccines and I can choose then I'm less concerned with new research on that and more on how the UK population will change its behaviour when they get the vaccine

• I saw the news yesterday about the new vaccine so we now have two, great. I assume work is already done on it's effectiveness and am less concerned now we have options. Priority needs to be on behaviour until everyone is vaccinated.

- News of another vaccine is going to change perceptions. I think people were concerned about safety but are probably thinking about how to get more people vaccinated now that there are more options
- Talking to friends after the announcement of the AZ vaccine it's made me think about whether my top priority is vaccine safety or whether we should be looking at how people behave and influence

that until everyone is vaccinated • Until enough of the population get the vaccine you need to prioritise research into the uptake of the

vaccine more now because there are options and more vaccines

• Look at how the population behaves as this is going to be key to move forward the work now that we have a couple of vaccines here and in America

### **Additional comments**

• Please look at robust integrated routine data systems for positivity vaccination & long COVID

• Was it justifiable to exclude pregnant and lactating women from the first wave of phase III C-19 vaccine trials?

• Evaluate all ethical issues of the vaccine

### Not specific to new vaccines research but of interest, relevance or importance:

### **Effects of Vaccines**

• What follow up is planned to assess efficacy? Are recipients being encouraged to report adverse effects.

- How is the data recorded and followed up? GP records / private?
- I think if it is difficult to access the vaccine this might influence the results of having the vaccine.
- Options to access vaccinations

• Should long-term & widespread deleterious effects of vaccination arise in future, what would be the government's / health authorities' best response?

### **Understanding Priority Groups for Vaccination Roll-Out**

• Probably not relevant for these purposes, but I and most people I have spoken with, wonder why care home residents are priority? they do not go out, work, mix in the community, travel, most stay in their own room therefore they are Not spreading the virus. many people go into care home at end of

life and will die there within a relatively short time. Priority should first and foremost be with front line staff in hospitals, GP surgeries, paramedics, nursing homes, district nurses, care home workers. followed by teaching staff in schools. These people are vulnerable to the virus, and furthermore the

level of absenteeism in the hospitals and other NHS services is dreadfully high, which is precisely why they should have all been vaccinated first. vaccinating care home patients does nothing to stop spread of the virus.



### **Research Development**

• There are questions about how to persuade regulators to require the inclusion of pregnant and lactating women as the default in vaccine studies rather than their automatic initial exclusion as at present. This runs counter to WHO and other guidance

• How can research be aligned so that it uses the same set of outcomes data and therefore can be delivered efficiently

### Needing more information and understanding of the vaccines available

• Concerns that the vaccines were rushed through.

• How to view trial data on immuno patients on meds that lower the immuno system? Or has there been any?

• We've all heard or read about the various international vaccines, their origins and effectiveness.

Distribution is now the key to achieve the UK's resistance & so 24/7 prioritisation by our medical/NHS/GPs/First responder volunteers needs to be mobilised. The Oxford/Astra Z. vaccine has practical advantages, it's optimisation with more research into the first & second dosing levels & time lapse between them needs verification. Other world vaccines should be compared on equivalent bases. Pandemics can & will arise again so this research should be continued. World recovery has

been patchy, why? cf. China is booming? What else can we do to improve UK recovery?
What are the relative effectiveness and side effects of each vaccine type, maybe for different age groups and health profiles. Given a choice - which one.

### Use of social media to communicate

- Social media reporting can also have an effect
- Maybe social media ie anti-vax messages needs its own question?
- What legal options are available to counter anti-vaccine propaganda especially on social media?

### Long-COVID

- How long Covid-19 affects people lives the age ranges?
- How people are affected by Long Covid-19 how it affects their lives. What help is available for them?

### Patient and public perceptions on restrictions and national guidance

• Different areas of the country are placed in different tiers. This has not helped people feel they are being treated fairly.

• I understand infections within households are the greatest threat; also, I don't altogether agree that the rules have been chosen properly, & in particularly mask-wearing whenever outdoors should be mandatory.

• The message needs to be simple: space-face-hand and open windows

• We need life to get back to being functional, so people can get back to work, school, travel etc but an individual should still take apply personal hygiene as normal, and should be honest if they have any

symptoms, personal hygiene is an everyday importance, not just around Covid, it seems shocking that some members of public need to be reminded to wash hands regularly! People need to behave responsibly, but that does not mean paranoia.

• Whether immunity passports can be used for travel. There seem to be big issues with this, but some airlines are already talking about using them.