

Frequently asked questions about the vaccination programme for COVID-19

The BIMDG (British Inherited Metabolic Disease Group – the professional society for doctors, nurses, dietitians, scientists and psychologists involved in the diagnosis and management of individuals with inherited metabolic disease) has prepared these responses.

The BIMDG is strongly supportive of the vaccination programme for COVID-19 and hopes that any patient who is offered vaccination will take up the offer.

- **1.** Is there any particular inherited metabolic or lysosomal storage disorder where patients would be advised not to have a COVID-19 vaccination?
 - NO. Vaccination is considered safe for all inherited metabolic disorders.
- 2. Can I have the vaccine if I need to follow a prescribed low protein diet?
 - YES. The amount of protein in the vaccines is negligible and having the vaccine will neither affect how well your condition is controlled, nor will you need to reduce your protein intake (exchanges).
- 3. If I am offered vaccination would I need to have it done locally or with my specialist centre?
 - The NHS will aim to give you the vaccination within your local area. If they are not able to do so then you will be invited to a designated hospital which has been identified as a vaccination centre. You do not have to go to your specialist centre to be vaccinated.
- 4. Which vaccine should I have? Do go I get choose?
 - At this moment, the NHS is not able to give you a choice as to which vaccine you will be offered. Patients will be given the vaccine that is available in their local area.

Read about the approved Pfizer/BioNTech vaccine for COVID-19 by MHRA on GOV.UK

Read about the approved Oxford/AstraZeneca vaccine for COVID-19 by MHRA on GOV.UK

5. Do the vaccines contain any live COVID virus?

• NO. The current vaccines do not contain any live COVID virus. The current vaccines also do not contain any animal products or egg.

6. What side effects might vaccination have?

- Most side effects are mild and should not last longer than a few days to a week such as;
 - i. A sore arm where the needle went in
 - ii. Feeling tired
 - iii. Headache
 - iv. Feeling achy

7. Why are some patients with the same inherited metabolic disease being offered vaccination before (or after) me?

- Even if patients have the same named condition, it does not mean that they are affected in the same way. Some patients may be very mildly affected with their inherited metabolic disease; others may be much more seriously affected with many complications of their condition. It is these complications that may put them more at risk of complications of COVID-19. Older patients and those who are deemed 'clinically extremely vulnerable' will be offered vaccination earlier on in the programme.
- Other patients may have a second, more common condition, such as diabetes or severe asthma, that makes them more vulnerable – and so it will be this, rather than their inherited disorder of metabolism, that puts them more at risk of complications of COVID-19.

8. Do you have to follow restrictions once you have been vaccinated?

 YES. After vaccination, most people will be protected against COVID-19 symptoms. However, there is a small chance you might still get COVID-19 even after vaccination. We also do not know for certain yet whether people who have had the vaccination might be able to pass on COVID-19, even if they have no symptoms. For these reasons it is important that EVERYONE continues to follow social distancing guidance, wear a face covering in public and adhere to local lockdown measures.

9. I am pregnant - can I be vaccinated?

- The available data do not indicate any safety concern or harm to pregnancy, but there is insufficient evidence to recommend routine use of COVID-19 vaccines during pregnancy. If you are currently pregnant therefore you should wait until after your baby is born to be vaccinated.
- However, *if a pregnant woman meets the definition of being clinically extremely vulnerable*, then she should now discuss the options of COVID-19 vaccination with her obstetrician and/or doctor. This is because her underlying condition may put her at very high risk of experiencing serious complications of COVID-19. The benefits

and risks of COVID-19 vaccination in pregnancy should be discussed on an individualised basis and for some clinically extremely vulnerable pregnant women vaccination may be offered.

10. I am breastfeeding - can I be vaccinated?

• There is no known risk in giving these vaccines to breastfeeding women. Breastfeeding women will therefore be offered vaccination if they are otherwise eligible.

11. Will the vaccines affect any of my medication?

• The current vaccines are not known to interact with any medications. If you are worried about this please contact your specialist centre or speak with your pharmacist.

12. Will I be able to go abroad following vaccination?

• It is recommended to follow government guidance on travel abroad - this is regularly updated.

13. Can I eat and drink as normal, do my normal activities on the day I have my vaccination?

• YES. You should be able to continue activities that are normal for you, as long as you feel well.

14. I have severe allergies - can I be vaccinated?

- It is advised that any person with a significant allergic reaction to a vaccine -- such as previous history of anaphylactoid reaction, or those who have been advised to carry an adrenaline autoinjector -- should not be vaccinated at present.
- You will be asked about allergic reactions when you attend for vaccination and the nurse / doctor / pharmacist will determine if it is safe for you to go ahead with vaccination.

15. Can my child be vaccinated against COVID-19?

- NO. Not just yet. COVID-19 vaccine trials have only just begun in children and there are, therefore, very limited data on safety and effectiveness in this group. Children and young people have a very low risk of COVID-19, severe disease or death due to COVID-19 compared to adults and so the vaccines are not routinely recommended for children and young people under 16 years of age.
- Recommendations on vaccinating children with other underlying conditions will be reviewed after the initial roll-out phase by which time additional data on use of the vaccines in adults should allow a better assessment of risks and benefits.

16. I am receiving regular intravenous enzyme replacement therapy - do I need to consider the timing of this in relation to COVID vaccination?

• If you are offered COVID vaccination over the next few months then we suggest you prioritise this. If you turn down the initial time-slot(s) offered to you then you may have to wait a bit before you are offered another slot.

Information correct as of 04 January 2021 (includes updating of answers to questions 4, 9, 10 and 14; and additional questions 16 and 17)

Some basic principles to consider:

- 1. You should feel well, without a temperature on the day you have your COVID vaccination, and on the day you have your ERT infusion.
- 2. Avoid having your COVID vaccination and your ERT infusion on the same day.
- 3. If time-slots for COVID vaccination are very limited then please take up the offer of vaccination and arrange to delay or miss your ERT infusion that week if needed.
- 4. Because some people have reactions to vaccines (slight temperature, muscle aches, sore arm, flu-like feeling), then you should wait 3 days (until these symptoms settle) after your COVID vaccination before having your next ERT infusion.
- 5. It is however fine to have your COVID vaccination the day after your ERT infusion as long as you feel well.

17. Will the current vaccines impact on my ability to have potential gene therapy for my inherited metabolic disease in the future?

- NO. Some confusion has arisen on social media because of the similarity in the names of adeno-associated viruses (AAVs) which are used in gene therapy, and adenovirus-based vaccines.
- However, the two types of virus are completely different from each other and do not share any genes or proteins. Having an adenovirus-based vaccine will not produce any antibodies which could react with AAV and will therefore have no effect on whether or not a person can take part in a gene therapy trial using an AAV vector.

References:

Greenbook chapter 14a (publishing.service.gov.uk)

Coronavirus (COVID-19) vaccine - NHS (www.nhs.uk)