Frequently Asked Questions about the Covid-19 Vaccination, for those living with Sickle Cell Disease, Thalassaemia and other Haemoglobin Disorders.

The following information has been provided by Dr Rhodes, Dr Sikorska and the rest of the Red Cell Team, with consultation with other medical doctors within the trust and other sources of medical information.

We want you to feel you have accurate information to make a decision about whether to have the COVID-19 Vaccine. We are aware that some people have concerns about the vaccine, and that there is a lot of potentially inaccurate or unhelpful information circulating, so please do consider the source of any information to make sure it is relevant to you and accurate.

Our belief is that this vaccine is safe for people with sickle cell disease (SCD) and thalassaemia, and we believe it offers very important protection against coronavirus. Vaccines have a long history of saving lives in sickle cell disease and thalassaemia – for example the pneumococcal vaccine helps prevent patients with sickle cell disease getting sick from specific types of pneumonia. We also know that coronavirus can be very dangerous for people with SCD and thalassaemia, and so any concerns about the vaccine must always be weighed against the potential impact of getting coronavirus.

Below we hope to answer some of the most commonly asked questions, but please do contact the clinical team if you have further concerns. We have also listed a number of resources at the end of this document, so please do look at these, hear what others are saying about their experience of the vaccine, and use the information presented here to make your decision.

The vaccine and sickle cell disease or thalassaemia

We believe that the vaccine is safe for people with sickle cell disease and thalassaemia. We recommend many vaccines throughout the life time for people with these conditions, and they are usually very well tolerated.

We know that some people with sickle cell disease or thalassaemia are at risk of having a more severe illness if you do get COVID, and so we think it is very important for you to have the vaccine if offered, to give you the best chance of protection. There is a small chance you might still get coronavirus even if you have the vaccine, so it is important to continue with social distancing/shielding until the government issues further advice about this. It is possible that patients with haemoglobinopathies may not respond as well to the vaccine as the general population and it is not yet known how long the protection against the virus will last.

Some people have asked us about whether it makes any difference if you have co-morbidities of these conditions such as higher iron levels/on chelation, an absent or abnormal spleen, changes to your lungs, acute chest syndrome, if you take anti-coagulant medication (such as warfarin) – there are no contraindications (reasons that the vaccine isn't suitable), other than having a current fever, having had COVID in the past month and having had a severe reaction or allergy to a vaccine or the specific ingredients in the vaccine in the past. Otherwise, we believe it is safe to have the vaccine with any other medical condition, and these conditions make it even more important to have the vaccine.

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About the vaccine and its safety more generally

How does the vaccine work?

Vaccines work by helping the body develop an immune response, so that if the body encounters the Covid-19 virus in the future, the immune system will recognise it and act against the virus so it cannot develop into an illness. The vaccines that have been approved for use do this in slightly different ways (see below). The COVID vaccine only has what it needs to produce the fighting cells and things to make it safe, able to be delivered and able to be stored. Nothing goes into a vaccine unless it is absolutely needed. The parts of the virus in the vaccine cannot reproduce in your body and cannot give you COVID 19.

The Pfizer/BioNTech vaccine is an mRNA (messenger RNA) vaccine. Messenger RNA contains a small part of the genetic code which tells the body's cells to create the spikes that are on the surface of the coronavirus. These spikes can be recognised by the immune system. The vaccine does not contain any live virus.

The Oxford vaccine also contains the genetic sequence of this surface spike protein, so like the Pfizer/BioNTech vaccine, the vaccine tells the body's cells to produce the surface spike protein of the coronavirus using this genetic code. Instead of mRNA, the Oxford vaccine uses a harmless adenovirus (a different virus that also has the 'spike' protein on its surface). It has been genetically changed so that it is impossible for it to cause an illness.

The Moderna vaccine works in a very similar way to the Pfizer/BioNTech vaccine, as it is also an mRNA vaccine. It uses mRNA, so that the immune system can respond to them. It does not contain any live virus.

Which vaccine should I have?

Pfizer/BioNTech, Oxford/Astra Zeneca or Moderna are the three vaccines currently approved in the UK, although the Moderna is not likely to be available until the spring. There are some differences in the way the vaccines work and how they are stored, but they have similar effectiveness after two doses. Furthermore, there is no data yet to suggest any particular vaccine works better for people with certain conditions or has a particularly different side effect profile. You are also unlikely to be able to choose which vaccine you have, and we don't want people to wait for a specific vaccine. Our advice would be therefore to have whichever vaccine you are offered, as they are all safe and effective. Whichever vaccine you are offered, it will have been through all the safety processes. It will also have been recommended by the Joint Committee on Vaccination and Immunisation (JCVI) for people of your age and risk group.

Can the vaccine alter your genetic material?

No. Whilst the technologies in the vaccines both use genetic codes to produce the spike protein inside the body, this code cannot be incorporated into the body's DNA. These vaccines cannot replicate inside the body and only stay in the body for a few days. After helping the cells to produce an immune response against the spike protein, the vaccine is removed by the body.

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How was the vaccine developed so quickly?

Medicines, including vaccines, are highly regulated and that is no different for the approved COVID-19 vaccines. The vaccines were developed so quickly because there were a lot of additional resources available compared to what is usual for a vaccine. This allowed the different phases of the clinical trials to run at a similar time instead of running one after the other, which sped up the clinical process. Also, the clinical trials managed to recruit people very quickly as thousands of people were willing to volunteer. Also, the experts at the MHRA could review as the trial was being delivered, ask questions along the way and request extra information as needed – as opposed to getting all information at the end of a trial. Therefore the vaccine was developed much more quickly than is usual, but has passed through exactly the same tests and precautions as other vaccines available in the UK.

Who has it been trialled on?

The Pfizer/ BioNTech vaccine trials were in the United States, Europe, Turkey, South Africa, and South America. The Oxford/AstraZeneca vaccine trials were in the UK, Brazil and South Africa.

In the Pfizer trail, 9.8% of the trail participants were black, and 4.4% were Asian (very similar numbers were seen in the Moderna trials of 9.7% and 4.7%). Importantly, similar vaccine efficacy results were observed across racial and ethnic groups in both the Pfizer and Moderna trials.

Has it been trialled in patients with sickle cell disease or thalassaemia?

No, not specifically – but there is no medical reason why the vaccines would cause any particular problems for patients with sickle cell disease or thalassaemia. As mentioned earlier vaccination has played an important part in improving care for patients with haemoglobin disorders.

Are there any animal products in the vaccine?

No. There is no material of fetal or animal origin, including eggs, in either vaccine. All ingredients are published in healthcare information on the MHRA's website. For the Pfizer/BioNTech vaccine information is available here:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/955901/Temporary_Authorisation_Patient_Information_BNT162_6_0_UK_clean.pdf

For the Oxford/AstraZeneca vaccine information is available here:
GOV.UK: Oxford/AstraZeneca vaccine for COVID-19 approved by MHRA

For the Moderna vaccine, information is published here:
GOV.UK: Moderna vaccine for COVID-19 approved by MHRA

What are the side effects?

Serious side effects are very rare in all of the approved vaccines. Most side effects of the COVID-19 vaccine are mild and should not last longer than a week, such as:

- A sore arm where the needle went in
- Feeling tired

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• A headache
• Feeling achy
• Feeling or being sick
You can take painkillers, such as paracetamol, if you need to.

None of the currently approved vaccines use a live Covid virus in them, so you cannot get COVID-19 from them. It is common to get symptoms that feel the same as an infection for a few days after you have a vaccine (e.g. feeling "fluey"). This is a sign that your immune system is responding to the vaccine, not that you have got an infection.

What if I get a temperature after my vaccination?

You can, rarely, get a mild temperature rise following vaccination, including the Covid vaccination. Please remember that a high temperature is also a symptom of Covid, and you should take care to ensure you have a Covid test if you are exhibiting a high temperature (over 38 degrees) or any other Covid symptom.

Can I have the vaccine if I have had anaphylaxis and serious allergic reactions in the past?

It's very rare for anyone to have a serious reaction to the vaccine (anaphylaxis). If this does happen, it usually happens within minutes. Staff giving the vaccine are trained to deal with allergic reactions and treat them immediately. Tell healthcare staff before you are vaccinated if you've ever had a serious allergic reaction resulting in admission to hospital or anaphylaxis. You should not have the vaccine if you've ever had a serious allergic reaction to:
• A previous vaccine
• A previous dose of the same COVID-19 vaccine
• Some medicines, household products or cosmetics: please discuss this during your appointment. It would be helpful to bring any hospital letters or details about your previous reaction, in order to check the vaccine doesn't contain any of the same ingredients

Do people who are shielding still need to shield after their vaccination?

Yes, at the moment they do. Even if you have had both doses of the vaccine, you should continue to follow this shielding advice, until further notice, as we continue to assess the impact of vaccination among all groups. The people you live with should continue to follow the public health rules and guidance as long as they are in place. The vaccine will not prevent all transmissions of Covid, so you should continue with precautions as you were doing before the vaccine.

Is the vaccine compatible with my religion?

The British Islamic Medical Association has considered all varieties of the vaccine and recommends that Muslims have the vaccine. The Muslim Council of Britain is also recommending the vaccine, and Imams across the UK have confirmed that all the varieties of the vaccine are halal.
The British Sikh community has also supported the vaccine, as have Hindu leaders.

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The Church of England says that all clinically recommended vaccinations can be used with a clear conscience.
The Catholic Church has said that the vaccine, including the Oxford/AstraZeneca vaccine, is acceptable and can be morally justified.
More than 80 Jewish doctors in the UK have signed a letter to confirm that the Pfizer vaccine does not contain any ingredients that are not kosher. Orthodox Jewish groups including the Orthodox Union and the Rabbinical Council of America have also encouraged their community members to get vaccinated.

Pregnancy, breastfeeding and fertility

You can have the COVID-19 vaccine if you're breastfeeding, if you are pregnant and if you are planning a pregnancy. There is no evidence that the vaccine affects fertility. Please see the links in the resources at the end for further reading about this.

Practical questions about the vaccine

When will I get my vaccine?

The vaccines are being organised in a set order decided centrally, but many people who are considered extremely clinically vulnerable (all of those with sickle cell disease and some of those with thalassaemia) have started to be contacted, so you may hear soon. You may be offered it at the hospital, at your GP surgery, or in a vaccine centre.

What are the arrangements about the second dose of my vaccine?

All second doses of vaccine will be given within 12 weeks of the first dose, as recommended by the UK's Chief Medical Officers. The delay of the first dose from the original 3/4 weeks to 12 weeks was a decision taken by the national Joint Committee on Vaccination and Immunisation. The full details of the science, public health benefit and reasoning behind that can be found here:
https://www.gov.uk/government/publications/letter-to-the-profession-from-the-uk-chief-medical-officers-on-the-uk-covid-19-vaccination-programmes/letter-to-the-profession-from-the-uk-chief-medical-officers-regarding-the-uk-covid-19-vaccination-programmes#

What if I have had the flu vaccine recently?

You should wait for at least 1 week between the vaccines

What if I have had Covid recently?

If you contract Covid, you must wait 1 month after infection before your first vaccine dose. If you contract Covid in the period coming up to your second dose, then please contact the bookings team to discuss further. Most people should be able to have the second dose as scheduled, as long as they no longer have Covid symptoms, but this should be discussed on an individual basis. Please do not attend for your vaccine if you have any Covid symptoms or are still within your isolation period.

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Will my family members also be offered a vaccine, as I am classed as extremely clinically vulnerable?

Vaccinating family members does not seem to be currently planned for, as the vaccine works primarily to stop you getting unwell with COVID, rather than reducing transmission.

Are children with SCD/thalassaemia on the list for the vaccine?

No, the vaccines currently in use have not been approved for use in children. Children do not seem to be as badly affected by COVID, and our data on those children with SCD/thalassaemia in the UK who have had COVID show good outcomes.

For further information please contact

Carol Rose, Lead Clinical Nurse Specialist on 07825 978812
Haematology consultants (via secretary): 0208 725 0885
Red Cell Pain Management and Psychology Team: (Jenna Love, Rebecca McLoughlin, Yvonne Whelan) – 07798 581198

To join our Whats app group, where we circulate information like this, please text us (St George's patients only) on 07798 581198.

We are running a remote support group to support people living with sickle cell disease and thalassaemia at this time, with the next session on 24th February 2021 – please contact us on 07798 581198 or SCDpain@stgeorges.nhs.uk for more information.

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Resources and further information

Films/webinars

- The Emergency Conversation Part 2: Lockdown, Vaccines and the Virus https://www.youtube.com/watch?v=YxbgRpNBLvw

- A recording of a talk by the Caribbean and African health Network, which has many different black doctors talking about their experience of having the vaccine and answering some questions https://www.youtube.com/watch?v=XGFqlbPbuaQ&feature=youtu.be

- Dr Rachel Kesse-Adu (Consultant Haematologist) and Dr Abbie Wickham (Clinical Psychologist) and patients from Guy's & St Thomas' Hospital talking about the vaccine and sickle cell: https://youtu.be/hISzRE42Jlw

- COVID-19 Vaccine with Dr Anna Goodman (Consultant in Infectious Diseases at Guys & St Thomas' Hospital): https://youtu.be/71q3T0fkgK0

Leaflets/webpages

- The Vaccine knowledge project has some clear and helpful information, though not specific to haemoglobinopathies https://vk.ovg.ox.ac.uk/vk/COVID19-FAQs

- NHS information about the COVID vaccines https://www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/coronavirus-vaccine/

- NHS Covid Vaccine- What to expect after Leaflet https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/951769/PHE_COVID-19_vaccination_guide_what_to_expect_after_your_vaccination_English_v2.pdf

- NHS Covid Vaccine leaflet https://www.ulh.nhs.uk/content/uploads/2020/12/PHE-vaccine-leaflet.pdf

Information about the vaccine and pregnancy

- https://www.rcog.org.uk/globalassets/documents/guidelines/2021-01-12-covid-19-vaccine-info-sheet.pdf
- https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy.