

Patient information on COVID-19 in haemoglobinopathy and rare inherited anaemia patients

Since the start of the COVID-19 pandemic, some groups of patients have been classed as 'clinically extremely vulnerable' and advised to 'shield' in order to avoid becoming infected. Many patients and patient support groups would like to know how **frequent** and how **severe** COVID-19 has been for people with inherited anaemias, including:

- Sickle cell disease
- Thalassaemia (transfusion dependent and non-transfusion dependent)
- Diamond Blackfan anaemia
- Congenital dyserythropoietic anaemia
- Congenital sideroblastic anaemia
- Pyruvate kinase deficiency (with and without a spleen)
- Hereditary Spherocytosis (with and without a spleen)
- Other types of rare inherited anaemia

Since March 2020, a national group of doctors and nurses looking after people with inherited anaemias (called the National Haemoglobinopathy Panel) have been meeting via videoconference once a week to discuss how COVID-19 has affected their patients. **This discussion is entirely confidential, with no patient-identifiable details discussed at all.** The group reviews guidance issued by NHS England and advises NHS England and patient support groups about specific COVID-19 risks. Hospitals across the England have sent in **anonymised** data to the group regarding the number of cases of COVID-19 and what happens to people who get it.

How many people with inherited anaemias have had Covid-19?

As of June 25th, 240 people had been reported with proven or suspected COVID-19. Of these, 218 were adults and 22 children. Most had Sickle cell disease, but a small number of thalassemia and rare inherited anaemia patients were also affected.

How many people were admitted to hospital?

About three quarters of patients were admitted to hospital, and the rest managed at home. Just as many women as men were admitted to hospital. Of the patients admitted to hospital, about seven percent (19 people) needed intensive care. Of the 22 children suspected or proven to have COVID-19, none suffered serious complications or required intensive care.

What was the outcome for people admitted to hospital?

The picture is not yet complete, because some people are still being treated for COVID-19. The information is updated regularly. For the moment we can say that:

- the available results show that for every 100 patients infected, 87 (87%) have recovered and 8 (8%) have died
- the people who died were more likely to have other medical problems such as heart disease, cancer, kidney disease, diabetes and high blood pressure
- it is too early to say whether patients with inherited anaemias do any worse than the general population
- children with sickle cell disease, thalassaemia and rare anaemias who do not have other risk factors, do not seem to be at increased risk of having severe disease
- adults with sickle cell disease should still be considered 'clinically extremely vulnerable' and follow government guidance about shielding
- in the case of adults with thalassaemia and rare anaemias, the advice on shielding should be assessed for each person by their doctor
- it is important to note that there have been many people with inherited anaemias who have had few or no symptoms with their COVID-19 infection, and who have fully recovered (213 people)

What do I do if I think that I or my child may have Covid-19?

Please do not stay at home without telling anyone- it is important to contact your medical team and discuss whether or not you should be assessed in hospital.

Isn't coming to hospital dangerous?

There are many people who have been extremely concerned about presenting to hospital, some have delayed at times when they have been very unwell. If someone with these important health conditions is unwell, please seek advice from your specialist team. Hospitals have been re-organised to protect people who come in with non-COVID admissions.

What can I do to stay well?

We recommend that continuing to focus on physical and mental health in all areas is also important eg. taking prescribed medication, improving your diabetes, exercising, or eating healthy foods.

If you have any concerns about you or your child's individual risk please discuss it with your specialist team.