



Haemoglobinopathy HCCs advice on recovery COVID-19 26.06.2020

# Advice to clinicians on planning for recovery from COVID-19

This information has been produced following virtual meetings with representatives from the Haemoglobinopathy Co-ordinating Centres (HCCs) for Haemoglobin Disorders, the Clinical Reference Group for Haemoglobin Disorders, the National Haemoglobinopathy Panel, NHS Screening Committee and NHSBT as well as national experts on Sickle Cell Disease, Thalassaemia and Rare Anaemias and patient groups.

The topics covered include:

1. Updated shielding advice
2. General advice
3. Inpatient care
4. Day care management
5. Outpatient care and care of long term complications
6. Hydroxycarbamide
7. Annual Reviews
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19. Management of patients who have had a Haematopoietic Stem Cell Transplantation /Gene therapy

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## *1 Updated shielding advice*

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The shielding advice was updated on June 22<sup>nd</sup> 2020. Further advice is available on the GOV.UK website <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting->

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[extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19](#)

This letter, from the Chief Medical Officer & NHS Medical Director, outlines the latest Government advice for people considered clinically extremely vulnerable to COVID19, the epidemiological basis on which this advice has been developed and plans for a more individualised approach to risk stratification in the future. It contains useful FAQs

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/06/C0624-shielding-letter-to-nhs.pdf>

This guidance has always been, and will remain, advisory.

These changes will be implemented in two stages over the next few weeks.

**From 6 July** shielding advice will be relaxed so that the 'clinically extremely vulnerable' may:

- Meet in a group of up to 6 people
- No longer observe social distancing with members of their household
- Form a 'support bubble' with one other household in line with wider governmental advice

From 1 August the guidance will be further relaxed and shielding will be paused:

- People can go to work, if they cannot work from home, as long as the business is COVID-safe
- Children who are clinically extremely vulnerable can return to their education settings if they are eligible. They should practise frequent hand washing and social distancing
- People can go outside to buy food and for exercise but should maintain social distancing
- People should remain cautious as they are still at risk of severe illness if they catch Coronavirus, so the advice is to stay at home where possible and if they do go out to follow strict social distancing.

Further advice for managing children is available here

<https://www.rcpch.ac.uk/resources/covid-19-shielding-guidance-children-young-people>

Some practical considerations are that the food deliveries will continue until the end of July. Supermarkets will continue to provide priority supermarket slots and NHS Volunteers will continue to provide help.

The shielding lists will be maintained and a risk assessment tool is being developed by the government in case it is necessary for some patients to return to shielding later in the year.

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### *2 General advice*

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Patients should be advised to:

- 1) Follow national PHE advice on staying alert and staying safe  
<https://www.gov.uk/government/publications/staying-alert-and-safe-social-distancing/staying-alert-and-safe-social-distancing#clinically-vulnerable-people>
- 2) Continue to stay at home except for essential trips and should practice strict social distancing at all times

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- 3) Continue to work from home as much as possible. For those employees who cannot work from home, they should only return to work if it is COVID-safe. For patients for whom neither of those options is possible, we recommend working with their local haematology team to find an appropriate resolution with their employers
- 4) Continue their routine clinical care through telehealth or telephone appointments where possible
- 5) Attend hospital for investigations and treatment where needed
- 6) Ensure they attend hospital or contact local triage service with fever
- 7) Contact their haematology team for further queries

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### *3 Inpatient care*

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Haemoglobinopathy services may need to review their way of working in view of the COVID-19 pandemic. This may include minimising patients contact and utilising different ways of discussing care with patients and families e.g. provision of nursing or psychology support on the phone or virtually whilst inpatients.

Advice on the management of acute complications and of patients with suspected or proven COVID-19 infection are given in the previous document:

<https://b-s-h.org.uk/media/18153/hbp-hccs-response-to-covid-v-6-21st-march-2020.pdf>

**Management of acute pain:** Patients should be encouraged to treat pain as usual but to contact their clinical team if they have a fever or respiratory symptoms. Patients should be encouraged to access an acute pain service/day unit if this is available.

**Red flag symptoms:** Patients should be encouraged to attend the Emergency Department (A+E) or call 999 if any of the following occur:

All patients:

- Respiratory distress (new shortness of breath or increased breathlessness compared to baseline particularly at rest or on minimal exertion) +/- chest pain
- Persistent fever >38°

Patients with SCD:

- Uncontrolled pain >7/10 despite usual home analgesia
- Severe headache, confusion or neurological changes

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Clinicians should be aware that patients with SCD and Thalassaemia may present with these symptoms in the absence of COVID-19 and usual pathways for investigation and management should be followed.

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### *4 Day care management*

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Day care units have an important ongoing role in the management of non-COVID related complications including acute pain management and provision of transfusion therapy.

If units have access to day care areas which are COVID-negative areas, these should be utilised to provide acute pain management day services.

Units providing transfusion therapy will need to review their services to provide treatment to COVID positive or suspected cases to reduce the risk of transmission to other patients.

Patients receiving long term transfusion should be offered face to face review whilst attending for their transfusions, rather than being offered separate outpatient appointments.

Further advice on blood transfusion is given in the document:

<https://b-s-h.org.uk/media/18230/supporting-the-transfusion-needs-of-patients-with-inherited-red-cell-disorders-during-the-covid-19-pandemic-in-england-v15420.pdf>

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### *5 Outpatient care and care of long term complications*

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Initial advice was to provide virtual consultations and postpone non-essential investigations. As the COVID-19 pandemic continues we will need to re-introduce some face to face contact and to re-introduce routine screening tests. The risk of postponing screening investigations will need to be balanced against the risk of attending hospital appointments.

In particular it is essential that patients are encouraged to attend for investigations such as transcranial Doppler screening and MRI monitoring of iron overload.

Teams should set up/continue to provide a generic phone advice and generic email for patient queries, which will be staffed by clinical staff.

Teams should consider setting up email lists (with appropriate GDPR) to aid rapid patient communication.

Teams should consider setting up mechanisms of communication between nearby trusts/networks so that they can provide clinical advice in the event of staff sickness (e.g. WhatsApp or email groups).

Haemoglobinopathy teams should consider how patients can access specialist acute and community CNS and psychology support in this climate; strategies may include reviewing clinic list remotely as an MDT, agreeing joint MDT consultations in specific individuals and ensuring that other issues are fed back from the outpatient clinic to the CNS and psychology teams.

Clinicians should aim to provide virtual consultations where possible. This could be either telephone or video consults.

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Offsite phlebotomy services should be utilised if possible. This may include drive-through services.

Home delivery pharmacy services should be utilised if possible.

Patients should not attend outpatients or day unit if they have temperature/respiratory/coryzal symptoms.

Patients should avoid using public transport if possible, or if using avoid busy times, wear a mask and strictly social distance.

Services should consider reviewing patient/carer and staff feedback on telephone and video consult processes.

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### *6 Hydroxycarbamide*

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There is no evidence that being on hydroxycarbamide will increase risk of COVID-19 as long as there is no related myelosuppression. Initial advice at the onset of the pandemic was that patients should be urged to remain on their usual hydroxycarbamide dosages to maintain good health and avoid hospital admissions. It was advised to avoid routinely starting or dose escalating hydroxycarbamide to reduce need for repeated phlebotomy and hospital visits until the situation has stabilised. For stable patients it is reasonable to extend the interval between blood monitoring (maximum interval 4-6 monthly).

As lockdown restrictions are relaxed this advice will need to be updated and will need to consider:

- Timing to re-introduce dose escalation and starting new patients on hydroxycarbamide where indicated; these will need a robust system for monitoring blood tests in place and will vary depending on local provision
- Utilization of off-site phlebotomy and pharmacy services
- Moving hydroxycarbamide monitoring to a virtual service where possible (i.e. off-site phlebotomy followed by phone calls).
- Further discussion of sperm cryopreservation is needed if this is not being provided currently, as it is re-introduced
- Patients should have a face to face review at least annually to complete annual review investigations

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### *7 Annual reviews*

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Initial advice was that these should be done virtually or delayed. These will need to be re-started as the situation stabilises. It is likely that social distancing advice may continue into 2021 and we should continue routine care during this time.

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We should aim to see patient as a face to face appointment at least once per year if feasible. This is to enable physical examination, routine observations and blood and urine testing. A plan for restarting face to face annual review may need to wait until further national advice is available. Other consultations can be done virtually.

If annual reviews are going to be done virtually it may be useful to for a notes review prior to annual review to ensure that all investigations have been performed e.g. off-site phlebotomy, TCDs.

For patients on a regular transfusion regimen, annual review appointments could be organised to coincide with a transfusion visit to reduce multiple attendances.

Routine ophthalmology, echocardiography and imaging may be being provided, but a list of outstanding investigations should be kept in the patients notes so these can be re-ordered as needed. Urgent investigations should be requested as appropriate.

There are financial implications for centres in moving to virtual or tele-conferencing. These new technologies are unlikely to reduce the time spent by clinicians and the need for alternative funding should be discussed with local management teams and NHSE.

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### *8 Trans-cranial Doppler (TCD) screening*

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Initial advice was that these should be postponed, except for essential groups. Patients with HbSS and SB<sup>o</sup>Thal needing their first TCD and patients with previous conditional or first abnormal TCD should be prioritised. TCDs in younger patients (especially those <10 years) should also be prioritised unless they are already on transfusion and stable, in which case their scans can be delayed. As social distancing is extended, clinicians should discuss with their vascular scientists about how this service can be provided for all patients. The use of public transportation should be minimised. Clinicians should consider changing patients who are currently on transfusion for primary stroke prevention to hydroxycarbamide as per the TWITCH protocol.

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### *9 Multi-specialist clinics*

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Many services provide multi-specialist clinics for patients, where a sickle specialist sees the patient together with an additional specialist (e.g. neurology, obstetrics, orthopaedics). Patients who are awaiting appointments in these clinics should be reviewed. Decisions about whether to continue will depend on clinician availability and feasibility for virtual clinics e.g. some clinics (neurology) may work well as virtual clinics or utilizing tele-medicine, whereas others may need to be postponed until social isolation has been relaxed.

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### *10 Off-site clinics*

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Many HCCs and SHTs provide off-site clinics. These will need to be reviewed on a clinic by clinic basis but it may be possible to use telemedicine platforms to run these. If these clinics provide the TCD screening, they may need to continue.

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### *11 Management of iron overload*

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Routine monitoring for iron overload and for the effects of iron chelation should be continued but this could be done virtually and on an extended schedule. For patients on regular transfusions, outpatient review could be co-ordinated to take place at the same time as transfusion. Clinicians should consider if routine MRI monitoring for iron overload can be postponed (e.g. in stable patients, on long term chelation).

If a fever develops, all chelation agents should be stopped and the clinical team immediately contacted for advice.

More detailed advice is available for patients with cardiac iron overload:

<https://b-s-h.org.uk/media/18229/iron-chelation-therapy-covid-version-2-150420.pdf>

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### *12 Multi-disciplinary meetings*

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It is likely that these have been postponed in the initial phase of the COVID-19 pandemic. Teams should aim to reinstate these processes as virtual meetings.

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### *13 Transition clinics*

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Transition clinics and transition of patients from paediatric to adult teams has been interrupted in the initial phase of the COVID-19 pandemic. Teams should consider how they can re-introduce this process over the next few months. It may be sensible to keep complex patients, including those on regular transfusion therapy, within the paediatric services until the situation stabilises. Transition clinics could be reinstated as virtual clinics.

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### *14 Psychology services*

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This will be a very challenging time for our patients and they may need additional psychology appointments. Many of these appointments could be offered as virtual appointments. Video applications could be used to offer group meetings

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### *15 Community services*

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Community services are likely to be hard pressed at the present and their role in provision of antenatal and neonatal screening services will need to be prioritised. Community services should consider how they provide community support and if some of this can be done virtually. They may be able to assist with community phlebotomy.

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### *16 Education*

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HCC and SHT provision of education has been halted during the initial phase of COVID-19 management. As the situation stabilises they should investigate the possibility of provision of virtual educational events and online resources.

Teams will need to consider ongoing education of junior staff. As the numbers of staff on ward rounds is reduced and clinics are increasingly run virtually there will be reduced opportunity for learning and education for junior staff. Medical trainees are likely to be re-deployed into acute medical provision and this will impact on their training objectives. This will need to be considered by Training Programme Directors.

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### *17 Research*

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The majority of interventional research trials have stopped recruiting during the initial phase of COVID-19 management. With respect to previously ongoing trials these are beginning to re-open but this will depend on local trust and national advice and on the clinical judgement of the balance of risk and benefits of continued monitoring and/or treatment with a given trial on a case by case basis.

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### *18 Additional advice on management of thalassaemia and rare anaemias*

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For those patients on long term transfusion therapy, outpatient review and annual review could be planned to coincide with visits for transfusion.

Additional guidance is available on the management of patients with cardiac iron overload  
<https://b-s-h.org.uk/media/18229/iron-chelation-therapy-covid-version-2-150420.pdf>

Additional advice has been produced on the management of patients with Diamond Blackfan Anaemia.





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<https://b-s-h.org.uk/media/18174/nhp-covid-19-dbaversion-224032020.pdf>

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### *19 Management of patients who have had a Haematopoietic Stem Cell Transplant/Gene therapy*

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Transplantation and gene therapy for non-urgent non-malignant conditions (SCD and thalassaemia) will be halted until the situation stabilizes. Pre-transplant workup investigations should be put on hold.

Patients with thalassaemia/rare red cell anaemias who have had a Haematopoietic Stem Cell Transplant or Gene Therapy/Editing within the last twelve months are at increased risk of complications from COVID-19 infection and should be advised to shield. Patients with sickle cell disease who have had Haematopoietic Stem Cell Transplant or Gene Therapy/Editing or any patient who has had a Haematopoietic Stem Cell Transplant and is still on immunosuppression are advised to shield regardless of the time that has elapsed since the procedure.

Haemoglobinopathy Co-ordinating Centres

26th June 2020