MANAGEMENT AND FOLLOW UP REQUIREMENTS OF HAEMOPHILIA CARRIERS WITHIN HAEMOPHILIA SERVICE

Trust Reference: C21/2024

1. Introduction and Who Guideline applies to

This guideline provides guidance for nursing, medical and support staff working within the Haemophilia Service at University Hospitals Leicester on the different pathways in place for the follow up of female carriers of Haemophilia A and B.

2. Guideline Standards and Procedures

The following flow charts are to be used:

- Pathway for Registering new/potential Haemophilia A and B Carriers
- Haemophilia A and B Carrier pathway for a female under 16 years of age and under.
- Haemophilia A and B Carrier pathway for a female of 16 years and over.

3. Education and Training

All HCP's working within the Haemophilia Service will be appropriately trained in the genetic inheritance of bleeding disorders and be able to explain this to the patient population.

3. Monitoring Compliance

NONE

| What will be measured to monitor compliance | How will compliance be monitored | Monitoring Lead | Frequency | Reporting arrangements |
|---|----------------------------------|--------------------|-----------|------------------------|
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5. Supporting References

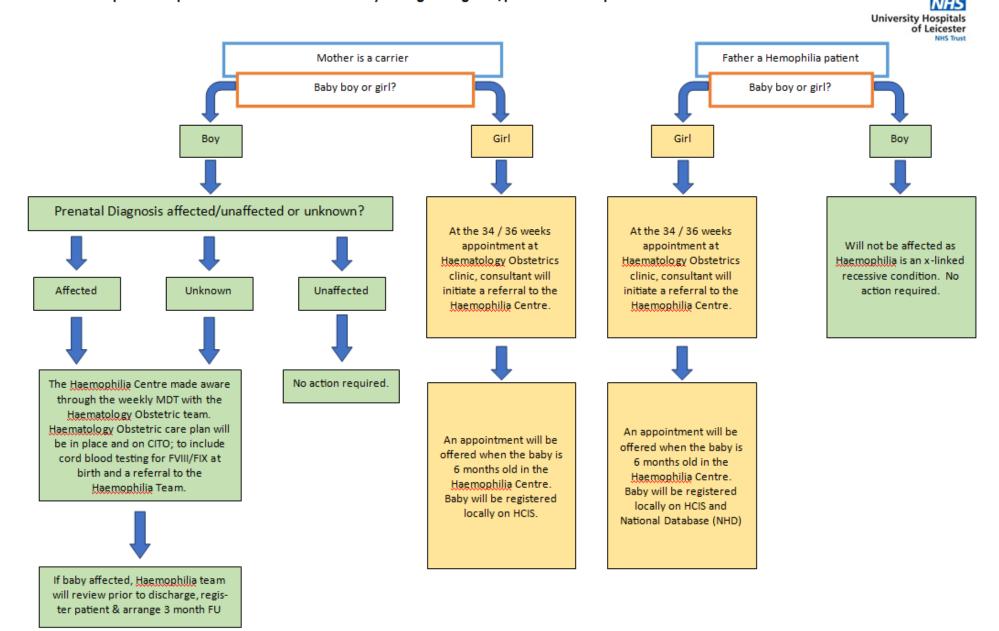
NONE

6. Key Words

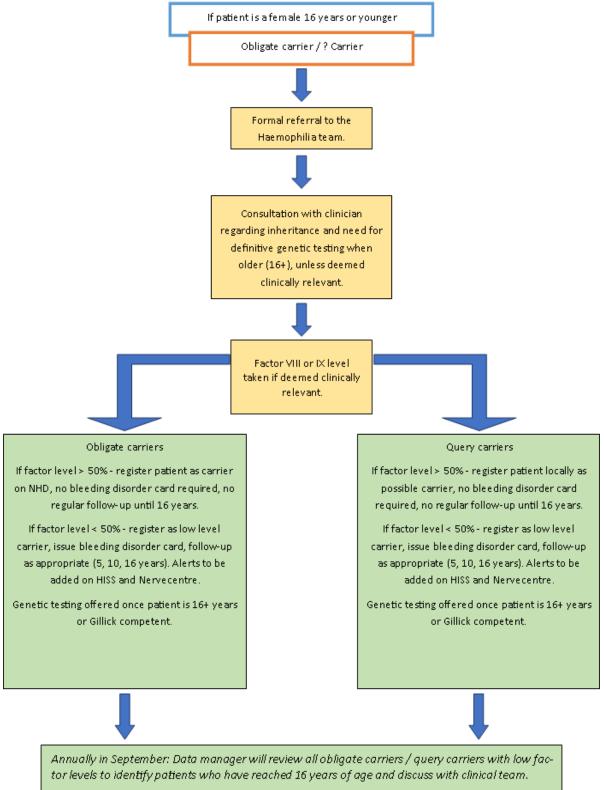
Haemophilia / Carriers / Pathways

| CONTACT AND REVIEW DETAILS | | | |
|---|----------------|--|--|
| Guideline Lead: Dr S.Salta –Haemophilia Centre Director / Sarah O'Connell Haemophilia Lead Nurse | Executive Lead | | |
| Details of Changes made during review: | | | |
| New guidline | | | |

Leicester Haemophilia Comprehensive Care Centre - Pathway for registering new/potential haemophilia carriers



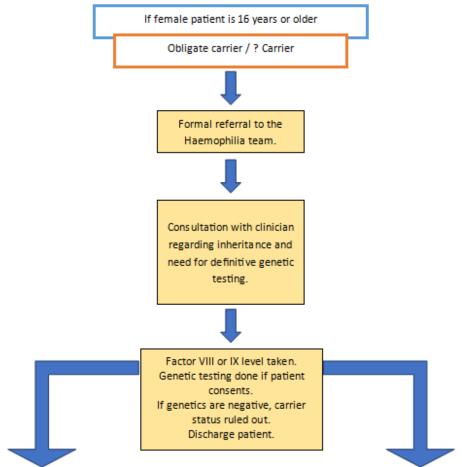




A letter will be sent to patients inviting them to attend a clinic to discuss genetic testing, and if patient wishes to proceed.

Leicester Haemophilia Comprehensive Care Centre Haemophilia Carrier pathway for over 16 years of age





If factor level > 50% - register patient as carrier, no bleeding disorder card required, discharge from regular follow-up.

Full discussion about inheritance of Haemophilia, advice regarding pregnancy counselling if appropriate, and implication for future children.

If pregnancy counselling needed, refer to Haematology Obstetrics. If factor level < 50% - register as low level carrier, issue bleeding disorder card. Patient will have follow-up as appropriate. Alerts to be added on HISS and Nervecentre.

Full discussion about inheritance of Haemophilia, advice regarding pregnancy counselling if appropriate, and implication for future children.

If pregnancy counselling needed, refer to Haematology Obstetrics.