

Ref: FOI/GS/ID 5605

Please reply to:
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Trust Management
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19 March 2020

Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Genetic Haemochromatosis.

You asked:

- a. For the period 1st January 2018 to 31st December 2018 (or the most recent 12 month period available), the number of patients diagnosed with genetic haemochromatosis (GH) under your care.*
- b. For the period 1st January 2018 to 31st December 2018 (or the most recent 12 month period available), the average time in days from first referral from primary care to the patient's first appointment within your trust.*
- c. A copy of the protocol and/or patient pathway applicable to the care of people with genetic haemochromatosis.*
- d. The date that your protocol/patient pathway for genetic haemochromatosis was last reviewed or revised.*
- e. A copy of your clinical protocol(s) for therapeutic venesection.*
- f. The date that your protocol(s) for therapeutic venesection were last reviewed or revised.*

Trust response:

a.

As a trust, we do not collect diagnosis data for outpatients on our patient record system. Therefore, we can only provide data on patients who had had an In Patient admission and have the diagnosis code of E831 (Genetic Haemochromatosis GH), recorded. This does not mean that their admission was related to that condition. There are 158 patients who were referred between January and December 2019 and have a primary diagnosis of GH.

b. Unable to answer this question.

c. d. e & f.

Please see the following documents. The Trust acknowledges that whilst Trust policies have a recommended review period of 4 years, or sooner if there are

changes in practice, new equipment, law national and local standards that would require an urgent review of the policy/procedure.

However, a review date is not an expiry date and a policy and procedure does not become automatically unfit for purpose solely because its review date has passed.

MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST

Policy and Procedure for a Nurse Led Venesection service

| | |
|------------------------------------|--|
| Requested/ Required by: | <i>Haematology and Cancer Services</i> |
| Main author: | Haemato-oncology Clinical Nurse Specialist |
| Other contributors: | Lead Cancer Nurse |
| Document lead: | Lead Consultant Haematologist |
| Supersedes: | New Policy |
| Approved by: | Haematology Management Team |
| Ratified by: | <i>List committee [or Board] and date where ratification was noted</i> |
| Review date: | <i>2019</i> |

Document History

| | |
|---|---|
| Requirement for document: | To support appropriately trained registered general nurses ensuring they have they have the competencies in performing bone marrow procedures on haematology patients, |
| Cross References / Associated Documents: | <ul style="list-style-type: none"> • MTW “Equality and Human Rights Policy, March 2008” • Management & Prevention of Sharps/Splash Injuries Policy and Procedure 2014 • 12 Key points on consent: The law in England • Development and Production of Written Patient Information Policy and Procedure 2015 • Hand Hygiene Policy and Procedure 2014 • Infection Control Policy and Procedure 2014 • Medicines Policy and Procedure 2015 • Policy and Procedure for Blood Sample Collection 2015 • MTW “Template for Trust Policy / Procedural Documents, April 2009” • MTW formulary available on http://www.mtw.nhs.uk/formulary/default.asp |

| Version Control: | | |
|-------------------------|--|--------------|
| Issue: | Description of changes: | Date: |
| 1 | None – 1 st iteration of the policy | |
| | | |

Policy Statement for

Policy and Procedure for a Nurse Led Venesection service

The purpose of this policy is to ensure that registered nurses and Assistant Practitioners carrying out venesections within within the Maidstone and Tunbridge Wells NHS Trust (MTW) have received appropriate training to carry out this procedure. They will have been assessed as competent before be allowed to become independent practitioners

Patients under the care of Maidstone and Tunbridge Wells NHS Trust (MTW) should have the opportunity to make informed decisions about their care and treatment, in partnership with their health care professionals and the Trust will provide a service which is consistently promoting safe and best Evidence Based Practice.

Policy and Procedure for a Nurse Led Venesection service

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1.0 Introduction

Venesection is a clinical procedure involving the removal of a specified amount of blood by venepuncture, as a treatment for certain haematological disorders. This includes Primary and Secondary Polycythaemia, Haemochromatosis, Transfusion Associated Iron Overload and Porphyria Cutanea Tarda.

2.0 Scope

This policy applies to inpatients and outpatients, aged over 18, under the care of a Consultant Haematologist at Maidstone and Tunbridge Wells Trust, who require therapeutic venesection.

This procedure may be carried out by a registered nurse or an Assistant Practitioner who has undertaken a programme of training in this procedure and been assessed as competent. (Appendix four)

The following patients are not suitable for venesection by a nurse and therefore should not be referred by the doctor.

- Any patient requiring local lidocaine anaesthetic.
- A child under the age of 18.
- Any patient who declines nurse led services.
- Any patient requiring central vascular access for Large Volume Venesection
- Any patient deemed not suitable by a Consultant.

3.0 Definitions

Venesection: Venesection involves the removal of a specified amount of blood by venepuncture. Venesections are regularly carried out as a treatment for several haematological disorders, including Polycythaemia and Haemochromatosis. More commonly it is a procedure used for blood donation.

Isovolumetric Venesection The removal of a specified amount of blood by venepuncture whilst receiving intravenous fluid replacement. This can be used in patients with cardiac problems or a history of fainting.

Haemochromatosis: Haemochromatosis or genetic haemochromatosis (GH) is a genetic disorder causing the body to absorb an excessive amount of iron from the diet: the iron is then deposited in various organs, mainly the liver, but also the pancreas, heart, endocrine glands, and joints

Polycythaemia: The concentration of red blood cells in the blood is higher than normal. This may be because there are actually more red blood cells than usual, or because the amount of liquid (plasma) is less than normal. There are two types which are primary Polycythaemia and secondary polycythaemia.

Primary Polycythaemia or polycythaemia rubra vera or (PRV)

This condition occurs if the bone marrow produces too many red blood cells. Over 90 per cent of those affected have a

mutation of a gene called the JAK2 gene, which does not seem to cause PRV directly but predisposes towards its development. PRV is rare, and predominantly affects those aged 60 and older.

Secondary Polycythaemia: Once again the bone marrow makes too many red blood cells, but this time it's in response to a lack of

oxygen. This may be due to a lung condition such as chronic obstructive pulmonary disease, or COPD) or when someone lives at high altitude.

Porphyria Cutanea Tarda (PCT) This is a rare metabolic disorder, which is caused by a deficiency of an enzyme called Uroporphyrinogen Decarboxylase.. Venesection can reduce the level of porphyrins and thus alleviate some of the symptoms.

4.0 Duties

Consultant Haematologists

- The Consultant will retain overall responsibility for the patient referred to the nurse.
- A Consultant Haematologist or Haematology Registrar must request the procedure using an electronic action sheet (EAS) ensuring all fields are filled in including parameters of when not to venesect and frequency of blood tests.
- Written consent must be obtained prior to the procedure (Consent form 3) to include the benefits and the risks of the procedure.
- It is the responsibility of the ordering doctor to prescribe local anaesthetic

Trained Nurses/ Assistant Practitioners performing Venesections

- To complete a period of training under the supervision of a Practitioner already competent in venesections.
- The procedure must be documented on KOMS (Kent Oncology Management System) or the patient's notes if available.
- Inform the HAEM CNS and/or Haematology Medical Team if patients' blood falls below the required therapeutic limits, resulting in cancellation of a treatment
- Ensure that all bloods for patients scheduled to have venesections are checked a day before treatment ideally, to ensure that patients, where possible, are given plenty of warning if treatment needs to be cancelled.
- To assess the patient on the day so that procedure can go ahead. If patient is unwell, venesection should be postponed after discussion with a Haematology CNS/Doctor.

- Ensure that any bloods taken post procedure are followed up and recorded on KOMS, and any concerns reported to the Haematology Medical or CNS Team.
- To ensure competencies are up to date

The Haematology Clinical Nurse Specialist (CNS)

- Review all incidents related to venesections and in collaboration with the Haematologists and Lead Cancer Nurse.
- Ensure that all policies and procedures are kept up to date and that any changes to this policy and procedure are communicated to all staff involved in venesections.
- Carry out Audits annually to review service.
- Carry out lower arm venesections for those with difficult venous access- consider the Needle and Syringe Technique

5.0 Training / Competency Requirements

This procedure can be performed by a Registered Nurse/ Assistant Practitioner who has:

- Demonstrate understanding of the knowledge and skills necessary to perform therapeutic venesection
- Undertaken training and supervision provided by a competent Practitioner already performing venesection
- Be supervised on at least 5 occasions by senior medical or nursing staff experienced in the procedure and have a countersigned statement of competence. (Appendix four)
- Demonstrate competency in performing the procedure.
- Maintain clear and accurate records of the procedure

The nurse must be performing this procedure regularly with the requirement of one procedure per month.

6.0 Procedure

Equipment

- Antiseptic skin cleansing agent/Chlraprep
- Sterile pack
- Venesection collection pack
- Disposable tourniquet
- Specimen bottles and transportation bags.
- Bandage and tape
- Sharps bin/pactosave

Venesection Procedure

- Confirm identity of patient and obtain verbal consent
- Review patient's blood results and medical instructions regarding procedure according to the parameters set on the EAS
- Fully explain the procedure to the patient and answer any questions relating to the procedure or its outcome.
- Ensure patient comfortable on trolley or chair at approximately 45O angle, particularly for first venesection. Support the arm by using an arm rest during the procedure
- Gather equipment on a cleaned tray or trolley and take to patient.

Wash and dry hands using 7 step technique.

- If for IV fluid replacement, establish assess and commence prescribed infusion
- Apply tourniquet and find appropriate vein for use. Clean with Chloraprep.
- Insert needle into the vein, support at correct angle with gauze and secure with tape.
- Stay with the patient during the procedure – check regularly that the blood continues to flow
- If blood sample is to be taken for Hb or Ferritin levels, sample must be taken from the reservoir on the venesection pack.
- At the end of the procedure remove the BP cuff / disposable tourniquet. Clamp the tubing and remove the needle. Pull the needle into the safety guard on the venesection pack and place in the burn bin. Apply sufficient local pressure to the insertion site until bleeding has ceased.
- Provide patient with oral fluids and encourage patient to rest to recover.
- Record all necessary information on KOMS or in the patient's notes.
- Ensure all specimens are correctly labelled and sent to the laboratory with the necessary form.

7.0 Monitoring and Audit

- Any incidents relating to venesections must be reported to the Haematology CNS Team, who will all incidents relating to the procedure and in collaboration with both the Haematology Consultants and Lead Cancer Nurse.
- A yearly audit of the service will be performed using a patient satisfaction survey.

APPENDIX ONE

Process Requirements

*The following three sections are **compulsory** and should always be located in Appendix One:*

1.0 Implementation and Awareness

The policy will be disseminated to all members of the Haematology Team and once ratified will be brought to the attention of the team at the Haematology Management meetings..

Email administrator will notify staff that policy has been approved.

The policy will be held on the Datix Policy System.

2.0 Review

Policy and Procedure for a Nurse Led Venesection Service
Written by: Haemato-oncology Nurse Specialist
Review date: Insert date for next review
Document Issue No.1

The policy shall be updated every three years unless new evidence suggesting a change of practice is deemed necessary.

3.0 Archiving

The Trust intranet retains all superseded files in an archive directory in order to maintain document history.

APPENDIX TWO

CONSULTATION ON: Policy and Procedure for a Nurse Led Venesection service

Consultation process – Use this form to ensure your consultation has been adequate for the purpose.

Please return comments to: Insert name of author / email address

By date: Insert date (all documents must undergo a minimum of two weeks consultation)

| Name: Name: <i>List key staff appropriate for the document under consultation. Select from the following:</i> | Date sent | Date reply received | Modification suggested? Y/N | Modification made? Y/N |
|--|-----------|---------------------|--------------------------------|---------------------------|
| Local Counter Fraud Specialist | | | | |
| | | | | |
| | | | | |
| The author must identify the staff that need to be included in the consultation. There is no fixed list, except for the compulsory inclusion of the staff above, and will depend on the | | | | |

| | | | | |
|---|--|--|--|--|
| document under consultation | | | | |
| | | | | |
| | | | | |
| | | | | |
| As an example you should consider the following | | | | |
| | | | | |
| Relevant Directors/ DD/ ADO/ ADNS etc. | | | | |
| Relevant GM's/ CD's/ Matrons etc. | | | | |
| Relevant risk leads/ governance leads etc. | | | | |
| Infection Control representative | | | | |
| Estates and Facilities representatives | | | | |
| Trust Competent Officers and advisors etc. | | | | |
| Clinical governance assistant | | | | |
| Staff Side chair | | | | |
| Members of key committees | | | | |
| Staff Side chair | | | | |
| Staff required to implement the policy | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| The role of those staff being consulted upon as above is to ensure that they have shared the policy for comments with all staff within their sphere of responsibility who would be able to contribute to the development of the policy. | | | | |

APPENDIX THREE

Equality Impact Assessment

In line with race, disability and gender equalities legislation, public bodies like MTW are required to assess and consult on how their policies and practices affect different groups, and to monitor any possible negative impact on equality.

The completion of the following Equality Impact Assessment grid is therefore mandatory and should be undertaken as part of the policy development and approval process. Please consult the Equality and Human Rights Policy on the Trust intranet, for details on how to complete the grid.

| | |
|--|---|
| Title of Policy or Practice | Policy and Procedure for a Nurse Led Venesection service |
| What are the aims of the policy or practice? | To provide a service which is consistently promoting safe and best evidence based practice within the Trust. |
| Identify the data and research used to assist the analysis and assessment | |
| Analyse and assess the likely impact on equality or potential discrimination with each of the following groups. | Is there an adverse impact or potential discrimination (yes/no). If yes give details. |

| | |
|--|---|
| Males or Females | N |
| People of different ages | Y Over 18s only |
| People of different ethnic groups | N |
| People of different religious beliefs | N |
| People who do not speak english as a first language | N |
| People who have a physical disability | N |
| People who have a mental disability | N |
| Women who are pregnant or on maternity leave | PREGNANT LADIES WILL NOT BE VENESECTED |
| Single parent families | N |
| People with different sexual orientations | N |
| People with different work patterns (part time, full time, job share, short term contractors, employed, unemployed) | N |
| People in deprived areas and people from different socio-economic groups | N |
| Asylum seekers and refugees | N |
| Prisoners and people confined to closed institutions, community offenders | N |
| Carers | N |
| If you identified potential discrimination is it minimal and justifiable and therefore does not require a stage 2 assessment? | Y |
| When will you monitor and review your EqIA? | EVERY 3 YEARS AT POLICY REVIEW |
| Where do you plan to publish the results of your Equality Impact Assessment? | WITHIN THE POLICY |

APPENDIX FOUR Competencies for venesection

The purpose of these competencies is to clarify the knowledge and skills expected of Practitioners, to ensure safe practice in Venesection.

The self-rating scale is to be used by the individual Practitioner for self assessment of present performance during supervised practice, and to help identify learning needs. Their line manager or other experienced practitioner must then assess these skills and sign to confirm competency.

The Practitioner will be expected to demonstrate the following competencies when performing venesection.

Key For Self Assessment

- 1 No knowledge/experience
- 2 Some knowledge/experience

- 3 Competent
- 4 Competent with some experience
- 5 Competent, experienced and able to teach others

Assessment of competence for Venesection

I confirm that I have self-assessed as competent to practice venesection as below:

Practitioner Name:

Practitioner Qualification:

Practitioner Signature: Date:

I confirm that I have assessed the named practitioner above as competent to perform the above skill.

Name & Title:

Signature: **Date:**

| Knowledge and skills for Venesection | | Self Assessment | | | Formal Assessment | |
|--------------------------------------|---|-----------------|------|-------------------|-------------------|-------------------|
| | | Score | Tick | Date and Comments | Signature | Date and Comments |
| 1 | Describe the anatomy and physiology of the veins of the upper limbs including the differences between veins and arteries | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 2 | Identify all potential risks or complications associated with venesection. State action to minimise these and what action to take if they should occur. | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 3 | Demonstrate knowledge of following in relation to venesection: <ul style="list-style-type: none"> • Range of blood tests required • Ability to select and prepare equipment used • Safe and correct disposal of equipment | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 4 | Demonstrate the ability to identify to identify a suitable vein for a safe venesection procedure | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| | | 1 | | | | |

| | | | | | | |
|---|---|---|--|--|--|--|
| 5 | Demonstrate correct technique in skin cleansing, and safe needle insertion. | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 6 | Understand the need for obtaining correct volume of blood for procedure | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 7 | Applies appropriate dressing over venesection site following procedure | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 8 | Demonstrates the correct labelling of samples and the relevant forms | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |
| 9 | Records information correctly in patient documentation including reporting any adverse reactions. | 1 | | | | |
| | | 2 | | | | |
| | | 3 | | | | |
| | | 4 | | | | |
| | | 5 | | | | |

Guidelines for Investigation of Elevated Ferritin and Transferrin Saturation and testing for Hereditary Haemochromatosis (HH)

Consider testing for Hereditary Haemochromatosis in patients with:

- Raised serum ferritin (see box 1)
- History of HH in first degree relative
- Unexplained abnormal liver function
- Clinical features which raise clinician's suspicion of HH
 - Arthralgia / arthritis
 - Skin pigmentation
 - Diabetes, amenorrhoea, secondary hypogonadism, loss of libido, impotence
 - Congestive cardiac failure



If serum ferritin elevated (>300mcg/L men, >200mcg/L women) consider

Inflammation
Liver disease
Malignancy

Genetic iron overload: Hereditary Haemochromatosis (HH)



If ferritin is elevated then check
fasting transferrin saturation



Fasting transferrin
saturation >45%
or history of HH in first
degree relative
(even if ferritin and fasting TS
are normal)



HFE genetic testing
[http://hospital.blood.co.uk/
diagnostic-services/hi/hi-
test-request-forms/](http://hospital.blood.co.uk/diagnostic-services/hi/hi-test-request-forms/)

Negative

Consider non-HFE
mutations



Fasting transferrin
saturation <45%



No genetic testing
for HH required

Positive

Refer to MTW
HH service

Non HFE-mutations

These are rare.

May be considered if ferritin and fasting TS raised in absence of HFE mutations e.g. hemojuvelin (HJV), transferrin receptor-2 (TfR2), ferroportin (SLC40A1), hepcidin (HAMP), African iron overload.

These should be discussed with Consultant Haematologist.

**Guidelines for managing patients diagnosed with Genetic Haemochromatosis
(C282Y homozygosity, C282Y/H63D compound heterozygosity, H63D/H63D homozygosity)**

At diagnosis all patients should have:

1. Assessment of iron status with fasting ferritin and fasting transferrin saturation (TS)
2. Endocrine assessment with fasting glucose, TFTs and serum testosterone
3. Liver assessment:
 - a. Liver function tests, including γ GT and α -fetoprotein, hepatitis B and C and autoimmune profile
 - b. Liver ultrasound
4. Cardiac assessment with ECG and transthoracic echocardiogram



Refer to Consultant Gastroenterologist if:

- Ferritin >1000
- Abnormal LFTs on more than one occasion
- Viral or autoimmune hepatitis
- Any abnormality on liver USS (including fatty liver)



Start venesection

1. Refer to MTW venesection policy
2. **Commence venesection if ferritin is above 200 in women or 300 in men.** If ferritin is below these levels then check ferritin annually and commence venesections when threshold reached.
3. Aim to get ferritin below 50. This may take 6-12 months (up to 30 venesections)



Maintenance venesection

Aim for ferritin 50-100 and TS < 50%
Average is 3-4 venesections per year

Annual review

Check venous access
Check alcohol consumption, LFTs and α -fetoprotein
Ask specifically for complications of iron overload
Diabetes
Arthritis
Erectile dysfunction

Screening of family members:

First degree relatives should have fasting ferritin and transferrin saturation and HFE mutation screening
If liver disease present then HFE mutations are cofactors for liver disease and patients should be referred to gastroenterologist

