Guideline for The Nurse-Led clinical follow-up of Patients with Chronic Myeloid Leukaemia

University Hospitals of Leicester NHS
NHS Trust

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Introduction

The Haematology Services for patients at the University Hospitals of Leicester NHS Trust are based at The Leicester Royal Infirmary Site and housed within the Osbourne Building.

This is a large city centre Hospital with good public transport links but car parking can be challenging for patients. The rationale for a Nurse-led clinic is to allocate a dedicated time slot for the patient to be seen by a Clinical Nurse Specialist (CNS) with in-depth knowledge of Leukaemia to avoid waiting in a consultant –led clinic. This may reduce pressure on the Haematology Service, allowing for patients to be reviewed by an expert CNS. The clinic will also offer virtual consultations by telephone or by electronic patient reported outcome measures (ePROMs) via accurx, which will reduce the need for patients to attend the hospital, benefitting the patients so that they have no travel to hospital or car parking / transport costs.

The purpose of this guideline is to set out the terms under which the Leukaemia Myelodysplasia Clinical Nurse Specialist (CNS) will review Chronic Myeloid Leukaemia (CML) patients in the clinic on Thursday afternoons between 12:30 and 1:30 for patients being seen face to face, and between 1:30 and 5:30 for patients reviewed by telephone call.

The CNS will be trained to authorise their relevant treatment on Chemocare, and plan for their follow up. All consultations are listed under The NURHAM clinic code

Scope

This document applies to all Clinical Nurse Specialists within the Haematology department who have the knowledge, skills and competency required to undertake the Nurse Led follow-up clinic for patients with Chronic Myeloid Leukaemia under the care of The University Hospitals of Leicester NHS Trust.

Procedure / Process for Chronic Myeloid Leukaemia Clinical Nurse Specialist Led follow-up Clinic	
No.	**Action**
	Clinic profile The clinic will run on Thursday afternoons between 12:30 and 1:30 for patients being seen face to face, and between 1:30 and 5:30 for patients reviewed by telephone call. Face to face and telephone consultations are listed under clinic code NURHAM and this code is exclusively for this group of patients. The CNS will check the patients' blood results via UHL ICE clinical system take a clinical history and authorise their treatment on Chemocare, if their condition remains within a stable range, the CNS will plan for the patients' follow up. The follow up plan is documented in the patients' medical notes and a letter is dictated to the patient and GP. If the assessment concludes the patients' condition is not stable they will refer back to a Senior Doctor, Specialist Registrar or above, in clinic on the day of the patients' appointment. Alternatively the same weeks Multi-Disciplinary Team (MDT) meeting is acceptable to discuss the patient if only a slight change in blood test or physical symptoms is noted. This will ensure that the patient is reviewed and has a treatment plan going forward. This is documented in the patients' medical notes and a dictated letter sent to patient and GP as above. **Clinic Inclusion Criteria** Patient group • Patients with Chronic Myeloid Leukaemia who have been previously under the care of a Consultant Haematologist and have been assessed by the Consultant Haematologist and the Multidisciplinary Team to be clinically stable. They must be discussed at MDT prior to referral into the Nurse-Led Chronic Myeloid Leukaemia service. • Patients who are on Tyrosine Kinase Inhibitors or who are in a treatment free remission. • Both patient groups described above will have stable Full Blood Counts as per the definitions below. **Definition of stable blood counts for the purpose of this Nurse-Led clinic** • White Cell Count, Haemoglobin, Platelet and Neutrophil counts do not fall by greater than 10%.

- A rising White Cell Count or Platelet count unless adequately explained (e.g. by recent infection) indicates unstable disease.
- Patients on treatment also have Alanine Transaminase levels less than 3 times the upper limit of normal (53) and Bilirubin (21).
- Patients who are off treatment do not need Liver Function Tests (LFTs) taking.
- Patients will have stable BCr-Abl levels measured by the Cambridge Blood test, their IS Ratio (level of disease measured at molecular level), consistently shows the level of detectable disease at, or around zero, or no more than a one log increase from the point at which they were referred to CNS e.g. 0.001 to 0.01, 0.005 to 0.01.

Process for the Nurse-Led CML Follow-up clinic

- Prior to reviewing the patient either face to face or by telephone each patient will have been given a blood request form to have Full Blood Count, Cambridge Blood test and patients on treatment (as described in the previous section), will have liver function tests.
- Bloods will be reviewed by the CNS ensuring the blood tests are within the agreed ranges laid out in these nurse-led guidelines, using UHL ICE clinical system.
- This process takes place prior to the clinic to allow time for discussion with the patient at their allotted appointment time and to ensure that the
- Therapeutic drugs are already prescribed by a doctor and checked by a pharmacist, then released by the chemocare system into the final authorisation stage for the CNS to authorise the prescription to be released for the patient to collect from pharmacy.

Actions from the Nurse-Led Clinic

If bloods are not within required range the CNS will decide whether changes are part of a defined trend or a one-off. A change that may be explained such as an infection leading to a raised white cell count or a sudden low neutrophil count which can be an anomaly.

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	Action: - Repeat and review the blood count a week later. Any changes to patient blood results which do not fall within the parameters set out in the guideline will be referred to a Doctor in clinic (Specialist registrar or consultant).If the patient is in clinic they can be reviewed by the Dr or Consultant, if the patient is reviewed by telephone only, a clinical history as below will be taken, relayed verbally to the consultant or Dr in clinic to decide if to call the patient into clinic. If the consultant or Dr is satisfied with the patient history, they may refer the patient's case to the next MDT meeting if the patient appears physically well and the change in blood results is deemed not urgent. The outcome will be relayed verbally to the patient. The referral and discussion with the Drs in clinic will be documented in the patients' medical notes and a letter dictated to the patient and GP. Where there is a Cambridge IS result, the CNS must ensure that the depth of remission is not changing, therefore, the IS Ratio is staying at or close to 0.000 or no greater than a one log increase. **Action: -** If the Cambridge IS result is not within described range, refer back to Senior Dr at the time of the clinic or the same week's MDT. Where there is no Cambridge result, the CNS must investigate with the patient at the time of the appointment, why it has not been done and advise the patient about the importance of having the blood test. If non-compliance of having the test is an ongoing problem, a compromise on how often or whether the test is required must be reached by MDT within a week of the clinical discussion. **Action: -** Refer case to MDT for discussion and document in patients notes the outcome as well as informing the patient by telephone and letter. The CNS will discuss any concerns about a change in blood results during the clinic appointment with the patient, before seeking advice from the team. **Action**: - In case of need to refer to MDT, the patient must be informed of the plan and rationale. **Assessment of physical symptoms affecting health or lifestyle** A symptoms checklist must be completed with the patient during their appointment to ascertain any physical deterioration or reactions to the treatment they are having. The same questions will be asked to patients

who are assessed over the telephone or via the ePROMs questionnaire.

Symptoms to report to Referring Consultant

- Ongoing nausea, which doesn't settle after one to two weeks.
- An upset stomach or any signs of blood either in vomit or stools.
- A progressive rash which is not resolved with antihistamines or creams.
- A persistent cough not attributed to a viral cold.
- Oedema (peri-orbital is common, peripheral merits investigation)
- New 'acid reflux'
- Increasing tiredness/ fatigue

Action :-

The extent of these as a problem needs discussing with the patient and referring on to a doctor, if they are affecting quality of life, or if the patient might benefit from medication to ease the side effects. Referral to MDT for discussion should take place to consider change of treatment if necessary, within a week of the nurse-led clinical assessment.

Follow-up plan, documentation and outcomes of clinic. Feedback to patient their blood results including Cambridge result during the clinical consultation either face to face or telephone

- If all is stable and patient is physically well with none of the previously described side effects, then the patient will continue on their medication as prescribed with no change to the dosage.
- Provide general clinic outcome sheet to the patient and make their next appointment if face to face, if telephone appointment, it will be posted to patient.
- Provide blood request forms with instructions when to have them done ready for their next visit, or post out to telephone patients.
- The CNS will authorise prescription at the time of the consultation once the CNS is satisfied that all bloods are within limits as laid out in this guideline and the patient has no side effects or debilitation as already indicated in this guideline. This will be authorised on Chemocare having previously checked that there is a Dr and a Pharmacist in the previous steps of allocation and confirmation of treatment. TrustMed pharmacy will be emailed to confirm these steps are completed and arrange for the medication to get to the patient (either by collection or delivery)

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	• Document the patient's follow-up review, including reference to blood results, clinical history of any side effects or ongoing symptoms, actions taken as required, such as referral back to MDT or onto Drs for review, in the patients' medical notes, once the patient has left the room. • Dictate a letter to GP, with all of the above information which is copied to the patient.

3. Education and Training

The Leukaemia / MDL Clinical Nurse Specialist will have completed and be competent in administration of oral Systemic Anti- Cancer Therapy.

They will be competent in authorising medication on Chemocare as per UHL training package and competencies which will be assessed as per chemo care training policy

They will be assessed as competent as per UHL triennial Medicines management policy.

4. Key Words

Chronic Myeloid leukaemia

Nurse-Led Follow-up

CONTACT AND REVIEW DETAILS	
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Details of Changes made during review: updated to reflect current clinic processes	