



Appendix

Title	Greater Manchester Cancer Polycythaemia Vera (PV) & Essential thrombocytosis (ET) Patient Pathway
Author & Owner	Greater Manchester Cancer

Version Control		
Version/ Draft	Date	Revision summary
1.0	01.06.2018	Initial draft for review
2.0	11.06.2018	Approved

Pathway Details/Supporting Information

The PV & ET pathway also incorporates the supportive and palliative care pathways. Key discussion points, contacts with the Key-Worker, holistic assessment points and key information points are identified by symbols along the pathway. The Patient Information Pathway supports the steps in the PV & ET pathway such as referral, diagnostic procedures and tests, diagnosis, treatments, side effects and support services. Additional national resources or information to meet patient/carer needs may be offered at any stage along the pathway

a) First Appointment

- Patient is seen in OPD clinic, ward or Haematology Day Unit
- Assessment of risk factors for thrombosis

PV Investigations: FBC, biochemical profile and JAK2 mutation. Consider ferritin, serum erythropoietin, abdominal ultrasound and bone marrow aspirate, trephine & cytogenetics.

ET Investigations: FBC, biochemical profile, ferritin, JAK2 mutation; if negative test for CALR and MPL. Consider bone marrow aspirate, trephine and cytogenetics.

b) Specialist MDT Discussion

- Patient treatment plan/management plan discussed at relevant Specialist Haematology MDT (listed below) in line with Manchester Cancer guidelines:
Central Sector (Manchester Foundation Trust)
North East Sector (Pennine Foundation Trust/Oldham)
North West Sector (Salford Royal, Bolton, Wrightington, Wigan & Leigh)
South Sector (The Christie, East Cheshire, Stepping Hill, Tameside)
- Participation in clinical trial to be considered where available
- If 16-18 years old refer patient to the Teenage and Young Adult Unit (TYA) at The Christie. If 19-24 years offer the option of referral and a visit to The Christie and follow the Teenage and Young Adult with cancer pathway

c) Consultation for Diagnosis

- Patient attends clinic or is seen on ward/Day unit to discuss diagnosis and treatment plan
- Clinical trial options discussed with patient
- Holistic assessment undertaken at diagnosis, disease progression or change in circumstances
- Breaking Bad News – CNS and family/carer to be present where possible
- Contraception and fertility issues to be discussed and referral to Reproductive Medicine Unit made as appropriate
- Discussion around tissue typing of patient and siblings (if appropriate)
- GP to be informed of cancer diagnosis within 24 hours of discussion with patient
- Patient to be offered summary of the consultation at which the treatment options were discussed.
- Patients should have access to information in different formats as appropriate i.e. written / video / different languages / for those with visual/hearing impairment etc
- Patients should be offered to receive copies of letters sent to their GP

d) First Definitive Treatment

- Active monitoring on anti-platelet agent
- Venesections
- Outpatient based cytoreductive treatment; once stable consider shared care protocol for hydroxycarbamide with GP input.
- Clinical Trial if available/appropriate
- Palliative Care

e) Survivorship

Provide treatment summaries for people with PV and ET (and their GPs); as treatment is on-going over longer periods consider one treatment summary every 2 years. Discuss these with the patient, highlighting personal and general risk factors, including late effects related to their treatment.

Provide information to people with PV and ET during the course of treatment about how to recognise possible disease progression and transformation and advise on late effects of current/previous treatment.