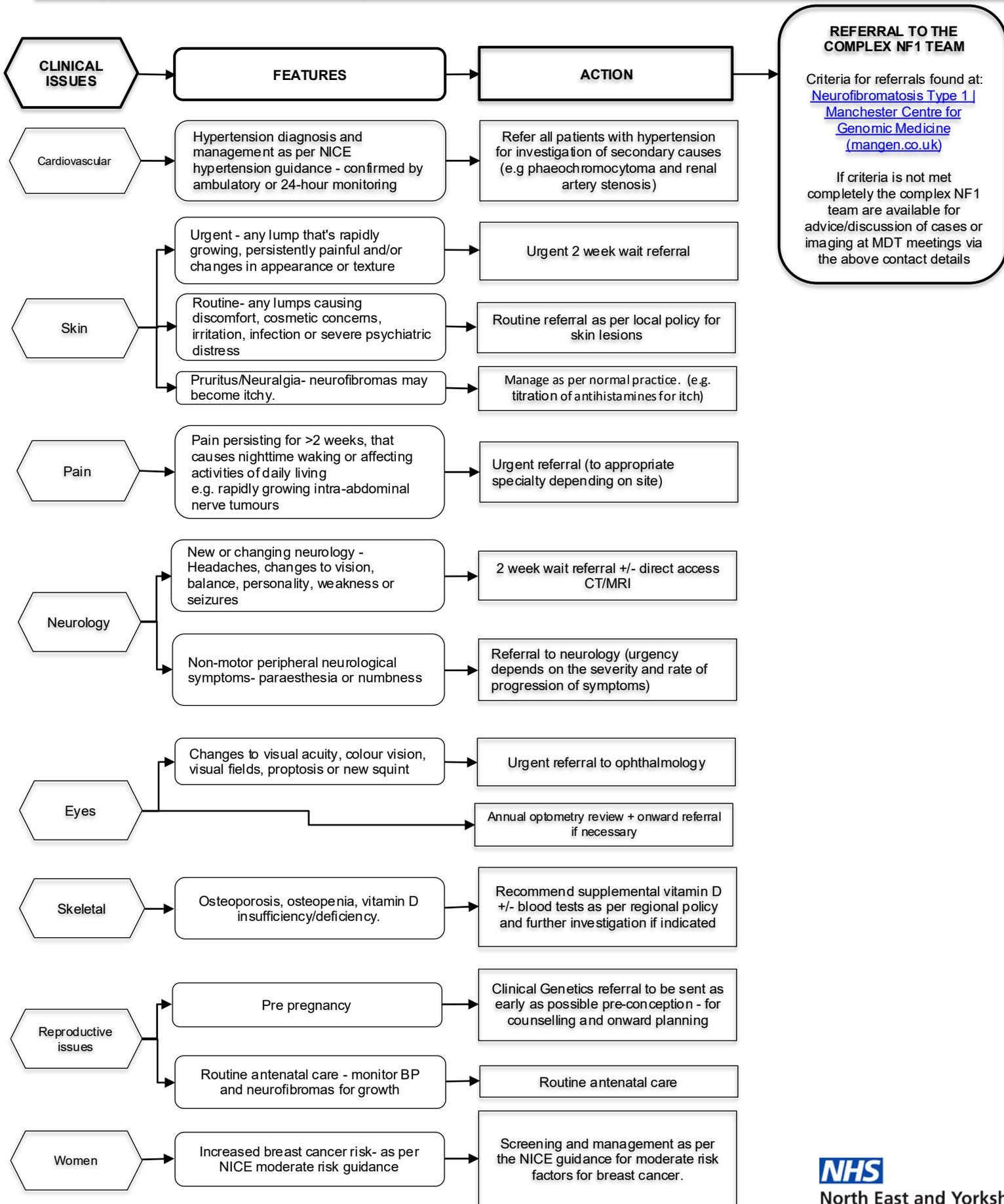


Neurofibromatosis type 1 (NF1) - onward care in adults

Depending on complexity of the patient's NF1, their care is transferred to the appropriate service at transition by the paediatrician or transition clinics:

Non-complex NF1 - under the care of primary care physicians
 Complex NF1 - under the care of NF1 services Complex service

Every patient should have an annual blood pressure review



NF1 features to be aware of:

- Learning difficulties and behavioural disorders e.g. ADHD and autism - NF1 patients are at higher risk
- Psychological issues
- Fatigue
- Generalised muscle aches and pains
- Scoliosis, congenital bowing or pseudoarthrosis of long bones usually tibia
- Short stature

Red flags

- Vision: changes to visual acuity, visual fields etc. - may indicate an optic glioma or CNS tumour
- Central neurology: headaches, seizures, vision disturbance, gait - may indicate a CNS tumour
- Skin: painful, rapidly growing or changing skin lesions - may indicate malignant peripheral nerve sheath tumour
- Cardiovascular: hypertension, episodic headache, sweating, tachycardia - may indicate phaeochromocytoma
- Pain: new onset, severe in nature, waking from sleep, not resolving after 2 weeks - may indicate malignant transformation of internal neurofibroma

Resources:

- [Nerve Tumours UK | Home | Nerve Tumours UK](#)
- [Childhood Tumour Trust](#)
- [Neurofibromatosis Type 1 | Manchester Centre for Genomic Medicine \(mangen.co.uk\)](#)
- NICE Hypertension in adults: diagnosis and management | Guideline NG136
- NICE breast cancer guidance. (NICE CG164)