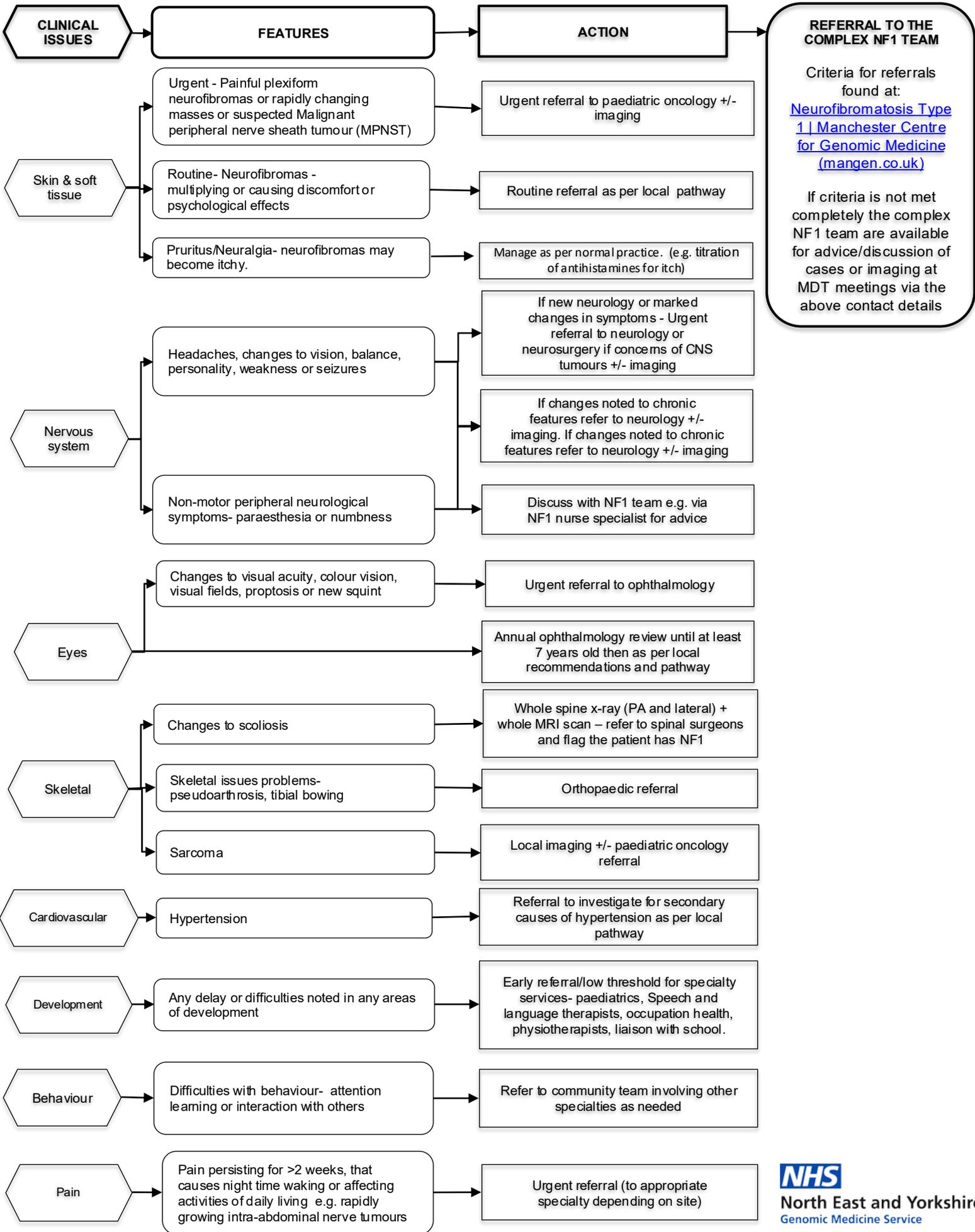


Neurofibromatosis type 1 (NF1) - onward care in children

For children less than 5 years old with signs or symptoms suggestive of NF1 - carry out genetic testing for NF1
 If testing is negative, review at 5 years old - if they do not meet clinical criteria for NF1 discharge
 All children with NF1 should have an annual review with a paediatrician
 At each appointment check height, weight, OFC and blood pressure



At transition (16-17 years old) refer back to Clinical Genetics to determine care settings for on-going care.
During transition between children's and adult services, important areas to discuss:

- Red flag signs and symptoms to be aware of
- Family planning and pregnancy
- Psychological aspects of NF1
- Routine checks - BP and vitamin D
- Support - Primary care, NF1 nurse specialist, patient resources (support charities)

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 \(mangen.co.uk\)](#)
- Hypertension criteria resource - Lurbe E, et al. 2016 European Society of Hypertension guidelines for the management of high blood pressure in children and adolescents. J Hypertens. 2016 Oct;34(10):1887-920. doi: 10.1097/HJH.0000000000001039. PMID: 27467768.