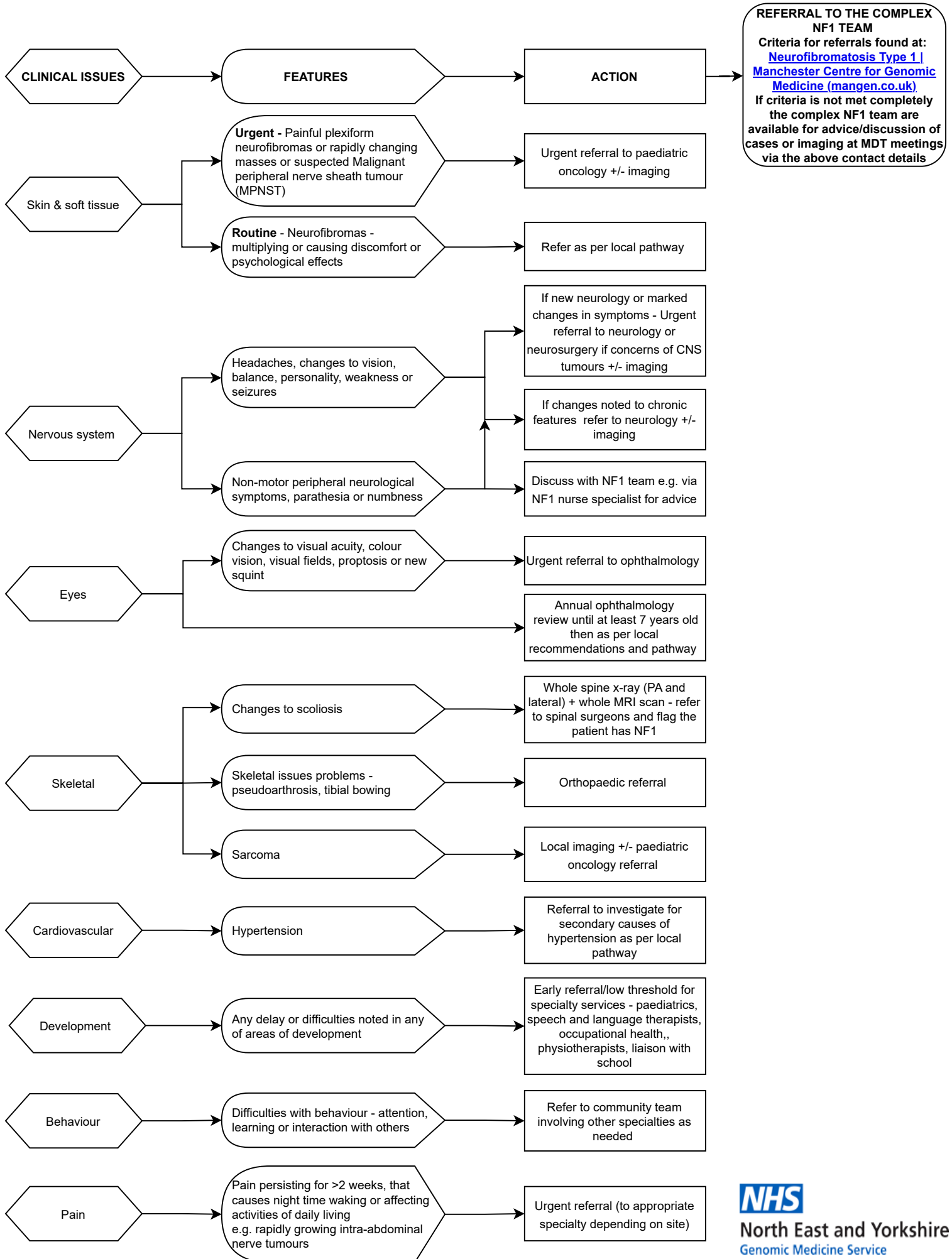


## Neurofibromatosis type 1 (NF1) - onward care in children

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 tumours**
- **Skin: painful, rapidly growing or changing skin lesions - may indicate malignant peripheral nerve sheath tumour**
- **Cardiovascular: hypertension, episodic headache, sweating, tachycardia - may indicate pheochromocytoma**
- **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](#)
- [Neurofibromatosis Type 1 | Manchester Centre for Genomic Medicine \(mangen.co.uk\)](#)
- Hypertension criteria resource - Lurbe E, Agabiti-Rosei E, Cruickshank JK, Dominiczak A, Erdine S, Hirth A, Invitti C, Litwin M, Mancia G, Pall D, Rascher W, Redon J, Schaefer F, Seeman T, Sinha M, Stabouli S, Webb NJ, Wühl E, Zanchetti A. 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.