## ATAXIA UK ACCREDITED CENTRES

Ataxia UK Accredited Centres are ataxia centres of excellence. They are based in NHS Trusts in the UK and are headed by a neurologist with expertise and interest in ataxia. In order to become an Ataxia UK Accredited Centre a number of criteria need to be met (see below). These have been devised following consultation with people with ataxia, their carers and with expert neurologists. The Centres aim to provide excellent diagnostic and follow-up services, referrals to relevant professionals and good communication between professionals and patients. The lead neurologist must also have an ongoing interest in research into the ataxias. There is a willingness to collaborate between Centres in order to ensure the best services to patients and in order to help in research efforts.

## CRITERIA FOR ATAXIA UK ACCREDITED CENTRES

1. Involvement of clinician(s) with interest/expertise in ataxia who are regularly seeing ataxia patients in a designated ataxia clinic every month. In this context 'ataxia patients' are defined as people with ataxia as their dominant clinical syndrome. The service is likely to expand over time following accreditation; however, clinicians must run an ataxia clinic at least once a month.

2. Involvement of clinician(s) with a track record of engaging with and willing to be involved in research on the ataxias.

3. Access to **all** relevant available genetic and non-genetic diagnostic tests.
   It is important that people attending any of the Centres have access to the most up-to-date diagnostic tests and that there is equality in the availability of tests in all centres. Where particular tests are not easily available then agreements should be reached on pathways to obtain these. Testing should include all relevant imaging, neurophysiological, biochemical, immunological and genetic tests.

4. Provide appropriate follow-up and continuity of care

(a) Follow-up offered at least once a year

(b) Patients receive continuity of care. Examples below:

(i) See the same neurologist at least 50% of the time

(ii) Clinicians discuss cases and allocate cases to an appropriate clinician prior to clinic appointments

(iii) Patients have a named healthcare professional who coordinates their care. This is in line with the NICE Rare Diseases Quality standard 2026, Quality statement 5 – review the document here

5. As per the NICE Rare Diseases Quality standard 2026, Quality statement 1 (review the document here) and under the NHS Constitution in England, people should wait

no longer than 18 weeks from GP referral for consultant-led treatment for non-urgent conditions. Centres should ensure that there is a system in place to monitor this.

6. Good, supportive handling of diagnosis and other sensitive information (monitored by feedback from people attending the centre and/or carers).

7. Evidence of good referral system to support services including, but not limited to, physiotherapists, OT's, speech therapists, mental health services and Ataxia UK.

8. Direct referral to other specialist clinical services (e.g. cardiologists, orthopaedists, psychiatrists, ophthalmologists, genetic counselling etc.) with fast-track potential for relevant cases. It is recommended that referrals should be to an allocated named specialist.

9. Evidence of comprehensive, accurate and timely communication, including with primary care, the patient and other specialists.
   Examples of good practice:
   *a) regular correspondence with clinic letters and specialist referrals sent out within 1 month from visit*
   *b) send GPs copies of correspondence with other specialists*
   *c) telephone contact with GPs*
   *d) copying letters to patients*
   *e) copies of letters sent to GP also sent to other professionals working with patient (e.g. physiotherapists, other specialists) when relevant*
   *f) brief information on the natural history of the condition to be included in the letter to the GP when a diagnosis is reached, to help GP to manage the person with ataxia and, for example, to help discriminate which symptoms are part of the condition*
   *g) provide useful information leaflets (e.g. Ataxia UK's leaflets) and provide clear and accurate information on the condition and to aid self-management of the condition*

10. Evidence of links with and support between adult and paediatric neurologists to support the transition of younger patients into adult care.

11. (a) Evidence of a system for providing both medical information and support /advice for people with ataxia and carers between clinic visits.
    (b) Evidence of patients being made aware of the availability and mechanism of this system.

12. Willingness to collaborate with other Ataxia Centres in research (e.g. for recruitment to trials, validation of novel genes or other research projects).

13. Preparedness to accept GP referrals from non-local patients, including patients from devolved nations, or from the region if a Regional Ataxia Centre. It is acknowledged that accepting referrals for patients from devolved nations requires an agreement between health boards which may be a barrier and is out of the Ataxia Centre’s hands.

14. Evidence that the relevant NHS Trust supports the development of an Ataxia Centre.

15. Agreement to implement an annual monitoring system based on patient feedback.

16. (a) Willingness to attend and participate in biannual meetings of Ataxia Centres (for problem solving, best practice and research discussions).
    (b) Willingness to provide information annually to support Ataxia UK's annual Ataxia Centre reaccreditation review.

**Document updated Sept 2026**