

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Suspected neurological conditions: recognition and referral

Topic

The Department of Health in England has asked NICE to develop a clinical guideline on the recognition and referral of suspected neurological conditions.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

Who the guideline is for

- Healthcare professionals in primary and secondary care.
- Neurology departments
- People using services, their family members and carers, and the public.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to disabilities, communication difficulties, functional symptoms and psychiatric disorders.

1 What the guideline is about

1.1 *Who is the focus?*

Groups that will be covered

- Children, young people and adults who present in non-specialist settings with symptoms suggestive of a neurological condition.
- Children aged 5 years and under have been identified as a subgroup needing specific consideration.

Groups that will not be covered

- Neonates (infants aged 28 days and under)

1.2 *Settings*

- Primary and secondary care.

1.3 *Activities, services or aspects of care*

Key areas that will be covered

- 1 Indications for referral to specialist care, including referral for people with existing neurological conditions in the event of a change in symptoms.
- 2 Examinations, assessment tools and investigative tests that non-specialists could use to help them decide whether a person with symptoms suggestive of a neurological condition should undergo further investigation or be referred to a specialist.
- 3 Information, support and initial management advice for people with a suspected neurological condition and their family members and carers.

Areas that will not be covered

- 1 Assessment, diagnosis and management of suspected neurological problems after referral to specialist neurological services.
- 2 Neurological conditions for which recognition and referral by non-specialists is already adequately covered by NICE guidance that is published or in development. If recognition and/or referral are already covered in existing NICE guidance, then this guideline will cross-refer.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, as appropriate.

1.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

- 1 Indications for referral to specialist care.
 - 1.1 Which criteria (symptoms, signs, risk factors and red flags) indicate the need for referral for further neurological assessment?
 - 1.2 Which criteria (symptoms, signs and risk factors) indicate there is no need for referral for further neurological assessment?
- 2 Examinations, assessment tools and investigative tests that non-specialists could use to help them decide whether a person with symptoms suggestive of a neurological condition should have further investigation or be referred to a specialist.
 - 2.1 What examinations should non-specialists carry out when a person presents with symptoms suggestive of a neurological condition?
 - 2.2 What assessment tools, such as algorithms, could non-specialists use when a person presents with symptoms suggestive of a neurological condition?
 - 2.3 What investigative tests should non-specialists use when a person presents with symptoms suggestive of a neurological condition?
- 3 Information, support and initial management advice for people with a suspected neurological condition and their family members and carers.
 - 3.1 What are the information, support and initial management advice needs of people who have a suspected neurological condition and their family members and carers?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

- 1 Time to referral.
- 2 Time to diagnosis.
- 3 Number of referrals.
- 4 Positive predictive value of symptoms.
- 5 Diagnostic accuracy of tests.
- 6 Patient satisfaction.
- 7 Carer satisfaction.
- 8 Quality of life.

2 Links with other NICE guidance, NICE quality standards, and NICE Pathways

2.1 NICE guidance

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to neurological conditions:

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- [Motor Neurone Disease: assessment and management](#). NICE guideline.
Publication expected February 2016.

- [Cerebral palsy: diagnosis and management](#). NICE guideline. Publication expected January 2017.
- [Parkinson's disease: diagnosis and management in primary and secondary care](#). NICE guideline. Publication expected April 2017.
- [Dementia: assessment, management and support for people living with dementia and their carers](#). NICE guideline. Publication expected September 2017.
- [Primary brain tumours and cerebral metastases](#). NICE guideline. Publication expected July 2018.

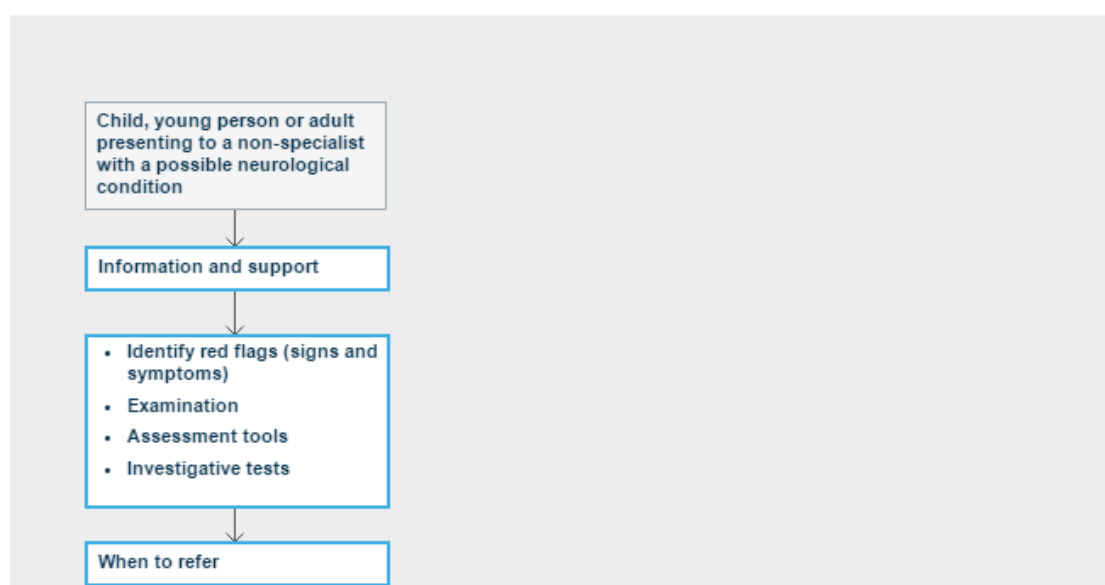
2.2 NICE Pathways

[NICE Pathways](#) bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

When this guideline is published, the recommendations will be incorporated into the existing pathway on [neurological conditions](#).

An outline of the new pathway, based on the scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

Neurological conditions: recognition and referral overview



3 Context

3.1 *Key facts and figures*

Neurological conditions account for about 1 in 10 GP consultations, around 10% of emergency medical admissions (excluding stroke), and result in disability for 1 in 50 of the UK population ([Local adult neurology services for the next decade: report of a working party](#), Royal College of Physicians). It is estimated that 2–3% of children will have special needs or some level of disability, with most disabilities being neurological in origin.

Onset, progression, prevalence and severity vary across different neurological conditions. Some neurological conditions are present at birth, while others begin during childhood or as adults. Some conditions can be recovered from completely, but others can cause rapid deterioration or have a slower, more sustained disease course. Some conditions are fairly common, such as migraine (which affects 1 in 5 women or 1 in 15 men) and others are rare, such as Guillain–Barre syndrome (which affects about 1200 people in the UK per year). Most neurological disorders have an impact on quality of life, and some cause serious disability and have a substantial impact on the person and their family members and carers.

People often present with symptoms that are difficult to diagnose (functional symptoms) and can make diagnosing neurological conditions hard. Up to one-fifth of new neurology outpatients have functional symptoms.

3.2 *Current practice*

People with suspected neurological conditions often need referral to a specialist to be diagnosed. However, some referrals are unnecessary. On the other hand, some people with neurological conditions are initially misdiagnosed or have a delayed referral to a specialist. These issues with referral come from a lack of support and knowledge among non-specialists about neurological conditions. A report from the Neurological Alliance ([The invisible patients: revealing the state of neurology services](#)) found that nearly

one-third of people with a neurological condition had to see their GP 5 or more times before being referred to a specialist.

People suspected of having neurological conditions may have additional information needs because of the type of investigations that need to be done; as well needing information on the possibility of living with a neurological condition.

3.3 Policy, legislation, regulation and commissioning

Legislation, regulation and guidance

Many specialist professional and charitable bodies have produced guidance for specific neurological conditions, but there is a lack of guidance available for neurological conditions in general. This lack of support, particularly for uncommon neurological conditions, was highlighted by the National Audit Office in the report on [Services for people with neurological conditions](#). It made the recommendation that 'the Department [of Health] should instruct NICE to develop a generic quality standard covering other neurological conditions'.

The [UK Strategy for Rare Diseases](#) (Department of Health) highlights issues with delays to diagnosis and aims to improve the overall patient journey from first contact with the NHS.

4 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in January 2018.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.