NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Neurological problems: assessment, diagnosis and referral

**Topic**

The Department of Health in England has asked NICE to develop a clinical guideline on the assessment, diagnosis and referral of neurological problems.

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**

- Non-specialist healthcare professionals in primary and secondary care.
- 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 problem.
- 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

Settings that will be covered
- Primary and secondary care.

1.3 Activities, services or aspects of care

Key areas that will be covered
1 Examinations, assessment tools and tests that non-specialists could use to help them decide whether a person with symptoms suggestive of a neurological problem should be referred to a specialist.
2 Indications for referral to specialist care.
3 Information, support and initial management advice for people with a suspected neurological problem and their family members and/or 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 on which NICE guidance already exists or is in development will not be covered in this guideline. However if recognition of symptoms by non-specialists is covered in other guidelines, then this guideline will cross-refer. NICE guidance includes the following:
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. Examinations, assessment tools and tests that non-specialists could use to help them decide whether a person with symptoms suggestive of a
neurological problem should undergo further investigation or be referred to a specialist.

1.1 What examinations could non-specialists carry out when a person presents with symptoms suggestive of a neurological problem?

1.2 What assessment tools, such as algorithms, could non-specialists use when a person presents with symptoms suggestive of a neurological problem?

1.3 What investigative tests could non-specialists use when a person presents with symptoms suggestive of a neurological problem?

2 Indications for referral to specialist care.

2.1 Which criteria (symptoms, signs, risk factors and red flags) indicate the need for referral to specialist neurological care?

3 Information, support and initial management advice for people with a suspected neurological problem and their family members and/or carers.

3.1 What are the information, support and initial management advice needs of people who have a suspected neurological problem and their family members and/or 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.
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:

- Cerebral palsy: diagnosis and management. NICE guideline. Publication expected January 2017. This guideline will cross-refer.
- Dementia: assessment, management and support for people living with dementia and their carers. NICE guideline. Publication expected September 2017. This guideline will cross-refer.

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.
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. Onset, progression, prevalence and severity of neurological problems differs. Some neurological conditions are present at birth, while other problems 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 extremely 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, having a substantial impact on the person and their family members and/or carers.
People often present with symptoms that are difficult to diagnose (functional symptoms) and can make diagnosing neurological problems hard. People with functional symptoms make up to one-fifth of new neurology outpatients.

### 3.2 Current practice

People with suspected neurological conditions often need referral to a specialist to be diagnosed. However some of these referrals are unnecessary. On the other hand, some people with uncommon neurological disorders are initially misdiagnosed or have a delayed referral to a specialist. These problems in referral come from a lack of support and knowledge among non-specialists about neurological conditions. The invisible patients: Revealing the state of neurology services report from the Neurological Alliance (January 2015) 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 as being provided with information on the possibility of living with a neurological condition.

### 3.3 Policy, legislation, regulation and commissioning

#### Legislation, regulation and guidance

Legislation, regulation and guidance typically focus on diagnosis and/or management of common neurological conditions, for example the Department of Health's National Service Framework for Long Term Conditions.

For uncommon neurological conditions there is guidance provided by many specialist charitable bodies, but no overall guidance is available for these conditions. This lack of support was highlighted by the National Audit Office in the report on Services for people with neurological conditions (July 2015). They made the recommendation that ‘the Department [of Health] should instruct NICE to develop a generic Quality Standard covering other neurological conditions’.
4 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 4 December 2015 to 8 January 2016.

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.