NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Draft quality standard for headache in young people and adults

1 Introduction

Headache disorders are classified as primary or secondary. The cause of primary headaches is not well understood and they are classified according to their clinical pattern. The most common primary headache disorders are tension-type headache, migraine and cluster headache. Secondary headaches are caused by underlying disorders and include, for example, headaches associated with medication overuse, giant cell arteritis, raised intracranial pressure and infection. Medication overuse headache most commonly occurs in people taking medication for a primary headache disorder. Headaches are one of the most common neurological problems presented to GPs and neurologists.

Most of the health and social burden of headaches is caused by primary headache disorders and medication overuse headache. The impact on the young person or adult is not just during a headache; the anticipation of a headache can cause a significant anxiety between attacks.

This quality standard covers the diagnosis and management of headaches including tension-type headache, cluster headache, migraine and medication overuse headache in adults and young people aged 12 years and older. For more information see the topic overview.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. The quality standard, in conjunction with the guidance on which

it is based, should contribute to the improvements outlined in the following frameworks:

- NHS Outcomes Framework 2013–14. (Department of Health, November 2012).

The table below shows the outcomes, overarching indicators and improvement areas from the framework that the quality standard could contribute to achieving:

NHS outcomes framework 2013–14	
Domain 2: Enhancing quality of life for people with long-term conditions	**Overarching** 2 Health-related quality of life for people with long-term conditions **Improvement areas** *Ensuring people feel supported to manage their condition* 2.1 Proportion of people feeling supported to manage their condition
Domain 4: Ensuring that people have appositive experience of care	**Overarching indicators** 4a Patient experience of primary care (i) GP services

2 Draft quality standard for headache in young people and adults

Overview

The draft quality standard for headache in young people and adults states that services should be commissioned from and coordinated across all relevant agencies encompassing the whole headache care pathway. A person-centered approach to provision of services is fundamental to delivering high quality care to young people and adults with headache.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should cross refer across the library of NICE quality standards when designing high-quality services.

Patients, service users and carers may use the quality standard to find out about the quality of care they should expect to receive; support asking questions about the care they receive; and to make a choice between providers of social care services.

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in diagnosing and managing headache in young people and adults should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

No.	Draft quality statements
1	People diagnosed with a primary headache disorder have their headache type classified as part of the diagnosis.
2	People with a primary headache disorder are given advice on the risk of medication overuse headache.
3	People with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache are not referred for imaging.

4	Public awareness (placeholder)

Other quality standards that should also be considered when commissioning and providing a high-quality headache service are listed in section 7.

General questions for consultation:

Question 1	Does this draft quality standard accurately reflect the key areas for quality improvement?
Question 2	If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?
Please refer to Quality standards in development for additional general points for consideration.	
Statement-specific questions for consultation:	
Question 3	For draft quality statement 4 (placeholder): Do you know of any evidence-based guidance in this area? If not, would new evidence-based guidance relating to public awareness for headache disorders improve practice? If so please provide details.

Draft quality statement 1: Classification of headache type

Draft quality statement	People diagnosed with a primary headache disorder have their headache type classified as part of the diagnosis.
Rationale	Classifying headache type will allow people with a primary headache disorder to receive appropriate treatment for their headaches and for prevention, and may improve quality of life and reduce unnecessary investigations.
Draft quality measure	**Structure:** Evidence of local arrangements to ensure that people diagnosed with a primary headache disorder have their headache type classified as part of the diagnosis. **Process:** Proportion of people diagnosed with a primary headache type who have their headache type classified as part of the diagnosis. Numerator – the number of people in the denominator who have their headache type classified as part of the diagnosis. Denominator – the number of people diagnosed with a primary headache disorder.
Description of what the quality statement means for each audience	**Service providers** ensure systems are in place for people diagnosed with a primary headache disorder to have their headache type classified as part of the diagnosis. **Healthcare professionals** ensure people diagnosed with a primary headache disorder have their headache type classified as part of the diagnosis. **Commissioners** ensure they commission services that classify headache type for people diagnosed with a primary headache disorder as part of the diagnosis. **People with a headache disorder** with no known cause have the type of their headache classified as part of their diagnosis.
Source clinical guideline references	NICE clinical guideline 150 recommendation 1.2.1 (key priority for implementation), 1.1.1 and 1.1.2.
Data source	**Structure:** Local data collection. **Process:** Local data collection. **Outcome:** Local data collection.
Definitions	The diagnosis of primary headache disorder should include: • excluding other causes • history taking • classifying headache type according to the headache features table. (See NICE clinical guideline 150 for the headache features table for the diagnosis of tension-type

	headache, migraine and cluster headache.) **Excluding other causes** NICE clinical guideline 150 lists the signs and symptoms of secondary headaches for which further investigations and/or referral may be considered as: • worsening headache with fever • sudden-onset headache reaching maximum intensity within 5 minutes • new-onset neurological defect • new-onset cognitive dysfunction • change in personality • impaired level of consciousness • recent (typically within the past 3 months) head trauma • headache triggered by cough, valsalva (trying to breathe out with nose and mouth blocked) or sneeze • headache triggered by exercise • orthostatic headache (headaches that change with posture) • symptoms suggestive of giant cell arteritis • symptoms and signs of acute narrow-angle glaucoma • a substantial change in characteristics of their headache. NICE clinical guideline 150 also states criteria for which further investigations and/or referral may be needed for people who present with new-onset headache. These are: • compromised immunity, caused, for example, by HIV or immunosuppressive drugs • age under 20 years and a history of malignancy • a history of malignancy known to metastasise to the brain • vomiting without other obvious cause.
Equality and diversity considerations	The diagnosis of a primary headache disorder is usually based on subjective symptoms. Some people may need support to accurately describe their symptoms. The support should be tailored to the person, especially those with additional needs such as physical, sensory or learning disabilities and people who do not speak English. People presenting with a headache should have access to an interpreter or advocate if needed.

Draft quality statement 2: Preventing medication overuse headaches

Draft quality statement	People with a primary headache disorder are given advice on the risk of medication overuse headache.
Rationale	Medication overuse is a cause of secondary headache in people with primary headache disorder. Providing appropriate advice to people with primary headache disorder about the risk of medication overuse may prevent secondary headaches.
Draft quality measure	**Structure:** Evidence of local arrangements to ensure that people with a primary headache disorder are given advice on the risk of medication overuse headache. **Process:** Proportion of people with a primary headache disorder who are given advice on the risk of medication overuse headache. Numerator – the number of people in the denominator, given advice on the risk of medication overuse headache. Denominator – the number of people with a primary headache disorder. **Outcome**: Incidence of medication overuse headache
Description of what the quality statement means for each audience	**Service providers** ensure systems are in place for people with a primary headache disorder to be given advice on the risk of medication overuse headache. **Healthcare professionals** give people with a primary headache disorder advice on the risk of medication overuse headache. **Commissioners** ensure they commission services that give people with a primary headache disorder advice on the risk of medication overuse headache. **People with a headache disorder** with no known cause are given advice about the risk of too much medication causing more headaches.
Source clinical guideline references	NICE clinical guideline 150 recommendation 1.3.6.
Data source	**Structure:** Local data collection. **Process:** Local data collection. **Outcome**: Local data collection.
Definitions	Primary headache disorders include tension-type headache, migraine and cluster headache. Medication overuse headaches are headaches associated with taking too much medication. They most commonly occur in those

	people taking medication for a primary headache disorder especially tension-type headaches and migraine.
Equality and diversity considerations	All advice given about the risk of medication overuse headache should be culturally appropriate, accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with a primary headache disorder should have access to an interpreter or advocate if needed. It may be appropriate in some cases, particularly with young people, to provide information to parents and carers as well as the person with the headache disorder.

Draft quality statement 3: Imaging

Draft quality statement	People with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache are not referred for imaging.
Rationale	When healthcare professionals are confident about the diagnosis and classification of a primary headache disorder, imaging provides no more information and can lead to delays in diagnosis, treatment and unnecessary anxiety for people
Draft quality measure	**Structure:** Evidence of local arrangements to ensure that people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache are not referred for imaging. **Process:** Proportion of people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache who are referred for imaging. Numerator – the number of people in the denominator referred for imaging. Denominator – the number of people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache. (Imaging for reassurance is not recommended for people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache therefore an audit standard of 0% should be expected in this process measure.)
Description of what the quality statement means for each audience	**Service providers** ensure systems are in place so that people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache are not referred for imaging. **Healthcare professionals** ensure they do not refer people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache for imaging. **Commissioners** ensure they commission services that do not refer people with a primary headache disorder of a classified type who do not have signs or symptoms of secondary headache for imaging. **People with a headache disorder of a classified type who do not have signs or symptoms of conditions known to cause headache** are not referred for imaging.
Source clinical guideline references	NICE clinical guideline 150 recommendation 1.3.3 (key priority for implementation), 1.1.1 and 1.1.2.
Data source	**Structure:** Local data collection. **Process:** Local data collection.

Definitions	**Classification of headache type** Classified primary headache disorders include tension-type headache, migraine and cluster headache. **Signs and symptoms of secondary headache** NICE clinical guideline 150 lists the signs and symptoms of secondary headache as: • worsening headache with fever • sudden-onset headache reaching maximum intensity within 5 minutes • new-onset neurological defect • new-onset cognitive dysfunction • change in personality • impaired level of consciousness • recent (typically within the past 3 months) head trauma • headache triggered by cough, valsalva (trying to breathe out with nose and mouth blocked) or sneeze • headache triggered by exercise • orthostatic headache (headaches that change with posture) • symptoms suggestive of giant cell arteritis • symptoms and signs of acute narrow-angle glaucoma • a substantial change in characteristics of their headache. NICE clinical guideline 150 also states criteria for which further investigations and/or referral may be needed for people who present with new-onset headache. These are: • compromised immunity, caused, for example, by HIV or immunosuppressive drugs • age under 20 years and a history of malignancy • a history of malignancy known to metastasise to the brain • vomiting without other obvious cause. **Imaging** Imaging includes computerised tomography (CT), magnetic resonance imaging (MRI) or MRI variants.
Equality and diversity considerations	Some people may be anxious about not being referred for imaging and may need reassurance. Reassurance should take into account the needs of the individual particularly any cultural needs, physical, sensory or learning disabilities, and to people who do not speak or read English. People should have access to an interpreter or advocate if needed.

Draft quality statement 4 (placeholder): Public awareness

What is a placeholder statement?	A placeholder statement is an area of care that has been prioritised by the Quality Standards Advisory Committee but for which no source guidance is currently available. A placeholder statement indicates the need for evidence-based guidance to be developed for this area.
Rationale	Raising public awareness of headache has the potential to improve the quality of life for people with a primary headache disorder. This disorder remains under-diagnosed because often people do not consult a healthcare professional. In some cases this leads to self-medication, which may be inappropriate and result in medication overuse headache. Raising public awareness could increase the number of people consulting healthcare professionals, leading to an increase in accurate diagnoses and appropriate treatment for headaches and for their prevention.
Specific questions for consultation	Do you know of any evidence-based guidance in this area? If not, could new evidence-based guidance on public awareness for headache disorders improve practice?

3 Status of this quality standard

This is the draft quality standard released for consultation from 18 March to 16 April 2013. It is not NICE's final quality standard on headache in young people and adults. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 16 April 2013. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee considerations. The final quality standard will be available on the NICE website from August 2013.

4 Using the quality standard

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered by commissioners, providers, health and social care professionals, patients, service users and carers alongside current policy and guidance documents listed in the evidence sources section.

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of health care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice when taking account of patient safety, patient choice and clinical judgement, and therefore desired levels of achievement should be defined locally.

We have indicated where national indicators currently exist and measure the quality statement. National indicators include those developed by the Health and Social Care Information Centre through their Indicators for Quality Improvement Programme. If national quality indicators do not exist for a quality statement, the quality measures should form the basis for audit criteria developed and used locally to improve the quality of health and social care.

For further information, including guidance on using quality measures, please See NICE's What makes up a NICE quality standard?

5 Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between healthcare professionals and people with headache is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with headache should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

6 How this quality standard was developed

The evidence sources used to develop this quality standard are listed in appendix 1, along with relevant policy context. Further explanation of the methodology used can be found in the Quality standards process guide.

7 Related NICE quality standards

7.1 Published

Patient experience in adult NHS services. NICE quality standard 15 (2012).

7.2 Future quality standards

This quality standard will be developed in the context of the full list of quality standards referred to NICE, including the following topics scheduled for future development:

Medicines optimisation (covering medicines adherence and safe prescribing)

8 Development sources

Evidence sources

The documents below contain clinical guideline recommendations or other recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- Headaches. NICE clinical guideline 150 (2012).

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- Department of Health (2005) The National Service Framework for long term conditions.
- The All-Party Parliamentary Group on Primary Headache Disorders (2010) Headache disorders – not respected, not resourced. A report of the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD).