NICE National Institute for Health and Care Excellence

NICE quality standard

Rare diseases

Quality standard

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Quality statement 1: Referral for investigation and treatment

Quality statement

People referred to a consultant-led service because of concerns about a rare disease undergo diagnostic investigations and have first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatment.

Rationale

The time taken to diagnose and treat rare disease varies widely across the healthcare system and delays can negatively impact quality of life. For many rare diseases, the diagnostic pathways cross multiple specialities and use regional and national referral routes. NHS England's Genomic Medicine Service and National Genomic Test Directory are relevant enablers for rare disease diagnosis.

Having a measurable goal for diagnostic investigations and first definitive treatment will help reduce unwarranted variation. 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.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Structure

Evidence of processes to ensure that people referred for non-urgent consultant-led treatment because of concerns about a rare disease undergo diagnostic investigations and have first definitive treatment in line with national maximum waiting times.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

Process

a) Proportion of people diagnosed with a rare disease who had diagnostic investigations and first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatments.

Numerator – the number in the denominator who had diagnostic investigations and first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatments.

Denominator – the number of people diagnosed with a rare disease.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements. Specific data sources are available for individual rare diseases, for example, the British Society for Rheumatology's National Early Inflammatory Autoimmune Diseases Audit (NEIAA).

b) Proportion of people referred to a consultant-led service because of concerns about a rare disease who had diagnostic investigations and first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatments.

Numerator – the number in the denominator who had diagnostic investigations and first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatments.

Denominator – the number of people referred to a consultant-led service because of concerns about a rare disease.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements. Hospital trust data at speciality level is available from NHS England's consultant-led referral to treatment waiting time data. However, this data is not specific to referrals because of concerns about a rare disease.

What the quality statement means for different audiences

Service providers (secondary and tertiary care) ensure that care pathways are in place to undertake diagnostic investigations and provide first definitive treatment or a decision on non-treatment in line with national maximum waiting times for people referred for non-urgent consultant-led treatment because of concerns about a rare disease.

Healthcare professionals (such as hospital consultants) carry out investigation of symptoms and provide first definitive treatment or a decision on non-treatment in line with national maximum waiting times for non-urgent consultant-led treatments.

Commissioners ensure that they commission services with sufficient capacity to carry out diagnostic investigations and provide first definitive treatment or a decision on non-treatment in line with national maximum waiting times for referrals for non-urgent consultant-led treatment because of concerns about a rare disease.

Peoplereferred to hospital becauseof concerns about a rare disease have investigation and first treatment in line with national maximum waiting times. In some cases, it may be more appropriate to decide that their condition should be monitored for a period of time without treatment.

Source guidance

Guide to NHS waiting times in England. NHS Digital (2019), maximum waiting times for non-urgent referrals.

Definitions of terms used in this quality statement

First definitive treatment

First definitive treatment is an intervention intended to manage a patient's disease, condition or injury and avoid further intervention. Often, first definitive treatment will be a medical or surgical intervention. However, it may also be judged to be other elements of the patient's care – for example, the start of counselling. In all cases, what constitutes first definitive treatment is a matter for clinical judgement, in consultation with others as

appropriate, including the patient. [Department of Health and Social Care's guidance on consultant-led treatment: right to start within 18 weeks]

Non-treatment

A waiting time clock stop for 'non-treatment' as outlined by rule 5 in the Department of Health and Social Care's guidance on consultant-led treatment: right to start within 18 weeks.

Equality and diversity considerations

People should be supported to overcome potential difficulties in accessing diagnostic services, which may result from the person having to travel a long way to attend appointments, or from them having a disability, cognitive difficulties, or financial barriers. As rare diseases can be identified during pregnancy, diagnostic pathways should include maternity services. If virtual or remote access is used, consideration should be given to minimising digital exclusion.

Quality statement 2: Undiagnosed conditions

Quality statement

People with a suspected rare disease that remains undiagnosed after diagnostic investigations are recognised as a distinct patient group by healthcare services and are on a care pathway that can support future diagnosis.

Rationale

Definitive diagnosis is not always possible immediately after diagnostic investigations. Recognising people with a suspected, but as yet undiagnosed, rare disease as a distinct patient group will improve the safety, efficiency and effectiveness of their diagnosis process. This involves giving people opportunities to discuss their needs throughout the diagnosis process, ensuring they feel heard.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Process

Proportion of people with a suspected rare disease that remains undiagnosed after diagnostic investigations who have a documented plan for ongoing review and re-evaluation.

Numerator – the number in the denominator who have a documented plan for ongoing review and re-evaluation.

Denominator – the number of people with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (such as general practices, hospitals, community services and local authorities) have care pathways in place that can support future diagnosis for people with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Healthcare professionals (such as doctors and nurses) ensure people with a suspected rare disease that remains undiagnosed after diagnostic investigations are on a care pathway that can support future diagnosis.

Commissioners ensure that they commission services that have care pathways that can support future diagnosis for people with a suspected rare disease that remains undiagnosed after diagnostic investigations.

People with a suspected rare disease that has not yet been formally diagnosed understand the planned pathway to diagnosis.

Source guidance

Patient experience in adult NHS services. NICE guideline CG138 (2012, updated 2021), recommendations 1.3.1 and 1.3.4.

Babies, children and young people's experience of healthcare. NICE guideline NG204 (2021), recommendation 1.2.17.

Equality and diversity considerations

People should be supported to overcome potential difficulties in accessing services, which may result from the person having to travel a long way to attend appointments, or from them having a disability, cognitive difficulties, or financial barriers. As rare diseases can be identified during pregnancy, diagnostic pathways should include maternity services. If virtual or remote access is used, consideration should be given to minimising digital

exclusion.

Quality statement 3: Information provision

Quality statement

People undergoing diagnosis for a rare disease, with a newly diagnosed rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations are provided with clear and accurate information to aid self-management.

Rationale

Clear and accurate information about rare diseases can help people self-manage these diseases, undertake activities of daily living and make informed choices. Information needs can change over time as these diseases progress. When information is unclear or inconsistent, it can increase anxiety and reduce people's ability to participate in decisions about their care. Many disease-specific patient and community organisations provide information on living with a rare disease. The Patient Information Forum publishes a list of certified organisations with information on rare diseases.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Process

a) Proportion of people undergoing diagnosis for a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations who receive clear and accurate information.

Numerator – the number in the denominator who report receiving information.

Denominator – the number of people undergoing diagnosis for a rare disease or with a

suspected rare disease that remains undiagnosed after diagnostic investigations.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

b) Proportion of people with a newly diagnosed rare disease who receive clear and accurate information.

Numerator – the number in the denominator who report receiving information.

Denominator – the number of people with a newly diagnosed rare disease.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (primary, secondary and tertiary care providers) ensure that their staff have access to information to help people undergoing diagnosis for a rare disease, with a newly diagnosed rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations with self-management. They also ensure staff can signpost these people to holistic support.

Healthcare professionals (such as doctors, nurses and allied health professionals) ensure that they know where to find information to help people undergoing diagnosis for a rare disease, with a newly diagnosed rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations with self-management. Staff also know how to signpost these people to holistic support.

Commissioners ensure that the services they commission to support people with a rare disease provide information to help with self-management and signpost to holistic support.

People having tests for a rare disease, with a newly diagnosed rare disease or with a suspected rare disease that has not yet been formally diagnosed are given information on their condition and any relevant patient organisations to aid with day-to-day self-

management of their condition. Any information provided as part of discussions with a healthcare professional should be age-appropriate and meet the person's accessibility needs. Family members and carers should be provided with information as needed.

Source guidance

Patient experience in adult NHS services. NICE guideline CG138 (2012, updated 2021), recommendation 1.5.11.

Babies, children and young people's experience of healthcare. NICE guideline NG204 (2021), recommendation 1.2.17.

Equality and diversity considerations

Information provided as part of discussions with a healthcare professional should be age-appropriate and meet the person's accessibility needs.

Quality statement 4: Shared decision making

Quality statement

People diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations are supported to make shared decisions throughout all stages of care.

Rationale

Clinical outcomes and patient satisfaction are likely to be better when decisions about care are made jointly between the person with the rare disease and their healthcare provider. A person's preferences about treatment options and outcomes should be discussed, including the impact of travel to specialised centres. People need to have enough information to make informed choices. This should include knowing how to access trusted sources of information.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Structure

a) Evidence that healthcare providers actively promote shared decision making for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

b) Evidence that healthcare providers promote the use of available decision aids, which

take account of the trade-off between potential benefits and harms, to help people make informed choices about treatments.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (such as primary, secondary and tertiary care) actively promote shared decision making for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations and provide staff with access to relevant patient decision aids.

Healthcare professionals (such as doctors, nurses and allied health professionals) ensure that people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations are given opportunities for shared decision making and to use relevant patient decision aids.

Commissioners ensure they commission services that embed shared decision making for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Peoplediagnosedwith a rare disease or with a suspected rare disease that has not yet been formally diagnosed reach joint decisions about care and treatment with healthcare professionals. This joint process helps people make decisions about their care that is right for them at that time (including the options of choosing to have no treatment or not changing what they are currently doing). Family members and carers should be included in shared decision making as appropriate.

Source guidance

Shared decision making. NICE guideline NG197 (2021), recommendations 1.2.1 and 1.3.1.

Definitions of terms used in this quality statement

Shared decision making

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about their care. It could be care that the person needs straightaway or care that may be needed in the future, for example, through advance care planning. It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. [NICE's guideline on shared decision making]

Equality and diversity considerations

Information provided as part of discussions with a healthcare professional should be age-appropriate and meet the person's accessibility needs.

Quality statement 5: Named healthcare professional

Quality statement

People diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations have a named healthcare professional who coordinates their care.

Rationale

Rare diseases often affect multiple parts of the body and involve multiple specialities and multidisciplinary teams. Having a named healthcare professional can help ensure care and support is coordinated and that the person can access relevant healthcare professionals, as needed.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Structure

Evidence of agreed specifications of the role and functions of named healthcare professionals for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

Process

a) Proportion of people diagnosed with a rare disease who have a named healthcare

professional.

Numerator – the number in the denominator who have a named healthcare professional.

Denominator – the number of people diagnosed with a rare disease.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

b) Proportion of people with a suspected rare disease that remains undiagnosed after diagnostic investigations who have a named healthcare professional.

Numerator – the number in the denominator who have a named healthcare professional.

Denominator – the number of people with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (such as specialist centres) agree a specification for the role and function of named healthcare professionals to coordinate care for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Healthcare professionals (such as GPs, specialists and allied health professionals) ensure that they know who the named healthcare professional is for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations and share information with them. If they are assigned as a named healthcare professional, they ensure that they carry out the role in accordance with the locally agreed specification.

Commissioners ensure that the services they commission to support people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after

diagnostic investigations have local agreement on the role and responsibilities of named healthcare professionals to coordinate care.

Peoplediagnosedwith a rare disease or with a suspected rare disease that has not yet been formally diagnosed are assigned a named healthcare professional. This person will support them to manage their condition, coordinate care, navigate the various services and ensure regular reviews of their care take place. Family members and carers are also provided with the contact details as appropriate.

Source guidance

Patient experience in adult NHS services. NICE guideline CG138 (2012, updated 2021), recommendation 1.4.1.

Babies, children and young people's experience of healthcare. NICE guideline NG204 (2021), recommendations 1.10.12 and 1.10.17.

Transition from children's to adults' services for young people using health or social care services. NICE guideline NG43 (2016), recommendation 1.2.5.

Social care for older people with multiple long-term conditions. NICE quality standard 132 (2016), quality statement 3.

Definitions of terms used in this quality statement

Named healthcare professional

A named professional with appropriate skills and knowledge who becomes familiar with the person and coordinates care and support to meet their long-term needs. Their responsibilities include working in partnership with the person to:

- arrange regular meetings to discuss the person's care and support, and invite people in the person's support network to contribute, including family, carers, independent advocates and practitioners from all services that support the person
- recognise and use the expertise brought by all members of the person's support network (not only those who are paid)

- develop and review the person's care and support plans.

[Adapted from NICE's quality standard on learning disability: behaviour that challenges (2015, updated 2019), statement 4]

Quality statement 6: Holistic needs assessment

Quality statement

People diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations have physical, psychological and emotional support needs assessed at key points of the care pathway.

Rationale

The physical, psychological and emotional support needs associated with rare diseases can change over time. They should be assessed during the diagnostic process and reassessed regularly to inform care plans. They can result in signposting to relevant support and referral to additional specialist services.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Structure

Evidence of arrangements to ensure that people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations have physical, psychological and emotional support needs assessed at key points on the care pathway.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

Process

a) The proportion of people diagnosed with a rare disease who had their physical, psychological and emotional support needs assessed when they reached a key point on their care pathway.

Numerator – the number in the denominator who had their physical, psychological and emotional support needs assessed.

Denominator – the number of people diagnosed with a rare disease who have reached a key point on their care pathway.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

b) The proportion of people with a suspected rare disease that remains undiagnosed after diagnostic investigations who had their physical, psychological and emotional support needs assessed when they reached a key point on their care pathway.

Numerator – the number in the denominator who had their physical, psychological and emotional support needs assessed.

Denominator – the number of people with a suspected rare disease that remains undiagnosed after diagnostic investigations who have reached a key point on their care pathway.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (such as specialist services) ensure that physical, psychological and emotional support needs are assessed at key points on care pathways for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Healthcare professionals (such as doctors, nurses and allied health professionals) assess physical, psychological and emotional support needs of people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations at key points on their care pathways. They use the results to inform each person's care plan and offer appropriate support.

Commissioners ensure that they commission services that assess physical, psychological and emotional support needs at key points on care pathways for people diagnosed with a rare disease or with a suspected rare disease that remains undiagnosed after diagnostic investigations.

Peoplediagnosed with a rare disease or with a suspected rare disease that has not yet been formally diagnosed are asked about physical, psychological and emotional support needs at key stages in the diagnosis and management of their condition.

Source guidance

Patient experience in adult NHS services. NICE guideline CG138 (2012, updated 2021), recommendations 1.3.1 and 1.3.4.

Babies, children and young people's experience of healthcare. NICE guideline NG204 (2021), recommendations 1.1.6 and 1.1.7.

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), psychosocial care: page 74, paragraphs 1 to 4.

Definitions of terms used in this quality statement

Key points on the pathway

These include:

- at referral for investigation
- at diagnosis
- transition between children's and adults' services

- during long-term follow up
- during palliative care.

[Adapted from NICE's guideline on improving outcomes in children and young people with cancer, psychosocial care: page 74, paragraph 3]

Equality and diversity considerations

People should be supported to overcome potential difficulties in accessing services, which may result from the person having to travel a long way to attend appointments, or from them having a disability, cognitive difficulties, or financial barriers.

Quality statement 7: Access to treatment

Quality statement

People with a rare disease have equitable access to treatments when recommended by each nation's health and care guidance body.

Rationale

Access to new treatments is subject to nation-specific commissioning criteria, and routing and funding mechanisms. For rare diseases, access can also be restricted because of a lack of awareness among healthcare professionals and where a person lives. People unable to access specialist centres are more likely to miss out on treatment. Monitoring uptake of treatments will ensure that people with a rare disease have equitable access to treatment.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Process

Uptake of recommended treatments for rare diseases.

Data sources:NHS Business Services Authority's data on NICE technology appraisals in the NHS in England (Innovation Scorecard). Data on the prescribing of NICE-approved medicines is also available on systems such as 'blueteq'.

What the quality statement means for different audiences

Service providers (primary, secondary and tertiary care) monitor and raise awareness of

recommended treatments for rare diseases and compare practice with other similar providers.

Healthcare professionals (such as doctors) ensure that they are aware of the recommended treatments for people with a rare disease and have mechanisms for monitoring any emerging treatments that may be an option.

Commissioners monitor the provision of treatments for rare diseases and compare practice between similar providers.

People with a rare disease are informed about and able to access recommended treatment that is appropriate for their condition.

Source guidance

NICE's commentary on achieving and demonstrating compliance with NICE-approved medicines or treatments.

Definitions of terms used in this quality statement

Equitable access

People can access care, treatment and support when they need to and in a way that works for them, which promotes equality, removes barriers or delays and protects their rights. [Care Quality Commission's Assessment Framework (2024)]

Equality and diversity considerations

People should be supported to overcome potential difficulties in accessing treatment, which may result from the person having to travel a long way to attend appointments, or from them having a disability, cognitive difficulties, or financial barriers.

Quality statement 8: Clinical research

Quality statement

People with a rare disease are offered the opportunity to take part in clinical research, if available and they are eligible.

Rationale

Barriers to accessing clinical research can be greater for those people with a rare disease who do not have access to specialist centres and multidisciplinary teams. Measuring participation in clinical research will help improve equitable access. Healthcare providers, specialist centres and networks should identify relevant active research on rare diseases and help the person make an informed choice about whether or not to take part in research.

Quality measures

The following measures may be useful to support assurance and improvement. They are examples of how the statement could be measured but may require adaption depending on local, regional and national commissioning arrangements.

Structure

Evidence of arrangements to ensure that people with a rare disease are assessed for eligibility for relevant clinical research and offered the opportunity to take part.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

Process

The proportion of people with a rare disease and eligible for clinical research who are offered the opportunity to take part.

Numerator – the number in the denominator offered the opportunity to take part.

Denominator – the number of people with a rare disease and eligible for clinical research.

Data source: Data may need to be collected at local service, specialist service or network level depending on the commissioning arrangements.

What the quality statement means for different audiences

Service providers (secondary and tertiary care providers) ensure that multidisciplinary teams discuss whether people with a rare disease are eligible for any clinical research and, if they are, promote participation in the research.

Healthcare professionals (such as doctors, nurses and allied health professionals) identify relevant clinical research for people with a rare disease, assess eligibility and offer opportunities to take part.

Commissioners ensure that the services they commission for people with a rare disease identify relevant clinical research and support participation.

Peoplewith a rare disease are offered the opportunity to take part in clinical research that has been identified as suitable for them and are supported to participate.

Source guidance

Improving outcomes in children and young people with cancer. NICE guideline CSG7 (2005), psychosocial care: page 123.

The Department of Health and Social Care's England Rare Diseases Action Plan 2025 recognised the need to improve access to research for people with rare diseases based on data from the NIHR's Be Part of Research Platform. Steps have been taken to increase the number of rare conditions included on the platform and the number of relevant clinical trials available. The measures in this statement will aim to increase this further. Other local actions will also improve access to research.

Equality and diversity considerations

People should be supported to overcome potential difficulties in participating in clinical research, which may result from the person having to travel a long way to attend appointments, or from them having a disability, cognitive difficulties, or financial barriers. Proactive measures should be used to improve participation in research among under-represented groups. Information provided as part of discussions should be age-appropriate and meet accessibility needs.

About this quality standard

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. NICE quality standards draw on existing NICE or high-quality external guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

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, this may not always be appropriate in practice. Taking account of safety, shared decision making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standards advisory committees for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this quality standard are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

For all quality statements where information is given, it is important that people are provided with information that they can easily read and understand themselves, or with

support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age-appropriate. People should have access to an interpreter if needed. People should also have access to an advocate, if needed, as set out in NICE's guideline on advocacy services for adults with health and social care needs.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's Accessible Information Standard or the equivalent standards for the devolved nations.

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

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Endorsing organisations

This quality standard has been endorsed by the following organisations, as required by the Health and Social Care Act (2012):

- NHS England
- Department of Health and Social Care