



# NICE strategic principles: a complementary approach to public health, social care and rare disease topics

Education

Published: 29 May 2024

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# Overview

NICE brings a set of unique strengths to the areas of public health, social care and rare diseases. However, guidance on these topics may draw on a wider evidence base, and population benefits and value for money of interventions in these areas is often harder to articulate. Therefore, we are introducing a set of complementary strategic principles to guide prioritisation in these areas and ensure they are not disadvantaged by the new NICE-wide topic prioritisation process.

The strategic principles outlined are designed to be used alongside NICE's prioritisation criteria and will help to ensure we are delivering against NICE's core purpose and objectives. They sit alongside, but do not replace, the core principles that underpin all NICE guidance and standards. It is intended that they will be applied to all relevant areas of work at NICE and support the prioritisation board's decision making in these areas. Prioritisation board membership will include representation from public health and social care to support interpretation of these principles in practice.

## Oversight and engagement

This work was guided by a strategic principles working group, with oversight from the NICE Clinical Directorate. In 2023, the working group met with key internal representatives for each area before holding a series of internal and external engagement events with relevant stakeholders. The external stakeholders engaged included representatives from the voluntary and community sector; patient advocacy groups; professional membership organisations; topic-specific advisory groups, boards and forums; local government; public health, health and social care partners; academia and other arms-length bodies.

# Strategic principles for public health

## 1.1 Definition

Public health works to protect and improve the health of the population as a whole; supporting all people in society to stay healthy, avoid getting ill and live longer healthier lives. For NICE, this includes work on a range of areas including early detection of symptomatic disease, supporting healthy behaviours, and promoting access to healthy environments.

## 1.2 Background

The regulations arising from the Health and Social Care Act 2012 provide NICE with a function of giving advice or guidance, providing information and making recommendations about any matter concerning or connected with the provision of public health services in England. The legislation also provides that the function is only exercisable on the direction of Secretaries of State.

Public health and prevention are increasingly important in a landscape of limited resources and increasing demand for health and care services. The public health landscape has changed greatly in recent years with the creation and dissolution of some central organisations, and the establishment of integrated care systems in England. In light of this shifting landscape and NICE's new centralised prioritisation approach, it is timely for us to work with partners to clearly define our role and set out where we can add most value to the system.

## 1.3 Principles

The following principles will be used to guide our approach to the prioritisation and development of public health guidance:

- We will prioritise developing and updating public health guidance only where there is new evidence, an opportunity for system support and health gain, and a clear route to effective implementation.

- We will recognise the importance of prevention as well as treatment when scoping guidance across the NICE portfolio.
- We will focus our selection of public health guidance to support implementation in practice. This will mean being explicit about our intended audience wherever possible and thinking beyond implementation in traditional health settings.
- Where there is appropriate evidence, we will consider the impact of the wider determinants of health (such as social, economic and environmental factors) on health outcomes during the prioritisation of new and updated guidance across NICE.
- We will recognise that the nature of evidence within public health may be different to that available within clinical medicine.
- We will ensure alignment with other relevant organisations within the health and care system, such as NHS England, UK Health Security Agency and the Office for Health Improvement and Disparities. We will collaborate on areas of joint interest and avoid duplication of effort by focusing on the areas where we can add the greatest value.
- We will work closely with research partners to highlight where research gaps limit evidence-based recommendations.

# Strategic principles for social care

## 1.4 Definition

NICE recognises that social care comprises a wide range of activities delivered by a complex system of organisations and professionals. This includes areas such as social work, residential, domiciliary and rehabilitation services, safeguarding, community and family support alongside many other services. Predominantly led by local authorities, the underpinning values of social care are centred around supporting the independence, choice and autonomy of individuals, safeguarding vulnerable people from harm and developing communities that are inclusive, accessible and respect diversity. Unlike healthcare, social care is not always free at the point of access and many aspects of social care are charged for or self-funded by individuals and families.

## 1.5 Background

The regulations arising from the Health and Social Care Act 2012 provide NICE with a function of giving advice or guidance, providing information and making recommendations about any matter concerning or connected with the provision of social care in England. The legislation also provides that the function is only exercisable on the direction of Secretaries of State.

Evidence-based practice is becoming increasingly important within social care and, in an extremely challenged system, there is a moral imperative to use resources for maximum benefit. NICE can help to ensure social care is based on reliable evidence regarding what works. The move towards new and integrated ways of working, including the establishment of integrated care systems in England, offers new opportunities. NICE is well placed to bridge the gap between health and social care and support best practice within integrated systems of care.

## 1.6 Principles

NICE recognises the significant interdependence between health and social care. We are committed to supporting an equal partnership that recognises the importance of both in addressing current challenges in the health and care system.

The following principles will be used to guide our approach to the prioritisation of social care guidance:

- We will seek to integrate social care in all our guidance, where appropriate, embedding a social care lens across prioritisation and subsequent guidance development.
- We will use the partnership working opportunities presented within integrated care systems and other models of integration to inform our approach to prioritisation. Preference will be given to the interface between health and care provision, favouring integrated outputs over standalone guidance where this is feasible, useful and usable.
- We will not prioritise standalone social care guidance unless there is a compelling reason to do so. For example, where there is significant new evidence emerging on a cross-system priority combined with a clear route to effective implementation.
- We will focus on the questions that matter most to the sector and topic areas where sufficient evidence exists to support recommendations, and there are clear routes to implementation.
- We will recognise that the nature of evidence within social care may be different to that available within clinical medicine.
- We will focus our selection of social care guidance to support implementation in practice. This will mean being explicit about our intended audience wherever possible and thinking beyond implementation in traditional health settings.
- We will work closely with research partners to highlight where research gaps limit evidence-based recommendations.



# Strategic principles for rare diseases

## 1.7 Definition

A rare disease, as defined by Orphanet, is a condition that affects less than 1 in 2,000 people, and NICE considers diseases that affect less than 1 in 50,000 people to be ultra rare.

## 1.8 Background

Rare diseases are often severe, usually life limiting and often occur in the paediatric population where the impact of effective treatments on the individual and their family are profound. The [Department of Health and Social Care's UK Rare Diseases Framework](#) estimates that there are over 7,000 rare diseases, 80% of which have an identified genetic origin. One in 17 people in the UK are affected by a rare disease at some point in their lives, which amounts to over 3.5 million individuals. People with rare diseases can be at risk of becoming unsupported in the healthcare system. Populations are small and geographically dispersed, and so the impact of national work can be underestimated. This, coupled with the lack of evidence on disease course and effective treatments, means that guidance on rare diseases may be overlooked. It is therefore important to ensure that these patients are afforded an equitable focus. The highly specialised technologies programme provides guidance for ultra-rare diseases with the aim of encouraging research and development while securing fairer and more equitable access to treatment in this area of high unmet need.

## 1.9 Principles

The following strategic principles outline NICE's approach to developing guidance relating to rare diseases and will inform decision making by NICE's prioritisation board:

- We aim to create an attractive environment that stimulates innovation for global researchers, developers and pharmaceutical companies to find and develop innovative and cost-effective treatments for severely life limiting or debilitating rare diseases with few or no treatment options currently available. We will do this by considering whether a condition significantly shortens life or severely impairs its quality, how rare it is and

the availability of existing treatments before evaluating topics and new technologies for cost effectiveness.

- With the exception of health technology evaluations, where NICE's responsibilities are clearly defined, we will not routinely produce guidelines that relate to single rare diseases. Instead, we will seek to identify commonalities between conditions that enable us to provide products that can be applied across multiple rare disease groups.
- We will proactively collaborate with rare disease stakeholders, ensuring we communicate with patients and experts across multiple organisations to inform a shared understanding of NICE methods and processes in both clinical guidelines and technology appraisals. We will also ensure alignment with the [UK Rare Diseases Framework](#) and work with stakeholders to increase the evidence base relating to rare diseases.

ISBN: 978-1-4731-6154-2