

May 2024

# NICE Listens | Prioritisation dialogue

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Full research report for NICE

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## Executive summary

### Objectives and methodology

The [National Institute for Health and Care Excellence](#) (NICE) helps practitioners and commissioners deliver the best care, fast, while ensuring value for the taxpayer. NICE is transforming to ensure it can meet the opportunities and challenges of the changing health and care landscape.

Every year, NICE produces hundreds of guideline recommendations and guidance on numerous medical technologies. This guidance provides evidence-based recommendations to help health and care professionals to prevent ill health, promote good health and improve the quality of care and services. With the health and care system under significant pressure, NICE needs to prioritise guidance development activity to focus on what matters most. It is doing this by developing a NICE-wide prioritisation and topic selection approach, which will be underpinned by stakeholder engagement.

How NICE prioritises its activities will have consequences on health and social care delivery, so it is essential that it understands the opinion of the public (as taxpayers funding the health service, and as potential users) on this significant change.

In September 2023, NICE and [Sciencewise](#) commissioned [Thinks Insight & Strategy](#) to run a public dialogue to:

- Engage a diverse and reflective section of the public on how NICE should prioritise topics for the guidance it produces.
- Explore and define which aspects of prioritisation are most important to people.
- Understand the values and principles that underlie people's views, focusing on how they balance trade-offs when prioritising one aspect over another.

The dialogue involved a total of 14 hours of engagement over 5 workshops, in 4 locations across England (Plymouth, London, Preston and Birmingham), with 56 people in total. The 5 workshops were conducted over 4 weeks in November and December 2023.

As a starting point for the discussions, NICE proposed 6 domains or factors to consider when weighing up different guidance topics. The domains were:

- health and care need
- evidence availability
- system impact
- budget impact
- health inequalities
- environmental sustainability.

The dialogue was designed with the input of stakeholders and an oversight group. Their role was to provide feedback, through consideration of which topics to cover, what information to provide to participants (for example, selection of case studies), and which specialists to invite to take part in the workshops.

NICE will use the findings from this dialogue to help develop a prioritisation framework, which will be used to guide decisions on prioritisation and topic selection.

## Key findings

Participants joined the dialogue with a clear understanding, learnt from personal experience, word of mouth, and the news, that the health and care system faces considerable challenges. But they acknowledged that they had little awareness of NICE's role or the full complexity of the health and care system.

Participants were supportive of the 6 domains that NICE proposed. They agreed that they were important criteria for NICE to use when prioritising topics for guidance. However, health and care need and evidence to support guidance development were considered the most important areas for NICE to consider.

While initial discussions about prioritisation were structured around NICE's 6 proposed domains, participants discussed their own priorities, preferences, and values much more widely. These wide-ranging discussions have been summarised in a series of principles, which represent the values and criteria that participants think should underlie NICE's prioritisation process.

**Principle 1: Use a broad definition of health and care need and be transparent about how decisions are made.** There was a clear consensus among participants that health and care need should focus on people, rather than conditions, outcomes, systems, or budgets. Across locations, participants consistently maintained that health and care need was the most important domain for NICE to consider when prioritising topics for guidance. They described a range of dimensions within health and care need that should be considered:

- scale and severity of a condition
- people's experiences
- quality of life
- the burden of care
- people's ability to contribute to society and the economy.

Participants acknowledged that focusing on these multiple dimensions might be challenging in practice, and judgement would need to be applied if all are not pointing in the same direction. They were open to each of these dimensions being considered as long as NICE was transparent about how its decisions had been informed by them.

**Principle 2: Prioritise having a direct impact.** All participants understood that NICE has limited resources. They wanted NICE to develop guidance that would have the most impact, that is, where they could see a clear link to improved health outcomes. They thought this was most likely when guidance related to health and care settings. This principle underlies many of the wider views that shaped participants' views on how NICE should prioritise topics.

**Principle 3: Support fairness within the health and care system.** Health inequalities is a complex and ethically challenging concept, on which public views have been shown to change over time and in response to new information. The health inequalities domain was divisive when first introduced and remained so throughout this dialogue. The views of some participants changed as they discussed how health inequalities are defined, how they arise and how they can be addressed. Some participants were initially resistant to the existence of health inequalities, particularly where they did not understand or acknowledge the cause. These views shifted when participants deliberated over case studies that were clear about the impact of health inequalities – and where the discussion focused more on impacts, and less on causes. Participants' recognition of the role played by health inequalities in health grew over the course of the dialogue, but they were sceptical about how much influence NICE could have. For example, when trying to address the wider determinants of health, such as housing and employment, which they preferred to be addressed by the Government or the private sector. While this scepticism never wholly dissipated, they arrived at a broad consensus that 'fairness' was an important principle for NICE to uphold through the guidance it chose to produce. Despite the varied views on the specific health inequalities domain, there is a strong link between the principle of NICE supporting fairness and participants' preference for NICE to focus on those with the greatest health and care need (see principle 1).

**Principle 4: Prioritise prevention where NICE can directly impact people's health outcomes.** Participants believed that prevention is important in reducing health and care need, and system and budget pressures. Given the importance, they felt prevention should be part of NICE's approach to prioritising topics. However, participants thought prevention should only be a priority for NICE guidance where this could have a clear direct impact on people's health outcomes (for example, better self-management of conditions and early diagnosis). They believed prevention relating to people's individual health behaviours, such as smoking, physical activity and alcohol consumption, should not be a high priority for NICE because of scepticism over the extent to which NICE, or the health and care system, can influence them. This view is consistent with that raised in relation to prioritising based on health inequalities.

**Principle 5: Identify and act on 'quick wins'.** Participants wanted NICE to be pragmatic and take advantages of opportunities to have an impact, when they arise. They believed NICE should pursue opportunities to produce guidance

quickly. And to produce guidance that can be implemented quickly and make a real difference, without imposing significant costs or negative impacts on people's outcomes and experiences.

**Principle 6: Reflect a broad definition of evidence.** The availability of evidence was considered a prerequisite for creating guidance. However, participants defined evidence as including expert opinion and people's experiences, as well as randomised controlled trials. This meant participants assumed evidence is almost always available for guidance to be developed and therefore should not determine priority to the same degree as health and care need. They were comfortable with decisions being based on limited evidence in some situations – evidence availability was not seen as a reason to deprioritise a topic involving a significant health and care need. They also wanted evidence to be developed in an iterative way, with NICE taking an active role in directing the generation of new evidence where needed through high quality research.

**Principle 7: Budget and system impact considerations should not lose sight of the people receiving care.** Participants were aware of, and concerned by, the financial, resource and infrastructure pressures facing the health and care system. Participants expected NICE to reduce budget and system pressures where possible through its guidance. But they also wanted NICE to ensure that people's experiences of receiving care were not compromised. Guidance should not add an unnecessary burden on the system, but system impact should not act as a barrier to addressing urgent health and care need. Participants consistently emphasised that they did not want to see a focus on budget and system impacts distract from a focus on the people receiving care.

**Principle 8: Address sustainability, as long as there is no detrimental impact on people's care.** Despite initially struggling to see the relevance of environmental sustainability to NICE's prioritisation framework, participants' views shifted over the course of the dialogue. They discussed the links between healthcare and sustainability, as well as the responsibilities that public institutions have in taking steps to minimise their environmental impact. Consequently, participants suggested that, if there are no negative impacts on people's care, NICE should ensure environmental sustainability is part of prioritisation decisions.

# 1. Introduction to the dialogue

## Background to the dialogue

### What is NICE?

The [National Institute for Health and Care Excellence](#) (NICE) is a non-departmental public body of the Department of Health and Social Care in England. NICE's role is to improve outcomes for users of the NHS, public health services, and social care. It does this by providing guidance that promotes high quality care across health, public health, and social care.

### How can NICE decide what matters most?

NICE is transforming to ensure it can meet the opportunities and challenges of the changing health and care landscape. One of NICE's key priorities is to focus on what matters most. Understanding the preferences and aspirations of health and care system users and the wider public is important to NICE. With the health and care system under significant pressure, engaging the public on how NICE should prioritise its guidance is of growing importance.

NICE cannot produce guidance on everything all at once. Therefore, it is developing a NICE-wide prioritisation and topic selection framework. The framework will help NICE:

- deliver guidance that has the most positive impact for people using the health and care system
- allocate resources
- make effective use of NICE's skills.

In September 2023, NICE commissioned [Thinks Insight & Strategy](#) to engage members of the public in a dialogue about how NICE should prioritise topics for guidance to the health and care system. The project was supported by [Sciencewise](#).

Sciencewise is an internationally recognised programme that enables policy makers and researchers to develop socially informed policy and strategy, with a particular emphasis on science and technology. The programme is led and funded by [UK Research and Innovation](#).

## Objectives of the dialogue

The objectives of the dialogue were to:

- engage a diverse and reflective section of the public on how NICE should prioritise topics for the guidance it produces
- explore and define what aspects of prioritisation are most important to people
- understand the values and principles that underlie people's views, focusing on how they balance trade-offs when prioritising one aspect over another.

As a starting point for the discussions, NICE proposed 6 domains or factors to consider when weighing up different guidance topics. The proposed domains formed the lens through which participants discussed NICE's prioritisation challenge, and are described in more detail in section 2.

NICE will use the findings from this dialogue to help develop a framework to guide decisions on prioritisation and topic selection.

### **Scope of the dialogue**

NICE produces a range of guidance that support the health and care system to improve care. This dialogue focused on NICE guidelines and guidance on medical technologies.

NICE also plays a central role in deciding which medicines should be available through the NHS; however, this was not within scope for the dialogue as it is governed by a [separate topic selection process](#).

### **A note on this dialogue and its findings**

NICE's guidance has the potential to influence the whole health and care system, in all its complexity. It can focus on incredibly specific processes, or some of the broadest challenges that society faces.

The challenge of prioritising NICE's guidance is similarly complex, and many of the factors that NICE is considering are difficult to define or have the potential to be controversial.

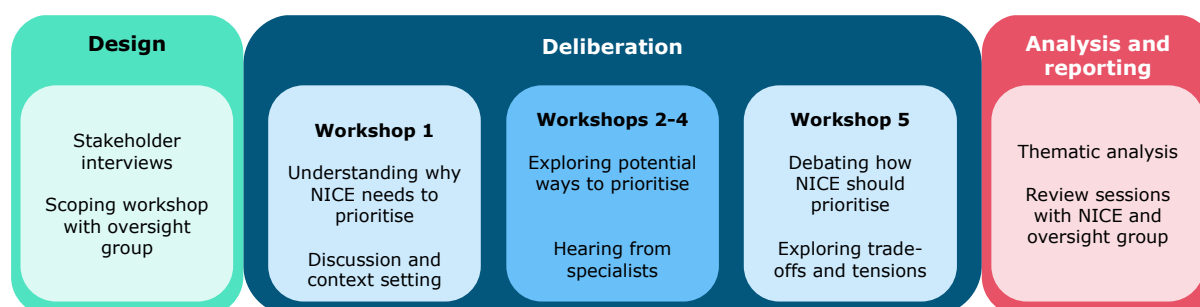
NICE wanted to know what the public thinks about a wide range of factors affecting the health and care system, which meant individual topics were not covered in as much depth as they were in the previous NICE Listens dialogues on health inequalities and sustainability. This gives a different perspective on the topics, less informed by specialist evidence and closer to the views participants held before taking part. With this in mind, it is important to consider the findings alongside other evidence.

## 2. Methodology

The NICE Listens prioritisation dialogue used deliberative methods and was designed in line with the [Sciencewise Guiding Principles and Quality in Public Dialogue](#). It brought together a diverse sample of the public who were provided with information and engaged with subject specialists.

Participants were supported to consider the full breadth of the issues relating to prioritisation of topics for NICE guidance development. They explored areas of consensus and disagreement, rather than aiming to come to a single view or conclusion. Figure 1 illustrates the dialogue process.

**Figure 1: Overview of the dialogue process**



### Designing the dialogue

Thinks Insight & Strategy, the NICE project team and the oversight group designed the dialogue process through a series of meetings.

The oversight group met 3 times over the course of the project. They reviewed and provided feedback on the dialogue design, as well as discussing the implications of the findings from participants.

Stakeholders were engaged to understand how the prioritisation framework will be used by NICE and to explore key issues and potential areas of contention.

Stakeholders with expertise in the domains proposed for the prioritisation framework, including those working at NICE and external staff (including within the NHS, charities, and think tanks) gave presentations.

Interviews were conducted with stakeholders with wider expertise or experience of the health and care system and using NICE guidance.

A full list of the oversight group and stakeholders is included in appendix 1.

Discussions with stakeholders and the oversight group informed the dialogue design, through consideration of which topics to cover, what information to provide to participants (for example, selection of case studies), and which specialists to invite to take part in the workshops.

## The workshops

The dialogue took place between Saturday 18 November and Saturday 9 December 2023. It consisted of 2 half-day face-to-face workshops and 3 online workshops lasting 2 hours; a total of 13 hours of deliberation.

Below is an overview of the structures of each workshop. Full details of this – including the discussion guides used and information shared – can be found in appendices 3 to 5.

### Understanding why NICE needs to prioritise: workshop 1

Workshop 1 introduced the participants to the dialogue process and established the context for their discussions. Participants were provided with information about the health and care system and NICE's role and remit. They explored the topic of prioritisation and why it is important for NICE. Discussions were broad, exploring what mattered most to participants in health and care, as patients and citizens, and capturing spontaneous views of what NICE should consider when prioritising. The participants were then introduced to NICE's 6 proposed domains to gather their initial responses.

Table 1 gives an overview of the structure of workshop 1, which introduced NICE's prioritisation challenge and the proposed domains.

**Table 1: Workshop 1 overview**

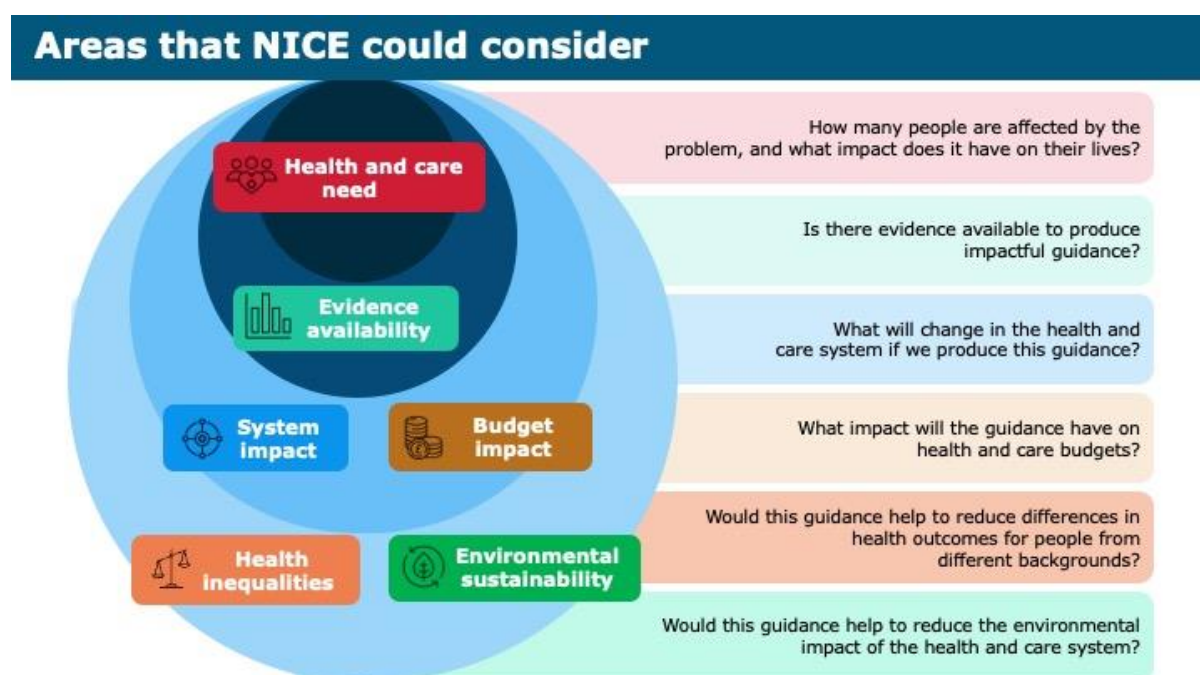
| Workshop | Topics                                                                                                                                                                                                                                                                                                                                         | Information provision and stimulus                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1.       | <ul style="list-style-type: none"> <li>• Introductions and getting to know each other.</li> <li>• Discussion of the challenges and opportunities facing the health and care system.</li> <li>• Discussion of prioritisation and why it is important and necessary for NICE.</li> <li>• Initial reactions to the 6 proposed domains.</li> </ul> | <ul style="list-style-type: none"> <li>• Information on how the health and care system operates and the challenges it faces.</li> <li>• Introduction to NICE and its role and remit.</li> <li>• Explanation of NICE guidance, including examples.</li> <li>• NICE representatives present to answer questions.</li> <li>• Introduction to NICE's prioritisation challenge – "how can NICE decide what matters most?"</li> <li>• Introduction to the 6 proposed domains and their definitions.</li> </ul> |

## Exploring potential ways to prioritise: workshops 2 to 4

Workshops 2 to 4 comprised a deep dive into NICE's 6 proposed domains or factors to consider when weighing up different guidance topics for prioritisation. Two domains were covered at each workshop, and discussion of the challenges and trade-offs within each domain was prompted by sharing information.

Figure 2 represents how the proposed domains were presented to participants during the workshops.

**Figure 2: NICE's 6 proposed domains for prioritising guidance topics**



When the diagram in figure 2 was presented to participants, facilitators reiterated that the proposed domains were not placed in any intended order – other than the order in which they would be covered in workshops 2 to 4. Questions about their initial reactions to the proposed domains and general importance were asked, followed by a ranking exercise, to avoid 'leading' participants to interpret the diagram in a particular way (that is, that those appearing at the top of the diagram are more important).

Table 2 provides an overview of workshops 2, 3 and 4, which covered NICE's proposed domains in turn.

**Table 2: Workshops 2 to 4 overview**

| <b>Workshop</b> | <b>Topics discussed</b>                                                                                                                                                                                                                                                                 | <b>Information and stimulus material provided</b>                                                                                                                                                                                                                                                                                                           |
|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>2</b>        | <ul style="list-style-type: none"> <li>Information about health and care need and evidence availability, and why these are important for NICE to consider.</li> <li>The implications and trade-offs of prioritising based on health and care need and evidence availability.</li> </ul> | <ul style="list-style-type: none"> <li>Detailed definitions of the health and care need and evidence availability domains.</li> <li>Specialist presentations of the current challenges and opportunities within each area.</li> </ul>                                                                                                                       |
| <b>3</b>        | <ul style="list-style-type: none"> <li>Information about budget and system impact, and why these are important for NICE to consider.</li> <li>The implications of prioritising based on budget and system impact through case studies.</li> </ul>                                       | <ul style="list-style-type: none"> <li>Detailed definitions of the budget impact and system impact domains.</li> <li>Panel discussion with specialists.</li> <li>Case studies for budget impact (wound care, treating glaucoma, managing type 1 diabetes) and system impact (virtual wards, fall prevention programme).</li> </ul>                          |
| <b>4</b>        | <ul style="list-style-type: none"> <li>Information about health inequalities and environmental sustainability, and why these are important for NICE to consider when prioritising.</li> <li>The trade-offs and what is important within each area.</li> </ul>                           | <ul style="list-style-type: none"> <li>Detailed definitions of the health inequalities and environmental sustainability domains.</li> <li>Question and answer session with specialists.</li> <li>Case studies for health inequalities (weight management, living in cold homes) and environmental sustainability (asthma inhalers, cannulation).</li> </ul> |

## Debating how NICE should prioritise: workshop 5

Workshop 5 explored trade-offs between, and within, the domains. This exposed underlying values, beliefs, and attitudes that informed participants' responses. Participants also discussed key considerations that they believed should underlie NICE's prioritisation framework.

Table 3 provides an overview of the workshop 5, which invited participants to move beyond consideration of each domain in isolation.

**Table 3: Workshop 5 overview**

| Workshop | Topics                                                                                                                                                                                                                                                                                                                                                                                             | Information provision and stimulus                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|----------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 5        | <ul style="list-style-type: none"> <li>Recap and review of key content covered in workshops 2 to 4.</li> <li>Exploration of the trade-offs between and within areas.</li> <li>Exploration of what matters most – the importance ascribed to the different domains.</li> <li>Discussion of case studies to identify key principles that should underlie NICE's prioritisation framework.</li> </ul> | <ul style="list-style-type: none"> <li>"What if..." case studies:               <ul style="list-style-type: none"> <li>There is not much evidence? (COVID-19)</li> <li>Evidence will never be good? (rare conditions)</li> <li>We put some people at a disadvantage? (digital health technology)</li> <li>It is very hard to do? (barriers to implementation)</li> <li>There is a chance to make a difference? (desflurane anaesthetic gas)</li> <li>Some people have worse health outcomes than others? (maternal mortality among Black, Black British, Caribbean and African women)</li> </ul> </li> </ul> |

## Information sharing and stimulus

Across the course of the dialogue, participants were introduced to information that helped them develop their understanding of prioritisation, the 6 proposed domains and the challenges facing NICE. This information included:

- wider contextual and background information
- case studies on hypothetical topics for prioritisation
- specialist input via presentations and discussion with participants.

The case studies covered a range of specific health and care needs. This enabled participants to draw out issues that they might not have spontaneously considered – for example, by presenting participants with situations outside of their own personal experience.

In workshop 5, further case studies were used, which encouraged participants to consider caveats and trade-offs around what could or should be prioritised when making decisions about guidance. Some of these case studies focused on topics that would score particularly well or poorly in a particular domain, or on topics that had produced polarised views in workshops 2 to 4. The case studies were chosen to highlight the following issues:

- evidence of stark inequalities for some health outcomes
- topics for which there is a lack of high quality or substantial evidence
- changes in practice that:
  - have an overall positive impact on the health and care system but put some groups at a disadvantage
  - have a positive environmental impact but little or no impact on people's care.

## **Who was involved in the dialogue**

### **Members of the public**

Professional recruiters (accredited by the Market Research Society) were used to recruit 56 people from across England, who were broadly reflective of the general population in terms of demographic criteria.

Participants were recruited from 4 locations (Birmingham, London, Plymouth and Preston).

Quotas were used to ensure the diversity of the sample in terms of health experiences, health behaviours, and potential experience of health inequalities. These quotas reflected the intended sample and were largely met in the sample ultimately achieved.

A detailed breakdown of the demographics of those who took part can be found in appendix 1.

All participants received an incentive payment of £375 as a thank you for their time and effort.

### **Specialists**

Specialists were recruited from:

- a wide range of professional backgrounds
- academia
- policy making
- the public sector
- those working day-to-day on the frontline of health and social care services.

The specialists' role involved presenting information and engaging in discussions (for example, challenging and probing participants' viewpoints with the support of facilitators).

Each specialist was briefed by a senior member of the Thinks Insight & Strategy's team.

A table listing the specialists who took part is included in appendix 1.

Participants also had the opportunity to hear from NICE representatives, including those with specific expertise in the 6 proposed domains, the chief medical officer at NICE, and members of the team developing the prioritisation framework.

## **Analysis**

Each workshop was recorded and transcribed. Notes were analysed to identify common themes and areas of difference between participants. These were sometimes reflective of where participants lived.

Following each workshop, the project team discussed and compared emerging findings and observations.

The common themes and areas of difference expressed by participants were used by Thinks Insight & Strategy to generate a series of principles. These principles capture the key areas that participants think NICE should focus on when prioritising its guidance.

The facilitators noted the level of agreement or disagreement between participants, the strength of any emotions expressed and non-verbal cues. Details of the method of analysis can be found in appendix 6.

## **About this report**

NICE's 6 proposed domains were used to organise the workshops and information giving, but discussions went beyond the domains and views on each domain varied widely.

This report provides an analysis of the key dialogue themes and their implications for NICE. It does not follow the same structure as the workshops (that is, exploring each domain in turn). Instead, it is centred around an analysis of the principles that appeared to inform participants' views on how to prioritise what matters most. The report presents the participants' opinions, which may not always be aligned to the facts or evidence-based knowledge.

The principles are covered in sections 5 to 12 and are presented in order of importance, starting with those where there was most consensus between participants, through to those where there was more variation or disagreement.

Each of these sections provides detail on:

- **what participants said** – their views, how they changed through the dialogue, and where there was more or less consensus
- **what this means for NICE when prioritising** – here, the Thinks Insight & Strategy's team reflect on the implications of participants' views for NICE.

A glossary of terms used throughout this report is included in appendix 7.

### 3. Participants' views on the challenges facing the health and care system and NICE

#### Participants' views on the health and care system and the Government

##### The health and care system in England

At the start of the dialogue, participants shared their lived experience of navigating the health and care system. Discussions mostly focused on NHS settings, but social care was mentioned when referencing how the COVID-19 pandemic had impacted the system. In workshop 1, participants across the 4 locations spontaneously raised the following issues:

- an ageing population

staffing numbers in both health and social care

- waiting times for routine treatment
- people's experiences within the health and care system.

"You go to the GP for a quick ache or pain but wait 2 years for an appointment."

Throughout the dialogue and regardless of location, they frequently mentioned system pressures (for example, waiting times, lack of integrated care). The NHS staff strikes and working conditions (for example, pay, wellbeing) were also top-of-mind for participants.

"Sickness rates of NHS staff are very high. And just going back to the paramedics before they took me to my hospital...there was 2- and 3-hours backlogs of ambulances."

This experience of the current challenges meant participants tended to be sceptical that the health and care system had the capacity to do more.

Participants' dissatisfaction with health services is supported by wider polling data. A [report on the Mood of the Nation 2023 by Thinks Insight & Strategy](#) found that 54% of the public feel the NHS and social care is doing 'badly'. Another report on the [Public perceptions of health and social care \(May 2023\) by the Health Foundation and Ipsos](#) found that the public's top priorities for the NHS were:

- addressing the pressure on, or workload of, staff (40%)
- increasing staff numbers (39%)
- reducing waiting times (34%).

Furthermore, participants acknowledged that they had little awareness of the complexity of the health and care system, and of the multiple organisations involved. This meant their views on prioritisation (and how this works in practice) changed over time as they were exposed to information, spoke with specialists, and discussed issues together.

## Trust in the Government

During workshop 1, some participants voiced their lack of trust in the Government, saying it is not running public services effectively. They frequently shared their view that poor government handling of the COVID-19 pandemic created additional pressures for the health and care system. It should be noted that the workshop took place during the time of the COVID-19 inquiry, which meant that this topic was regularly in the news and may have influenced discussions.

Low trust in the Government among participants resulted in broad pessimism about the resilience of UK public services – including health and care services, specifically – and their ability to change or improve. The [May 2023 polling by the Health Foundation and Ipsos](#) found similar attitudes in relation to pessimism about the resilience of the NHS.

## How participants define 'prioritisation'

Participants were tasked with discussing what the term 'prioritise' means to them, thinking about their own lives and how they prioritise tasks day-to-day. Several factors emerged:

- whether the task is essential or non-negotiable
- the immediacy or urgency of the task
- their own capability to complete the task.

Initially, participants viewed prioritisation as choosing 1 task over another. They struggled to separate the process of prioritising (that is, the 'how') from the outcomes of prioritising (that is, the 'what'). This meant participants initially found it challenging to see how NICE could come to a decision about what to do when faced with equally pressing needs.

"It's going to be impossible to determine what to focus on. If there's 2 large groups of people who have completely different conditions, how are we going to decide which one needs NICE's guidance and expertise? Would you choose that over the other one ... if they both have equal importance?"

## Participants' views on NICE's prioritisation challenge

Figure 3 was used throughout the dialogue as a reminder of the purpose and importance of NICE hearing public views.

### Figure 3: NICE's prioritisation challenge and the purpose of the public dialogue



Over the course of the dialogue, participants developed an understanding of the challenges facing NICE when it is making decisions about prioritisation. They initially described 2 specific challenges they felt NICE must face, which they returned to throughout the dialogue:

- **Current resource pressures on the health and care system.** Participants thought NICE must also be facing resourcing challenges.
- **Health being an emotive subject.** Participants thought it must be hard for NICE to make decisions that affect the health of people and the care they receive. They described the difficulties they themselves would likely face if weighing up health-related decisions.

"It's very difficult to be dispassionate about this. Where do NICE's requests for interventions originate? ... How you get to it, who makes the decisions? Well, they're better people than me, because I have no idea how you would prioritise."

## Views on NICE's role and remit

Initial awareness of NICE was low, and participants had limited knowledge of NICE's role and remit. Most participants tended to associate NICE with the health service, and with the Government. The low trust in the Government (detailed above) led, initially, to scepticism about NICE and its aims. However, participants' trust in and understanding of NICE increased as its role and remit became clearer over the course of the dialogue.

During the dialogue, particularly when discussing the example guidance topics, participants developed a wider view of NICE as acting across the health and care system. However, this did not necessarily convince participants that NICE had a role to play beyond core health and care settings (for example, in local authorities and the private sector). Participants were more comfortable with NICE acting in a targeted way within health and care.

Furthermore, when the 6 proposed domains were introduced, participants strongly felt that NICE might be at risk of over-stretching and factoring in too many different areas when making decisions. This concern was strongest at the outset of the dialogue but remained throughout.

## **4. Summary of participants' views on NICE's proposed domains for prioritising guidance**

By the end of the dialogue, participants were supportive of the 6 domains proposed by NICE. While initially concerned that NICE might risk 'over-stretching' by considering all 6 areas, they did feel that all were useful and presented important criteria for NICE to use when prioritising topics for guidance. However, the relative importance placed on each domain did vary, as did participant definitions of what each domain should cover.

Health and care need and evidence availability were the most important domains for most participants. These were spontaneously raised by many participants as 2 of the most important areas before they were shown NICE's 6 proposed domains.

Health and care need – and its impact on people – remained participants' top priority throughout the dialogue.

Evidence availability was seen as a prerequisite to producing guidance, but participants used a broad definition of evidence and rarely saw lack of evidence as a barrier to prioritising a topic.

Budget and system impact were described by most participants as the next most important potential domains. These 2 domains were seen as particularly interconnected. The order of importance given to these domains by participants alternated throughout the dialogue and depended on which they felt would have the biggest impact on addressing health and care need.

Participants rated health inequalities and environmental sustainability as least important of the 6 domains. However, they did not want them to be ignored. For example, all participants were keen that environmental implications should be considered in prioritisation decisions, as long as doing so did not negatively impact people's care.

## 5. Use a broad definition of health and care need, and be transparent about how decisions are made

### What participants said

#### Participants describe health and care need through a people-centred lens

Participants' starting point was to talk about health from the perspective of the individual person. There was a concern that, when NICE prioritises based on systems and budgets or sustainability and health inequalities, the person and their immediate care need would be compromised – possibly even leading to a worse outcome. As a result, participants continually restated the importance of the individual, and of having empathy for them.

“Thinking about the human being who is being cared about.”

They readily put themselves in the shoes of those who might be experiencing the health and care needs under discussion, often relating this to their own experiences. For example, participants referred to their own experiences of caring for a sick spouse, relative, or child when engaging with case studies reflecting specific health and care needs. Initially, this led participants to suggest that members of the public might want topics prioritised based on their own needs. In practice, however, participants were able to move past personal preferences to consider prioritisation for the benefit of the entire population.

“If someone from your family suffers from a specific condition, then you're going to be more interested in that being looked at.

So, it's quite difficult when you're speaking to the public.

Everyone would prioritise something different to suit them and their family's needs.”

In the early workshops, most participants described 2 ways in which health and care needs impact on people:

- **Health outcomes:** that is, current or longer-term health and mortality. For example, life expectancy.

“You’ve got to look at how severe the condition is and its impact on patients – like if it’s a life-or-death situation.”

- **Experiences of the health and care system:** that is, their journey through the health and care system. For example, long waiting times or delayed diagnostics were seen to have a detrimental impact on both physical and mental health. This view seemed to be – at least in part – driven by participants' awareness of current pressures and their own experiences of being on waiting lists.

“One of the worst [challenges for the NHS] is paramedics and ambulances. With myself, there was about 25 ambulances

waiting outside to go in and there was people waiting 10 hours in the ambulance before even getting in line to wait a further 10 hours. People who have had falls at home because they are not priority, laying on the floor at home waiting for 10 hours to turn up at their house.”

Experiences of waiting lists rarely led participants to place system impacts above health and care need in terms of prioritisation decisions. There was a reluctance to place anything above health and care need, for fear this might compromise people’s care. Participants expressed concern about losing sight of the individual, despite hearing from NICE observers and specialists about the ways in which NICE would actively seek to avoid compromising care.

### **Participants considered multiple dimensions of health and care need**

Initially, participants mainly considered health and care need as a matter of scale and severity as follows:

- **scale:** how many people are affected?
- **severity:** in what ways, and how urgently, does it affect people and threaten or limit life?

“I think looking at statistics, what affects most people? So, if heart disease is the most affected thing in the world, or cancer, then you should probably focus on that. Because whoever is most affected, you want to help as many people as you wanted.”

However, as the dialogue continued, participants’ views changed. They identified the following dimensions of health and care need:

- quality of life
- burden of care
- ability to contribute to society and the economy.

This change was informed by hearing from other participants and through discussions of case studies illustrating different types of health and care need.

- **Quality of life:** this was described in terms of the ability to live a dignified life. Participants discussed significant negative effects on quality of life for some people requiring long-term health management – and for those caring for them.

“If you consider dementia, suddenly society and drugs have enabled people to live longer, but it’s not necessarily living well. I’ve known quite a few people that have got dementia, and you think to yourself, what quality of life have you got?”

- **Burden of care:** that is, the strain placed on an individual’s family, friends, and wider care system. This issue was especially apparent when

participants discussed conditions with a recognised impact on burden of care such as cancer.

- **Ability to contribute to society and the economy:** this was described in terms of people being healthy enough to work or contribute to their local community.

“[NICE] has to evaluate what difference it would make to those people's lives. And the impact on the economy...whether they could work if they weren't able to before, it would be positive thing for the economy and society.”

### **Health and care need is the most important domain for NICE to consider when prioritising guidance**

Participants viewed NICE's overarching objective as being to improve people's health and wellbeing.

“That's the juggling act that NICE has got to come up with a formula for. If there's anything but a positive impact for patients, would you just treat that as a lower priority?”

Participants emphasised that it is important that NICE ensures their prioritisation decisions always result in people getting the best quality care when they need it. This belief was expressed frequently throughout the dialogue, right up until the final reflections on what mattered most at the end of the final workshop.

“I agree, without health and care [need] it's all for nothing.”

### **Trade-offs exist between different ways of defining health and care need**

Participants deliberated on the tensions and trade-offs that arise when adopting a broad, people-centred approach to health and care need.

They identified 3 trade-offs that NICE must consider when deciding how to prioritise guidance:

- **Individual versus population.** Participants acknowledged that their gut reaction was to prioritise in a way that would improve conditions of which they had experience. However, they also identified that these conditions may not necessarily be those that evidence shows are associated with the greatest need at a population level. They felt that this could lead to disagreement over NICE's prioritisation decisions.

“I think everyone's personal experiences guide their priorities...so if you've got a specific disease, you'd want that prioritised. Whereas if you've got children, you might want that – but people who don't have children might not want that prioritised as much.”

- **Scale versus severity.** Approaching health and care need through a people-centred lens meant that participants often associated prioritising topics for guidance with prioritising 1 individual over another. This was particularly challenging in the case of rare diseases. Here participants struggled to reconcile deprioritising a topic impacting a small population with the implication that these people may not receive the best quality care when they need it.

“Couldn't you split NICE into 2, where one half [of the organisation] prioritises guidance for the larger group and the other one focuses on the niche one?”

- **High versus low profile conditions.** Participants highlighted that awareness and attention given to certain conditions is much lower than others. For example, women's health was mentioned as an area that has not historically been given much attention. They were concerned that guidance might be less up to date or 'fall behind' for lower profile conditions.

“Some [conditions] like endometriosis are really badly underdiagnosed, not many people know about it and how many people it affects. People don't get a diagnosis for years.”

### **What this means for NICE when prioritising**

Health and care need should be the most important factor that NICE considers when prioritising guidance. Guidance on topics that represent the highest level of need should be prioritised.

In assessing the level of health and care need, NICE should consider people's health outcomes and experiences of care. This should go beyond the scale and severity of a particular disease or condition to include areas such as:

- people's experiences of the health and care system
- quality of life
- burden of care on family and carers
- people's ability to contribute to wider society and the economy.

Participants acknowledged that tensions exist between specific dimensions of health and care need. They understood that this would make it difficult for NICE to prioritise based on all aspects of health and care need.

This suggests that it will be necessary for NICE to apply judgements when all aspects of need are not pointing in the same direction. As long as that judgement is made with the person receiving care in mind, then it would be acceptable to participants.

Participants would expect NICE to be transparent about why a particular decision was made, and which dimensions of health and care need were most influential in determining priority.

By considering the different dimensions of health and care need that were highlighted by participants, it will inevitably lead to a focus on groups experiencing health inequalities. For example, low life expectancy, poorer quality of life, high burden of disease, and poor experiences of the health and care system are all features of health inequalities. Although this link was never made explicitly by participants or facilitators in the workshops, it will be important for NICE to consider how health and care need and health inequalities are intrinsically linked.

## 6. Prioritise having a direct impact

### What participants said

#### Participants thought NICE should focus on health and care settings

NICE guidance was thought to have its greatest influence when it directly affected health and care settings. For example, participants said guidance for NHS hospitals should be prioritised over guidance for multi-organisation partnerships, such as local authorities and the housing sector. They questioned whether NICE should be focusing its resources on developing guidance outside the health and care sector.

#### Participants favoured guidance with a clear link to positive health outcomes

Throughout the dialogue, participants emphasised the importance of NICE prioritising guidance where it can see a clear link to improved health outcomes for people. Examples of guidance where participants could clearly see a link between NICE recommendations and positive health outcomes for people were viewed more favourably than guidance where the impact was less clear.

#### Participants were sceptical about NICE guidance tackling wider societal issues involving multiple organisations

Participants viewed health inequalities and environmental sustainability as extremely large and wide-reaching societal issues that involve multiple organisations and require behaviour change at an individual level. Participants generally thought that NICE would be a less effective influencer in these areas than the Government, which they felt could (and should) be driving change.

Participants were sceptical that organisations outside of the health and care system could be relied on to implement guidance. For example, if they had commercial, rather than health-related, priorities.

Furthermore, they were concerned that guidance that requires multiple organisations to be coordinated is not realistic. These views often arose due to the lack of trust in the Government, as detailed in section 3. For example, participants referenced examples of public infrastructure projects where they felt that this type of complexity resulted in inefficiency or lack of progress, such as the HS2 railway.

#### Case study: Living in cold homes

Participants were shown a case study describing how NICE could issue guidance to health practitioners and housing and energy suppliers to improve health outcomes. This case study was presented to illustrate how NICE could prioritise topics based on addressing health inequalities through wider determinants of health, such as living conditions.

Discussions raised concerns among participants about NICE prioritising guidance relating to a complex landscape involving multiple organisations.

While participants did not disagree that NICE should prioritise guidance seeking to improve health outcomes for those with a severe need, the direct impact of the guidance was unclear to them.

“Is it a health-related thing? Or when they say they give guidance to housing and energy suppliers as well ... I'm a bit lost as to what kind of guidance NICE gives to those other organisations and how it can impact them.”

“It's so political I wouldn't ever expect NICE, the NHS, to be looking after people in cold homes or obesity. I feel like it is more of a government agenda ... I'm not sure how much of an impact NICE would actually have on this situation?”

### **What does this mean for NICE when prioritising?**

Participants were consistent in their view that the route to impact should determine how NICE prioritises topics for guidance. They felt that having a direct impact was the best way for NICE to improve outcomes for people.

If there is potential for guidance to have a direct impact – framed by participants as relating to health and care settings – then this should make a topic more of a priority for NICE.

If the route to impact involves a complex set of multiple organisations, participants felt this should make a topic less of a priority for NICE as the potential for direct impact is diminished.

Participants' views on the route to impact underlie many of the principles derived from the dialogue. A perceived lack of direct impact led participants to doubt the value of NICE guidance in certain areas. For example, where the success of NICE guidance depends on uptake from a wide set of organisations outside the health and care system, as in the case of addressing the wider determinants of health (detailed in sections 7 and 8).

## 7. Support fairness within the health and care system

### Note on the findings

Health inequalities is a complex and ethically challenging concept on which people's views have been shown to change over time and in response to new information. For example, [NICE has previously commissioned a dialogue specifically focused on its role in tackling health inequalities](#), which explored this topic in more detail than was possible within this dialogue, but did not ask about the relative importance of health inequalities compared with other topics for NICE.

Discussions about health inequalities were among the most emotive in the dialogue. Differences of opinion and strong feelings were common, compared to the other domains. Over the course of this dialogue, participants' views on health inequalities typically changed more than their views on the other proposed domains. Views were particularly influenced by information participants received about health inequalities through case studies, specialist input or from their fellow participants. However, it is important to acknowledge the limits of the information given, which could not cover all aspects of health inequalities in the time available. Broadly speaking, participants fell into 1 of 3 categories, that is, they were:

- already aware of health inequalities, and accepted they exist (minority of participants) **or**
- initially unaware of health inequalities, but came to accept that they exist (most participants) **or**
- initially unaware of health inequalities and did not accept that they exist (minority of participants)

It is important to note these views were not always explicitly acknowledged by participants nor were they monitored or tracked by facilitators. In addition, the views appeared to overlap, shift over time, and were not always clear-cut in their differences. However, despite these different views, almost all participants expressed doubt over NICE's ability to address health inequalities when the cause was perceived to be outside the remit of the health and care sector. This made them doubt the relative importance of this proposed domain as a prioritisation criterion – a view which persisted throughout the dialogue.

This section explores the variation in participants' views, how they changed over time, and the conclusions they reached about the importance of health inequalities as a prioritisation criterion for NICE.

### What participants said

#### Participants had varying levels of awareness of, and belief in, health inequalities

Initial awareness of the existence of health inequalities varied between participants, and locations. It was rarely raised spontaneously as a challenge for the health and care system in workshop 1 before being introduced as a proposed domain. Other issues, such as waiting lists and other system pressures were more top-of-mind.

Personal experience was influential in shaping awareness overall, though being from a particular group that experiences inequality was not in itself indicative of attitudes held. Participants from different locations and backgrounds – including those from ethnic minorities who have heard about, or experienced, the effects of health inequalities, for example – could be sceptical about the existence of some types of health inequalities, or the value of NICE considering inequalities when prioritising. This suggests that having personal experience of health inequalities does not necessarily lead to people viewing this domain as more or less important for NICE to consider when prioritising.

There was a tension throughout the dialogue between participants' individual experiences and the evidence presented by facilitators and specialists, which some participants felt did not match up. For participants who had experienced, or were already aware of, inequalities, the case studies confirmed what they knew. For others, the information was new and could be difficult to accept. There was a sense of disbelief that health inequalities would exist but go unaddressed by the health and care system or by the Government.

“If these are the statistics for deprived areas, then why isn't anybody doing anything about it? Like bringing that deprived area up to standard – through levelling up.”

Throughout the dialogue, participants described different examples of how they thought health inequalities exist in society, based on their own personal experiences:

- **Access to the health and care system.** Participants from Plymouth were more likely to reference the fact that some parts of the country – such as coastal areas – are poorly served by the health and care system. This was surprising to participants from London, who are much better served (for example, do not have to travel for over 1 hour to visit a hospital).

“When I think about the equalities, I think about areas that people live in, and the different kinds of access they have to certain support - not all the areas people live in are getting the right access to the support. I think it's a really hard thing to navigate and really challenging for NICE.”

- **Variation in overall health outcomes.** Participants in Preston were more likely to reference regional health inequalities between northern and southern England, and how this impacts life expectancy.

“Life expectancy in the North West is much lower than the rest of the country – if you compare places like Blackpool with London.”

- **Prevalence of certain diseases among ethnic minority groups.**

Participants in London, and those from ethnic minority backgrounds, were more likely to state that certain health conditions are more likely to impact certain ethnic minority groups (for example, diabetes is particularly common within the Asian community).

“Different people from different backgrounds are more prone towards certain things. For example, like the South Asian ethnicity is more prone to like stuff like diabetes.”

### **Underlying beliefs about the causes of health inequalities influenced participants’ views on how NICE should address them, if at all**

While information about health inequalities presented to participants focused on differences in health outcomes, discussions tended to focus on the causes of health inequalities. Participants were interested in discussing and understanding the reasons behind different health outcomes, and their beliefs about causes strongly influenced their views on NICE’s role in addressing inequality.

Over the course of the dialogue, some participants expressed doubt about the value of NICE considering health inequalities when prioritising guidance. This doubt remained even when specialists made strong cases for its importance, both morally and to achieve overall improvements in the population’s health and wellbeing.

Three main causes of inequality were discussed, with each leading to a particular view on NICE’s role, and the potential use of health inequality as a prioritisation criterion:

#### **1. Wider determinants of health**

Many participants suggested that health inequalities are caused by a complex set of issues, including cultural norms and geographic, economic and political factors. Many are historic and deep-rooted. These are often referred to in the health and care system as wider determinants of health. The differences in life expectancy between regions of England was often used as an example of inequality caused by these issues.

“Some guidance could help for some inequalities such as gender and race, but personally I think most go deeper than that and it’s about socioeconomics, people’s backgrounds.”

Focusing on these causes of inequality led to widespread scepticism about how effective NICE guidance could be at addressing health inequalities. Some participants worried that this made health inequalities ‘inevitable’ – at least without concerted political effort beyond the scope of NICE and the health and care system. Participants were more likely to view the Government as having

responsibility for addressing these complex issues, and therefore to question whether it was an appropriate domain for NICE to use in prioritisation decisions.

“I said it wasn’t NICE’s job. It was the Government’s job in terms of the health inequalities. I thought NICE is responsible for advising professionals about medicines and stuff like that and how to treat things.”

This view was reinforced for some participants by a case study about a NICE guideline to reduce the health risks associated with living in cold homes, which would require cooperation from multiple organisations. Participants questioned whether NICE guidance could realistically influence organisations outside the health and care system. If prioritising health inequalities led to this type of guidance, then NICE’s influence would be diluted.

## **2. The role of individual behaviour in influencing health outcomes**

Many participants felt that lifestyle factors, driven by individual behaviour and choice, played a role in driving differences in health outcomes. For example, there was an assumption that individuals make their own choices about health behaviours such as diet and smoking. While some participants did make the connection between wider determinants of health and individual behaviour, many tended to see them as separate.

Participants who thought health inequalities were strongly related to individual behaviour also tended to be sceptical about the ability of interventions to change behaviour. They often described such interventions as advice or information giving. They were concerned that people lacked the ability or will to change, and that guidance would have no impact on this. As a consequence, they felt that guidance relating to changing individual behaviour should be a lower priority for NICE.

“It’s difficult because you give people advice but it’s about whether they would take it on board. So, you could be wasting money on all sorts of things saying you need to do this, but if the person doesn’t want to do it because they either can’t or due to other factors.”

## **3. Social inequality, bias and discrimination**

Some participants (particularly in London) perceived wider social inequality as playing an important role in creating health inequalities. They also talked about the existence of bias – and even racism – within other public services, such as the police. These participants were more likely to suggest that health inequalities might exist because of bias within the health and care system and were not inevitable.

“[Some ethnic minority groups] were avoiding the COVID jabs because they didn't agree with the evidence. But historically, [health and care] systems are institutionally racist.”

Some participants were uncomfortable discussing ethnicity and race, with facilitators observing some tense exchanges between participants with different views. This could in turn make them reluctant to accept health inequality as a domain for NICE to prioritise.

### **Case study: Maternal mortality, high priority for health inequalities**

Participants were shown a case study describing differences in maternal mortality rates based on ethnicity and disparities in delivery of care.

This case study had a strong impact on increasing the perceived importance of health inequalities as a consideration for NICE when prioritising, by drawing attention to an example of unfairness.

Participants initially struggled to accept that disparities might exist in the care delivered. However, the case study helped to shift their views in 3 ways.

1. **Highlighting severe health and care need.** Describing the impact of health inequalities in terms of maternal mortality placed this issue firmly within the context health outcomes (which participants strongly felt must be a priority for NICE).
2. **Humanising the impact.** Explaining health inequalities in terms of the impact on real people tangibly made the case for equality of care (that is, 'giving 1 person the same care as another').
3. **Clarifying NICE's role.** The case study demonstrated how NICE could influence health inequalities within health and care settings (which met participants' expectations of NICE's remit), as opposed to addressing complex wider societal factors.

“People assume that because you're different, you're a lesser person. That needs to be guidance-led – it shouldn't matter where you're from. You're a person.”

### **Differing views of inequality: equality of outcome versus equality of access**

Alongside the difference in views about the causes of inequalities, participants also talked about equality in different ways.

For some participants, equality meant equality of outcomes, and they were comfortable with health and care resources (and NICE guidance) being focused on particular groups experiencing poorer health outcomes.

“What stood out to me was [the specialist] mentioning something about people with learning disabilities – their life expectancy is 14 years less. If [NICE] don’t take inequalities into account, there will be worse outcomes in the long run.”

For others, the prioritisation of resources (and guidance) based on addressing health inequalities was difficult to accept. They worried that focusing resources on specific groups could exacerbate inequalities elsewhere, for either other minorities, or the majority. This led some participants to initially reject health inequalities as an area for NICE to consider when prioritising.

“My first thought is you're not going to be able to keep everyone happy. If you focus on one minority, you're going to upset another – if you focus on one type of disability, you're going to upset someone else.”

For some participants, equality meant equality of access to care. They saw access to care as an important factor in determining health outcomes (that is, people need to receive healthcare to get better). Participants who focused on equality of access tended to assume that the NHS is available to anyone who needs it – and that this is all that is needed if they take responsibility for their own health.

“Everyone still has access to the NHS, it's all free. You can just ring up the GP, you can go to the ED, you can go to the doctors, and it's there.”

This was particularly true for those living in areas well-served by the health and care system, who struggled to believe that unequal health outcomes could exist if everyone in the population is able to access care.

This argument was often connected to individual behaviour (that is, differences in rates of seeking out care) as a potential barrier to addressing health inequalities. While participants did discuss current system pressures (for example, long waiting lists) as a barrier to accessing care, they viewed this as a nationwide issue that affects everyone, rather than disproportionately impacting specific groups – and therefore contributing to health inequalities. This view was consistent throughout the dialogue, even when challenged by specialists, who reiterated that NICE guidance does not dictate spending by individual NHS trusts, for example.

### **Prioritise the greatest need, and talk about fairness rather than equality**

Overall, there was greater support for NICE prioritising guidance for groups in very poor health when framed in terms of their health and care need, rather than in terms of the extent or cause of the inequality. Participants agreed that specific examples of poor health outcomes and experiences – from the shorter

lifespans of travellers and those with learning disabilities, to the experiences of Black women giving birth – were unacceptable.

“It's just really unfair isn't it that just because you're from a travelling community, whether it's education or whether it's the fact that they're moving around, that they're missing out on good healthcare.”

While there were very few explicit mentions of fairness early on, this term increasingly became part of discussions as the dialogue progressed. It was often used when participants deliberated with others who had different experiences, which challenged their assumptions. These exchanges prompted participants to move beyond discussions of specific examples of health inequalities, where views tended to vary, to discuss the principle of ‘fairness’, which almost all participants agreed was important.

“I was particularly interested in what [the specialist] was saying about the idea of everybody being equal getting the same levels of care. Why shouldn't everyone have that?”

Participants mentioned existing types of health inequalities when they talked about fairness. There was a sense that the existence of inequalities – whether by ethnicity, gender, or region – is unfair, which jarred with participants’ expectations around health and social care in England.

This suggests that participants did support NICE considering health inequalities when prioritising in principle, but barriers may exist in relation to the language used around health inequalities, which participants noted is a politicised issue in wider society. Where a consensus emerged among participants with different views on the importance of addressing health inequalities, it was around the idea of fairness through ensuring equal access to the same quality of care.

“I think everybody should get the same access to health, no matter where you're from.”

One specific example of fairness that participants agreed was important, was that NICE itself should avoid creating further health inequalities. Any guidance topics considered should have regard to this potential, and it should be avoided wherever possible. With health inequalities encompassing a large number of factors, participants cautioned NICE that focusing on 1 factor may exacerbate issues in other areas.

### **What this means for NICE when prioritising**

Findings from the previous public dialogue commissioned by NICE showed that people think it is important that NICE should address health inequalities. While the findings from this dialogue do not necessarily challenge these views, they do indicate that there are nuances to the ways in which participants expect NICE to

consider health inequalities when prioritising. It is important to note that this dialogue focused on prioritisation, and the relative importance of health inequalities when considered among other criteria in making decisions about prioritising guidance.

Participants agreed that NICE should prioritise guidance for those with the greatest health and care need – including for specific groups where the need is severe. They felt ‘need’ rather than ‘inequality’ should influence decisions about prioritisation. The intrinsic link between health and care need and health inequalities was not explicitly acknowledged by participants, so NICE should consider how views around need and inequality interact when taking these findings into account.

There was little consensus on the causes of health inequalities and consequently what NICE should do about these. Most participants believed that NICE should not prioritise guidance that seeks to target the wider determinants of health. There was scepticism about how influential NICE guidance could be in this area. Some also felt that individual behaviour influences health outcomes, which they felt is difficult for NICE guidance to change.

Many participants felt NICE should focus on ensuring equal access to good quality care, not preventing the need for care that arises because of wider determinants of health.

Participants agreed it is important that NICE does not introduce or exacerbate health inequalities with the topics selected for guidance.

All participants felt that fairness is an important principle for NICE to uphold within the health and care system through the guidance it chooses to produce. This language of fairness was more widely accepted by participants than health inequalities, suggesting a need for NICE to consider carefully how it talks publicly about the proposed domain on health inequalities.

## 8. Prioritise prevention where NICE can directly impact people's health outcomes

### What participants said

#### Participants thought prevention was an important area for NICE to consider when prioritising

Prevention was raised spontaneously by some participants in workshop 1, before the proposed domains were introduced. When the domains were introduced, these participants felt that prevention was missing as an explicit area of focus for NICE. Participants saw prevention as important to improving people's health and connected it with the long-term reduction of system pressures. Given the current issues they perceived in health and care, it felt logical to look ahead and be 'proactive'.

"Be a bit more proactive. Prevention. Looking down the line, this is going to become a problem, we should focus on it now, so it doesn't get out of hand in 10 years' time."

Through the course of the dialogue, participants' views changed, as they identified connections between prevention and other domains, and also talked about what kinds of prevention NICE should prioritise.

#### They believed prevention could have a positive impact on people's health outcomes, now and in the future

Participants talked about prevention in 2 ways:

1. Avoiding illnesses from occurring in the first place (for example, through public health interventions)

Particularly early in the dialogue, participants primarily associated prevention with education. They referred to education as a form of information provision encouraging individuals to take personal responsibility over their health condition or lifestyle.

"I think education is more to do with prevention. So, if you know how to prevent a disease, then you're less likely to clog up the system, and the waiting lists and you're controlling your health outcomes."

2. Stopping existing conditions from worsening (for example, through medical interventions)

As the dialogue developed, participants began to view improved self-management as a form of preventive action where NICE could have the biggest impact on people's health outcomes. Participants believed that personal interventions would help people to better manage long-term conditions on their own (for example, by using wearable devices, such as closed loop systems, to

manage type 1 diabetes). They also referenced early diagnosis as a way in which conditions could be stopped from worsening.

### **Participants described long-term health and care system benefits associated with prevention**

Participants felt prevention is important for NICE to consider because of the potential long-term impact on the health and care system of worsening health issues. This included long-term costs and capacity issues, such as increased patient numbers leading to longer waiting times.

“[Taking a preventive approach] means less pressure on care homes, hospitals, plus health and social care, less pressure on relatives looking after elderly people.”

Here, the benefit of preventive action in stopping existing conditions from worsening was clear for participants.

“What is the trade-off of not doing it? What does the curve look like in 5, 10, 15 years? And how much is that going to cost the NHS? So, there's got to be a decision based on what does it look like if we don't do it?”

In discussions on prevention, some participants gave more thought to the long-term impact of prioritising guidance on prevention. These participants believed that, while there may be more immediate upfront costs of taking a preventive approach, there would be greater cost savings in the future through reduced demand on the health and care system if health outcomes are improved.

Participants expressed this view when discussing case studies that demonstrated how NICE guidance could have an impact on the system and budget, such as through cost and time savings (for example, the wound care case study found in appendix 4).

### **Tensions and trade-offs exist between prevention and treatment**

Participants had mixed views on how to balance prevention against treating an existing condition. Tensions most frequently arose when participants deliberated on whether NICE should prioritise guidance focusing on future generations, or on older people who currently have high health and care needs:

- **Future generations.** Some participants felt that NICE should focus on children and young people. These participants held the view that this group are the future, and that their health outcomes are therefore best served by preventive interventions. Improving health outcomes among future generations was assumed to have the potential to alleviate future pressure on the health and care system.

“I would put maternity first, because those babies are our future, so they've got to be looked after. I feel awful about saying this

about dementia, [but] there's no cure. So you've got to put your funding elsewhere."

- **Older people.** However, others disagreed with prioritising children and young people for preventive action. These participants raised the importance of prioritising older people because of the more immediate pressures associated with this population. They noted that increasing multimorbidity in an older population, and the associated health and care needs, will increase pressures on the health and care system.

"As people like living longer, there's more complex problems that are coming up. So, then that's the argument, prioritising the elderly as well, because there'll be more issues that come up."

### **The potential to directly improve health outcomes was most important to participants**

Participants were particularly supportive of prevention to stop existing conditions from worsening, both to improve health outcomes and experience for current patients, and to reduce the burden of illness in the long term. Some specific types of preventive action were flagged:

- **Early diagnosis and screening.** Some participants recognised the potential benefit of diagnosing a disease in its initial stages and therefore preventing it from getting worse. They were sceptical of how feasible early diagnosis would be in practice due to current challenges of getting an appointment but were keen for this to be addressed.
- **Self-management.** Participants saw this as an opportunity to prevent the worsening of some diseases such as diabetes. They saw failure to effectively manage these conditions as placing significant pressure on the health and care budget and system in the longer term.

"They [patients] can manage a lot of these things themselves. And this is what would be, I think, a very good investment of money."

### **Participants' views on prevention were more negative when it was seen as straying into areas of personal responsibility**

Participants thought prevention should only be a priority where NICE guidance can have a clear impact on people's health outcomes (for example, preventive measures in health and care settings to manage existing conditions). In the context of 'lifestyle issues' such as negative health behaviours (for example, smoking, poor diet), most participants felt individuals have a responsibility for their own behaviour – and ultimately, the associated long-term health outcomes. They were therefore less supportive of NICE prioritising guidance that focused on influencing health behaviours.

"You know what's in the box, it does harm. But once you're addicted, you carry on doing it. And then it's left for the healthcare service and friends and family to mop up. There's an element of self-inflicted damage there."

### **What this means for NICE when prioritising**

Prevention was important to participants. It was seen to have a clear role in reducing health and care need, now and in the future, and in reducing demands on the health and care system.

They supported opportunities to improve management of existing conditions and increase early diagnosis. Preventive actions to influence health behaviours were viewed as less likely to make a direct impact. Participants wanted NICE's prioritisation of topics to take this into account, and avoid the perceived risk of NICE's efforts being wasted on guidance that would not be effective.

Participants discussed prevention throughout the dialogue, seeing it as cutting across all the proposed domains, most clearly in health and care need, system and budget impact, but also in terms of sustainable healthcare and addressing inequalities. This suggests that NICE should consider prevention across the domains.

## 9. Identify and act on 'quick wins'

### What participants said

#### Participants saw an opportunity for NICE to increase its impact through quick wins

As the dialogue progressed, participants increasingly differentiated between guidance that appears easier or more difficult for the health and care system to implement, or for NICE to produce. The case studies introduced participants to how NICE guidance could vary in complexity depending on the topic and its scope, from guidelines on changing whole care pathways to guidance on a specific piece of medical equipment.

Participants identified 2 types of quick win.

One type is where guidance could be produced quickly, for example, where clear evidence is readily available to support a discrete change in practice that improves health outcomes. They saw this as a way for NICE to focus resources on more complex topics.

The other is where guidance could be implemented quickly and easily, provided it delivers positive effects on 1 or more of the proposed domains and does not worsen health outcomes. They highlighted 3 scenarios for this type of quick win:

- **To deliver cost savings** – by recommending changes that lead to better use of existing assets or resources or switching to a less costly way of delivering the same care or processes.
- **To improve system efficiency** – by recommending changes to the health and care system that improve efficiency or relieve pressure on the system (for example, freeing up more bed space could alleviate waiting lists).
- **To deliver environmental benefits** - for example, switching from 1 wound dressing to an equally beneficial, but more environmentally friendly, dressing.

#### Case study: Cannulation

Participants were shown a case study describing a potentially more economical use of cannulas at a London A&E department.

This case study was presented to show how NICE could prioritise guidance based on its impact on the environment. However, as well as acknowledging the environmental benefit, participants perceived this example as a 'quick win', which would warrant prioritisation based on 3 aspects of the changes:

- **minimal disruption** – no additional resource or staff time needed, with a positive rather than any negative impact for patients

- **cost saving** – by reducing waste and unnecessary spending
- **immediate impact** – can implement straight away and leads to noticeable changes within 12 months.

For these reasons, participants described the example as a 'no brainer' for NICE to prioritise as a guidance topic.

"It's something you can more or less implement from now. Rather than the inhalers [case study], where it would be a slow process. This is something that can be quite quickly implemented."

### **What this means for NICE when prioritising**

Within the prioritisation process, there should be some flexibility for NICE to change its approach to prioritise quick wins when opportunities arise, even in cases where the topics might not rank highly within the proposed prioritisation domains. To avoid missing out on opportunities for these quick wins, participants suggested that NICE should have processes in place to identify these topics and produce guidance.

Participants felt that NICE should prioritise guidance that is quick and easy to implement, and that minimises adding pressure to the system. However, they made an important caveat that prioritising guidance on quick wins does not mean deprioritising areas that have a higher or more complex system or budget impact.

## **10. Reflect a broad definition of evidence**

### **What participants said**

#### **Participants define evidence broadly**

Participants wanted to ensure that a range of relevant perspectives – including expert opinion and people's experiences – are factored into establishing health and care need as well as prioritisation decisions. This is partly a result of their participation in the dialogue – they explicitly stated that hearing from specialists and other participants was influential in shaping their views.

"You've got the scientific evidence. You also need to look at the clinicians. And also, the people that experience it. The 3 together. The individual with the illness or whatever the condition is going to be able to tell you the impact on them."

Participants thought NICE should consider a wide range of evidence types as follows:

- **Expert opinion.** Participants expected that NICE would consider the views of specialists and frontline workers, making use of professional and academic experience.
- **People's experience.** Participants felt that individual experience is an important piece of evidence. This reflects participants' wider emphasis on a people-centred approach to decisions about prioritisation.
- **Cross-system learnings.** Participants were open to knowledge and case studies on experiences of trialling new interventions being shared across the health and care system.
- **International and comparable research.** Participants wanted NICE to consider evidence from outside England and the UK, as they expected this to have relevance for the English population's health outcomes, and efficiency of the health and care system.

"You need it to be good, solid validated information, either from the research or the frontline – care workers, your GP or nurse – and also their people with lived experience. They all need to be involved in it."

### **Participants view evidence as an essential prerequisite to the development of impactful guidance**

There was consensus that evidence is an essential prerequisite to the development of impactful guidance. Defining evidence in broad terms meant that participants had expectations that there will almost always be some form of evidence that NICE can look to when producing guidance. As a result, it was not clear to them why considering the availability of evidence might determine the priority of a topic.

However, evidence was considered a non-negotiable for NICE to establish before producing guidance. Despite the broad definition participants gave for evidence, they felt there still needed to be some evidence available before NICE develops guidance on a given topic. However, quantity of evidence was not the most important consideration. They found it more important that NICE considers a broad range of qualitative and quantitative evidence types.

If the evidence meets the criteria described below, participants believed it should be considered:

- **accurate** – because decisions made based on NICE guidance will impact people's lives
- **credible** – that is, from trusted and verifiable sources, in order to ensure it is genuine and accurate
- **up to date** – because scientific research and understanding are constantly evolving.

“You need as much accuracy as possible when you are making these guidelines as well, because it is something that's impacting people who are practising and patients.”

Participants struggled to grasp situations and scenarios where evidence would be unavailable. However, case studies and specialist input played an important role in demonstrating that there could be scenarios where evidence might be limited.

“We didn't even think about whether the evidence was there, I just assumed it was.”

There was acknowledgement of the risk of producing guidance based on limited evidence. Certain topics were thought to require a higher standard of evidence. For example, discussions were particularly emotive in relation to guidance that could impact children. Situations like this were considered exceptions to the overall view, as some participants strongly felt that topics impacting children need intense scrutiny and a high level of existing evidence.

“When it comes to children, I think the evidence has to be pretty clear ... If the doctor was practising something that the evidence wasn't clear on, I'd be pretty cheesed off if they got it wrong.”

### **Certain situations might justify NICE developing guidance based on limited evidence**

There were some situations where participants agreed that having a broad range of evidence was less of a priority. That is, where the potential benefits of NICE guidance outweigh the potential risk of it being based on limited evidence. Participants pointed to:

- **urgent and life-threatening situations** – where the health and care system faces a pressing threat to human life at a widespread population level, such as a pandemic
- **terminal illnesses** – where there is little perceived downside for people receiving care in taking a risk by trialling a new treatment or intervention
- **potential for innovative treatments** – where the only way to improve the way in which a condition is managed, and outcomes improved, is by trialling new interventions – with these trials forming the basis of future evidence
- **rare diseases** – where evidence is expected to be limited but this should not be a barrier to producing guidance.

“I think it depends on your situation. If, for example, my child had cancer, and they were developing some sort of treatment, but there wasn't enough evidence to support it, but my child might then be cured. Would you take that risk?”

### **Case study: COVID-19, high health and care need, low availability of evidence**

Participants were shown a case study describing the need to make decisions despite a lack of evidence during the COVID-19 pandemic. This example aimed to illustrate how NICE could prioritise guidance in cases where evidence is lacking.

Participants generally felt that COVID-19 presented a clear health and care need – a large-scale threat to human life that required an urgent response. They felt that a degree of risk-taking was acceptable, as the potential benefits might significantly outweigh any risk associated with 'unknowns'. Most participants therefore agreed that NICE should prioritise developing guidance in this scenario.

"When the COVID struck people, I don't think we had enough evidence when we had the vaccination. But we went ahead. So again, it depends on the severity of the problem."

### **Participants want NICE to play a role in generating evidence when it is limited**

When presented with scenarios where evidence would be limited, participants frequently suggested that NICE could play a role in the generation of evidence.

Two key roles were suggested:

- supporting the production of evidence through clinical research and engagement with experts and people receiving care
- facilitating collaboration and knowledge sharing between organisations (both in the UK and internationally), as well as within the English health and care system.

Building on this, participants were open to NICE taking an iterative approach to evidence gathering and prioritising updates to guidance as, and when, new evidence becomes available. The caveat for participants was that NICE must be transparent when prioritising a topic for guidance in which this approach needs to be taken. NICE must be open about which evidence has been considered, and how new evidence will be collated and used.

"Things are moving so fast. Like in technology, if they didn't respond to some new research, that can be a critical reason for failure. And it's important that that work that has already been done is periodically looked at again."

### **What does this mean for NICE when prioritising?**

In determining health and care need, and more broadly in producing guidance, participants expected NICE to consider a broad range of evidence, as long as it is accurate, credible, and up to date. This could include a wide range of sources if required.

When making prioritisation decisions, participants rarely expected availability of evidence to influence NICE's prioritisation of topics. Evidence availability is not expected to be the most important prioritisation factor because there was an assumption that some evidence will always be there.

Participants are open to NICE producing guidance based on limited evidence, but only in specific circumstances; if there is an urgent or life-threatening situation (for example, COVID-19), terminal diseases, or a potential for clinical advancement (for example, rare diseases).

NICE should look for opportunities to identify evidence gaps, and work with research partners to address these in areas of high unmet need. A lack of evidence should not necessarily prevent NICE from prioritising a topic for guidance, and participants are open to NICE taking an ongoing, iterative approach to updating guidance once evidence becomes available.

## 11. Budget and system impact considerations should not lose sight of the people receiving care

### What participants said

#### System pressures are top-of-mind for participants

Participants were aware of, and concerned by, the pressures facing the health and care system. This was seen most clearly in areas like Plymouth where health services are seen as less readily accessible than elsewhere. There was also mention of a lack of communication across the system – participants shared stories about how their care suffered because of poor information sharing between hospitals, for example.

“The hospital trusts, they don't communicate. If I had an accident in London, they [Birmingham] wouldn't be able to access my record. I don't understand that. They should be accessible from every hospital. It's put all my treatment back months and months because of this.”

A few participants spontaneously raised “sorting out” health and care system issues as a potential priority for NICE in workshop 1, before it was raised as a proposed domain. However, the experiences and outcomes for individuals remained the top priority.

“... those kinds of things, which is a big fat mess of red tape, that would be important to kind of align those and make them a bit clearer. And that will save a hell of a lot of time, so that nurses and doctors can spend their time treating the patients...”

#### Participants wanted NICE guidance to reduce budget and system pressures where possible

Participants expected that NICE's prioritisation decisions would be influenced by system and budget impact. They felt that people's health outcomes, and experiences, cannot be improved if the health and care system is not functioning effectively and efficiently. This view was consistent throughout the dialogue and was often influenced by personal experiences of system challenges (for example, being on a long waiting list or experiencing delayed ambulance services). Participants therefore felt that NICE should aspire to reduce system and cost pressures when developing guidance.

“People end up going to A&E and is that wasting hospitals time? So I wondered if there are any [NICE] guidelines that they could have that makes it easier for patients to see their GP?.”

## **But people's individual experiences should never be compromised**

People remained participants' top priority throughout the dialogue. When deliberating system and budget impact, they emphasised that these proposed domains should never take precedence over people's health outcomes and their experiences of receiving care. Participants often assumed that, if these domains were used to prioritise, it would mean producing guidance that would relieve pressures and reduce costs. However, they were concerned that guidance that met these criteria might have a negative impact for people elsewhere in the system.

In terms of budget impact, participants were worried that prioritising guidance through a lens of cost-efficiency might override people's experiences (that is, 'cost cutting' leading to lower quality care). In relation to system impacts, they also felt that innovations that might reduce system pressures could result in lower quality care for some patients.

### **Case study: Virtual wards, high priority for system impact, potential negative impact on health inequalities**

This case study described how virtual wards would allow more patients to remotely monitor their own health and receive care where they live, rather than in hospital. The case study aimed to illustrate how NICE guidance might help to relieve a system pressure.

Despite broad enthusiasm for virtual wards, participants also expressed misgivings, all framed around the risk of negative impacts on people receiving care. Providing these risks are avoided and people's experiences and outcomes are, at least, not made worse, participants were supportive of system impacts being part of NICE's prioritisation decisions.

Participants saw the value of NICE prioritising guidance that would relieve system pressure, through the example of virtual wards. They were particularly positive about NICE prioritising guidance that would also lead to better care for those most in need (that is, clinicians having more time to delivery in-person care to those in hospital).

"We can try to start saving the hospitals, both for the people that need it, like the elderly. I've got the option to be treated at home, using monitors and stuff. I can give someone else my bed, even a child. It frees up a lot of infrastructure in hospitals."

However, this case study highlighted concerns held by participants about compromising people's care in favour of positive system impact. For example, they noted that virtual wards may not be suitable for older, less tech-savvy or digitally enabled, people – who are likely to also have the most significant health and care needs.

"I think I'm worried about virtual wards. There's a very slight margin that people might be overlooked."

Participants continued to emphasise this point, despite being reassured by NICE observers and specialists that NICE would never develop guidance that compromised people's outcomes and experiences in favour of a positive system or budget impact. For example, they did not want NICE to miss opportunities to improve quality of care just to reduce waiting times.

"Quality of care is always going to be the priority...I'd rather wait a few months [for treatment] if the quality was going to be better."

### **NICE should prioritise guidance that minimises adding pressure to the system**

Participants strongly felt that it was important for NICE to only prioritise guidance that is actually feasible for the system to implement. While they thought that guidance that relieved pressures should be a priority, they were concerned that broader challenges – or additional system pressures – might arise from implementing guidance in the short term. For example, if large numbers of staff require new training to use a piece of technology, or if hospital systems would need to be overhauled to facilitate a new treatment or process.

"If it's difficult to implement. It would take time and resource which would have a knock-on effect on [the budget and system]. So, I think making sure it's easy to implement is massive."

### **But implementation challenges should not act as a barrier to addressing urgent health and care need**

Participants felt that the potential to address an unmet need for people could justify NICE prioritising guidance that adds significant pressure to the system or budgets. For example, participants were open to NICE prioritising guidance on a costly technology if it could substantially improve people's health outcomes.

"For me, it's about people first...just because something costs more, doesn't mean it shouldn't be dealt with."

This reflects participants' view that the impact on people's health outcomes and experiences matter most – and that improvements to these are most important for NICE to consider when prioritising guidance. That is, if there is a clear and urgent need, implementation challenges should not be a barrier to prioritising.

"An improvement to a [patient's] care or their condition is the benefit."

### **What does this mean for NICE when prioritising?**

This was an area where participants clearly articulated the outcome they wanted NICE guidance to achieve – reduced system and cost pressures for the health and care system without negative impacts on people.

When it came to implementing budget or system impact as prioritisation domains their views were more complex.

System and budget impact are important for NICE to consider when prioritising guidance. Relieving system and cost pressures should be a priority for NICE, particularly in the context of current challenges facing the health and care system.

However, NICE should ensure that consideration of system and budget impact does not override decisions about what might be best for people. It is particularly important that NICE guidance, and the prioritisation process, do not result in a negative impact for people receiving care.

Participants consistently emphasised that people's experiences and outcomes should remain the top priority for NICE. This suggests that, if there is a clear unmet health and care need, NICE should prioritise guidance on a given topic – even if it has potential to incur significant budget or system pressures.

## 12. Address sustainability, as long as there is no detrimental impact on people's care

### What participants said

#### Participants were unclear on the link between environmental sustainability and health and care before the dialogue

Participants initially considered environmental sustainability to be less relevant than other domains for NICE to consider when prioritising topics. In line with findings from the previous [NICE dialogue focused on sustainability](#), at the start of the dialogue, participants acknowledged that they had little awareness of the impact of the health and care system on environmental sustainability, or the impact of environmental factors on health outcomes. This was despite recognition of the importance of tackling climate change across society.

"I didn't realise they made as much of a carbon footprint...Maybe there are smaller things that can be done that will make a big change. Maybe it's something that can be considered."

As the dialogue progressed, particularly through greater exposure to case studies and specialist input, the link between environmental factors and health outcomes grew stronger. Participants, prompted by specialist presentations, discussed 'sustainable healthcare' and how this can have positive co-benefits on the health and care system.

As they heard more about the connection between health and environmental sustainability, participants saw it as more relevant for NICE when prioritising topics.

#### Participants view environmental sustainability as less important for NICE to consider than the other proposed domains

Participants view climate change as the responsibility of all public institutions (among others) and believe that they should take steps to tackle it where they can. However, it was often considered less of a priority for NICE when compared with the other domains. But this did not mean participants wanted NICE to ignore it. Where a positive environmental impact could be made – without creating a worse health outcome or experience for people – then most participants felt it should be a consideration in prioritisation.

"NICE is not going to solve everything [to do with environmental sustainability] overnight, it's gradual. It's not a revolution, it's an evolution. NICE and the NHS needs to be part of that."

Discussions about sustainable healthcare covered areas of perceived efficiency, such as reduced waste and the adoption of virtual wards (reducing journeys and lowering emissions). If these things could be addressed through NICE's guidance without harming people's experiences and outcomes, then participants were

keen for sustainability to be part of prioritisation decisions. Given the size of the health and care system, participants felt that its environmental impact should be something that NICE considers when choosing topics for guidance.

“When you look at the NHS, it's the largest employer of people in the UK, it's a huge organisation. So, I think it's sort of natural that sustainability and environmental should be on their blueprints.”

### **What does this mean for NICE when prioritising?**

For participants, sustainability should not be a differentiating factor when deciding which topics to prioritise, unless all other domains are equal. But reducing the environmental impact of the health system should be a consideration for NICE.

This is particularly true when opportunities arise for ‘quick wins’, where a positive environmental impact can be achieved with little disruption to the system or people receiving care. This was 1 way in which participants saw NICE as being able to tackle environmental sustainability through the development of guidance.

Participants consistently viewed people as the key focus for NICE throughout the dialogue. Guidance must focus on the health and care need of people, with a positive health outcome for individuals as the key factor for prioritisation decisions. While guidance should aim to be as environmentally friendly as possible, it should not negatively impact quality of care or people’s experience within the health and care system.

### 13. Conclusions: What does this mean for NICE?

This dialogue framed the prioritisation challenge in terms of how NICE can decide what matters most. A complex picture of prioritisation emerged, with the dialogue producing a series of principles for NICE to consider. Yet alongside that complexity, there was a clear consensus on what really matters most for the public. Participants emphasised again and again the need for NICE to never lose sight of people when prioritising guidance.

There were some cases where participants clearly identified domains that are most important for NICE to consider when prioritising. Identifying the greatest health and care need should always come first, followed by assessing where NICE is best placed to have a direct impact on people's health outcomes. Participants thought NICE should take opportunities to make a difference as they arise (for example, through quick wins).

Despite the varied views on the specific health inequalities domain all participants agreed that 'fairness' was an important principle for NICE to uphold through the guidance it chooses to produce. They thought it was important for everyone to have equitable access and experience in the health and care system. And they did not want NICE guidance to exacerbate health inequalities. This links to participants' strong preference for NICE to focus on the people with the greatest health and care need, as those with the greatest need will include those experiencing health inequalities. Although this link was not explicitly acknowledged by participants, it will be important to consider how the 2 domains are intrinsically linked.

There are other areas that participants believe are important and relevant for NICE to consider – but which are not, on their own, reasons for prioritising a topic. System impact, budget impact, and environmental sustainability were important to participants, and they could see how NICE could add value by making improvements in these issues, but this had to be secondary to people's care. Evidence was similarly important to participants, and critical to guidance creation. Yet participants rarely saw a lack of available evidence as a reason not to prioritise.

Figure 4 illustrates how the principles can be grouped into these 2 categories.

**Figure 4: Summary of findings from the public dialogue**

