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Patient-Reported Outcomes

Adult Social Care Outcomes Toolkit and ICEpop Capability Measure in Decision Making: A Review of NICE Social Care and Public Health Guidelines

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ABSTRACT

Objectives: When the National Institute for Health and Care Excellence (NICE) assesses whether interventions in health and social care offer value for money, where possible, it considers health effects expressed in quality-adjusted life-years. NICE's preferred measure of health-related quality of life is EQ-5D. For nonhealth effects, NICE cites Adult Social Care Outcomes Toolkit (ASCOT) and ICEpop Capability Measure (ICECAP) as possible outcomes. To date, to our knowledge, their use in NICE guidelines has not been reviewed. The objectives of this study were to (1) review how ASCOT and ICECAP have been used in NICE social care and public health guideliens and (2) contextualize the review via expert interviews.

Methods: NICE social care and public health guidelines published before August 26, 2025 were reviewed, and information on the use of ASCOT and ICECAP was extracted. Five experts were interviewed to contextualize the review findings.

Results: Of the eligible guidelines, ASCOT appeared as an outcome in 4% and ICECAP in 1%. Neither measure significantly affected committee's decision making. Interview findings were grouped into 2 themes: (1) reasons behind the limited use of these measures (with 3 subthemes: conceptual, system-wide issues, and implementation challenges) and (2) ongoing developments and future opportunities.

Conclusions: ASCOT and ICECAP appeared infrequently in the NICE guidelines reviewed, and when used, their impact on committee decision making was limited—either because of trial-specific limitations or reliance on other forms of evidence. Experts suggested several barriers to the use of these measures, and although these barriers are not insurmountable, it is unclear whether such measures may appear more in future NICE social care and public health guidelines.

Keywords: ASCOT, ICECAP, outcome measures, preference-based measures, public health outcomes, social care outcomes.

VALUE HEALTH. 2026; 29(1):108–118

Highlights

- National Institute for Health and Care Excellence (NICE) favors EQ-5D for health-related quality of life and quality-adjusted life-year estimations but cites Adult Social Care Outcome Toolkit (ASCOT) and ICEpop Capability Measure (ICECAP) as possible measures for non-health effects. However, their use in NICE guidelines has not been reviewed.
- ASCOT evidence featured in 4%, and ICECAP evidence in 1% of NICE guidelines reviewed. Neither measure substantially influenced decision making. Experts suggested several reasons for their limited appearance: underfunding, structural differences from health, scarce training/resources, no established willingness-to-pay thresholds, and multiple versions with differing value sets.
- Although there is interest in incorporating measures beyond EQ-5D, barriers resulting in relatively few studies using such measures may limit their wider utilization in decision making.

Introduction

The National Institute for Health and Care Excellence (NICE) in England assesses value for money by considering an intervention's costs and benefits compared with the next best alternative, expressed, where possible, as the cost per quality-adjusted life-year (QALY) gained. The EQ-5D is NICE's preferred instrument for capturing health-related quality of life (HRQoL) and calculating QALYs.[1] For social care and public health interventions, where factors beyond health are important considerations, broader outcome measures may be needed.

When NICE evaluates interventions funded by the public sector with health and nonhealth outcomes or with a social care focus, it allows for the consideration of nonhealth effects.[1] Two measures are cited as possible outcomes in NICE's manual for guideline development: the Adult Social Care Outcomes Toolkit (ASCOT) and the ICEpop Capability Measure (ICECAP).[1]

The ASCOT Self-Completion Tool, four-level version (ASCOT-SCT4), is a utility index designed for social care economic evaluations, that measures social care-related quality of life (SCRQoL).[2] It measures 8 attributes: personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, safety, social participation and involvement, occupation, control over daily life, and dignity.[2] Other versions of ASCOT for different populations and means of data collection can be found online.[3]

ICECAP-A, is a self-reported measure of capability for adults.[4] It measures 5 attributes: enjoyment, achievement, autonomy,

stability, and attachment.[4] Other versions of ICECAP for different populations and settings can be found online.[5]

Although both measures have been cited in NICE's guidelines manual since 2014,[6] their use in NICE guidelines has not been reviewed. This study aimed to examine their use in NICE guidelines and contextualize these findings through expert interviews.

Methods

This study had 2 parts: (1) a review of NICE social care and public health guidelines to assess use of ASCOT and ICECAP and (2) expert interviews to contextualize these findings.

Review

Search strategy

NICE's published social care or public health guidelines were included. Guidelines were identified by selecting "Public health guidelines" and "Social care guidelines" under the "Guidance programme" on NICE's browse guidance webpage.[7] Because ASCOT and ICECAP were created at different times, the timelines reviewed for each measure differed. The first appearance of ASCOT and ICECAP in publications was established by reviewing the publications section of the ASCOT (see Appendix: ASCOT References Webpage in Supplemental Materials)[60–63] and ICECAP websites.[8,9] ASCOT first appeared in 2008; therefore, guidelines published between 2008 and 10 June 2023 were reviewed. ICECAP first appeared in 2011; therefore, guidelines published between 2011 and 10 June 2023 were reviewed. NICE guidelines were reviewed again on 26 August 2025 to identify any guidelines published or updated since the date of the original search. We use the years these measures first appeared in publications, rather than the year they were first explicitly referenced in NICE's manual for guideline development, as our starting points. This is because although NICE's manual did not explicitly reference them until 2014, they may have appeared in guidelines before this, and the lack of explicit mention does not mean they were prohibited or absent. For all included guidelines, all documents on the "evidence" tab were searched to see if ASCOT or ICECAP appeared. If a guideline had reviewed a study that used either measure as an outcome, the full texts of these studies were reviewed.

Assessment and data extraction

One author (Z.Z.) conducted guideline identification, document review, and data extraction, which was checked by a second author (J.D.). Data were entered into a prepiloted Excel form (see Appendix Table 1 in Supplemental Materials). Extracted items included guideline title, type (social care, public health, or both), document name, whether ASCOT or ICECAP were included, and how (eg, in the protocol, search strategy, etc). If a study used ASCOT or ICECAP as an outcome, it was recorded along with its impact on committee decision making. In several of the included studies, the specific version of ASCOT or ICECAP was not explicitly reported, likely reflecting the naming conventions at the time of publication. Where the version was clearly listed, we reported it as such. In situations in which the measure was mentioned generically (eg, in protocols or search strategies), we referred to it generically. In situations in which ASCOT or ICECAP was used as an outcome measure but not explicitly specified, we inferred the most likely version based on the study population, setting, and cited references, and we have indicated these versions throughout this manuscript for clarity.

Interviews

Interview motivation

Although the review showed how ASCOT and ICECAP were used in NICE guidelines, it did not explain why. The interviews aimed to explore the reasons behind these findings and what might support greater uptake.

Data collection and analysis

A targeted approach was used to identify and engage interview participants. Invitations were sent to 7 individuals: researchers with expertise in ASCOT or ICECAP, NICE employees with experience in guideline development, and a EuroQol member. Five agreed to participate (see Appendix Table 2 in Supplemental Materials). Although small, the sample was designed to capture a range of perspectives rather than to be representative. Ethical approval for the interviews was granted by London School of Economics (LSE) Ethics Board (No: 238156). Interviews were conducted via videocall in August 2023 in a semistructured manner. A pre-determined question set was used (see Appendix: Interview guide questions in Supplemental Materials), with follow-up questions tailored to each response. The interviews were exploratory, allowing participants to elaborate on their experiences, opinions, and recommendations regarding the use of ASCOT and ICECAP in NICE guidelines. All interviews were recorded and transcribed for thematic analysis.

Data were analyzed using the framework approach, a structured form of thematic analysis developed for applied policy research.[10] This approach identified central themes and patterns in the interview data, enabling focused exploration of key ideas.

Results

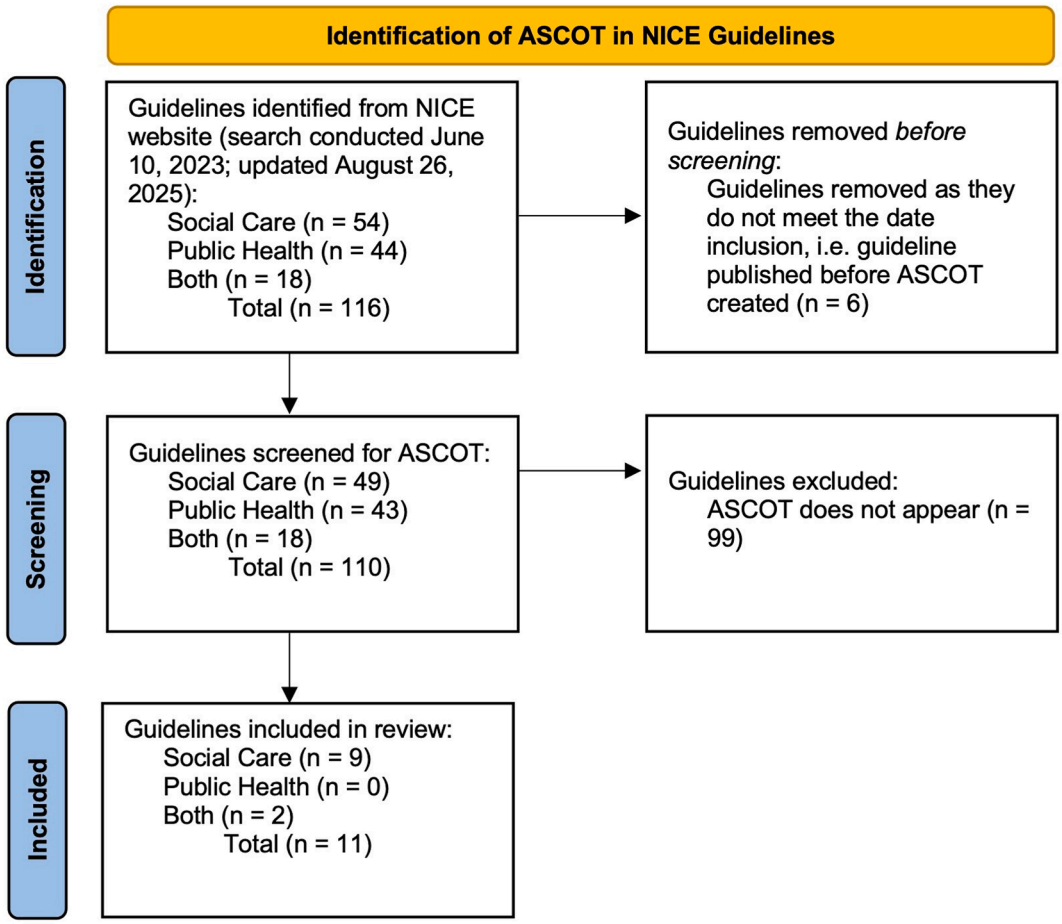
Review

ASCOT and ICECAP in NICE guidelines

Modified PRISMA diagrams summarize the results of the review (Figs. 1 and 2).[11] In total, 116 social care and public health guidelines were identified (see note with Appendix Table 3 in Supplemental Materials). For ASCOT, 110 guidelines were reviewed, of which 11 (10%), include ASCOT in some way. For ICECAP, 96 guidelines were reviewed, of which 4 (4%), include ICECAP in some way. Where each measure appeared in each guideline varied. We have grouped these appearances into categories detailed in Table 1.[1,12-23,24] Further detail on the exact location and guideline document where each measure appears is available in Appendix Table 4 in Supplemental Materials.

Where each measure appeared can be condensed into 2 categories: (1) ASCOT or ICECAP were used as an outcome, and this evidence was presented to the committee for decision making (eg, in an included study or in an economic model) (2) ASCOT or ICECAP have only been referenced (eg, in the search strategy or protocol). Regarding the former category, 4 social care guidelines (NG189, NG86, NG22, and NG21)[12-15] included a study(ies) in which ASCOT is used as an outcome, and 1 social care and public health guideline (NG105)[16] included a study in which ICECAP is used as an outcome. Additionally, 1 social care guideline (NG21)[15] used ASCOT as an outcome in an economic model developed for the guideline. This equates to 4 of the 110 (4%) guidelines

Figure 1. Modified PRISMA 2020 flow diagram for the identification of ASCOT in NICE social care and public health guidelines.



ASCOT indicates Adult Social Care Outcomes Toolkit; NICE, National Institute for Health and Care Excellence; PRISMA, Preferred Reporting Items for Systematic reviews and Meta-Analyses.

reviewed for ASCOT and 1 of the 96 (1%) guidelines reviewed for ICECAP that had evidence using these outcomes that was presented to committee for decision making. The remaining 7 guidelines belong to the latter category, only referencing ASCOT or ICECAP (NG150, NG53, NG27, NG236, NG216, NG214, and NG32).[17-23]

Figures 3 and 4 are plots showing the total number of social care, public health, and guidelines listed as both produced each year, and the number of each of these that include ASCOT or ICECAP. ASCOT first appears in a guideline in 2013 (1 year before it is first cited in NICE's guidelines manual) and ICECAP first appears in a guideline in 2015. Both measures have only appeared in social care guidelines (either in guidelines categorized only as social care or in those categorized as both social care and public health). Finally, neither measure follows a clear trend, the frequency of their use has neither increased nor decreased over time, and their appearances are sporadic, with noticeable gaps rather than continuous or clustered use.

Impact on decision making

Across 5 guidelines, a total of 10 pieces of evidence in which ASCOT or ICECAP were used as outcomes were presented to committees for decision making (9 publications and 1 original economic model).[24-33] The 5 guidelines, the evidence presented to the committee, their interpretation of it, and the outcome on decision making are detailed in Table 2.[12,14,17,18,20,25-34]

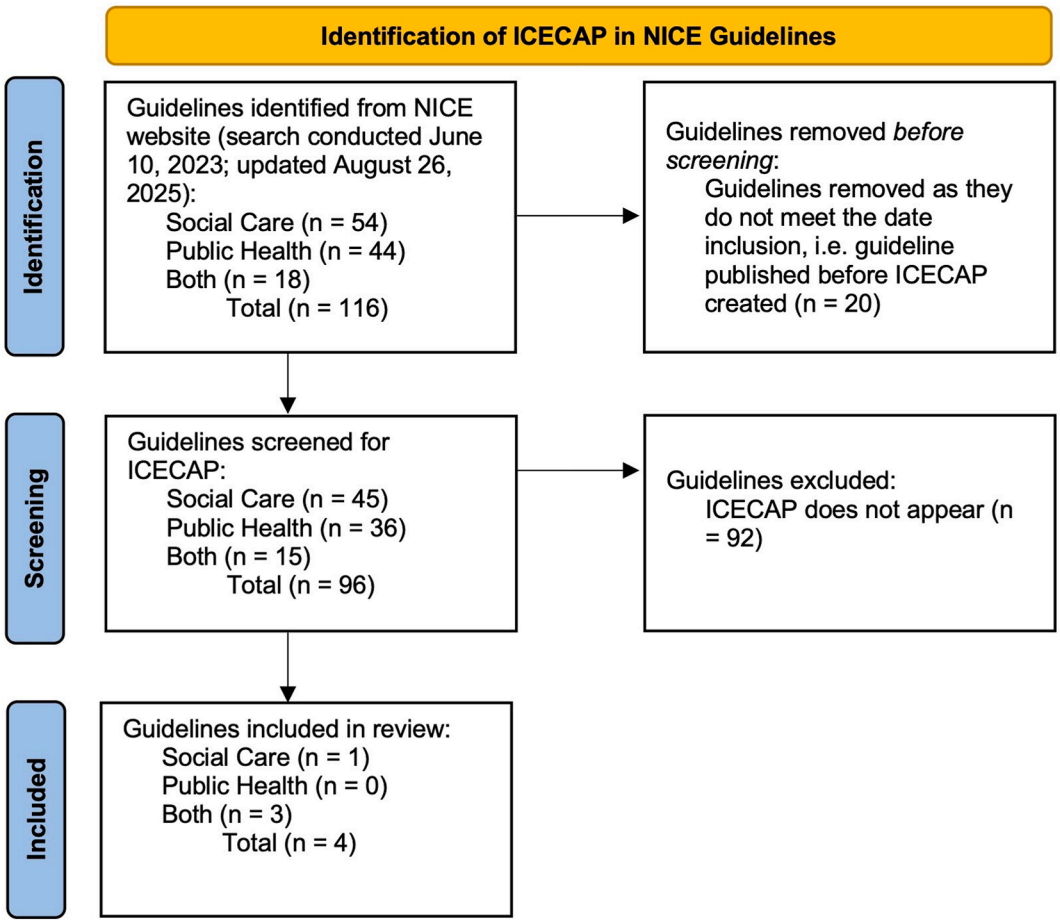
Interviews

Interviews were grouped into 2 main themes. The first theme explores reasons behind the limited use of ASCOT and ICECAP in research, as well as a specific question about their limited use and impact in NICE guidelines. This is divided into 3 subthemes: (1) conceptual, (2) system-wide issues, and (3) implementation challenges. The second theme focuses on ongoing developments and future opportunities.

Reasons behind the limited use of these measures

Conceptual issues. All interviewees acknowledged theoretical differences between health (eg, EQ-5D) and nonhealth measures. These measures differ in conceptualization (how concepts are defined and understood), perspective (the viewpoint from which they are assessed—individual or societal), and evaluative space (the specific criteria or dimensions used), capturing distinct outcomes. Interviewees emphasized the most appropriate measure depends on the intervention being evaluated, not just the setting. For instance, EQ-5D might be more appropriate than ASCOT for some social care

Figure 2. Modified PRISMA 2020 flow diagram for the identification of ICECAP in NICE social care and public health guidelines.



ASCOT indicates Adult Social Care Outcomes Toolkit; ICECAP, ICEpop Capability Measure; NICE, National Institute for Health and Care Excellence; PRISMA, Preferred Reporting Items for Systematic reviews and Meta-Analyses.

interventions. An example of this is reablement in interventions aimed at improving functioning: reablement did not affect ASCOT-SCT4 scores, but it did affect EQ-5D scores.[34]

> "It's the conceptualization and the perspective and the evaluated space is different to just looking at health and HRQoL." (Interviewee 1).

In health economics, it is important to understand the value placed on outcomes. In its guidelines manual, NICE states interventions with an incremental treatment cost below £20 000 per QALY gained generally represent an efficient use of National Health Service (NHS) resources.[1] There was consensus among interviewees that the absence of established willingness-to-pay (WTP) thresholds may be a barrier to using these measures because of the perception that decision making is more difficult without such a benchmark. However, 2 interviewees questioned the significance of this barrier, noting currently accepted UK thresholds for cost per QALY evolved implicitly, and only later gained explicit recognition—rather than being derived from evidence on societal preferences, implying this could also happen for other measures.

> "When we talk about either ICECAP or ASCOT, we're not talking about one measure, we're talking about a family of different measures. The attributes on ICECAP-A and ICECAP-O are similar, but their value sets are different. So even though we've come up with a monetary threshold for ICECAP-A, we can't assume that the same monetary threshold applies for ICECAP-O." (Interviewee 2).

System-wide issues. Participants emphasized systemic challenges for conducting research in social care compared with healthcare, primarily the lack of funding. Less funding results in fewer social care studies conducted, meaning social care outcome measures are not used as often and researchers are less familiar with them. These issues are further exacerbated by structural difference: clinicians can work simultaneously as an academic, whereas social care practitioners cannot, contributing to fewer studies and reduced innovation in developing methodologies. In addition, local authority-funded research may prioritize outcomes directly relevant to service provision (eg, focusing on resolving specific issues such as financial problems), which might limit the use of broader measures.

> "I think there are like, five proper research centres for social care in the UK, compared to like every single university having a Health Research Centre." (Interviewee 5).

The disconnect between social care practice and research is linked to another issue that was highlighted by interviewees: limited integration into decision making. There was consensus that these measures are mostly used in academic research. Commissioners and local decision makers with short-term

Table 1. Guidelines that include ASCOT and/or ICECAP and where the measure appears.

Guideline (Guidance programme)	Where in the guideline it appears									
	Surveillance documents*	Protocol	Search strategy	Excluded studies	Included studies	Expert testimony	Economic documents	Committee discussion	Research recommendations†	Abbreviations/ glossary
ASCOT										
NG189 (Social Care)[12]		X			1					
NG150 (Social Care)[13]		X								
NG86 (Social Care)[14]			X		3	X				
NG53 (Social Care)[15]							X			
NG27 (Social Care)[16]				1						
NG22 (Social Care)[17]					2		X			X
NG21 (Social Care)[18]	1			1	3		X			
NG236 (Social Care)[19]		X								X
ICECAP										
NG105 (Both)[20]					1					
ASCOT and ICECAP										
NG216 (Social Care)[21]		X	X					X	X	
NG214 (Both)[22]		X						X		
NG32 (Both)[23]		X								X

Note. For the surveillance, excluded and included studies columns, numbers are used to signify how many studies included ASCOT or ICECAP. In all other columns an X is used to denote if the measure appeared.
ASCOT indicates Adult Social Care Outcomes Toolkit; ICECAP, ICEpop Capability Measure; NICE, National Institute for Health and Care Excellence.
*After guidelines are published, NICE monitors information that may alter or affect any recommendations that have been made. This process is referred to as surveillance. You can read more about surveillance in Chapter 13: "Ensuring that published guidelines are current and accurate" of Developing NICE guidelines: the manual.[1]
†During guideline development, there may be areas where evidence is lacking. Committees can make recommendations for research in these areas. You can read more about research recommendations in NICE's process and methods guide.[24]

budget constraints might prioritize other outcomes. However, 1 interviewee noted that some local authorities mandate the collection of ASCOT data; but that they do not necessarily use it for economic evaluations. This raises concerns about the accessibility and utilization of this data, potentially leading to missed opportunities.

> "It's not there because you can't do the studies—not because of some failing of the measures … an alternative measure would make not the blindest bit of difference." (Interviewee 3).

Implementation challenges. Health technology assessment (HTA) agencies prefer to use a single outcome measure to provide standardization and comparability across evaluations of different interventions in different populations and settings. Although EQ-5D may not be as relevant or appropriate for social care contexts, introducing other measures reduces comparability. For example, the attributes on ICECAP-A and ICECAP-O are similar, but the value sets are different, meaning that the weights assigned to different dimensions vary between the 2 measures. The lack of a single gold-standard outcome measure for social care and public health was identified as one reason why ASCOT and ICECAP are not widely used.

There are also challenges specific to collecting and analyzing data. Researchers have more familiarity with EQ-5D compared with other measures. Relative to the EQ-5D, there is less training material and support available for researchers who want to use ASCOT and ICECAP. It was also commented that ICECAP is more time consuming to complete because its broader scope leads to deeper contemplation. Thinking about the ability to maintain usual activities (EQ-5D) may be more straightforward than thinking about whether people do activities that make them feel valued (ICECAP).

Moreover, EQ-5D benefits from extensive international infrastructure, including translations and country-specific value sets, which facilitate its use in multinational studies and local HTA processes. In contrast, ASCOT and ICECAP are still undergoing development in this area. Recent efforts to translate these measures and develop national value sets (eg, for ASCOT-Carer in Germany[35] and ICECAP-A in Japan[36]) represent important steps forward, but coverage remains limited compared with EQ-5D.

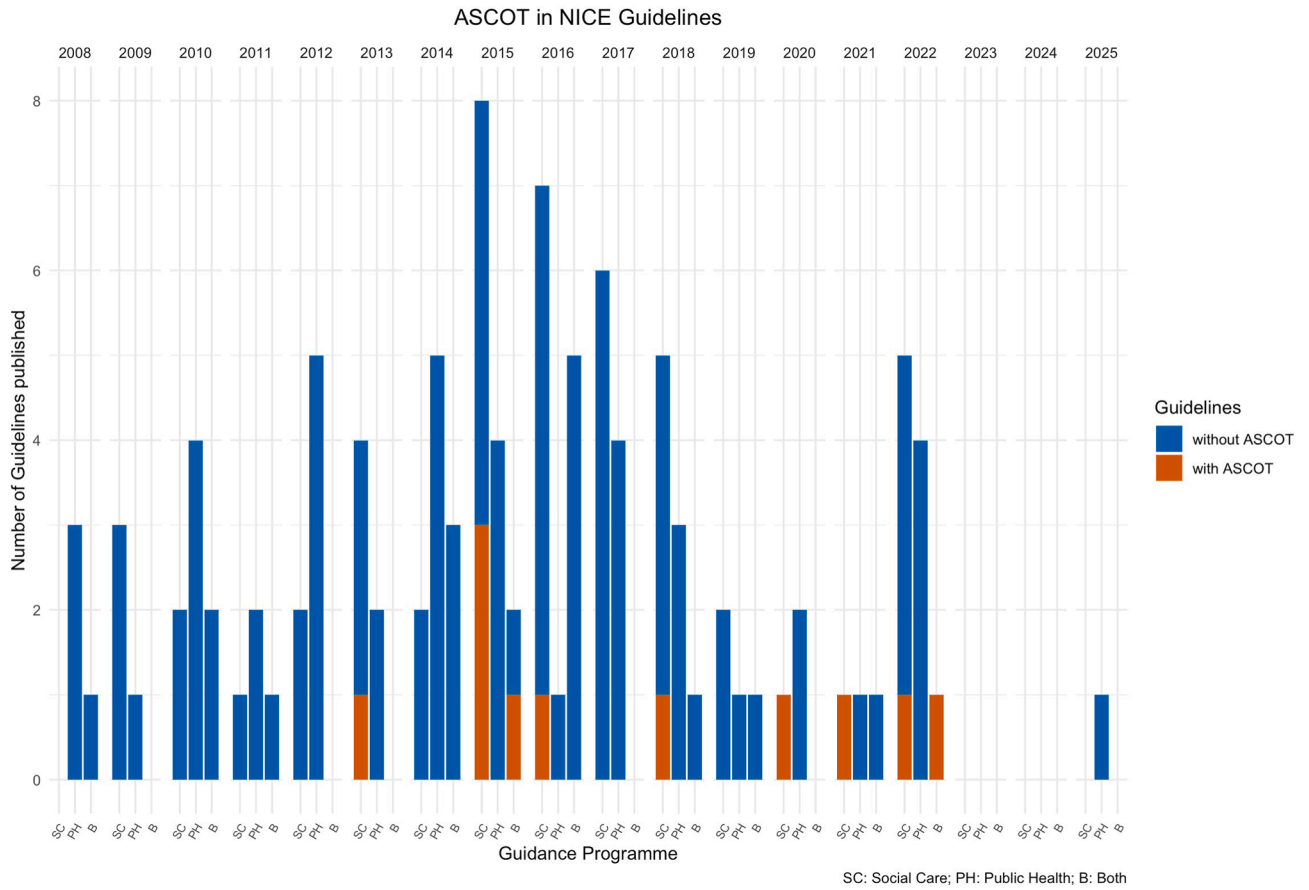
Future directions and opportunities

Advancements in both ASCOT and ICECAP are paving the way for researchers to be able to reach more groups (ICECAP for children and young people, ASCOT easy-read version for older adults expected to be used in people with dementia[37-39]). These versions may fill gaps, producing new evidence that one day may be included in NICE guidelines.

One interviewee was critical of such measures and highlighted the need to clearly establish the objectives of outcome measures and how this aligns with the remit of the NHS. This interviewee believed the NHS's role should focus on improving health rather than quality of life or well-being. It is important to note that in England, although the NHS is primarily concerned with improving health outcomes, adult social care is designed to support people to live well with long-term conditions or disabilities—for whom improvement in health may not be possible. The Care Act 2014 places well-being at the heart of adult social care, requiring local authorities to promote individual well-being in all their functions,[40] including personal dignity and control over daily life—areas not typically captured by health measures such as EQ-5D.

> "My understanding is we fund healthcare to improve health—not to improve life satisfaction, quality of life, happiness, wellbeing or anything else. These are secondary gains that derive from improving functional performance or preventing death." (Interviewee 1).

Figure 3. Number of NICE social care and public health guidelines produced between 2008 and 2025 and the number that include ASCOT.



ASCOT indicates Adult Social Care Outcomes Toolkit; NICE, National Institute for Health and Care Excellence.

Another interviewee stated the importance of perspective in economic evaluations. NICE's reference case perspective is to use an NHS and personal social services perspective (which focuses on costs and health benefits directly related to the NHS and personal social services, such as treatment costs, administration, and monitoring), whereas the use of measures such as ASCOT might align with a broader societal perspective (including impacts such as productivity losses or transportation costs). They suggested that it would be helpful to explore the public's preferences regarding what outcomes NICE should use to assess interventions.

Interviewees acknowledged the difficulty of establishing WTP thresholds for gains in the outcomes measured by these instruments, adding any such threshold would be version specific (ICECAP-A would not be applicable to ICECAP-O). There was also skepticism around the value of estimating WTP thresholds for SCRQoL or capability. One interviewee considered it "a wasted effort" because of the mixing or confounding of different measurement concepts. Another related issue raised was the adaptation of any threshold by decision-making organizations. Although research funding could support creating such a threshold, its impact and adoption remain uncertain.

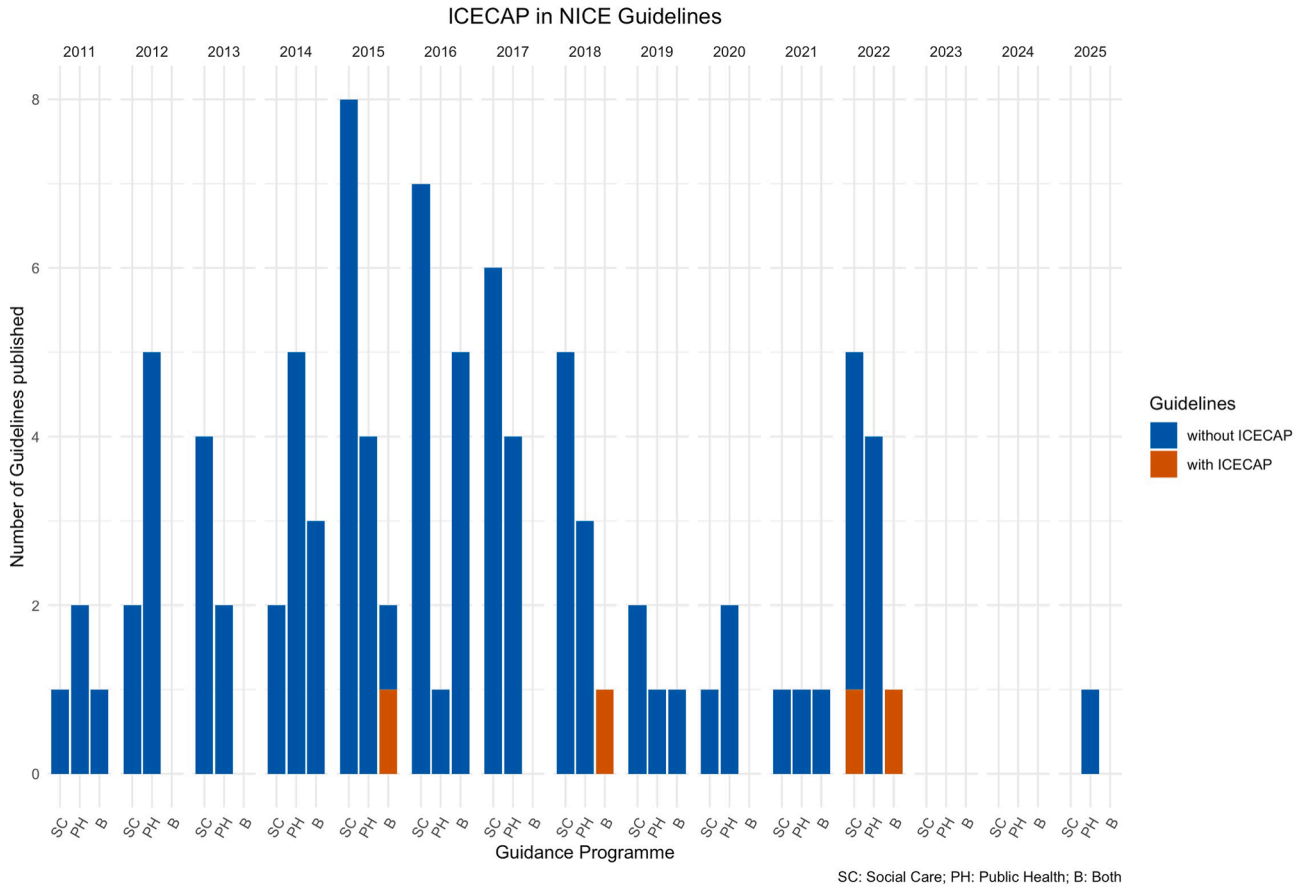
Finally, improving the methods and infrastructure for conducting economic evaluations in social care was identified as an area of focus. New research funding streams available for social care, such as from National Institute for Health and Care Research, were mentioned as positive developments and an opportunity to increase the evidence base for ASCOT and ICECAP. These developments are part of a broader effort to build research capacity in adult social care, aiming to embed research within local authorities and support practitioner-led inquiry.[41,42] Such initiatives may help address longstanding barriers to evaluation and support the wider use of these measures.

Discussion

Main Findings

To our knowledge, this is the first study to explore the use of ASCOT and ICECAP in NICE social care and public health guidelines. Although both measures are cited in NICE's guideline manual, they rarely appear in guideline evidence reviews, and when they do, their overall impact on decision making appears limited. Three guidelines made recommendations that diverged from the observed ASCOT or ICECAP results (NG22, N21, and NG105), 2 made recommendations aligned with ASCOT findings (NG189 and NG21), and 1 drew on ASCOT-related evidence without explicitly naming the measure (NG86). Several caveats qualify these findings, implementation challenges likely obscured the true impact of 1 intervention (NG22 and NG21); in others, recommendations were based on different outcome measures showing benefit (NG105) or ASCOT findings aligned with other sources of evidence (NG189 and NG21). In NG86, the measure had not yet been sufficiently validated. Overall, although

Figure 4. Number of NICE social care and public health guidelines produced between 2011 and 2025 and the number that include ICECAP.



ICECAP indicates ICEpop Capability Measure; NICE, National Institute for Health and Care Excellence.

committees appear open to using ASCOT and ICECAP, their influence has been constrained by study-specific limitations or the need to contextualize alongside other measures. Interviewees identified several factors contributing to this limited use, including conceptual differences from traditional health measures, such as EQ-5D, system-wide issues, such as limited social care and public health funding, and implementation challenges, such as reduced comparability, and the absence of established WTP thresholds. The interviews offer insight into how methodological features are interpreted in real-world contexts, complementing past research.

Findings in the Context of Previous Literature

Over the past decade, ASCOT and ICECAP research has shifted from methodological development to their application in economic evaluations. A 2024 scoping review identified 30 social care economic evaluations,[43] ASCOT-SCT4 was used in 4,[33,44-46] and ICECAP-A was used in 2.[47,48] A 2019 review noted that the EQ-5D remains the primary outcome, with ICECAP-O often included only as a secondary outcome.[49] This reflects broader challenges in moving away from traditional health-based metrics, despite growing recognition of the relevance of other measures in certain situations. Interviewees echoed this, noting that it took many years for EQ-5D to gain traction, suggesting that ASCOT and ICECAP may still be in the early stages of wider adoption. Although validity is established for both measures,[50,51] implementation challenges persist for both. Concerns exist about the complexity of certain questions in both ASCOT (although easy-read version of ASCOT have been developed[52,40]) and ICECAP[53] and about the risk of double counting when used alongside the EQ-5D.[54] Moreover, the relatively limited evidence base for both in economic evaluations may constrain their impact in NICE guidelines.[45]

In 2020,[55] a valuation approach was used to determine the monetary value of a year of full capability, as defined by ICECAP-A, in the United Kingdom. The estimated value derived from this assessment was £66 597.[55] Subsequently, the authors explored potential applications of these values through open discussions with the members of the public.[56] Participants suggested a WTP threshold of £33 500 per additional year of sufficient capability, reflecting the monetary value they placed on improvements in ICECAP-A scores.[56] If the absence of a clearly defined WTP threshold was a reason ICECAP-A was not being used in research, we may now begin to see more studies that use it as an outcome. This assumes that social care and public health researchers prioritize outcomes based on their potential use to decision-making bodies, such as NICE; however, in practice, both the appropriateness of the outcome for the population and its potential use in decision making are important and often complementary considerations.

Table 2. Impact of ASCOT and ICECAP evidence on decision making.

Guideline (Number-Guidance Program)	Evidence presented to the committee	Committee's interpretation of the evidence	Outcome and authors' interpretation
Safeguarding adults in care homes (NG189-Social Care)[12]	Evidence on different models of safeguarding training was reviewed. Of the 7 studies meeting inclusion criteria, one used ASCOT-SCT4 in an RCT evaluating a human rights-based training ("Getting It Right") for staff caring for people with dementia.[33]	The committee noted that the 'Getting It Right" training did not improve ASCOT-SCT4 or Quality of Life in Alzheimer's Disease (QoL-AD) scores.[33] The "Getting It Right" training did result in improved staff knowledge and attitudes, but this did not lead to better outcomes for people with dementia. Thus, the committee did not believe it could recommend the "Getting It Right" training. The committee also noted the other evidence presented was methodologically weak, due to the lack of randomization, imprecision in effect estimates and short-term follow-up.	The committee did not recommend or reject the "Getting It Right" training. Instead, general induction and training recommendations were made based on qualitative themes from the evidence, the committee's own experience and expertise, health and social care guidance and the Care Act 2014 and accompanying statutory guidance (Recs. 1.2.1-1.2.21). It appears the primary reason the committee did not recommend the "Getting It Right" training is because evidence showed it neither improved ASCOT-SCT4 or QoL-AD scores.
People's experience in adult social care services: improving the experience of care and support for people using adult social care services (NG86-Social Care)[14]	Evidence was reviewed to understand, "what methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective." Of the 10 studies meeting inclusion criteria, 3 studies related to developments concerning ASCOT: • Assessing the construct validity of ASCOT-SCT4 with older people.[32] • Developing and testing an accessible version (ASCOT-ER) for people with intellectual disabilities.[31] • Assessing the inter-rater reliability of ASCOT-CH3 with care home residents.[30]	The committee viewed ASCOT as a promising outcome measure for social care but noted the need for further validation across more diverse populations (further validation work has occurred since this guideline was published in 2018). It also noted that giving feedback to staff in one study led to improvements in care,[30] though the mechanism was focused on the act of giving feedback not the specific use of ASCOT-CH3 scores.	The committee recommended that local authorities consider collecting and analyzing data on people's experiences (Rec. 1.6.5), though ASCOT was not named in this recommendation. It appears the committee had a favorable view of ASCOT and believed data should be collected on people's experiences with social care services. ASCOT's omission either could be because the committee believed further validation work was needed (at the time of publication) or because they didn't want to specifically name any one measure. The committee also recommended giving feedback to staff (Recs. 1.6.10-1.6.11), again without specifically referencing ASCOT. It does not appear the committee made this recommendation due to ASCOT-CH3 scores.
Older people with social care needs and multiple long-term conditions (NG22-Social Care)[17]	Evidence was reviewed regarding personalized approaches to assessment, care planning and service delivery. One area where the committee saw evidence was with regard to the individual budget pilot program. The committee saw 2 publications from the same RCT comparing individual budgets (which brought together an individual's funds from various sources into a single source) vs continuing to have standard social care arranged by their local authorities for older people and other adults with social care needs.[26,34]	Individual budgets did not improve quality of life or ASCOT-SCT4 scores for those receiving individual budgets.[34] With regard to carers, individual budgets did improve quality of life but did not improve ASCOT-Carer scores.[34] However, the evidence had serious limitations due to implementation issues—very few participants assigned to individual budgets successfully had one implemented by the end of the trial. As a result, the true impact of individual budgets was uncertain.	The committee made 2 consensus recommendations about supporting older people and carers to either use or explore the use of personal budgets (Recs. 1.2.10 and 1.3.3). These recommendations suggest the committee still supported individual budgets even though trial evidence largely showed no improvements (except with regard to carer quality of life). This support can likely be explained due to the limitations of the trial (few participants had budgets in place), suggesting the actual effectiveness of individual budgets may be different than the results observed.

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Table 2. Continued

Guideline (Number-Guidance Program)	Evidence presented to the committee	Committee's interpretation of the evidence	Outcome and authors' interpretation
Home care: delivering personal care and practical support to older people living in their own homes (NG21-Social Care)[18]	Evidence was reviewed to understand what the significant features of an effective home care model are. Of the 6 studies meeting inclusion criteria, 3 used ASCOT-SCT4 as an outcome measure. Additionally, original economic modelling was undertaken for this guideline using ASCOT-SCT4 data. The committee saw 2 publications and original economic modelling from the same RCT comparing individual budgets described above in NG22.[25,28,34] The other publication that used ASCOT-SCT4, was a multi-methods comparative cohort study on self-directed care for older Australians with complex needs.[29]	The committee noted mixed results regarding individual budgets. One publication showed individual budgets did not improve quality of life or ASCOT-SCT4 scores.[34] However, a later publication showed there was improvement in ASCOT-SCT4 scores when the analysis was restricted to those for whom individual budgets had been successfully implemented.[28] The original economic modelling noted heterogeneity within the ASCOT-SCT4 results (some subgroups reported an improved score, whereas others reported reduced scores).[25] Given these findings were mixed and not robust, an incremental cost-effectiveness ratio on the ASCOT-SCT4 was not estimable.[25] The committee also noted that a stepped capacity-building approach, in general, improved ASCOT-SCT4 scores (including participant satisfaction with the care received).[29]	The committee recommended personal budgets as one of multiple options for people (Recs. 1.2.1 and 1.3.4)[28,34] as well as broader recommendations for people receiving home care (Recs. 1.1.1, 1.3.5, 1.3.8-1.3.9, 1.3.20, 1.3.24, 1.4.3). As with NG22, these recommendations suggest the committee still supported individual budgets as an option for people. Evidence that showed individual budgets did improve ASCOT-SCT4 when only looking at those for whom individual budgets had been successfully implemented[28] lends support to the idea that implementation challenges in the trial may have limited the ability to accurately assess the true effectiveness of individual budgets. The committee also issued recommendations to promote greater independence by supporting people to take more responsibility for their care (Recs. 1.3.12-1.3.13). These recommendations suggest committee confidence in these findings.
Preventing suicide in community and custodial settings (NG105-Social Care and Public Health)[20]	Evidence was reviewed on interventions for people bereaved or affected by suspected suicide. Of the 15 included studies, one used ICECAP-O in a retrospective study of a community crisis intervention ("StandBy") for people bereaved by suicide.[27]	The committee noted that the intervention found no improvements in ICECAP-O or quality of life but did report reduced suicidality.[27] Other studies showed reductions in anxiety and depression. In the grade tables in the appendices of this evidence review, it was noted that the committee confidence in the ICECAP-O results was "very low," suggesting they believed the true scores were likely to differ significantly.	The committee made recommendations to support people bereaved by suicide (Recs. 1.8.1-1.8.3). It appears these recommendations were based on the observed benefits (e.g. reduced suicidality, depression and anxiety), despite no change in ICECAP-O scores and "very low" confidence in that measure's results. This suggests these recommendations were not based on ICECAP-O outcomes.

ASCOT indicates Adult Social Care Outcomes Toolkit; ICECAP, ICEpop Capability Measure; NICE, National Institute for Health and Care Excellence; RCT, randomized controlled trial.

Limitations

This study has several limitations. First, it only reviewed NICE social care and public health guidelines. Future research could review NICE clinical guidelines and technology appraisals (TA). Such research would allow one to confidently understand the extent to which ASCOT and ICECAP have been used in NICE guidance; however, given that both clinical guidelines and TA's have a health remit, it seems unlikely that either of these measures would appear often (if at all). Additionally, in guidelines that included ASCOT or ICECAP evidence, published committee documents usually provided only limited detail on how these measures were considered. To avoid overinterpreting brief amounts of text, we adopted a conservative approach: reporting the evidence and offering our cautious interpretations of why it may or may not have informed recommendations. Consequently, our analysis is constrained by what is publicly available in committee documents.

Second, the interview sample size was small (n = 5), and all interviewees were from the United Kingdom, which may further limit the generalizability of the results. Although we aimed to interview 2 more NICE staff, they were unable to participate. Despite it being unclear if a larger sample would identify new themes or merely reinforce ones already identified, having more experts express similar views would increase confidence in the study's findings. Future studies could engage a greater number of experts (~15-20) and a more diverse group of experts, such as those using ASCOT or ICECAP in countries beyond the United Kingdom. Although the primary relevance of this study lies within a UK context, its findings are also pertinent to international audiences similarly grappling with the role of broader outcomes in decision making.

Furthermore, both measures were developed in the United Kingdom and therefore likely represent a UK-specific conceptualization of SCRQoL and capability.[57,58] Social care and public health are defined and operationalized differently across countries, reflecting distinct cultural, policy, and welfare contexts. Although both ASCOT and ICECAP are conceptually broad, they may not fully capture social care outcomes in other settings without adaptation. Simply translating these instruments may not address underlying conceptual differences. Versions of both measures have been translated and adapted for use internationally, offering an interesting basis for cross-cultural comparison with the United Kingdom. Further research is needed to assess whether these measures maintain validity and relevance across diverse systems and to explore how social care priorities differ internationally.

Research and Policy Recommendations

The study serves as a foundation for potential comparative analyses of nonhealth outcome measures within NICE guidelines, guiding potential future policy updates. Because NICE and other HTA agencies use QALYs when assessing value for money, this ensures that industry includes EQ-5D as an outcome in trials because of its necessity for HTA. However, this infrastructure is absent in social care and public health research because pharmaceutical companies rarely sponsor these trials. Consequently, there is less funding and a lack of familiarity with these outcome measures among researchers. The EQ-5D is a near-essential requirement for drugs to access the market, but there is no mandate for social care researchers to use ASCOT or ICECAP. The absence of such a mandate, combined with limited familiarity among researchers, contributes to their underuse. ASCOT appears more frequently than ICECAP in NICE guidelines, possibly reflecting the Department of Health and Social Care's endorsement[59]—highlighting the influence of policy maker support on measure adoption. To promote wider use of these tools, a dual approach is needed: (1) system-level requirements, such as those that mandate EQ-5D in HTA submissions, and (2) explicit support from decision-making bodies.

Conclusions

Although ASCOT and ICECAP have been cited in NICE's guidelines manual since 2014 as possible outcome measures to capture nonhealth effects, they have infrequently appeared in NICE's social care and public health guidelines. When they have appeared, their impact on decision making has been limited—either because of trial-specific limitations or reliance on other evidence. Interviews highlighted conceptual barriers, system-wide challenges, and implementation issues that contribute to their limited use. Despite these barriers, interviewees identified opportunities to support greater adoption, including increased funding and infrastructure for social care and public health, supporting international adaptations, and providing clear guidance on when and how such measures should be incorporated into decision making. The barriers identified are not insurmountable obstacles to the wider use of these measures; however, whether they will be overcome—and to what extent—remains uncertain.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section. The views expressed in this article are those of the authors and not necessarily those of LSE or NICE.

Supplemental Material

Supplementary data associated with this article can be found in the online version at https://doi.org/10.1016/j.jval.2025.08.021.

Article and Author Information

Accepted for Publication: August 29, 2025

Published Online: October 8, 2025

doi: https://doi.org/10.1016/j.jval.2025.08.021

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Authorship Confirmation: All authors certify that they meet the ICMJE criteria for authorship.

Funding/Support: The authors received no financial support for this research. Z.Z. conducted this research while being an MSc student in International Health Policy (Health Economics) at London School of Economics (LSE). This research was done while Z.Z. was on a summer placement at NICE, in agreement with LSE. Z.Z. submitted this research in part fulfilment of the requirements for her degree. T.A., S.C., and J.D. are employees of NICE.

Acknowledgment: The guidelines referred to in this article were produced for the National Institute for Health and Care Excellence (NICE). The authors extend their thanks to the experts who agreed to be interviewed, as well as Koonal Shah for reviewing.

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