**NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

Public Board Meeting
held on 25 September 2024 at 2 Redman Place, Stratford and via Zoom

# Unconfirmed

These notes are a summary record of the main points discussed at the meeting and the decisions made. They are not intended to provide a verbatim record of the Board’s discussion. The agenda and the full documents considered are available in accordance with the NICE Publication Scheme.

## Board members present

Sharmila Nebhrajani Chairman

Jackie Fielding Non-Executive Director

Gary Ford Non-Executive Director

Alina Lourie Non-Executive Director

Bee Wee Non-Executive Director

Justin Whatling Non-Executive Director

Sam Roberts Chief Executive

Jonathan Benger Deputy Chief Executive, Chief Medical Officer and Interim Director of the Centre for Guidelines

Mark Chapman Director, HealthTech

Helen Knight Director, Medicines Evaluation

Pete Thomas Director, Finance

## Directors in **attendance**

Nick Crabb Chief Scientific Officer

Jane Gizbert Director, Communications

Clare Morgan Director, Impact and Partnerships

Raghu Vydyanath Chief Information Officer

## In attendance

David Coombs Associate Director, Corporate Office (minutes)

Adam Linney Associate Director, People

Danielle Mason Associate Director, Strategic Communications and Marketing and Chair, Women in NICE Network (WIN)

Lorna Scoular Head of OD, Talent and Culture (items 7 and 8)

Tamara Diaz Co-Chair, Race Equality Network (REN) (item 8)

Fatima Salih Co-Chair, Race Equality Network (REN) (item 8)

Ahmed Yosef Chair, NICE and Proud (NAP) Network (item 8)

Abigal Stephens Vice-Chair, NICE and Proud (NAP) Network (item 8)

Jane Wright Vice-Chair, Women in NICE (WIN) Network (item 8)

Eleanor Donegan Chair, Disability Advocacy and Wellbeing Network (DAWN) (item 8)

Portia Dodds Vice-Chair, Disability Advocacy and Wellbeing Network (DAWN) (item 8)

Ben Dunbar Vice-Chair, Disability Advocacy and Wellbeing Network (DAWN) (item 8)

Jacoline Bouvy Programme Director, Medicines Evaluation (item 9)

Lorna Dunning Senior Technical Adviser, Methods (item 9)

Emily Leckenby Scientific Adviser (item 9)

Koonal Shah Associate Director, Science Policy and Research Programme (item 9)

Nick Baillie Associate Director, Insight and Programmes (item 10)

Louise Edwards Program Director, Implementation and Insight (item 10)

Helen Lovell Deputy Director, Medicine Regulation and Prescribing, Department of Health and Social Care

## Apologies for absence (item 1)

1. Apologies were received from Mark Chakravarty and Helen Brown, with the latter represented by Adam Linney.
2. Sharmila Nebhrajani noted that Michael Borowitz had resigned as a non-executive director (NED) of NICE following his appointment as Chief Economist at the UK Health Security Agency (UKHSA), which is an executive agency of the Department of Health and Social Care. Sharmila Nebhrajani thanked Michael for his contribution to NICE and also welcomed Pete Thomas to his first Board meeting as NICE’s new substantive Finance Director.

## Declarations of interest (item 2)

1. The following new interests were highlighted:
	* Alina Lourie: appointment as a non-remunerated non-executive director of Tellmi – a provider of a mental health app for young people.
	* Gary Ford: co-chair of the NHS England Cholesterol and Familial Hypercholesterolaemia Expert Advisory Group; member of NHS England’s Prevention & Long Term Conditions Board; and involvement in an AstraZeneca panel discussion at the NHS Confederation conference for which an honorarium was paid to his employer.
	* Bee Wee: Medical Delegate to Oxford University Press, University of Oxford; Review Panel Member to Health Research Board, Ireland; and external examiner, University of Otago, New Zealand.
2. In addition, Justin Whatling noted that his role on the Transition Committee for the Clinical Informatics Community Group, BCS The Chartered Institute of IT had ended as the transition was complete.
3. These, and the previously declared interests recorded in the register of interests, were noted and it was confirmed there were no conflicts of interest relevant to the meeting.

## Minutes of the last meeting (item 3)

1. The minutes of the public Board meeting held on 17 July 2024 were agreed as a correct record.

## Action log (item 4)

1. The Board reviewed progress with the actions arising from the public Board meeting on 17 July 2024 and confirmed those marked closed on the log were complete. It was noted that the Board’s discussion of the commercial strategy has been deferred to the start of the next financial year given the focus on planning for the Government’s spending review and the implications for NICE’s medium term financial plan.

## Update from the Department of Health and Social Care (item 5)

1. Helen Lovell provided an update from the Department of Health and Social Care (DHSC) and highlighted the recently published report from Lord Darzi, who was commissioned by the Secretary of State to carry out an independent investigation of the NHS in England. Lord Darzi’s findings included:
	* that the health of the nation has deteriorated over the past 15 years in many aspects, notably an increase in the number of people living with multiple long-term conditions;
	* too many people are waiting for too long to access the services that they need; long waits have become normalised across the NHS and public satisfaction has declined as a result;
	* performance on quality of care is mixed;
	* there has been growth in needs for mental health services, especially for children and young people;
	* the impact of the deterioration in access and the challenges around quality of care has not been felt equally: those in greatest need tend to have the poorest access to care;
	* delayed discharges have risen: nearly 14% of beds are being occupied by people who could be discharged if there was support for them in the community.
2. Helen Lovell highlighted that the Government has announced the development of a 10-year plan to address these findings and will focus on three main shifts: from analogue to digital; more care from hospitals to communities; and moving from sickness to prevention. Helen noted these are all areas where NICE can make an important contribution and the DHSC look forward to working with NICE as the plan evolves. Helen also noted that the Government is now advertising for a new Chief Executive for the MHRA, a key partner for NICE, following June Raine’s announcement that she is retiring after a long and distinguished career.

## Integrated performance report (item 6)

1. Sam Roberts introduced the update from the executive team and the integrated performance report that provided an update on progress with the 2024/25 business plan. Sam highlighted that NICE published its 1000th technology appraisal (TA) in September and noted that it took 18 years for NICE to publish the first 500 TAs, but only 6 years to publish the next 500, which demonstrates the escalation in both the volume of innovation and NICE’s activity.
2. Jonathan Benger updated the Board on progress with the business plan priorities in relation to focusing on what is most relevant and highlighted this work has an overall rating of ‘green’. The prioritisation board has been formally established, meeting since May, and making clear and consistent decisions that are published on NICE’s website. Jonathan noted the increased interest from the system in the prioritisation board and suggestions for topics. He also confirmed that NICE’s patient safety work is on track.
3. Sam Roberts updated the Board on progress with the business plan priorities in relation to providing high quality and timely advice, and noted the key performance indicators (KPIs) are largely positive. As discussed at the last Board meeting, there is a cross-organisation programme of work looking at what can be done to improve the timeliness of NICE guidance. There are no major concerns at this stage, but it is rated amber given the size of the task and the accompanying risks. In relation to the other activity in this business plan area, Sam noted that the work to incorporate TAs into guidelines is progressing to plan, and NICE and NHS England are working through the feedback from the consultation on the Medtech rules-based pathway. On methods, Sam noted that the Board will discuss the severity modifier later at this meeting and work is underway on updated methods for assessing health inequalities in guidance production.
4. Clare Morgan updated the Board on progress with the business plan priorities in relation to ensuring NICE’s advice is usable and has demonstrable impact. A key area of focus has been to develop a usable product strategy that seeks to deliver the long-term aim of making guidance more usable for practitioners, commissioners and providers. The initial work this year includes developing the foundations for the longer-term improvements, including content governance and ensuring recommendation wording supports strategy’s goals. The work on making sure NICE’s guidance has an impact and gets the best care to people fast is also progressing, with processes for inputting routine system intelligence and uptake measurement data into key guideline decision making processes now agreed. Implementation of the people and communities involvement and engagement strategy is also progressing, with Jackie Fielding supporting this from a NED perspective.
5. Adam Linney updated the Board on progress with the business plan priorities in relation to building a brilliant organisation and highlighted the positive position with the equality, diversity and inclusion (EDI) metrics. Adam noted that the overall business plan priority is rated amber due to the financial underspend. The Manchester office move is also rated amber due to the uncertainty around the completion of the connectivity works.
6. Pete Thomas updated the Board on the financial position and stated that at the end of August there was a £1.9m underspend. The current year-end forecast is a £1.1m underspend, however this is subject to a number of material uncertainties. Pete explained that the current underspend is largely due to the higher than planed income in the TA and highly specialised technologies (HST) programme, and the underspend on pay. The TA/HST income is forecast to remain ahead of plan, but there are risks to this income, and also to NICE Advice’s income. The pay underspend is due to a higher than planned vacancy rate and a decision to delay some recruitment due to the uncertainty around the longer-term financial position. However, the higher than expected pay award will likely to lead to an overspend on pay at year-end, although some additional DHSC funding may be provided for this. There are also uncertainties around the non-pay costs arising from the Manchester office move.
7. Raghu Vydyanath updated the Board on the delivery of NICE’s cybersecurity strategy, which includes a combination of preventative actions such as addressing the tech-debt and promoting staff training; ensuring NICE is prepared in the event of a cyber event through reviewing business continuity plans; and ensuring NICE has assurance over its resilience through external certifications such as cyber essentials plus. Alina Lourie, chair of the Audit and Risk Assurance Committee, highlighted that the committee spent considerable time reviewing this area at its recent meeting given it is the highest risk on the strategic risk register. The committee reviewed the plans for reducing the risk to the target rating and will consider this further at its next meeting in November after which a further update will be provided to the Board in December. Sharmila Nebhrajani highlighted the importance of understanding the plans for testing recovery arrangements, and to understand which data has been identified as business critical and how long the organisation could operate without this. The importance of understanding cyber security resilience within NICE’s supply chain was also highlighted.

Action: Raghu Vydyanath

1. Board members discussed the financial position and asked why income in the TA/HST programme was higher than planned. In response, Pete Thomas explained this partly reflects the prudent approach that was taken to setting the budget for 2024/25 and also the balance of TA/HSTs undertaken at the uplifted rates. Board members reflected there are a range of other sources of NICE’s income and further visibility was requested on the income received outside of NICE’s core Grant-in-Aid funding, whether this is recurrent or non-recurrent, and progress in delivering the work associated with this funding.

Action: Pete Thomas

1. In response to questions from the Board, Jonathan Benger provided further information on the plans to develop an approach for recognising guidance from other organisations in areas where NICE does not produce guidance itself. He noted that NICE has moved away from accrediting organisations and is instead seeking a more flexible approach of working with national and international partners, that would encompass a range of options for drawing upon other organisations’ high quality work on a guideline by guideline basis. It could also potentially mean developing quality standards based on guidelines produced by other organisations where NICE does not have an underpinning guideline, such as for rare diseases. Board members welcomed this work but noted it provides both opportunities and risks. Jonathan Benger agreed to provide an update on the proposals to a future meeting.

Action: Jonathan Benger

1. In response to questions from the Board, Clare Morgan provided further information on the work to provide targeted implementation support packages and confirmed 5 priority areas have been identified, starting with obesity. Clare noted that NICE is also developing an implementation strategy that will seek to define NICE’s role in implementing NICE guidance. Board members highlighted the importance of focusing on areas where NICE can most effectively support implementation of its guidance, while remaining mindful that the responsibility for implementation sits with other health and care organisations. The importance of working with NHS England medicines optimisation colleagues to ensure local formularies include medicines that have received a positive recommendation from the TA programme was also highlighted.
2. Subject to the actions noted above, the Board noted the report.

## Staff survey results and action plan (item 7)

1. Adam Linney and Lorna Scoular presented the report that summarised the results from the 2024 staff survey, and the planned next steps. It was noted that despite the significant organisational change the scores have remained stable and the results overall remain good. There are some areas for improvement, related mainly to personal development and stress levels due to work demands. While there have been dedicated organisational level initiatives to address these areas, there will now be directorate level action plans to address them at local level, which also seek to learn from the work in the People, Places and Improvement directorate and Impact and Partnerships directorate which have seen improvements in their engagement score following OD support.
2. The Board welcomed the results, and congratulated ET and line managers more widely for their success in maintaining the positive feedback in the context of the management of change programmes. The Board supported the planned next steps and noted the scores will continue to be monitored through the 6-monthly main surveys and intervening shorter surveys.

## Annual equality, diversity and inclusion report (item 8)

1. Lorna Scoular presented the annual equality report for 2024, which outlined the final year’s progress with the 2020-24 equality objectives. Overall, the position is positive with significant improvements in some key areas since 2020 including: a significant reduction in the non-disclosure rates for staff EDI data; the increased proportion of staff who are from an ethnic minority, supported by improvements in the interview to appointment conversion rates for ethnic minority staff; and the launch of the 5 year EDI roadmap with a new staff network framework that was co-created with the staff networks. Lorna stated that there are however areas of concern including staff with a disability having lower engagement scores than all other groups, along with lower trust in managers and greater risk of poor wellbeing. In addition, ethnic minority, LGBTQ+ and disabled staff are more likely to report having personally experienced bullying and harassment than the overall workforce, with this particularly notable for staff with a disability. Lorna noted that inquiry work to explore the bullying and harassment findings has been undertaken and actions identified.
2. The chairs and vice chairs of the staff networks provided a summary of their work over the year.
3. Eleanor Donegan highlighted the Disability Awareness Network (DAWN)’s work to support parent carers, and to support staff with disabilities with career progression. The network has also worked with the people team to explore the staff survey feedback regarding bullying and harassment and are discussing whether a dedicated disability policy would help address this and also demonstrate senior level commitment to supporting staff with a disability. Eleanor noted that elections will also be held for a new chair and vice chair for the network.
4. Fatima Salih and Tamara Diaz provided an update from the Race Equality Network (REN) and highlighted the network’s participation in a range of awareness events, including Black History Month, Islamophobia Awareness Month, South Asian Heritage Month, and Race Equality Week. The network is working with the people team to develop a race strategy and zero acceptance policy for racial discrimination. The network also provided a safe space for staff to discuss the race and Islamophobia-related riots in the summer and provided support to ET and NICE staff at an organisational level, initiating discussion around crisis management strategies and tailored support for staff.
5. Ahmed Yosef highlighted the NICE and Proud Network (NAP)’s focus on supporting trans and non-binary staff, including through the development of a transgender policy and trans and non-binary hub on NICE space. NAP have also sought to increase LGBTQ+ visibility in the organisation and have hosted events to highlight the experiences of people with different intersectional identities.
6. Danielle Mason and Jane Wright outlined the Women in NICE Network (WIN)’s work around the menopause, with the development of a new menopause policy and an awareness raising campaign linked to World Menopause Day. The network also held a series of listening events to hear the experiences of women who have undergone fertility treatment or experienced miscarriage while in the workforce. The findings were shared with the people team to inform updates to the parent policy. Danielle noted that elections will be held for a new chair and vice chair and thanked the Board for their support in establishing the network.
7. Board members thanked the network chairs and vice chairs for their leadership and for the networks’ impact across the organisation including through policies and awareness events. Fatima Salih and Tamara Diaz were thanked for the support provided to staff affected by the civil disorder in the summer. Board members asked what further support they could provide to the networks. The chairs and vice chairs thanked the Board and executive team for their support to date and highlighted the importance of ongoing senior support and suggested attendance at a wider range of events and network meetings. DAWN also suggested Board members utilise the disability passports where relevant to demonstrate senior buy-in to the scheme.
8. A question was raised about the pay gap reporting in the annual equality report given staff are paid under Agenda for Change (AfC) terms and conditions which limit the scope for negotiation on salaries. Lorna Scoular explained that the key action is to consider how to support staff from protected characteristics to move into senior roles, however it is also important to be mindful that due to NICE’s relatively small size, turnover in a small number of senior positions can disproportionately affect the data.
9. The Board received the report and welcomed the progress to date. The Board noted with concern the higher levels of bullying and harassment reported by staff with a disability and requested further information on the outcome of the inquiry work and the planned next steps. It was also requested that future reports include data on the overall composition of the advisory committees in addition to the characteristics of those applying and appointed to the committees in the previous year.

Action: Helen Brown

## Review of the implementation of the severity modifier (item 9)

1. Nick Crabb presented the report that outlined the findings of the review of the impact of the severity modifier. Nick explained that the severity modifier was introduced in 2022 to allow extra weight to be given to medicines that address severe diseases. It replaced a previous “end of life” modifier that only allowed extra weight to be given to medicines to treat end-of-life conditions. The severity modifier was therefore designed to benefit a broader range of diseases, such as non end-of-life cancers as well as non-cancer conditions that have dramatic and far-reaching impacts on patients, such as cystic fibrosis, which would not have qualified for additional weighting under the previous modifier. In so doing, NICE sought to better reflect the available evidence on society’s preferences.  The aim of this review was to assess whether the severity modifier is operating as intended, including whether it has been opportunity cost neutral compared to the end-of-life modifier it replaced. Nick explained that opportunity cost neutrality was an important principle: a higher severity modifier would have displaced health benefits elsewhere in the NHS and any changes to NICE’s methods that were cost inflationary would have to be approved by the DHSC.
2. The review concluded that the severity modifier is operating as intended and has been applied to a wider range of conditions as it was designed to do. Based on the data to date, it has remained opportunity cost neutral compared to the end-of-life modifier and the proportion of positive recommendations has been higher. Nick Crabb stated that it is therefore recommended that no change to the severity modifier is required but NICE should continue to monitor the impact of the severity modifier by looking at the mean weighting applied to technology appraisal decisions. Further research is also proposed to understand in greater depth the extent society places additional value on treatments for severe diseases.
3. Nick Crabb noted that NICE is aware that the Association of the British Pharmaceutical Industry (ABPI) has also been monitoring the implementation of the severity modifier and its findings vary from those in the report. Through helpful cooperation from the ABPI, Nick stated that NICE understands and can reconcile the differences, and consider the conclusions on opportunity cost neutrality compared to the end of life modifier set out in the report to be sound.
4. Sam Roberts stated that while the report is framed in technical health economics language it is essential to remain mindful of the profound impact of NICE’s recommendations, and the methods used to develop these, on individuals and their families. Sam highlighted that the review is concluding that overall, more conditions are benefiting from a positive recommendation as a result of the severity modifier, but acknowledged there are some heart-breaking circumstances when NICE has been unable to make a positive recommendation.
5. The Board discussed the report and the outcomes of the review. A question was raised whether the requirement to be opportunity cost neutral could be amended given the rebate payable under the voluntary scheme for branded medicines pricing, access and growth (VPAG). Helen Lovell explained that the VPAG rebate is not hypothecated, and also there is a time lag between the costs incurred by the NHS for medicines and the rebate which is then paid in a subsequent year. Helen stated that this issue is kept under close review and noted that it is important to start thinking about changes that could potentially feed into the next VPAG.
6. The Board noted that within the constraints of opportunity cost neutrality in which NICE is required to work, the severity modifier was operating as intended and has facilitated access to treatments for diseases including non-end-of-life cancers as well as non-cancer conditions that have dramatic and far-reaching impacts on patients, such as cystic fibrosis and chronic hepatitis D, which would not have qualified for additional weighting under the previous criteria. However, the Board was highly aware of the importance of the modifier and asked about the trigger for reviewing the severity modifier again following monitoring of the mean weighting. It was also asked whether it would be possible to supplement the proposed research into society’s preferences on how much additional weighting to apply to health benefits for people with severe diseases, with a quicker qualitative analysis using a deliberative exercise, such as the citizen juries used to consider complex issues such as society’s views to assisted dying. In response, it was noted that if the cumulative mean weighting falls below 1.10 for 2 consecutive quarters, NICE will investigate the causes and identify whether corrective action is needed. On the second point, it was noted that this is a challenging area to research, and the team felt the 2-year timescale was appropriate. However, it was agreed to consider whether there is scope for additional qualitative research, potentially through the NICE Listens programme or another deliberative exercise.
7. The discussion also highlighted the scope to consider how innovative commercial arrangements can facilitate access to new technologies, including through risk-share arrangements, instead of solely focusing on changes to NICE’s methods. It was noted that NHS England’s commercial framework is potentially an opportunity to explore such proposals further.
8. The Board:
	* Approved the recommendation that no change to the severity modifier is required at this time and to continue monitoring the impact of the severity modifier through the mean weighting applied to technology appraisal decisions.
	* Approved the progression of further research on societal preferences, supplemented by an interim qualitative analysis if feasible.

Action: Nick Crabb

## Measurement update – identifying insight to improve uptake of NICE guidance (item 10)

1. Clare Morgan, Louise Edwards and Nick Bailie presented the update on NICE’s use of measurement data to identify insight to improve uptake of NICE guidance. Given the nature of NICE’s role, and the number of organisations working in this area, the approach is to focus on where NICE can add most value and work in partnership with organisations that can directly influence the uptake of NICE’s guidance. Five prioritised topics have been identified to align with system priorities. Within these, NICE will identify a small number of measures reflecting priorities and monitor the proportion showing an improvement in national uptake, with benchmark data published by year end.
2. Board members welcomed the update and, as discussed earlier in the meeting, highlighted the importance of understanding the boundaries of NICE’s role in implementing, and monitoring the implementation of, NICE guidance. Clare Morgan noted this update was focused on measurement and confirmed the implementation strategy will come to the Board for a further discussion and discuss NICE’s role in implementation further.
3. Board members highlighted the value in looking at uptake across the eligible population, rather than whole population, and also to report at the level responsible for implementing guidance and which can address any variation – such as the integrated care board level. There was also encouragement to consider if any variation in uptake is due to the way guidance is written or presented, and if so, feed this into the work on NICE’s usable product strategy.
4. The Board noted the update and asked that when the Board discusses the proposed implementation strategy this sets out the system-wide range of implementation support activities for NICE guidance and outlines the rationale for NICE’s proposed priorities, taking account of the work by other organisations.

Action: Clare Morgan

## Annual report and accounts 2023/24 (item 11)

1. The Board formally received the annual report and accounts 2023/24 which had been laid before Parliament following approval by the Board in June.

## Any other business (item 12)

1. There was no further business to discuss.

## Next meeting

1. The next meeting of the Board will be held on 11 December 2024 at 1:30pm.