Questions from the public:
July 2024 public Board meeting

1. **The UK reimburses a lower proportion of rare disease treatments in relation to comparable EU countries. Recently, more and more rare disease treatments are being reimbursed directly through NHS commissioning. What steps are NICE taking to ensuring their processes - QALY thresholds and routing decisions - are keeping up with the pace of innovation and cognisant of year-on-year R&D costs for developing treatments?**
2. **When will NICE confirm their planned consultation for the revision highly specialised technologies (HST) criteria? And will NICE confirm whether it will seek to tighten eligibility or improve it so more rare disease treatments may be assessed via this route?**

In line with the commitment in the 2024 voluntary scheme for branded medicines pricing, access and growth (VPAG) NICE evaluates all new active substances and significant licence extensions, and NICE is not aware of an increase in rare disease treatments being reimbursed directly by the NHS without a NICE evaluation. The VPAG states that the QALY threshold will remain unchanged but NICE regularly reviews its methods and is currently looking at the impact of the 2022 methods manual in particular around rare diseases. NICE is also involved with delivering the government’s rare disease action plan.

Decisions on routing technologies to the highly specialised technologies (HST) programme are now taken by NICE’s prioritisation board. NICE will be reviewing the HST routing criteria this year. The threshold will not change but the aim is to improve the transparency and clarity of the criteria. NICE will publicly consult on any proposed changes following the review.

1. **Is NICE moving to new offices?**

NICE currently has an office in Stratford, east London and Manchester. The Manchester office will be relocating later this year to a smaller space in central Manchester that provides better value for the taxpayer.

1. **Are there specific reasons the improvement business case is framed as a service-focused approach?**

The business case for improving guidance production takes a cross organisational service approach in order to standardise processes across the organisation. Aligning processes across the organisation is central to enabling NICE to deliver the goal of providing integrated guidance.

1. **What are the timeframes for the further internal preparatory work mentioned in relation to what was originally proposed in terms of integration of technology appraisals into guidelines?**
2. **What are the next steps for the integration of technology appraisals in clinical guidance? Will it result in process guide change?**

Internal preparatory work to explore options for including technology appraisal guidance into guidelines when the interim methods and processes for incorporation are not suitable, has commenced. There is no timeline for further stakeholder engagement at this stage, and at this early stage there are no specific proposals for changes to NICE’s methods and processes.

1. **How will the members of the steering group for the new involvement strategy be recruited?**

The arrangements for recruiting the steering group are still being developed. This will be undertaken in an open and transparent manner and further information will be shared in due course.

1. **Can NICE share an update on the anticipated date for the severity modifier consultation to open?**

NICE is currently reviewing the evidence on the implementation of the severity modifier. Once the review has concluded, NICE will be able to consider if any action is required. Any changes to NICE’s methods and processes would be subject to consultation and progressed in line with the framework for modular updates.

1. **What role does/can the National Institute for Health and Care Excellence (NICE) play in supporting performance impact data measures in addressing heath and care inequities?How does, and will, NICE support better collection, analysis, interpretation, application, and reflection of performance impact measures on health inequities to provide assurance and reassurance within/external to NICE?How will NICE know, and what robust evidence will NICE use, that it is playing its optimal part in better performance impact measures for health and social care inequities to ensure improved health and social care access, experiences, and outcomes for people and communities, particularly for those in greater need?**

NICE has a formal role in developing indicators to be used in performance and quality frameworks for the health and care system. A number of indicators currently being developed and tested were selected because of known areas of health inequalities. Examples include CVD risk assessment in the previous 3 years for people with modifiable risk factors, annual review in people with COPD at high risk of admission, smoking cessation in people with serious mental illness, postnatal checks in women with complex social factors.

NICE has also made progress towards addressing health inequalities through a review of its methods and processes in guideline development and equality impact assessments, as well as the development of inequality briefings and identifying current evidence.

This year we are seeking to increase uptake of NICE guidance in populations with identified health inequalities and will establish way to measure a reduction in the uptake gap. We are working with partners to identify a small number of prioritised areas where we could actively improve uptake together e.g. the Race and Health Observatory.

The Working Alongside People and Communities Involvement & Engagement Strategy will initiate a programme of co-production with people, communities, voluntary sector organisations and our expert panel to co-produce our work, factoring in approaches to work more closely with those experiencing health inequalities. NICE will understand, act and evaluate the impact in collaboration with the people and communities we serve.