Questions from the public: December 2022 Board meeting

# What is being done to help the vaccine injured regarding the covid vaccines, as they are not being taken seriously or totally ignored?

*The Department of Health and Social Care (DHSC) responded to this question as it falls within their remit rather than NICE’s:*

The Vaccine Damage Payment Scheme (VDPS) is a no-fault scheme that provides a one-off, tax-free payment of £120,000 to claimants who have been found, in rare cases and on the balance of probabilities, to have been seriously disabled by a vaccine for a disease listed in the Vaccine Damage Payment Act 1979.

The VDPS incorporated COVID-19 from December 2020, and the scheme is now processing these claims and providing outcomes to claimants in a timely manner.

We [DHSC] have already scaled up the operations of the VDPS to allow cases to be processed at greater pace, including digitising the application process. We have improved the claimant experience by having named caseworkers, more regular updates and providing fuller responses to claimants to help them better understand decisions made. We recognise there is potential for further improvements and feedback is always welcome on how we can improve the scheme. We will continue to work with the NHS Business Services Authority (NHSBSA), who manage the scheme’s operations, to provide timely outcomes for claimants.

# There is help out there for people with long covid, are there any plans to help people that are vaccine injured?

*The Department of Health and Social Care (DHSC) responded to this question as it falls within their remit rather than NICE’s:*

Since the start of the pandemic, the NIHR has allocated more than £110 million in funding for COVID-19 vaccine research that has included consideration of vaccine safety, including robust monitoring of adverse reactions to COVID-19 vaccines.

The DHSC has commissioned a £1.6 million programme of work through the NIHR, to understand the extremely rare condition of blood clotting with low platelets following vaccination for COVID-19. The study is ongoing and due to complete in February 2023 and results will be published in due course following peer review.

In those very rare events where an individual may have suffered a severe adverse reaction to a COVID-19 vaccine, care would normally be managed by NHS local specialist services, augmented as appropriate by national specialist advice. Any ongoing care is likely to be best met by local NHS care services, in line with the support provided to those who have suffered disease or disability as a result of other causes.

# The issue for us is that NICE has no protocols for treatment of our symptoms; nothing to do with the vaccines. The vaccines have done their work - we are asking how we can accelerate getting treatments approved by NICE. All the time there are successful treatments pioneered abroad - that are not NICE approved - the NHS cannot provide this treatment.

NICE published a COVID-19 rapid guideline on [managing the long-term effects of COVID-19](https://www.nice.org.uk/guidance/ng188) in December 2020 and updated it in November 2021.

There are established treatments for managing the common symptoms often seen with the long-term effects of COVID-19, as set out in current national and local guidance, which can be followed for symptomatic relief. Advice for patients on managing common symptoms is available from the [Your COVID Recovery](https://www.yourcovidrecovery.nhs.uk/managing-the-effects/) and [NHSinform](https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-longer-term-effects-long-covid) websites. Self-management is recommended as the starting point for treatment as advised in the management section.

Since publication of the guideline and following the update in November 2021, we have conducted continuous weekly surveillance with a process in place to update our recommendations rapidly. The cumulative evidence has either been consistent with the current guideline or not conclusive enough to allow for new recommendations without further confirmatory studies. In 2023 we will continue to monitor ongoing trials and system intelligence from our expert panel to inform potential updates, ensuring we can get the best evidence-based care to people fast, while ensuring value for the taxpayer.

# What is the view of the NICE board on the recent announcement on VPAS, which confirms that industry payments as part of the scheme will be 26.5% of sales?

NICE is not a signatory to the voluntary scheme for branded medicines pricing and access (VPAS) but maintains an interest in the negotiations. We do not therefore have a view on this announcement.

# Will NICE be returning £1 million back to the DHSC - does that mean NICE will automatically receive £1 million next year? Sam has already stated that NICE funds will reduce over the coming years & stated that turnover isn't great. Can NICE use this money in ways to help retain staff instead of returning it?

# NICE has agreed to return £1m of its 2022/23 funding back to the Department of Health and Social Care (DHSC) to support the pressures elsewhere in the health and care system. Over the course of the spending review period NICE’s funding will reduce by £2m therefore it is important to ensure that any investment is affordable in future years. In the context of this reduced funding it is not possible to increase staffing, therefore the aim has been to look at how non-recurrent expenditure in 2022/23 can support and retain staff. This has included the investment in learning and development this year.

# The cost-per-QALY thresholds in NICE appraisals have not been updated since 1999, in effect devaluing patient lives YOY. In light of the cost of living crisis, is NICE taking another look at making these fit for purpose in today's economy, to be able to confidently say patients lives are truly valued?

# The QALY threshold of £20-30k is set out in the VPAS and it has been agreed between the DHSC and the Association of the British Pharmaceutical Industry (ABPI) that the threshold will remain unchanged during the current VPAS. The threshold recognise the opportunity cost of introducing new technologies and interventions, and that expenditure on one intervention displaces expenditure elsewhere.

# Does the NICE board have a view on the recent BMJ paper 'NICE’s new methods: putting innovation first, but at what cost?' which raises concerns that NICE's recent review of its methods suggests that organisation's "priorities and values have shifted away from its traditional gatekeeper role to focus on facilitating access to innovation"?

# NICE does have a role in facilitating access to innovation, but this is from the perspective of access to innovative new technologies for the benefit of patients.

# The severity modifier replaces previous specific consideration of life-extending treatments at the end of life and reflects evidence that people value more highly health benefits in the most severe conditions. In developing this approach, we explored the potential knock-on effects on the health system in detail. The severity modifier was carefully designed to balance the additional value applied in severe conditions with the care that would be displaced elsewhere in the NHS by the additional costs this creates (the opportunity costs).

# The article also noted a move within NICE to welcome broader sources of evidence, including real-world evidence. As the evidence landscape changes across health and care, setting clear expectations and standards for broader evidence sources (such as those in our methods, and in our real-world evidence framework) allows us to make the best use of the available evidence in different contexts and maintain our high evidential standards.

# We are monitoring the effects of these updates on the first appraisals subject to the new methods and process and will report on these findings.

# A fuller response to the article can be found here: <https://www.bmj.com/content/379/bmj-2022-071974/rapid-responses>.

# The paper refers to the forthcoming manual being updated and opportunity this presents for that wider perspective to be included. The new modular updated approach is certainly welcomed, however do NICE have a specific date when the manual will be updated, or is this just iterative? Will any proposed updates be consulted on?

# The guidelines manual is being updated in series of modules. It is anticipated that the module relevant to this paper will be subject to consultation in the summer of 2023.

# Why did the Board ask for this work [on wider societal perspective in NICE assessments] to be done? Adopting a wider societal perspective would in general increase the prices companies can charge. Payer would still be NHS - not the wider general budget, so would lead to more health foregone if health budget not increased to compensate?

# It sounds like some board members are very strongly pushing to change the perspective the NICE TA programme takes. Does DHSC and NHSE support this?

The Board is not pushing for a change. The work was commissioned as the question on the perspective that should be used in NICE assessments was being raised externally and therefore it was appropriate to explore the issue (which DHSC supported). Asking the question does not mean NICE is predisposed to an answer and the Board is not pushing to change the perspective used. The Board is keen to ensure that the finite health resource is used to maximum benefit.