Healthwatch Birmingham & Solihull's response to proposed changes to NICE regulations: cost-effectiveness threshold

Healthwatch Birmingham and Solihull responded to this online survey consultation regarding proposed changes to how NICE cost effectiveness thresholds are determined. Our responses to these proposals were as follows.

Proposal 1

Do you agree or disagree that a ministerial power of direction, as outlined under proposal 1 above, should be limited to the NICE standard cost-effectiveness threshold?

- Agree
- **Neither agree nor disagree**
- Disagree
- Don't know

Please explain your answer. (Optional, maximum 200 words)

If this change is to be made, we agree that it is key to limit the ministerial power of direction to maintain the independence of NICE and enable them to carry out their role effectively. We do however feel that by extending ministerial power of direction to even this extent there is a risk that ministerial priorities will take precedence over clinical evidence and health outcomes. This change also risks disadvantaging patients with rare or costly conditions. Under the current system for setting the cost effectiveness threshold, the cost of these treatments can be properly considered against the outcomes for patients due to the expertise of the professionals who set

the threshold. Ministers are unlikely to be able to spare the time to properly consider this impact which may cause delays or removal of treatment for these patients if the threshold is changed. Under the current system there are also clear opportunities for patients to make their needs heard through patient representatives and experience panels. As a champion of patient voice, we feel that decisions which can significantly impact patients' long term health outcomes should sit with patients and those who are able to properly consider the impact on patients.

Do you agree or disagree that the power to direct NICE about the standard cost-effectiveness threshold should apply to all NICE guidance that makes recommendations on health spending? This includes technology appraisal and highly specialised technology evaluation recommendations.

- Agree
- Neither agree nor disagree
- **Disagree**
- Don't know

Please explain your answer. (Optional, maximum 200 words)

Whilst the present example of changes to the cost effectiveness threshold may enable patients to access new medications, we feel that this should not be applied to all health spending guidance. We are concerned that this proposal allows for future decisions that may include a lowering of the cost effectiveness threshold without proper consideration. This may also force alternative treatments to be prioritised due to ministerial priorities which may lead to worse outcomes for patients. We feel that having the cost effectiveness threshold set by ministers who are outside of the organisation undermines NICE's independence and ability to design guidelines which balance public health needs and address health inequalities. This is due to

several impact considerations which may sit outside of ministerial knowledge or skillsets, potentially leading to negative implications for public health outcomes or deepening inequalities.

Proposal 2

Do you agree or disagree that NICE should not be required to consult on any proposed changes to its procedures that are necessary as a result of a ministerial direction on cost-effectiveness thresholds?

- Agree
- Neither agree nor disagree
- **Disagree**
- Don't know

Please explain your answer. (Optional, maximum 200 words)

The existing consultation process is essential to understand the impact that a change may have on public health and to consider inequalities that might arise from any change. We feel that it is impossible to properly understand the impact that a change to the cost effectiveness threshold as well as the guidance itself is likely to have on public health outcomes, without the inclusion of patient voice in the decision-making process. Removing the need to consult on changes to procedure risks sidelining the very people that this guidance is designed to serve. There is also a risk of unintentionally causing deepening inequalities without careful consideration. We therefore feel that if changes are made to NICE's power to set their own cost-effectiveness thresholds, those in charge of these decisions should be required to consult to properly understand the implications of a change. This also allows for greater transparency regarding the decision-making process when setting a new cost effectiveness threshold. Without the inclusion of patient voice in this process it is impossible for decisions to

properly reflect the needs of those who are impacted by changes to NICE guidance.

Additional comments

If there are any further comments you would like to make in relation to the proposed regulatory changes set out within this consultation, please include them here. (Optional, maximum 300 words)

Overall, despite the acknowledgement of the impact of this change on NICE's independence included, the proposed changes still risk undermining its capacity to provide effective guidance for management of public health needs. There is a clear risk within the proposed new way of working that ministerial priorities may take precedence over clinical outcomes in relation to public health spending. This would undermine NICE's ability to effectively guide healthcare practice and manage public health needs. This is compounded by the proposal to remove the need to consult on any changes to guidance resulting from these ministerial decisions, shutting the door to public voice regarding the impact that changes to spending may have on their long-term health. This change also risks deepening inequalities if patients' needs are not properly considered when setting thresholds under the new system. It is key that decisions are transparent and that patients can see rationale for decisions are made in their best interests. We therefore stress the importance of maintaining the independence of NICE when determining the cost effectiveness threshold to ensure that the impact on public health outcomes is not ignored in favor of budgetary tradeoffs or other ministerial pressures.