

Joint statement by organisations representing patients and carers on proposals to reflect Value Based Assessment in the assessment of novel treatments for use by the NHS in England -

“Disappointed, but ever optimistic”

We the undersigned wish to collectively express our disappointment that the methods and process that look to be adopted for use by the National Institute for Health and Care Excellence (NICE) in implementing Value Based Assessment (VBA) will fall far short of the vision that we would all support: “to give patients better access to effective and innovative medicines”ⁱ

Four years on, the opportunity to take a wider look at the value of new medicines has been reduced down to even greater reliance on the imperfect Quality Adjusted Life Year (QALY). This is an opportunity missed to bring in much more clearly the experiential value of new treatments as encountered by those best placed to know: patients and their carers. And with a limit set on the cost effectiveness threshold that is more restrictive than seen in the past and the loss of End of Life as a distinct modifier, there is even less flexibility in the system than before.

The consequence is a real risk that decision making remains unchanged: focusing on the clinical and cost effectiveness of a novel treatment, with only cursory consideration by NICE’s appraisal committees of Burden of Illness and Wider Societal Impact, with the role of innovation remaining opaque.

The changes proposed by NICE fall short of its reputation for innovation in assessment and appraisal of new medicines. The innovative spirit of NICE seems to be fading, and we urge NICE to focus as much energy on reinvigorating itself as it seems to expend on expanding its remit. We remain optimistic that this could occur and that NICE’s ambition, to “put the needs and preferences of patients and the public at the heart of our work”ⁱⁱ ceases to be just rhetoric and becomes a reality by working with us by refining the system to allow deliberation to place greater emphasis on all values.





ⁱ Department of Health, [A new value based approach to the pricing of branded medicines – a consultation](#), December 2010

ⁱⁱ National Institute for Health and Care Excellence, [NICE Charter](#), April 2013