

**“ASCO is trying to address the problem of the patient involvement – but are they a significant part of the discussion? No.”**

# Not nice

**Kevin Grogan is in Chicago as delegates launch fierce attacks on their drug pricing systems while kicking ours straight out of the park**

WORDS BY *Kevin Grogan*

**T**he American Society of Clinical Oncology (ASCO) meeting in Chicago once again provided a fascinating insight into the leading research being carried out into tackling cancer but, unsurprisingly, the price of drugs was a debate that rang around the halls of McCormick Place.

ASCO itself presented a modified version of its ‘Value Framework’ – originally published in June last year – which represents an attempt by the Society’s ‘Value in Cancer Care Task Force’ to develop a methodology which defines the currency of treatment within the context of rising costs, when applied to new and novel therapies.

Development of a software tool to aid cancer therapy decision-making will continue toward a pilot study by the end of the year, with the aim of conjuring up something much simpler for doctors to use while in conversation with patients.

Ah yes, patients. Fair play to ASCO, it is trying to address the problem of patient involvement – but are they a significant part of the discussion? No, I don’t think so.

With this in mind, I ventured out of the congress centre to actually speak to some American patients, and gauge their views on the cost of medicines. They have much to say and about one group in particular – the Institute for Clinical and Economic Research (ICER).

ICER is a Boston, USA-headquartered group, which describes itself as “a trusted non-profit organisation”, and has been in the headlines for a number of analyses. These studies have concluded that drugs

are too highly priced and, in May, it focussed on myeloma treatments, stating that the price of some should be cut by as much as 94% to justify their true value.

The methodology used by ICER uses the quality adjusted life year (QALY) measure, which has some similarity to the equation used by the National Institute for Health and Care Excellence (NICE) in England and Wales. In terms of myeloma, its methodology has been slammed by Amgen and Bristol-Myers Squibb and the latter has said that its limitations could set up “arbitrary barriers to patient access.”

B-MS acknowledges that while “assessments of cost-effectiveness may prove useful in comparing treatments, they have significant limitations”. It added that ICER’s assessments should “not be used for decision-making that determines access to innovative medicines”.

The problem is that they *are* being used for decision-making, according to Bob Goldberg of the Center for Medicine in the Public Interest. He told *PfMagazine* that the NICE comparison is not particularly accurate, as the process in the UK is open and involves robust science-based dialogue. “What ICER wants to do is limit the spending on medicines to pay for roads, bridges and police. I find that to be offensive – I can’t get my mind around it”.

He also stresses that the headline list prices of products give a false picture, and further negates ICER’s flawed models. Discounts of 30%–50% are commonplace, because of rebates that drug companies provide. These rebates, however, worth billions of dollars, and are arguably being

trousered by insurers and pharmacy benefit managers. Meanwhile, patients in the USA are being forced to pay 30% of the list price out of their own pockets.

Mr Goldberg believes that ICER sees healthcare in terms of cost – he essentially sees it as an investment. He acknowledges that cancer costs are increasing, but that is mainly because people are living longer, thanks to increased survival rates.

Is ICER therefore saying that survival is a problem? Quite the opposite, as it means that more people are alive to pay taxes.

At an event held at the home of the Chicago Symphony – concurrent with the ASCO conference – Jonathan Wilcox, co-founder and policy director of Patients Rising, said “the so-called ‘value-frameworks’ by ICER, and others, could re-shape the future of healthcare”.

He added that they “use complicated mathematical formulas to put arbitrary limits on the cost of new treatments.”

“The proposals could potentially harm the health and well-being of the millions of Americans with cancer and other life-threatening diseases,” he concluded.

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*Stacey Worthy, director of public policy for the Aired Alliance*

## WE ARE NOT WORTHY

Would following the example of NICE be better for our friends across the Atlantic? No thanks, says the brilliantly-named Stacey Worthy, director of public policy for the Aired Alliance, who was also at the Chicago Symphony event.

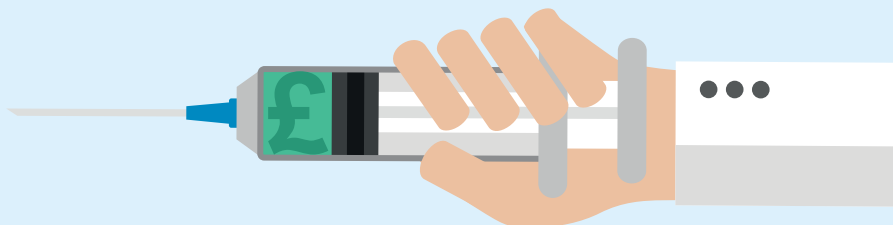
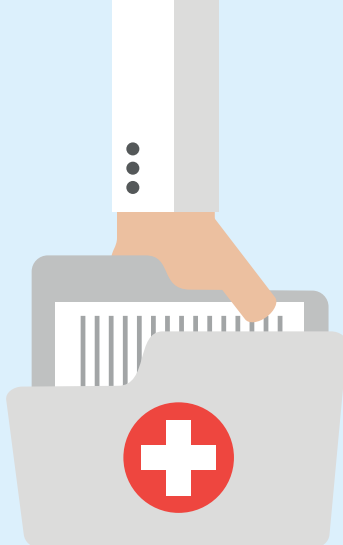
She has authored a report claiming that under NICE’s model, “priority in the UK has changed from providing healthcare to all consumers, to dividing up the care that is available, and distributing it equitably, regardless of individual circumstances and needs – the institutional rationing of healthcare. The same can be expected in the USA if insurers implement ICER’s price controls”.

Worthy believes NICE has led to “decreased quality of care, delays in treatment, increased mortality rates and a stifling of innovation”. Arguing that NICE has not approved a single breast cancer drug in the last seven years, she said, “England is a decade behind the other countries in Europe in terms of cancer survival rates”.

At present, England’s cancer survival rates are 15% lower than the USA’s rates. “We cannot afford that to happen here”, she added.

Worthy thinks that if the US healthcare system moves closer to the model on our side of the Atlantic, it will lead to higher mortality rates and poorer quality of care for patients. This may yield a short-term budget impact, but the long-term cost would be terrible for patients, Worthy insists.

Scorching words, but one thing is clear, the patient’s voice in the USA is getting louder and resistance to drug rationing will be ferocious.



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