Cancer drug decision: ‘NICE should take more account of quality of life’

The National Institute for Health and Care Excellence’s reluctance to recommend Kadcyla for routine NHS funding has sparked calls for a new approach to the funding of expensive drugs

By Jennifer Trueland

Samantha Heath’s message to politicians and policymakers is that she is not dying from cancer, she is living with it. Diagnosed with primary breast cancer in 2014, she was still on treatment the following year when a scan revealed a tumour in the liver.

A few years ago, the outlook would have been grim, but for Ms Heath, treatment with the advanced breast cancer drug Kadcyla (trastuzumab emtansine), has literally been a life-saver. ‘It’s really reduced the liver tumour. It was a large beast and it’s gone,’ says Ms Heath. ‘On Kadcyla, I’m able to work three days a week. I run a small charity that employs eight people. I’m able to enjoy my life with my partner and son. And I’m able to do things like sing in a choir, which has always been on my to-do list.’

Ms Heath, and others in her position living in England, have been able to get access to Kadcyla via the Cancer Drugs Fund, which was set up to pay for drugs that NICE has not recommended for routine use on the NHS. But changes to the way the fund works...
means that NICE is now set to make a decision on whether the drug should be made available.

At the end of December, after a process to reappraise the drug that it had previously rejected for routine use, NICE again turned down Kadcyla for use on the NHS in England, saying it was too expensive.

At the time, NICE said it had applied as much flexibility as possible, but that the cost – £90,000 per patient per year – was too high in relation to the benefits it offers for it to be recommended for routine commissioning. This finding took into account the criteria used for end of life medicine, and a discounted price offered by manufacturer Roche.

This was draft guidance only, and NICE made it clear it was open to hearing the views of patients and others before coming to a final decision. An announcement is expected this month; a NICE spokesperson told Nursing Standard that this will not be ‘final’ as it will still be possible to appeal. Alternatively, he said, NICE may decide to continue with another stage of consultation.

Importantly, those like Ms Heath who are already receiving the drug via the Cancer Drugs Fund will continue to do so, but it may be placed out of reach for other women.

Raising expectations
‘It has been difficult,’ says Breast Cancer Care senior clinical nurse specialist Rachel Rawson. ‘When you get to the point of Kadcyla, you’re a long way down the line and other treatments have failed. So the NICE decision has been anxiety-provoking.’

Calls to the charity’s helpline have revealed that women are concerned Kadcyla will be taken away from them.

‘They don’t realise that if they are on it, they’ll continue to get it,’ she says.

‘What we have found lacking is support for women with secondary breast cancer. It’s having someone they can call, whether it’s a breast cancer specialist nurse or a practice nurse. It’s someone to listen to them – that kind of support is crucial for patients.’

She adds: ‘Financially, the NHS is in a difficult place. It’s amazing when you hear about new drugs and the impact they have. This gives women another hope, another chance. But we know that it can be difficult to access the drugs.’

It’s also stressful for nurses caring for people with secondary breast cancer, she says, both clinically and in the wider support networks.
NICE is expected to announce its decision on Kadcyla (trastuzumab emtansine) being licensed to treat HER2-positive breast cancer that has spread to other parts of the body, cannot be surgically removed and has stopped responding to initial treatment.

At full price, the drug costs £90,000 per patient per year, and about 1,200 people would be eligible for treatment, NICE estimates.

Last year the NICE appraisal committee considered data that showed that people taking Kadcyla could live nine months longer than those taking the alternative, lapatinib plus capecitabine.

Even with a patient access scheme, in which the NHS would pay for the first 14 months of treatment and manufacturer Roche would cover the cost after that, NICE’s draft guidance concluded that the cost was too high in relation to benefits for routine commissioning.

NICE is expected to announce its decision this month.

The Scottish Medicines Consortium is also expected to review whether to recommend Kadcyla for routine use in the NHS in Scotland, with a decision expected in April.

About Kadcyla

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Petition

The NICE decision sparked immediate action from campaigners, including the research charity Breast Cancer Now, which launched a petition calling on NICE and Roche to work out a deal that gives women access to the drug. More than 115,000 people signed the petition, which was presented at the end of January.

Breast Cancer Now chief executive Baroness Delyth Morgan points out that the drug is currently available in 18 other countries, including France, Germany, Australia and Canada.

‘There are very few treatment options for secondary breast cancer patients as it is, and we cannot let a drug as good as Kadcyla pass England by.

We’ve been overwhelmed by the support from the public in a very short time,’ she says.

The NICE decision spurred Ms Heath into action. She spoke to childhood friend Siobhain McDonagh, the Labour MP for Mitcham and Morden, who was able to secure a debate in the House of Commons on 26 January, which was attended by Ms Heath and other women affected by secondary breast cancer.

The financial travails of the NHS are well-documented, and Ms McDonagh acknowledges that the health budget isn’t a bottomless pit. ‘NICE has an incredibly tough job to do, and I do know that we have to draw the line somewhere,’ she says.

‘But the problem is that we don’t draw a straight line. We need to be sure that the system that NICE uses is consistent and well understood.’

Ms McDonagh and Ms Heath would like to see a change to the way NICE makes decisions, with more emphasis on quality of life. Ms Heath says that it is considerably easier to function and have a good quality of life on Kadcyla than on traditional aggressive chemotherapy, and she has done both.

Like with like

They would also like policymakers to compare like with like when making decisions on whether to fund drugs. Kadcyla was compared to a drug that isn’t available on the NHS.

Meanwhile, Ms Heath would love to take a break from Kadcyla, which suppresses the immune system and involves a gruelling treatment every three weeks. Stopping the drug for a while would, of course, save the NHS money, but it’s not a risk she’s prepared to take. ‘If I came off it, and my tumour came back – which it would – then I wouldn’t be allowed to go back on it, so I have to stay on it.’

For her, and for other women with secondary breast cancer, the drug brings hope for the future. ‘One woman has been 14 years on Kadcyla,’ she says. ‘The thought that I could live that long is wonderful.’

‘We need to be sure that the system that NICE uses is consistent and well understood’

Siobhain McDonagh

Jennifer Trueland is a freelance health writer