Access routes and asking prices: Getting drugs to cancer patients

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What's a fair price for a drug? How can we make sure more patients have access to the latest treatments? And how can we speed up the whole process of bringing drugs to cancer patients?

These are tough questions, and stakeholders from across the life sciences spectrum have very different approaches to answering them. So the ICR brought together experts from across academia, industry, the charity sector and policy makers to understand the different views and come up with joint solutions.

Although we've come a long way in our understanding of cancer and in the development of cancer medicines, there are still serious challenges in place. There are stark differences in the rate of development for new cancer drugs between different tumor types, with some cancers of high unmet need missing out. And across the board it still takes too long for patients to be able to access the latest treatments.

This week the ICR published a nine point plan developed by a broad group of experts across the sector, which recommends practical ways to answer some of these big question around how to increase access to new cancer drugs.

I wanted to seek out a patient perspective and spoke to patient advocate and cancer drug campaigner Emma Robertson.

Emma, who was diagnosed with ER/PR+ primary breast cancer aged just 31, at the beginning of 2013, went through nine months of tough, but 'curative' treatment before being prescribed the drug tamoxifen. But after just a year of taking the drug, she received a devastating diagnosis of metastatic breast cancer which had spread to her lung, liver and bones.

Emma is now being treated with the immunotherapy palbociclib and campaigns with MetupUK for others with metastatic cancer to be given access to game-changing drugs such as this. She is all too aware of the problems with the status quo, and she gave us her insight on the points in the plan.

Making sure the price is right

Cancer drugs are often hugely expensive, and it's widely acknowledged that we face a major challenge in making new cancer treatments available to patients affordably for the NHS. And one of the issues behind this is the way prices are agreed.

One drug, one price. That's how things currently stand, but it's not always the best way to do things.

The ability to vary prices based on the outcomes a drug can give, as well as varying the price for different conditions, are promising ways of ensuring the NHS gets value for money for innovative new cancer medicines.

And crucially it also means that a pharmaceutical company can reduce the price of a drug for a rare disease where it would otherwise not be cost-effective, but maintain a different asking price for other existing conditions.

Emma agreed that this will be key to increasing access to a wider range of treatments.

"Metastatic patients don't just need one new drug to be made available—we need multiple treatments that we can access at multiple points and in multiple ways. Flexibility for pricing drugs could help improve the current lack of flexibility in the pathways by which patients are able to access medications" she told us.

"Limiting a treatment to just one price limits patient access and has negative consequences for so many people living with cancer. I'm really glad the group of experts at the summit recognize this issue and recommend it be addressed."

Last year Emma was involved in a piece of research undertaken by Cancer Research UK on an outcome driven approach to drug pricing, and she is supportive of this route.

"Outcomes based pricing makes sense for patients in the real world" Emma said.

But when it comes to making this happen in practice, data drives everything.

New models of drug pricing like these need detailed prescribing data to be collected from the NHS. The experts recommended that the Government and pharmaceutical industry work together to create the digital infrastructure and employ the right people to make this happen.

"I believe that there needs to be a sea-change in NHS culture towards an understanding of why data matters. Data is information that can be used to improve patient outcomes and experience but we seem to be continually bumping up against impenetrable bureaucracy" Emma said.

Swifter access to state-of-the-art treatments

In cancer, waiting for a treatment to show an overall survival benefit in clinical trials can take many years, and cause delays for patients in accessing new treatments. To combat this, the experts are calling for better 'surrogate' outcomes—something that serves as a proxy for long term benefit without having to wait months or years to collect the data.

For Emma, exploring this link is really important—"It would be incredibly helpful for stage 4 cancer patients to know whether 'progression-free survival' does actually correlate with overall survival. It is not enough to bring new and innovative drugs to market quickly. We need to know what the longer range effects of those medications might

be" she explained.

And it's not just access to new treatments that is important. To make sure patients are getting the right treatment, we need to be able to test for biomarkers to match the right drug to the right patient.

Initial plans to update the National Genomic Test Directory—the rolodex of these tests that are available for NHS patients—on an annual basis, could lead to delays of many months before the latest tests are available on the NHS. So the experts are calling for a clear route for these tests to reach the NHS in tandem with new treatments, so that patients can benefit without delay.

Emma said "Diagnostic tests need to be implemented even earlier than they are currently used. If biomarkers aren't taken from a patient when a biopsy is possible then that patient may miss out when a new treatment with a specific target becomes available".

Focusing effort on the right drugs

We now know that in order to tackle some of the biggest challenges such as cancer evolution and drug resistance, we are going to need a tool box of innovative targeted drugs that can be used in clever combinations.

And one of the biggest barriers we have found to doing this is actually quite a surprising one.

A quirk of competition law which means that companies can't share the prices of drugs with one another, means they are in the dark when it comes to pricing combinations of drugs from different companies and prevents them from collaborating effectively with each other to bring them to market. The experts highlight this issue and call to make it easier for companies to collaborate to price drugs.

In addition, lots of drugs being brought to market are 'me too' drugs—so called because they are similar to the drugs that have come before them, rather than being truly new and innovative. These drugs can have their place, but we think it's vital that we give patients access to innovative new treatments that attack cancer in brand new ways, and that drugs like this should be incentivised and rewarded appropriately.

The consensus panel also highlighted that some types of cancers have gone a significant period of time with no real innovation. They are calling for better incentives to deliver research dedicated to the discovery and development of drugs for cancers of particularly high unmet need so that patients with cancers that have poor survival rates, such as lung cancer and pancreatic cancer, don't get left behind.

"I'd like to see the public sector retaining more ownership over its innovation and deriving more benefit for the public" explained Emma.

The life sciences sector in the UK produces ground-breaking, life-changing science, and it's important that we do all that we can to make sure that we have efficient and effective routes to get this science to patients, taking discoveries at the benchside through to recoveries at the bedside.

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