

# NHS England urged to act as patients miss out on cancer drug tests

August 20 2015, by Emlyn Samuel

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The tests look for faults in the DNA code.

It's a wonder of modern science that, for at least some types of cancer, doctors are now able to exploit the unique genetic faults in a person's tumour to treat their disease with precision drugs.

These 'targeted medicines' are part of a new generation of [cancer](#) treatments that are revolutionising the way some patients are treated.

Several of these types of drugs are already available on the NHS; more are on the way.

But not every patient's tumour contains these faults. So to find out who could benefit from targeted drugs, patients need to be offered tests, known as 'molecular' [diagnostic tests](#).

But there's a problem. These tests aren't being offered to all patients equally across the NHS in England.

We've [blogged before](#) about this problem, and how we want the Government and NHS England to act.

But today, further highlighting the sad state of affairs, we've published a [new report](#) showing the extent of the problem in the NHS in England. The findings are stark: thousands of patients are missing out on tests entirely, some of whom may have gone on to receive a targeted medicine that could have helped them.

This is a long standing issue that needs to be rectified urgently. The recent cancer strategy recognises this, and recommends that NHS England "transform access" to these tests.

So what is the situation and what needs to be done?

## **Why is molecular diagnostic testing important?**

There's a full explanation of what these tests are in our [previous post](#). But to quickly recap, molecular diagnostic tests are used to identify specific [genetic faults](#) in a patient's cancer.

The tests are generally carried out in hospitals, on tissue samples (biopsies) taken from the patient's cancer, either at the time they're diagnosed, or later on (for example, after cancer comes back, or a previous treatment stops working).

The results give doctors valuable information about the best course of treatment, including whether a targeted [drug](#) could work or not. For those patients with 'targetable' cancers, getting the right treatment can mean months of extra time where their cancer is under control, and can even extend life.

But these tests can provide more information than just whether a patient is suitable for a particular drug. They can also tell doctors the likely course of a patient's disease – i.e. how they may react to different treatments – or whether they may be suitable for a clinical trial.

And for those for whom a targeted drug wouldn't be suitable, there are benefits too: it means they could avoid drugs that won't work for them, but which would still cause side effects.

This is good for the patient, but also for NHS – as it means it can use drugs more efficiently.

These tests aren't for every cancer patient at the moment – they are only really done for certain cancers where a targeted drug is available, or where a particular drug is being tested in trials.

But while only a handful of targeted drugs are routinely available at the moment, more are in the pipeline, and the options for cancer patients are increasing. This means more patients will need molecular diagnostic tests in the future.

## **How many patients are missing out?**

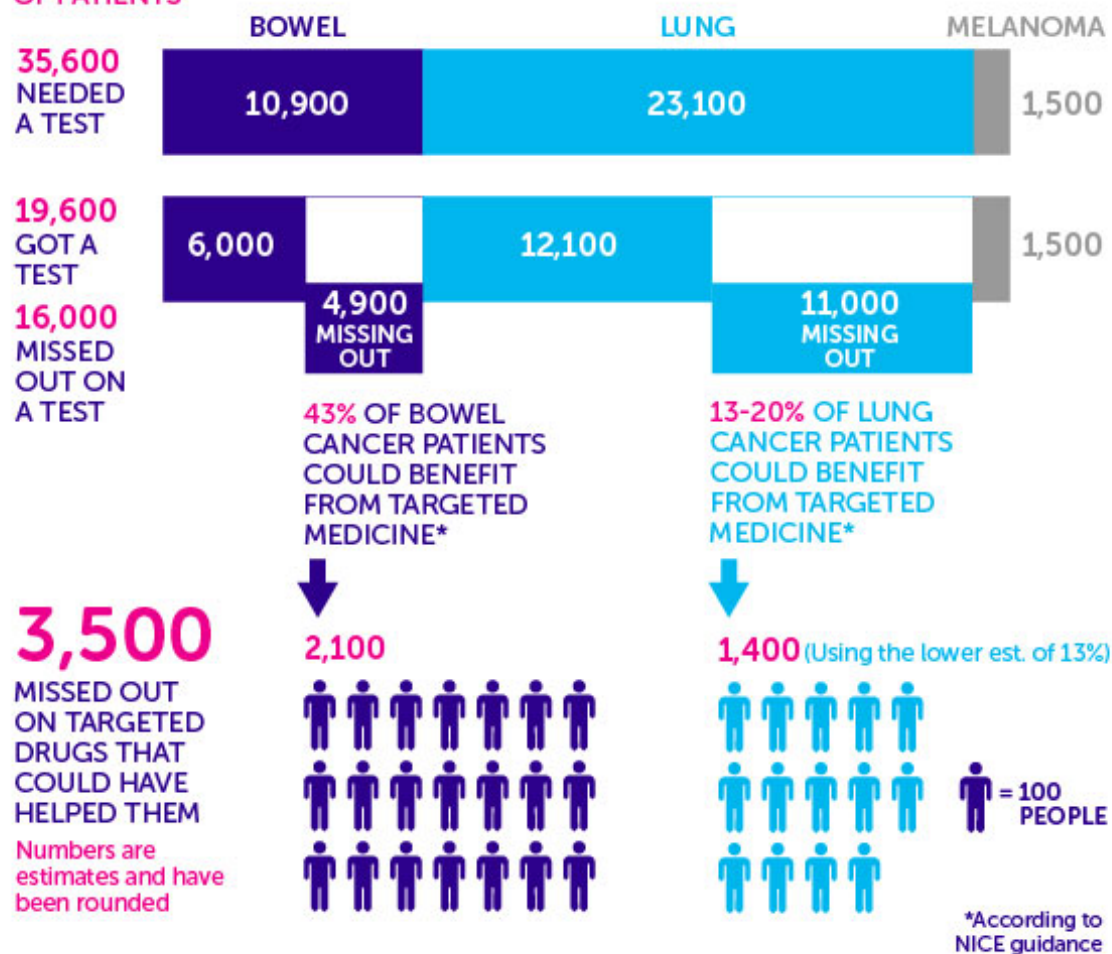
But how widely used are these tests on the NHS? To find out, we asked all NHS labs in England how many tests they are carrying out, focusing on three cancers where targeted drugs are routinely available: melanoma, lung and bowel cancers.

Then, based on the recorded number of patients with these particular cancers, we worked out how this compared with the amount of tests that should be done. The graphic below shows what we found.

# PATIENTS MISSING OUT ON MOLECULAR DIAGNOSTIC TESTS

2014 DATA ON TESTING OF MELANOMA, LUNG AND BOWEL CANCERS IN ENGLAND

NUMBER OF PATIENTS



Our report suggests that, in 2014, around 16,000 patients with lung and [bowel cancer](#) in England missed out on these tests completely.

Given what we know about how often patients' tests indicate they're eligible for targeted treatments, that means around 3,500 of these patients could have been eligible for a targeted drug that may have helped them.

And, in a sense, even those who wouldn't have gone on to get a targeted drug also missed out, in that their doctors hadn't explored every treatment option.

As well as melanoma, bowel and lung cancers, molecular tests are also done in many blood based cancers. So while this highlights the problem, it by no means provides a comprehensive picture.

The good news is that, although the situation is far from perfect for lung and bowel [cancer patients](#), it seems all suitable patients with melanoma are receiving tests.

This is likely for three reasons:

- the number of patients with advanced melanoma is relatively small compared with lung and bowel cancer
- the tests were paid for by the pharmaceutical company that makes the targeted drug
- and an enthusiastic clinical community exists in skin cancer who have kept this testing up.

## **Why are bowel and lung cancer patients missing out?**

We think the main reason for these patients not getting the tests is that there is no dedicated, national way to pay for them on the NHS in England. Where tests are being carried out, the money either comes from pharmaceutical companies – who may provide up-front funding to support testing for their drugs on the NHS – or the costs are being

absorbed into existing lab budgets.

Given the number of targeted drugs in the pipeline, neither option is sustainable.

Another reason is that not all doctors seem to be aware of these tests and the targeted treatments available. Previous work has shown that only around three in 10 doctors and laboratory professionals (30 per cent) rated themselves as having 'high' or 'expert' knowledge of the uses of targeted medicines. Testing won't happen if doctors don't ask for it.

## **What should be done?**

This is an issue that has been around for years, and there is a solution. The [2011 cancer strategy for England](#) recommended a national approach to both funding and providing molecular diagnostic tests. Along with others, we have been frustrated that little progress has been made.

Our report estimates that such an approach will cost around £13 million per year. That will both fill the gap in the number of tests provided, and create a national service that is set up for the future, when more tests will be needed for more targeted medicines.

And let's not forget that this will also help research, by making it easier to identify patients for clinical trials.

The NHS's [vision up to 2020](#) – the '[Five Year Forward View](#)' – puts personalised care and reducing variation in treatment at its heart.

And the new cancer strategy re-iterates the importance of "not delay[ing] any longer in establishing a modern molecular diagnostics service."

So NHS England must realise these ambitions and establish a nationally

funded molecular diagnostic testing service that provides tests for all suitable patients.

Ultimately, it's extremely worrying that [patients](#) are missing out on routinely available treatments, simply because they are not being given a [test](#) to see if they might benefit from them.

Now is the time to act.

Provided by Cancer Research UK

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