It's all about Me

The growth of personalised medicine threatens the communal approach that has brought our biggest health gains, says **Donna Dickenson**

ADVOCATES of personalised medicine claim that healthcare isn't individualised enough.

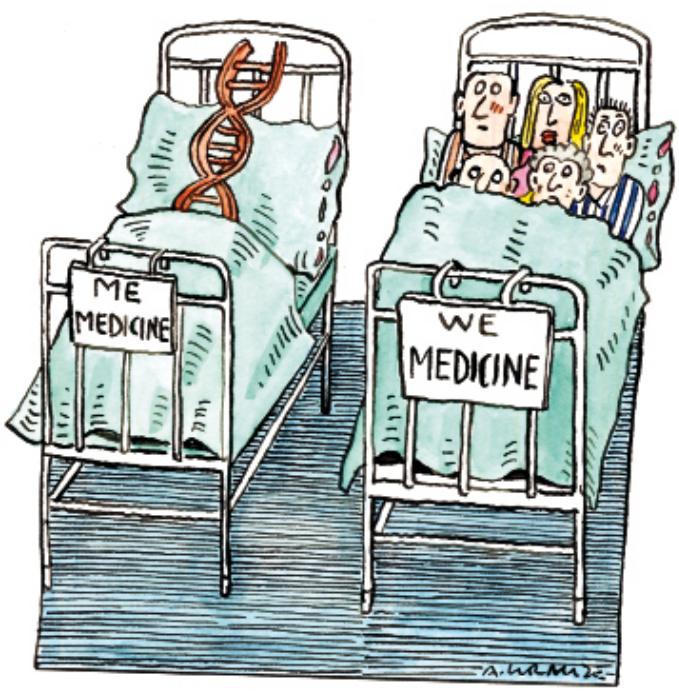
Backed up by the glamour of new biotechnologies such as direct-to-consumer genetic testing, personalised medicine – what I call "Me Medicine" – appears to its advocates as the inevitable and desirable way to go. Barack Obama, when still a US senator, declared that "in no area of research is the promise greater than in personalised medicine".

This trend towards Me Medicine is led by the US, but it is growing across the developed world.

In contrast, "We Medicine" – public-health programmes such as flu shots or childhood vaccination – is increasingly distrusted and vulnerable to austerity cuts. Yet historically this approach has produced the biggest increase in lifespan. Even today, countries with more social provision of healthcare and less individualistic attitudes have better health outcomes across all social classes.

Contrary to the claims of its proponents, the personalised approach hasn't yet delivered a paradigm shift in medicine. A 2012 Harris poll of 2760 US patients and physicians found that doctors had recommended personal genetic tests for only 4 per cent of patients. The Center for Health Reform & Modernization, run by US healthcare company UnitedHealth, put the figure at just 2 per cent.

But money is still pouring into Me Medicine. In July, the UK government announced that it would offer private companies a subsidy from a £300 million fund to encourage investment in its personalised medicine initiative, Genomics England. Last year the US administration increased the National Institutes of Health budget for personalised medicine, while cutting the budget for the Centers for Disease Control and Prevention's Office of Public Health Genomics by 90 per cent.



Of course it would be nice if we could afford both, but in reality there's a growing risk that "me" will edge out "we". If it does, it won't be because the science is better or the outcomes more beneficial. In some instances of Me Medicine, clinical outcomes are worse than the We equivalent. For example, according to the UK's Royal College of Obstetricians and Gynaecologists, private umbilical cord blood banks, which ostensibly provide a personal "spare parts kit" for the baby, produce poorer outcomes than public cord blood banking.

It is true that in some areas of Me Medicine, such as genetically individualised drug regimes for cancer care (technically known as pharmacogenetics), there has been genuine progress. For example, vemurafenib, a drug for aggressive melanoma, was reported in a 2012 *New England Journal of Medicine* article to extend the lifespan of 1 in 4 patients by seven months if they carry a specific genetic mutation in their cancer.

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But only about half of those with the "right" type of tumour responded, and the mutation in question only occurs in about half of such melanomas. What is more, pharmaceutical firms will probably charge more for such drugs than for mass-market ones. They will be expensive, may benefit only a subset of the population and could leave cash-strapped state healthcare systems facing difficult decisions about where to allocate resources.

A month after the melanoma study, much less encouraging results for pharmacogenetics were reported in another *NEJM* article. A genome-wide analysis of biopsies on four people with kidney cancer showed that separate samples from the same tumour can have different mutations, so a drug that targets one may leave other parts of the tumour untreated.

Given that the scientific evidence alone doesn't explain all the interest in personalised medicine, what does? Many retail genetics companies have "me" in their name – notably 23andMe, DeCODEme and Knome – so does it boil down to narcissism? I doubt it. There's nothing narcissistic about pharmacogenetics.

Another possible explanation is the favourable connotations of "personal" and "choice". "We" measures such as childhood

vaccination are routinely attacked as an invasion of parental choice, while accounts by people who have paid to have genetic profiles drawn up often include themes of individual self-discovery.

A third explanation is commercial: that in personalised medicine, pharmaceutical companies see a way to rescue themselves from the demise of profitable patents on mass-market drugs, so they promote the shift from We to Me.

As Mark Levin, former CEO of Millennium Pharmaceuticals, put it in 2012: "Business incentives must be put in place to encourage private investment and further develop the pipeline of new personalised medicine products."

The landscape has clearly changed. Twenty years ago, who could have predicted that people would pay to have a spit sample genetically tested or to bank their child's umbilical cord blood?

As well as unpicking and unpacking the science, we need to consider the social and economic context behind Me Medicine. How can we balance the role of the individual and the communal in healthcare? And how did we move from the original vision of genetic biomedicine as a communitarian endeavour – the Human Genome Project was ostensibly for the benefit of all humankind – to the personalised medicine paradigm?

These are big questions that need to be asked. If we do embrace personalised medicine, it should only be after a thorough review of the evidence and careful analysis of the social landscape in which we're making that choice. n

Donna Dickenson is emeritus professor of medical ethics and humanities at the University of London and research associate at the HeLEX Centre, University of Oxford. Her new book *Me Medicine vs. We Medicine: Reclaiming biotechnology for the common good* (Columbia University Press) is out now

One minute with...

Chris Rose & Alex Baker

Who needs a rocket when you can use a balloon? This pair of entrepreneurs offers low-budget missions into near space

Your new company, Sent Into Space, sells do-it-yourself kits to send objects up into the stratosphere. How did you get started?
Alex: Weather balloons have been around for a while as a way to collect data. We thought it would be fun to put a camera on one and see where it went. For the first flight a couple of years ago, we just botched something together: a camera, some foam we found in a bin and a GPS tracker normally used to track pets. It worked – but only just. We posted a video online, and some Canadian guys saw it and sent a Lego man up. Soon people were asking how they could have a go themselves.

How did you go from there to a business?
Chris: We didn't really anticipate the attention it would get. We gave a lot of tips to people, and were getting so many requests for help that we thought we should make a kit for the non-specialist. We designed and manufactured components to make it as reliable and simple as possible. We hope to sell the finished product in shops and through our website, so that anyone can do this themselves.

Will you still advise people?
Alex: That's the other side of it. If people have a project in mind, we see what we can do to make it happen. We did a launch for a music festival and a publicity campaign for the University of Sheffield. We have also worked with an astrobiologist who wanted to take samples from the stratosphere. And we do projects with schools, which is a great way to get kids enthusiastic about science in a hands-on way. They're putting stuff into space!

Does the kit contain everything you need?
Chris: You get the balloon, parachute, container for the payload, tracking devices and a computer system that we call the black box. It records the data – including GPS, altitude, pressure, humidity, temperature and acceleration. Schools really enjoy having all of that information after the flight. You just have to get the helium – we tell you the nearest provider – and apply for clearance from the Civil Aviation Authority a month in advance.

PROFILE
Chris Rose and Alex Baker are PhD students at the University of Sheffield, UK. They recently launched Sent Into Space, a firm that will sell space balloon kits at sentintospace.com

Can you describe a typical flight? How high and far can the balloons go?
Alex: They can go up to about 38 kilometres. That is technically near space rather than space, but you can see the blackness of space during the day. It normally takes a couple of hours for the balloon to reach that height. As the pressure drops with altitude, the balloon expands until it finally bursts; they start 2 metres across and get to about 10 metres. When the balloon bursts, a parachute opens and it takes about an hour to come down. On our website, we link to software that helps you make quite accurate predictions about where it will land – anywhere up to about 100 miles away.

What do people who buy the kits usually do with them?
Chris: Some people want to use it as a tool for taking pictures from high altitudes. Others want to send up their personal belongings just to be able to say they have been into space. But every project we do is exciting. We still get giddy when tracking the thing coming down.
Interview by Douglas Heaven