

Article

Keeping the Person in Personalised Healthcare

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Healthcare system · Patient · Technology · Innovation · Education

Abstract

Proponents of personalised medicine believe that the involvement of the patients, including in “risk-sharing agreements,” will result in cost savings, the use of the genetic makeup of an individual patient as the starting point will save resources and, indirectly, there will be great potential for startups and new business in many areas. But how can Europe ensure that the “person” is central stage and allow us to focus on the development of personalised medicine for his or her ultimate benefit? The EU has a clear role to play, argues the author. One way for this to happen is for the EU to focus investment in guidelines for governance. This will go a long way to ensuring that the citizen is the principal factor when it comes to utilising the new wealth of innovation in health. The citizen must always come first when innovation is harnessed.

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Responding to Technology

The innovations that human ingenuity has come up with over millennia – from Neolithic pots to induction heating – have been key influences in changing the way humans live. Innovation has been at the root of the evolution from nomadic or cave-dwelling hunter-gatherers to settled cultivators who master pastoral and arable techniques [1].

Innovation – in everything from construction techniques and drainage to the coining of money – enabled the emergence of sophisticated urban societies [2]. And the shift from an

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agrarian to an industrial society was possible only after materials science, transport facilities and new forms of social organisation opened up the path to unprecedented opportunities [3].

Great benefits have flowed to society in terms of travel from the invention of the wheel, to the Wright brothers' first flight, to the Boeing 787, or in terms of communications from the invention of the electric telegraph to the telephone and on then to the internet and the smart phone. People can now communicate effortlessly over long distances, personally or virtually.

But it is not the new technologies that change societies. It is the response to technology that causes change. If people had chosen to resist the wheel and had persisted in dragging their goods along on a sled, the axle and the differential and the internal combustion engine would never have been necessary – and doubtless never developed.

If people had opted to persist with the Pony Express out of fear of electric leaking out of telegraph wires, the most common form for delivering a billet doux might well still be a note wrapped around a brick and thrown into a bedroom window.

Because advances in science and innovation do no more than put opportunities in front of society, there is an element of choice in whether to make use of the opportunities – and how to use them or control them. So shortly after the automobile started to proliferate, governments stepped in with rules of the road – covering which side to drive on, how to behave at junctions, what qualifications were required to take a vehicle onto the road. Similarly, social norms and regulation govern the use of iPhones or the internet: you don't ring your friend in Australia from Belgium at tea-time, because you will wake them in the middle of the night; and governments impose limits on what sort of information can be legally uploaded to the internet, or how far social media companies can exploit personal information they gather [4].

When someone uses a Dodge to run down protestors, or employs a finely-honed kitchen knife to attack their wife, the choice is unsurprisingly considered wrong. Both a Dodge and a kitchen knife can be valuable and useful – but only insofar as the right choices are made over their use.

Advancing Innovation

The same principle holds true in more sophisticated areas of innovation. Any advance provides a choice: a choice over whether to use it, and how to use it. That choice will be informed not just by the intrinsic character of the technological innovation, but by broader considerations of an ethical, social, political or economic nature [5]. And the choices made can be positive or negative in the way they impact on any of those parameters.

What does this mean, in the realm of healthcare, at the personal level and at the public level? Healthcare technology is in constant and rapid evolution, and throws up a constant series of choices that must be made (or ducked!) by individuals and by society.

Even in a relatively straightforward issue such as infection control, the choices are multiple: should individuals take care to avoid infection, or, once infected, to avoid transmission? Should a mother abandon an infected child or remain at the bedside to care, with all the attendant risks? Should societies subject to infection heroically try to isolate themselves (as has occurred in remote villages during epidemics – such as Eyam in Derbyshire during the Great Plague of 1665)? Or should uninfected societies wall themselves off from the rest of the world as a defence mechanism – as developed countries tried to do during the recent Ebola outbreak? And should governments prioritise development of new therapies, or the improvement of on-the-ground social or hygienic conditions to reduce incidence?

Innovation and Healthcare

In a field as complex as personalised medicine, which involves so many disciplines, dimensions and stakeholders, the questions are all the more numerous. But they must be faced if society is to live in the real world, rather than seeking, out of timidity, to emulate the head-hiding behaviour of the ostrich [6]. A refusal to admit there are questions – out of apathy or of flat rejectionism – is not a responsible response.

This refusal is the mistake made by Luddite opponents of the industrial revolution – who had cheerfully and unquestioningly accepted all the benefits of the innovations that society had produced until the mechanised weaving machine, but who balked as soon as the use of an innovation threatened their particular interests [7]. Their opposition then had little impact on the outcome, since the choice of society as a whole outweighed their sectional considerations. The mistake they made was to identify the technology as the enemy – when in fact it was the wider (and more widely accepted) search for efficiencies that was the key factor [8].

The enormity of the difference between innovation itself and the use of innovation is demonstrated most aptly by the Manhattan Project. This took advantage of Einstein's new understanding of relativity. But Oppenheimer's application of relativity had the consequence of two atomic bombs falling on Japan. As Oppenheimer said, in reflecting on the use of this innovation, and echoing the phrase from the Hindu scripture, the *Bhagavad-Gita*: "Now, I am become Death, the destroyer of worlds" [9].

The responsibility for Nagasaki and Hiroshima cannot be pinned on the scientists themselves. It was the application of the science that ushered in a new age of destruction [10]. The decision on this exploitation of innovation was made by political and military authorities who were themselves embroiled in a deadly war and whose calculations took account of many conflicting factors [11]. To borrow another phrase from Oppenheimer, "There are no secrets about the world of nature. There are secrets about the thoughts and intentions of men" [12].

Even the most distinguished scientists and the most enlightened politicians do not have the benefit of hindsight when making the judgements they must make in the present. Consequently, it is necessary to maximise the acuity and quality of reflection that is brought to making judgements on innovation – aiming to provide as far as possible for the most socially apt use of them, without stifling the process of innovation itself.

How does this play out in the search to realise the promise of personalised medicine – the promise, that is, for patients and society? In a field so complex, there are obvious implications for healthcare systems and for healthcare actors, and for society as a whole.

But how to ensure the interests of the person are taken into account amid all the competing and conflicting priorities of multiple stakeholder/shareholders with their particular interests, each imparting a distinct dynamic? Even more challenging, how to establish effective governance of a process where there is no single creator, no overall design, but instead the ebullition of tens of thousands of simultaneous contributions – not chaos, but a process that is by its nature a challenge, and sets challenges in terms of attempts at identifying a shared vision, or in agreeing on mechanisms of coordination, guidance and control.

The broadly enterprise-friendly culture that has predominated since the age of the Enlightenment, and has been largely propitious for innovation, has functioned on the basis of a restrictive rather than permissive approach – that is to say, anything may be done as long as it has not been specifically restricted, rather than the antithetical permissive approach, in which nothing may be done unless it is expressly permitted [13].

In many respects the consequent innovations have been beneficial, lifting large populations out of poverty, generating wealth that has afforded unimaginably high standards of living to many, and providing unrivalled opportunities for work and leisure [14].

But that enterprise culture has come under question – notably because of the social costs associated with it, particularly since the evident excesses and abuses that accompanied the major industrialisation and urbanisation of the 19th century [15]. The reactions in terms of political movements – from the Chartists to the Russian revolution to the rise of Fascism – aimed at establishing alternative systems with different priorities, often with an emphasis on imposing controls on enterprise and on “managing” innovation. And now, although the impact of Marx and Mussolini is attenuated in contemporary western society, that hostility to enterprise has left a legacy of scepticism that continues to resonate in many of today’s consumer movements [16].

Healthcare, the interface between an individual patient and a professionalised and regulated system, is pre-eminently a nexus between private and public interests. And as a major area of continual research and technological development, it produces a constant stream of innovations – and consequently becomes a classic battleground on which conflicting views on the merits of innovation are played out.

The specific field of medical innovation offers a rich display of such conflicts – with controversies over high-profile issues such as the direction of research and how to incentivise it, the morality of medicine pricing systems and practices, the ever-multiplying options for gathering and exploiting health-related data, or the adequacy of regulatory controls [17].

The engagement of the individual too is a point of potential dissension, since for innovations to take effect, they must be accepted [18]. The system may be in place, and society may encourage the citizen to take advantage of an opportunity, but at the end of the day, the citizen must take the responsibility [19]. The controversy sweeping across Europe about rights and duties in respect of vaccination offers a compelling example: many parents, unconvinced of the merits of vaccination for their child, are withholding permission for the conduct of immunisation procedures. Here the contrast between private and public interests is also clear, as an individual’s insistence on refusing vaccination clashes with the public benefit of herd protection that vaccination affords [20].

Those who value innovation as a potential benefactor of society – or who value it in more personal terms as an expression of human assiduity and imagination – naturally seek maximum liberty to pursue it. Those who are cautious about it because of the possible perils or practical problems it may engender naturally seek to monitor its progress and assert controls and impose constraints.

Person-Centric Healthcare

Between these two tendencies, it is necessary to strike a balance in the policy world that will allow innovation to take place while providing appropriate reassurances to sceptics [21]. That can be done optimally only if the inevitable debates are informed by quality of reflection and soundness of evidence – on both sides. If either side feels it can arrogate on the basis of some presumed authority without taking due account of the issues or in disregard of other points of view, the outcome will be severely sub-optimal [22].

So in discussions of innovation relating to health, meticulous navigation is needed to chart the best path through a multitude of variables. And amid all the consequent discussion of the technology and its implications, the central element should be – in line with the logic of the subject – the person. More than just a patient, more than a member of a category or of a stratified group. The person, the citizen, who merits attention as such. A potential patient, of course, as we all are fated to be at some stage or another. And to that extent, therefore, the person, the citizen, in general – that is to say, all persons, all citizens. For irrespective of any other definition or criterion or quality or characteristic, that is what we all are. A person,

people. No amount of subsequent categorisation changes that: in the same way that you cannot salt salt to make it saltier, no additional epithets make a person anything other than what he or she fundamentally is – a person. And that is what the discussions should revolve around.

The issue therefore becomes how best to enable and empower the person, the citizen, so that the individual's identity and role are at the centre of care. This where personalised care and precision medicine find their place in these debates. The advances in medical innovation and ICT tools can then enable the person to have a constructive interaction with the healthcare system – on condition that the healthcare system is adjusted accordingly [23].

Constructive interaction with the system depends also on personal readiness to take account of what the system can offer. This may be readiness to adhere to a treatment. But it may also be unreadiness even to receive a diagnosis. The fear of being diagnosed, or learning the unfavourable results of a diagnosis, can interfere. Even with the best diagnosis or treatment, it is up to the citizen also to follow the guidelines [24]. As the "person" takes on more responsibility for his or her health journey, not only will access be wider to better health as healthcare technologies respond more closely to patient needs, but the outcome will also include some knock-on effect of bringing down the costs [25]. This progression cannot be taken for granted, and planning for the development of personalised medicine should recognise this, providing education and – where necessary – support from psychologists [26].

More involvement of the patient, the person, the citizen, also permits a new dimension to assessment of therapies. The individual receiving treatment is best positioned to know if a certain treatment is working or not. The person understands his or her body, so can work with health care professionals to devise adaptations to treatment cycles [27].

The growing range of apps will also make it easier for the individual to understand at an earlier stage if a treatment is needed or not, which will also boost the chances for cost savings on unnecessary treatments – and will also provide a psychological boost for the individual, a reassurance that he or she retains some control of their own lives [28]. Education plays an important role here as well as the governance structures. This will save time in dealing with concerns on many of the issues that occur now with low participation in clinical trials, concerns regarding consent, sharing of tissue samples for further research, screening etc etc [29].

Properly handled, the adjustments and adaptations can begin to give effect to citizens' rights and their legitimate – but largely aspirational – calls for attention. Because the notional right to access to healthcare only has value insofar as it is turned into a reality: a right of way through a mountain pass, no matter how much there is talk of the right of free movement, is meaningless if the road has not been built [30].

And just as a mountain pass requires collaboration among many actors, each with his own responsibilities and roles, the same is true for healthcare in general, and personalised healthcare in particular.

"Rights," Realities, and Governance

Oppenheimer and Einstein are not solely responsible for the devastation wrought on Japanese cities in 1945, nor was it their sole duty to extend their own scientific investigations into the creation of a bomb. In the same way, while citizens may have a right to the best healthcare – and to the fruits of personalised care – it is not the duty of the scientific community alone to ensure that this right becomes a reality. Nor is it the unique duty of industry, or of the health insurance sector, or of individual regulatory bodies. Each has their own role, but none of them has the specific duty of oversight of the whole.

That must come from somewhere else. Ideally, governance structures can act as the independent arbiter to guarantee that personalised healthcare is at the service of citizens [31]. But that may not be enough, particularly if governance structures, wherever and whatever they are, have not adapted to the new possibilities as innovation opens up new avenues for care – and particularly for something as radically different from traditional approaches as personalised care offers. Often, governance structures have not moved as far or as fast as they might to perform this function. Tradition and cultural inertia can impede the responses that allow innovations to deliver their benefits [32].

Nonetheless, governance is not always and eternally blind and deaf. It may have taken time to make an impact on the authorities, but examples exist of where action by the person – or by people – has made it possible, even inevitable, for governance structures to adapt.

Challenging the System

One of the most striking captures of the governance structures in recent healthcare history is the way that the new patient population suffering from HIV/AIDS acted as a model of change. As the result of a campaign of activism unprecedented in the health sphere, the AIDS movement accomplished results that have changed perceptions forever of the relation between people and health systems.

The movement transformed the public and official understanding of the condition, and drove a sea-change in governance [33]. The outcomes, as is now well known, included massive increases in public funds for research, the development of dozens of new therapies by the world's largest pharmaceutical companies, and the consequent downgrading of a death sentence to a chronic and largely containable disease [34].

The mechanisms the campaign employed have lessons for now and for the future. The campaigners pioneered patient-driven clinical trial designs, with self-educated patient activists working with physician and scientist allies to set the agenda for research. In a race to save their own lives, activists expanded access to new drugs by forcing re-evaluation and reduction of regulatory hurdles. And they promoted funding for prevention, care and assistance for people living with HIV [35].

To achieve this, they broke all the rules on influencing authorities. They utilised the media and mounted demonstrations to put a human face on the disease. They engaged in civil disobedience that offended people and made policy makers and officials uncomfortable, but that won the nation's attention. In the US, thousands of sick people lay down on Wall Street or chained themselves to the fence of the FDA or stormed the NIH or threw condoms in St. Patrick's Cathedral [36].

The deliberately theatrical approach of the AIDS movement, and the successes it delivered, raises an obvious question about whether present-day health movements are too complacent, too polite. Organisations may shy away from dramatic action and focus on building sophisticated relationships within the system and the rules so that they get facetime at top level – but they leave decision makers feeling safe. They do not challenge the notion that the system and the rules as constructed may not be in their best interest.

The disability community similarly seized the agenda, transforming themselves from an overlooked segment of a society that took only a utilitarian approach to social organisation, and offered only neglect. Vigorous – and again disconcerting – action by pioneers, such as irritating commuters by blocking traffic intersections – led in time to court decisions that required society to make adequate provision for disabled people so that they had equal opportunities to access and to make their way in society. They changed the governance structure and narrative about how decisions related to them were made, so that

their issues were taken into account and they were involved in the decision making framework [37].

What both of these examples show clearly is how the person can remain the principal focus – and if necessary be the prime mover – in securing a context that permits more personalised healthcare. They provide a roadmap of how these areas changed the governance context. These actions tackled discrimination, leading to legislation to support people with disabilities in employment, housing, and access to public services. They overcame negative prejudices so that HIV/AIDS came to be regarded as a disease rather than a stigma, and became a respectable field for research [38].

The Role of the EU

Nowadays, with science opening up so many new possibilities for diagnosis and treatment – and for identifying what treatments may or may not work, or be or not be necessary – analogous questions recur. Concerns must be faced about the risk of discrimination by employers, insurers or banks against people whose genomic tests suggest the propensity to a particular disease. Laws and jurisprudence will have to be used to support the person/citizen. The governance framework can be used to protect the person so that s/he as a citizen can have a good quality of life [39].

Or with science unveiling mis-diagnosed or unknown diseases, new sub-divisions arise, offering the chance for earlier diagnosis and possible prevention (catching a melanoma at stage 1 offers much more hope than the patient would have with a stage 4 tumour). The decisions made in providing guidance will depend on the quality of the debate as guidance is developed. And the quality of debate will depend on how far society as a whole – and the people it comprises – is positioned and equipped for the exercise.

It may be necessary to seek change in the systems where the systems are currently inadequate to meet the needs of successfully applying innovation. The HIV/AIDS example shows how patient intervention changed how healthcare was conceived and delivered, and led to access progressing at international level to antiretroviral drugs. The key questions also include whether society is ready to allocate sufficient resources to these areas – and that too is a debate in which informed opinion – on all sides – will be crucial to getting the best results [40].

The EU is well-placed to find the right mechanisms, the right balances, to keep the person at the centre of personalised healthcare. Some of its laws and its governance structures already tend in that direction, and democratic principles are embedded in the member states themselves and underpin systems that offer frameworks for collaboration, cooperation and coordination.

In the EU, legislators, healthcare professionals, HTA experts, and payer organisations all have social principles at their core. But, as was the case with HIV/AIDS activism, or the emancipation of disabled people, a necessary stage to make use of the benefits of new technology is to create more dialogue between different groupings. And for this to have any real impact, adequate governance frameworks need to be put in place, along with education in the intricacies of healthcare provision, from an earlier age. Better education will raise the level of understanding between different groupings, and help in establishing common goals and visions that take account of the other's perspective [41].

If the EU puts the right frameworks in place, it can act as a hub for the years ahead. The EU is the ideal testbed for such an approach, because of its unique experience in facilitating dialogue between deeply divided peoples and institutions after WWII.

Since the EU was formed, imagination and political will have given birth to programmes such as Erasmus, dedicated to assisting students to travel abroad, and to a wealth of laws and

frameworks to facilitate collaboration. A key focus now should be investment in guidelines for governance to ensure that the person is the principal in shaping the use of innovative technology, so that technology remains at all times subservient to the person.

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