



**Personalised
Medicine**
All-Party Parliamentary Group

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Norman Warner

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PHG Foundation
2 Worts Causeway
Cambridge
CB1 8RN

All-Party Parliamentary Group on Personalised Medicine Reception

Harnessing science and technology for personalised medicine

Wednesday 2 May 2018, 19:00 – 20:30

House of Commons, Churchill Room

Speakers

Lord O'Shaughnessy

Parliamentary Under Secretary of State for Health

Dr Adam Platt

VP & Head of R&I Precision Medicine and Global Genomics Portfolio, AstraZeneca

Prof Sir Munir Pirmohamed

David Weatherall Chair in Medicine, University of Liverpool; Consultant Physician at Royal Liverpool University

Apologies

There were a number of apologies from group members and other parliamentarians for their inability to attend.

Minutes

The reception began with a welcome from Chair Helen Whately MP, who gave a brief explanation of why she became involved in the All-Party Parliamentary Group for Personalised Medicine. She stated that this aspect of healthcare is positive and is moving very fast. She contrasted personalised medicine with mental health provision, where there are very few 'magic bullet' solutions, noting that the exciting thing about technology is that sometimes it does seem to offer magic answers in the form of new medical treatments and cures, especially in genomics.

Helen Whately MP then introduced special guest speaker Lord O'Shaughnessy.

Lord O'Shaughnessy said that he had been pleased to receive the invitation to speak at the reception and thanked the PHG Foundation for supporting the work of the APPG. Personalised and precision medicine is the goal that everyone in the room was after, he noted, that, like him, got them out of bed in the morning. He said that the last sixteen months since he became a health minister with no direct background in health background had felt like a voyage of discovery, especially with respect to the potential of the sector. Listening to debate on cancer research and care called and led by Baroness Jowell earlier this year had, he said, also brought it home to him in very human terms.

The Government was said to be trying to improve brain cancer outcomes for patients, and as part of this work Lord O'Shaughnessy had visited the Brain Tumour Research Centre of Excellence at Queen Mary University of London. Even this one type of cancer has hundreds of variant forms, and any given tumour can contain dozens of different genomic variants. It was therefore clear, he noted, that the idea of a one size fits all, 'blast it' kind of treatment was not appropriate – something radically different is needed.

Lord O'Shaughnessy next outlined five main areas of focus for the Government, in furthering personalised medicine, whilst cautioning that this was not exhaustive:

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1. Bring data that already exists about patients together

Patients expect medical professionals to be able to access their data, in order to build up a comprehensive picture; this is a critical part of providing personalised medicine, and patients are understandably frustrated if this does not happen. There are great examples of where data integration is already happening, he said, such as in Manchester, Leeds, Oxford, and Cambridge, and the Government is trying to speed this up through the creation of Local Health and Care Record Exemplars. This is an attempt to bring together health, social and local authority data to provide a complete record of someone's needs and care that they have had, which will help to inform personalised care.

2. New forms of data need to be brought in

Former Prime Minister David Cameron set up the 100,000 Genomes Project in 2012 – a far-sighted decision, Lord O'Shaughnessy said. The Project has sequenced 58,000 genomes and is aiming to reach 100,000 by the end of 2018. What, asked the Minister, could be more personal and informative than your own genomic data? It can be built into personal records to give health staff the relevant degree of information needed for care. The Government has also made a commitment to sequencing a further 500,000 genomes from the UK Biobank, and an additional 50,000 cancer genomes.

3. Mainstreaming genomics

The next stage is to mainstream genomics into the NHS; to this end, Lord O'Shaughnessy said that NHS England is working to embed the use of genomic information. Once this is up and running, every child with cancer is to have their genome sequenced as part of their diagnosis, which may also mean sequencing their parents too. This will be an exciting translation of genomic technology into everyday healthcare practice, requiring the development of specific skill sets.

4. Creating the right research environment

The UK has four of the world's leading universities, and the Government is also building on the country's £64 billion Life Sciences industry through the Industrial Strategy. Lord O'Shaughnessy highlighted the example of digital innovation hubs, which make sure that researchers can access the very best data (with appropriate consent in place), supporting more and better quality clinical trials. This is something that needs to be built on.

5. The power of AI must be harnessed

Artificial intelligence (AI) inspires and terrifies people in equal measure, but it is a UK strength. Companies such as Google and DeepMind are, the Minister said, working to battle disease and improve diagnostics, and also transforming pathology and radiology by using AI to spot trends in tumours and in other areas of the body.

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In conclusion, Lord O'Shaughnessy said that we have to have courage. Harnessing science and technology for personalised medicine is not going to be a smooth ride. We also, he said, need to strain every sinew to bring the public along with us on the journey. Personalised medicine needs to not sound like a science experiment, but rather to sound like something that is going to save mothers, children, or whoever it is. Reassurance will be needed about the kind of information that the state will hold about people and more importantly the purpose to which it will be put, which is saving and extending lives. It is a truly transformative field, and there is tremendous opportunity for the country to excel given our strengths in the NHS, academia, science, commerce and data. The government is taking this issue seriously, and looks forward to working closely with the APPG.

Helen Whately MP thanked Lord O'Shaughnessy and introduced Dr Adam Platt.

Dr Platt was particularly taken by Lord O'Shaughnessy's comments regarding genomics. AstraZeneca, he said, believes that genomics can help to deliver new knowledge about disease, which is fundamental for finding new targets for precision medicine. Genomics helps to select the right patients for clinical studies, and AstraZeneca can now have diagnostics to go with new drugs that can find out whether a patient is likely to benefit from that particular therapy. AstraZeneca are working with Genomics England, UK Biobank, Oxford Nanopore, and the NHS on developing genomics in this way.

In Dr Platt's view, the best research will be achieved if industry can link UK health records with genomic data and biomedical data. AstraZeneca plans to sequence the genomes of two million patients between now and 2026, 500,000 of them from their own clinical studies. They hope this will make an impact on all therapeutic areas in which they are working.

Dr Adam Platt then posed the following question to Lord O'Shaughnessy:

Do you believe guidelines like GDPR will reassure citizens about the use of their data?

The Minister applauded the work of AstraZeneca as being very impressive, and noted that constructive interaction between academia, NHS and industry is taking place at the Cambridge Biomedical Campus. He noted that the UK recently signed up to an agreement to deliver one million human genomes sequenced across the EU by 2022, recounted speaking to the Estonian delegate at this event who had informed him that Estonia alone was planning to generate half a million genome sequences, from a population of 12.4 million. The UK therefore needs to press on with genome sequencing if it wants to keep ahead.

Issues around data are those that both most excite Lord O'Shaughnessy and make him most anxious, he said, noting that there was history with regard to the area which was not necessarily good. Government is trying to promote the benefits of data sharing and provide adequate reassurance. It is reassurance that is critical to ensure that the public and patients will be willing not to opt-out of their data being used for health research and planning. He thought that implementation of the General Data Protection Regulation (GDPR) would help, along with the work of the National Data Guardian, with ten data standards already being embedded into NHS practice. A simple opt-out will also be available for all NHS patients. Lord O'Shaughnessy was overall hopeful that, through a range of measures such as these, the Government was providing suitable reassurance for the public. He urged consideration of the question of how we can turn genomic medicine into an absolutely understandable and simple offer, so the public and patients think it is worth 'taking the risk' - not that there is a risk!

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Helen Whately MP next introduced Professor Sir Munir Pirmohamed.

Prof Pirmohamed explained that he had worked for NHS for 30 years; he chairs the UK Pharmacogenetics and Stratified Medicine Network, and also works with the NIHR Clinical Research Network to try and improve recruitment to these studies because the evidence base to take these projects forward is needed. Prof Pirmohamed stated that he believed that the NHS is a fantastic place for conducting stratified medicine research, because it is an integrated healthcare system. He observed that collaboration was also needed with universities and industry – not only pharma, but also data sciences and diagnostics companies.

Prof Pirmohamed posed a challenge to Lord O’Shaughnessy, explaining that patients he saw were typically over 65-75 with multiple morbidities and medications, often fifteen or more different drugs, which is dangerous and inefficient; if precision medicine is going to make a difference for the NHS, he said, there needs to be consideration about how to develop transformative programmes that will really help the elderly. How can the UK develop precision medicine that will help an ageing population? Lessons learned here could let us lead the world, as similar demographics are being seen everywhere; he recently heard in Shanghai that they would have 250 million residents aged over 65 by 2025.

The real challenge, Prof Pirmohamed went on to say, was in making personalised medicine relevant for real populations. He emphasised that it was not a matter of precision medicine versus public health, there should be no competition, but rather the two must exist in cohesion. Personalised prevention must therefore also be thought about.

Prof Pirmohamed posed the following question to Lord O’Shaughnessy:

Affordability and cost-effectiveness will be an issue with personalised medicine. What processes do you think the government needs in order to reward innovation and ensure affordability for NHS?

The Minister began by acknowledging that the UK is a world leader in both the life sciences industry and healthcare. Some of Prof Pirmohamed’s points around ageing, had been addressed in the Life Sciences Industrial Strategy, he said, but the points around rationalising care on multiple treatments for individual patients could be a worthy bid to the Industrial Strategy Challenge Fund. New technology might also have a role to play in prevention and in promoting healthy ageing and self-care.

On the issue of affordability, he noted that the risks are visible. As health interventions become more targeted, they can get more expensive; however, there should be greater confidence that the medication will work. Hopefully these factors balance out. The Government is about to enter negotiations for a successor to the Pharmaceutical Price Regulation Scheme, and this will be an area which they will want to explore. He said that the give and take between industry and the NHS would need consideration around the issue of smaller recipient groups for more targeted medicines; the Government wants to see win-win partnerships, with the days of straight buyer and seller relationships long past.

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Helen Whately, MP concluded the spoken programme engagements by summarising the exciting opportunities that personalised medicine can provide for better prevention as well as diagnosis and treatment. She said that a greater scale of ambition in this area was needed by Parliament, with consideration of affordability and approvals regimes, and there would no doubt be debates in the House of Commons regarding data challenges and people's concerns over the use of their data. She agreed that Lord O'Shaughnessy had made good points about needing to make a compelling case about the safety of data sharing and the opportunity it provides. An example from her own constituency was used to illustrate this point, as she noted that there is a strong case and robust evidence for having fewer but better stroke care centres, but there is reluctance to proceed in this direction due to public and patient concerns. People need to have confidence in changes to the delivery of healthcare, she observed.

Finally, Helen Whately MP thanked all speakers and attendees.

