Interviews

This collection of interviews brings together leading voices from across rare disease research, clinical practice, and healthcare leadership to explore the advances and challenges shaping the field today. The conversations span a diverse range of conditions and perspectives, from improving diagnosis and developing targeted therapies to delivering innovative treatments and strengthening multidisciplinary care. Across the interviews, common themes emerge around precision medicine, gene therapy, translational research, patient-centred care and the importance of collaboration. Together, they offer a timely insight into the progress being made in rare diseases and the priorities that will shape the next generation of research and treatment.

Featuring: Lord David Prior, William Gahl, Helen Lachmann, Ari Zimran, David Lynch, and Derek Gilroy

Lord David Gifford Leathes Prior

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Q1 You've had a remarkably diverse career spanning healthcare, government, and the private sector. Looking back, what experiences have most shaped your approach to leadership and healthcare reform?

My time at British Steel, North Lincolnshire, UK, which was back in the 1980s, has most shaped my leadership style. At that time, British Steel were going through a period of restructuring with large numbers of tragic redundancies in parts of the country where it was going to be very difficult for employment to return to, such as South Wales, Scotland, Teesside, Scunthorpe, and Sheffield. As these areas had a heavy dependence on steel making, coal mining, shipbuilding, and heavy industry, making significant redundancies in those areas was tough. During the process, the experience of learning to be empathetic to people while delivering really bad news has stayed with me.

Q2 You have served in several influential NHS leadership roles, including Chair of NHS England. What are you most proud of from your time working within the NHS, and what lessons have stayed with you?

That's a difficult question. The NHS has often been compared to a national religion in the UK, which makes change difficult, particularly at a time in which technology is changing in nature and application.

I aimed to make the NHS more open to innovation, with limited success. It is very difficult for a state-controlled monopoly to ever be open to real change because of all the political pressures that it must deal with.

I would have most liked to change the NHS from being a sick care service to being a health care service. Essentially, keeping people healthy rather than treating them when they are very sick. Yes, you must treat people when they're very sick, but would it not be nicer to get ahead of the curve and keep people healthier for longer?

The introduction of glucagon-like peptide-1, for example, is a case where some countries are going to get ahead of the game by prescribing it on a much wider basis than the NHS. In the UK, people are going private. I think the future is going to be much more about consumer-driven healthcare. Now, with the NHS funding treatment in part for those who cannot afford it themselves, I think you are going to see a much more mixed system, and that will be difficult for the NHS because it is so heavily hospital-dominated. So how do you get a hospital-dominated provider to switch to consumer healthcare? It is going to be very difficult.

Q3 Cell and gene therapies have the potential to transform outcomes for patients with serious diseases. How well positioned is the NHS to deliver these advanced therapies at scale?

If we can cure genetic diseases and indeed cure some cancers through cell and gene therapies, it will make a remarkable change in healthcare. The problem is that they are very expensive and the NHS does not have the resources to fund that kind of medicine.

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The issue really is, can we reduce the cost, and can we have a different reimbursement system so that the reimbursement is spread over time based on outcomes, rather than an upfront payment? Because these are one-off cures that we are talking about, these do not treat chronic conditions over time. As a result, the reimbursement method must be very different from how we reimburse medication for chronic disease.

For example, if you take sickle cell disease, which can be treated with CRISPR-based therapies, treatment can cost between 2–3 million USD per person, which is unaffordable on any system at a population scale. If you think of the hundreds of millions of people living with sickle cell disease, reducing the cost of treatment to, say, 10% of its current level and spreading the cost over 10 years on an outcomes-based basis would make it mainstream medicine. But we've got to take the cost out of it.

Q4 We are at the Human Cell Forum 2026 event. Can you walk our readers through what this event entails and how you got involved?

I am the chairman of bit.bio, Cambridge, UK, which is an innovative discoverer and manufacturer of synthetic human cells. Along with AI, these will be the features that will completely change preclinical drug development, particularly when combined with new approach methodologies. This could massively change the cost structure of drug development in the UK, Europe, and the wider world. And if we could do it in Europe, rather than seeing it go to China, would that not be fantastic?

Q5 What have been your key takeaways from the discussions and presentations you have heard over the course of the event?

What struck me is the growing consensus that animal models are not sufficiently predictive to deliver successful clinical trials. As a result, there is a clear need to find alternatives, which are now beginning to emerge. The regulators, such as the FDA, EMA and the MHRA, are open to this and are providing clear guidance that they are willing to consider preclinical evidence that does not rely on animal models. I have been struck by the level of enthusiasm for this change, and I believe it will fundamentally change the drug discovery paradigm, making important medicines more widely available. This is what we all believe in.

Q6 Looking ahead, what developments in cell and gene therapy are you most excited about, and where do you believe the UK has the greatest opportunity to lead globally?

The UK has a long history as a leader in genomics, which I am optimistic will continue. The

double helix was discovered at the Laboratory of Molecular Biology (LMB), the 100,000-genome project was done in the UK, and we have some new genome-sequencing technology coming out of Cambridge University, UK. The UK also have one of the finest polygenic risk-all companies in the world in Oxford. In terms of both diagnostics and therapeutics, the UK is extremely well positioned in science. The next big project is getting that science into delivery within the NHS.

There is a growing momentum across the life sciences industry towards reducing reliance on animal models and instead increasing the use of models that are predictive of human biology in drug development. In terms of bit.bio's own work, we recently announced the launch of a new human iPSC-derived hepatocyte, with the hopes of addressing some of the limitations in liver toxicity testing and preclinical drug development.

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