

# [Global Conference for Media Freedom, London 2019: watch live](#)



World leaders, journalists and others gather in London today and tomorrow for a 2-day conference to agree ways to defend media freedom. Chrystia Freeland, Canadian Minister of Foreign Affairs, and Jeremy Hunt, the UK Foreign Secretary are hosting the conference, which is the first of its kind.

The first day of the conference will focus on defining the challenges to media freedom worldwide. The second will look at framing solutions to these challenges.

We will make some of the main sessions available to watch live on this page:

## **Main plenary and press conference**

Foreign Secretary Jeremy Hunt, Canadian Foreign Minister Chrystia Freeland and Special Envoy for Media Freedom Amal Clooney discuss the threats faced by journalists:

## **Safety and protection of journalists**

Chrystia Freeland, Canadian Minister of Foreign Affairs, hosts a discussion on the threats faced by journalists:

A selection of the other sessions will be available to watch on [YouTube](#) shortly after they have finished.

Keep up to date with all of the latest news from the conference and join the conversation on twitter: [#DefendMediaFreedom](https://twitter.com/DefendMediaFreedom).

---

## [We need national debate on rare diseases to offer the best possible care](#)

Good afternoon everyone.

It is such a pleasure to be here to celebrate and raise awareness of rare diseases with you all – and it is a pleasure to see some of you again who were present during the excellent event hosted in the Houses of Parliament earlier this year. And even more of a pleasure to be celebrating through eating cake!

So, thank you to the British Paediatric Surveillance Unit for inviting me to such a special and enjoyable event.

Today, I really want to address the incredible young people here in the audience. Like many of you, I got ill as a child and for a very long time nobody knew what was wrong with me.

I was undiagnosed and went through all the usual experiences of the diagnostic odyssey – getting very sick from childhood and being referred to many doctors who did their best but just couldn't find out what was wrong with me. This went on for 30 years. Finally, a wonderful neurologist realised what was wrong and referred me to a specialist who diagnosed me in just 20 minutes.

It was such a relief, but as I acquired more and more specialists and we began to try to get the right medical regime for me, I got much, much sicker and found trying to co-ordinate all the tests and appointments and new medications – while still working – impossible.

Then the NHS stepped in and saved me and gradually, the pieces fell into place and I have clawed my way back to stable health.

I still have my battles, you may have seen that the other day I fainted right in the middle of giving a speech in the House of Lords, but I know that this is nothing compared to many of you here today – and for that you have my deepest respect.

I am absolutely thrilled to be the minister for rare diseases again and committed to make a real difference. One thing I know from my own experience

is that without my family I simply would not be here. I am sure many of you here feel similarly about your families and carers.

I want to take a moment to thank all clinicians, researchers and others who are working so hard to improve care for people with rare diseases. I'd like to highlight a few recent achievements in this area.

## **Genomics**

Over the past years we've learned more and more about how our individual genetic make-up can lead us to develop a rare disease. And the UK's [100,000 Genomes Project](#) has helped with that. The headline is of course that in December 2018, the 100,000 Genomes Project completed its sequencing phase – a fantastic achievement by NHS England, Genomics England and other partners.

The project has already delivered life-changing results for patients, with 1 in 4 participants with rare diseases receiving a diagnosis for the first time. We are still returning results to some patients and will make sure that this is a priority over the course of 2019.

Let me tell you about one of these participants – a 4-year-old little girl called Jessica. She had a rare condition that caused epilepsy and affected her movement development. From looking at her specific DNA, Jessica received a diagnosis – 'Glut 1 deficiency syndrome' – and as a result her doctor recommended a very specific diet that has helped reduce seizures for others with her condition. Jessica and her family were able to take immediate action, help control her epilepsy and improve her condition.

I'm delighted that based on the amazing achievements from the 100,000 Genomes Project, NHS England launched the Genomics Medicines Service (GMS), making our country the first in the world to integrate genomic technologies, including whole genome sequencing, into routine clinical care. And here's the important part – seriously ill children who are likely to have a rare genetic disorder will be offered whole genome sequencing under the GMS. As demonstrated by Jessica and numerous others, we hope this will bring an end to the diagnostic odyssey for many ill children.

To continue cementing the UK as world leader in genomics, in February I announced that government is developing a UK Genomics Healthcare Strategy. I'm very pleased to say that the work is well underway and the strategy will provide a clear, national vision setting out how the genomics community can work together to make the UK the global leader in genomic healthcare – for the benefit of patients. My colleagues have been inviting key stakeholders and representative groups, including the rare diseases community, to share their views and contribute to the coherent national vision, and are continuing to do so. The strategy will be ready for publication this autumn... so watch this space.

## **NHS insert**

Another very exciting initiative I want to share with you is the NHS insert,

which I announced in February and the NHS are now implementing. The insert gives NHS England a way to hold providers to account and improve services for rare diseases. I have met with NHS England just this week, who have assured me that the insert has been included and will be monitored through the Quality Surveillance Systems, with trusts reporting on it for the first time this September.

There will be up to 3 criteria providers report on:

- care co-ordination
- an alert card
- transition

Let me explain these each in turn.

Firstly, the provider must ensure that there is a person responsible for co-ordinating the care of any patient with a rare disease. Secondly, the provider must give every patient with a rare disease an 'alert card'. This will include information about their condition, treatment regime and contact details for the individual expert involved in their care. Finally, the provider must ensure that every child has an active transition to an appropriate adult service, even if that adult service is not the commissioning responsibility of NHS England.

It is my sincere intention that changes like these make a difference to the lives of patients with rare diseases, people just like you.

## **Post-2020 framework**

There is still much to be done to improve the experience of patients with rare conditions. That's why I want to lead a national conversation on rare diseases, and how we care better for people.

We want to talk to staff, patients, experts and researchers.

We want to use in-person and online methods to capture views on the big strategic issues that affect you.

We recognise there are a range views, and that's why the department and I will be canvassing views – drawing them together into a big, compelling strategic framework to improve care for people with rare diseases.

It won't address every challenge – but it will be an ambitious attempt to build on our world-leading commitments, set out in the 2013 strategy.

We will be working with patient organisations and experts to develop a mechanism for capturing honest views on your experience. This is the start of the process towards a future framework, an opportunity to gather evidence and identify common themes and proposals to help us develop the vision for a post-2020 rare disease framework.

## Closing

There is so much more I would like to tell you today, but time is running away and I just want to close with this.

In the UK Rare Disease Policy Board, the forum and me as your minister and fellow patient, you have people advocating for you at the heart of the system. To the children and young people in the audience here – I am fighting as your minister so that you and future generations may grow up in a world where:

- the diagnostic odyssey is no longer an odyssey
- you know more about your rare conditions through significant research efforts and breakthroughs
- you may grow up in a system where you have a smooth transition to appropriate adult services

I assure you that government hopes to make a real difference on these matters and remains as committed as ever to improving the lives of those living with rare diseases.

I'm looking forward to hearing from the patients, researchers and advocates here today, and we can all look forward to discussing the important issues raised over some tea and cake later. So, let me finish by saying thank you very much for your patience and attention. Please enjoy today.

---

## [Keeping Britain at the forefront of healthtech](#)

It's great to be back in the beating heart of the City. Particularly, as I understand, you've been discussing my favourite subject today: the future.

Now, the truth is, none of us know exactly what the future will hold. Yet, it's clear from this event, from the number of people, and the range of people, that you all believe in backing Britain after Brexit.

But, whoever our next Prime Minister is, the task before us is going to be the same: building a Britain that's match-fit for the 2020s.

Delivering Brexit and then moving on to the things that are bigger than Brexit:

Tackling low pay, supporting enterprise, combating climate change, building new housing, and ensuring our health service will still be world-class, and will still be there for all of us, for generations to come.

And the biggest battle we face in the 2020s is ensuring everyone feels the benefits of free enterprise and economic growth.

So, for me, making sure that Britain remains at the forefront of healthtech, biotech, genomics, AI, scientific research, and healthcare innovation, isn't just about ensuring we have a world-class NHS – as important as that is.

It isn't just about ensuring we have a strong economy – as important as that is.

It's about making sure that Britain wins the 4th Industrial Revolution. That we create the high-skilled, well-paid, tech jobs of tomorrow here. That British businesses shape the technology of tomorrow, and British values drive progress for the benefit of everyone.

And, I believe, one of the ways we do that, is by embracing innovation in healthcare.

By opening up our health service to innovators, wherever we may find them: business, academia, or from anywhere around the world.

Create more porous borders into the NHS for people with new ideas and a shared mission to make things better.

And I'm delighted that today we're officially launching a new collaboration between the NHS and Amazon, pairing our expert medical advice with their market-leading Alexa device.

So when sick people need medical information, the information they'll receive will be NHS information: accurate, reliable, safe. And this will particularly benefit people who rely on voice-activated tech because they struggle with other devices – elderly people, blind and visually impaired people.

We all know that Dr Internet can potentially misdiagnose a minor ailment as something terminal, but what about the converse? What if something serious is missed because someone relied on a dubious medical source?

What this new collaboration means is that Alexa's algorithms will use medically verified information from the NHS to answer medical questions and provide guidance.

It means people will know when they should see their GP or go to A&E. And when, and how, they can treat common illnesses with the help of a pharmacist.

This collaboration will empower people to take greater control of their own healthcare, and reduce the pressures on the NHS.

And I want to see us build similar relationships with Google, Apple and anyone else who is building the tech that people use and rely on every day.

Because we have a unique opportunity in the NHS to leverage the expertise – and sheer size – of the world's largest healthcare system to become the biggest driver of healthcare innovation in the world.

We have the capability to help healthtech companies access the finance they need to spur innovation by being involved from the beginning: by specifying what we need for therapeutics, diagnostics, devices and digital management.

By becoming early adopters of tried and tested new tools and technologies in the NHS, we can help British healthtech firms and life sciences companies develop their products faster and bring the benefits to patients and staff sooner.

The future of the NHS, the future of healthcare as a whole, is shifting from a focus on treating illness to preventing illness, of maintaining good health through prediction and early intervention.

We know what the future health challenges are going to be: an ageing population with multiple conditions, with more cases of cancer and maybe dementia because of our success in helping people to live longer.

The real challenge is actually an innovation challenge: can we get the breakthroughs the NHS needs to meet the future health needs of our nation?

Well, Britain is home to some of the world's most innovative healthtech companies. British research institutions and life sciences are among the best in the world.

And, Britain is a place that's always been open to the world's best – and will continue to be in the future.

The revolution in genetic sequencing came from companies such as Oxford Nanopore and Illumina.

Breakthroughs in cancer immunotherapy and early diagnostics are being driven by mid-size companies where investors are willing to take big risks in exchange for the rewards that might follow.

The NHS is relying on these companies to drive innovation in healthcare. And we, as a society, desperately need these companies to succeed.

So what can the NHS do to support innovation?

Well, we're going to do what the world's best tech firms do.

NHSX, our new tech lead, launched last week and it's going to take the same approach to innovation that Apple and Google do.

NHSX is going to make the NHS a platform for innovation. It will simplify the system for developers and NHS decision-makers. It will set national policy and national standards, ensure systems can talk to each other.

But then it's going to take a step back and let the innovators innovate. Because the NHS, historically, has either been too closed to innovation from outside, or tried to drive innovation from the inside – with mixed results at best.

Partly, that's because new tech has driven up costs, but digital tech can save costs, and make money go further.

So we're not going to imitate the 10-year cycle of creating and testing a drug, which rightly adheres to the precautionary principle. Instead we're going to try the tech approach: collaboration, iterative development, testing and learning in real-world settings.

The NHS is going to move to a 'demand-led' innovation system.

NHSX is bringing together all of our tech leadership into one place, and the Accelerated Access Collaborative (AAC) is identifying what the NHS needs, and supporting new innovations with potential for nationwide roll-out.

The first 12 products being backed by the AAC could help more than half a million patients, and save the NHS up to £30 million.

But this is just a mere drop in the ocean. In the future, the NHS will be working in an ecosystem where driving innovation and saving taxpayers' money will go hand-in-hand.

The NHS will play a much bigger role in the development of new healthcare innovations.

I see a future in which every patient has the chance to have their genome sequenced, and every treatment can be improved by understanding each patient's genetic code.

Genomics will help us predict the likelihood of disease and enable targeted treatment and precision medicine.

Artificial Intelligence and machine learning will improve diagnosis and population-based risk assessment.

And there's other exciting technologies that hold so much potential: surgical robots, stem cell therapies, 3D bio-printing, artificial organs, and other new drugs and new treatments that are set to transform healthcare over the coming years.

I want the NHS to be a world leader in these technologies. I want us to seek out new partnerships with new innovators who share our mission.

Because, ultimately, this isn't just about the future of healthcare, or the future of our health service, but the future of our country.

What kind of country do we want to be? I believe we're at our best when we're open to the outside world, and optimistic about the future.

We're at our best when we back people.

It's why I've made it my mission to get the right tech in the NHS. So we can back our NHS staff in the life-saving work they do every day, and so we can back everyone in Britain to seize the opportunities good health brings.



And as investors, that's what you do: backing a business is about backing people.

Because what else is a business, but people coming together to create a solution to other people's problems? And solving the problem so well that people are prepared to pay you for the effort.

So let's back innovators, let's back our NHS and let's back Britain so we can keep leading the world in healthcare.

---

## **Iran: E3 Statement for the Special Session of the IAEA Board of Governors**

France, Germany and the United Kingdom associate themselves with the statement made by Finland on behalf of the European Union.

The Permanent Representatives to the IAEA of France, Germany, and the United Kingdom would like to thank the IAEA for its professional and impartial work in monitoring the JCPOA. We welcome the IAEA's prompt reports to this Board as mandated under UN Security Council Resolution 2231 and the Board's resolution of December 2015 mandating the Agency's monitoring and verification work on JCPOA requirements. We ask for similarly prompt reporting should further issues arise. It is essential that Iran continue to provide the IAEA full and timely access.

As our Foreign Ministers stated on 9 July, we are deeply concerned that Iran is pursuing activities inconsistent with its JCPOA commitments by exceeding its uranium enrichment and stockpile limits; and that Iran has also stated that it may take further measures in the future.

France, Germany and the United Kingdom have repeatedly set out our commitment to the JCPOA, which is a major achievement of international diplomacy. However, we have been consistently clear that our continued support relies on Iran implementing its commitments in full.

We therefore call on Iran to immediately reverse the actions and to avoid any further escalatory steps which undermine the integrity of this agreement. We believe the issues at hand should be addressed by participants to the JCPOA, including through a meeting of the Joint Commission to be convened urgently.

---

# Highways England goes multilingual with roadworks signs

Electronic message signs have gone multilingual in a ground-breaking initiative to improve roadworks information for lorry drivers.

Published 10 July 2019 From: [Highways England](#)



Pictured (left to right) alongside the westbound A66 near Penrith with one of the signs is Highways England project manager Jobert Fermilan, Keith Brown from HW Martin – one of the specialist suppliers supporting the pilot project – and Highways England senior project manager Steve Mason

Highways England has started giving roadworks information in nine foreign languages on several of its portable electronic variable messages signs.

The system works with an automatic number plate reader in the side of the road warning the electronic sign that a foreign lorry is approaching and the sign then selecting an appropriate foreign language message such as 'M6 J.44 Cerrado' – 'closed' in Spanish.

The pilot is taking place in Cumbria where £7 million of improvements are taking place along the M6 north of Carlisle. The latest phase of the work is focused on the roundabout at busy junction 44 of the motorway and lorry drivers are being warned in German, French, Polish, Romanian, Dutch, Spanish, Lithuanian, Slovak and Hungarian when the roundabout is closed for the overnight work.

It is believed to be the first time in the UK that electronic signs have been used in this way to get information to continental truckers.

Highways England senior project manager Steve Mason said:

We're a listening and learning organisation and we're determined to improve the way customers get roadworks information.

We carried out major improvements along the A66 near Penrith last year and while the communications and diversion routes worked well, we had some feedback from Cumbria Police that foreign lorry drivers were missing some of the messaging. This not only inconvenienced the drivers but also local communities as we had lorries on inappropriate diversion routes.

We've taken that learning on board and hopefully providing tailored messaging for foreign lorry drivers will improve everyone's experience of these roadworks.

The innovative multilingual signs have been placed along the A66 and A69 to warn drivers about the overnight junction closures.



Inspector Steve Minnikin (left) from Cumbria Police – which is backing the pilot project – is pictured with Highways England project manager Jobert Fermilan

Inspector Steve Minnikin from Cumbria Police said:

We provided a lot of support around the A66 closures last year and we're delighted to see that Highways England has responded to our feedback by trialling this idea by being more aware of language

differences and being considerate in meeting their needs.

We all believe this will assist the lorry drivers from other countries in rescheduling their journeys and avoid driving into a road closure with all the inconvenience that it can cause themselves and others.

Road user watchdog Transport Focus worked closely with Highway England's staff in Cumbria ahead of major work along the A66 last year – and the watchdog then used the A66 experience as a case study of how to better plan and communicate roadworks.

Transport Focus senior stakeholder manager Lee Rowbotham said:

Getting better, more helpful information to foreign HGV drivers was one of the things we all identified as a potential improvement from last year's A66 improvement works so full marks to Highways England for piloting this project in Cumbria.

Highways England staff, specialists and contractors are being encouraged to try new ways of operating, maintaining, repairing and improving the country's motorways and major A roads. A £150 million innovation fund has been set up to support new initiatives. For more information, visit our [Designated Funds page](#).

## **General enquiries**

Members of the public should contact the Highways England customer contact centre on 0300 123 5000.

## **Media enquiries**

Journalists should contact the Highways England press office on 0844 693 1448 and use the menu to speak to the most appropriate press officer.