News story: Health minister: NHS must lead the world in genomic healthcare

The government will today announce a new National Genomic Healthcare Strategy to ensure the UK is able to offer a predictive, preventative and personalised health and care service for people with rare diseases.

The strategy will set out how the genomics community can work together to make the UK the global leader in genomic healthcare.

The government will also set out how it will improve services for people with rare conditions. These include:

- every person with a rare disease will have a dedicated person responsible for co-ordinating their care
- every patient with a rare disease will be given an ‘alert card’, including information about their condition, treatment regime and contact details for the individual expert involved in their care
- every child with a rare condition will be transferred to appropriate adult services when they reach the age of 18, even if that adult service is not the commissioning responsibility of NHS England

Minister for Innovation Nicola Blackwood will launch the strategy in a speech to thank NHS staff who helped her to manage her own genetic condition, Ehlers–Danlos Syndrome (EDS), which went undiagnosed for 30 years.

She will speak about the difficulties of coping with undiagnosed disease, including her experiences of collapsing in Parliament on several occasions.

The new strategy will build on Health and Social Care Secretary Matt Hancock’s ambition to sequence 5 million genomes in the UK by 2023 to 2024.

The NHS will from this year offer whole genome sequencing to every adult and child in the UK with certain cancers and rare genetic conditions. This will be used to provide personalised treatments specific to the patient to improve their chances of recovery and quality of life.

The focus on genomics follows the success of the 100,000 Genomes Project, which helped 1 in 4 patients with rare diseases receive a diagnosis for the first time.

One in 17 people, or almost 6% of the population, will be affected by a rare disease at some point in their lives. This equates to approximately 3.5 million people in the UK and 30 million people across Europe.

Nicola Blackwood will say:

> I owe so many NHS workers – nurses, doctors, my GP, pharmacist, paramedics and more – my stable health today. I am not sure I will

> ever be able to communicate to them quite how dramatically they have changed my life.
>
> But this process has also taught me indelible lessons about how important it is to improve care for rare diseases for everyone – not just the lucky ones like me.
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> This is why we must never relent in our campaign to bring an end to the 'diagnostic odyssey' – it is pernicious and even after diagnosis the damage it does to mental health of patients and their families must not be forgotten. We must press even harder on clinical awareness and groundbreaking research so more patients can be diagnosed and treated earlier.
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> Co-ordinating your care can feel almost impossible when you are ill and the complexity of services for rare disease must not act as a barrier to access for care.

On the National Genomic Healthcare Strategy, she will say:

> Through the NHS Long Term Plan we want to lead the world in the use of data and technology to prevent illness – not just treat it.
>
> We want to diagnose conditions before symptoms occur. And we want to deliver personalised treatment, informed not just by our general understanding of disease but by our own personal, de-identified medical data – including our genetic make-up.
>
> In order to make this a reality, I am delighted to announce that we will be working with the National Genomics Board and the broader genomics community to develop a National Genomic Healthcare Strategy.