England Rare Diseases Action Plan 2022

The government has announced the launch of its England Rare Diseases Action Plan 2022. Around one in 17 people are affected by a rare medical condition at some time in their life. This amounts to more than 3.5 million people in the UK alone.

Each of the four home nations is to have its own action plan as a result of the 2021 UK Rare Diseases Framework. The action plan for England aims to help people to address the challenges they may face.

The action plan will include annual updates to chart any progress made, such as new initiatives. Over the course of the year, the government will work with service delivery partners and people with rare diseases to monitor the action plan's success and to drive change.

How many rare conditions are there?

There are an estimated 7,000 different rare conditions, each of which affects fewer than one in 2,000 people. As they are so rare, people living with one of these diseases will face specific challenges in finding suitable treatments in the health system.

Those being targeted include patients living with genetic and non-genetic conditions. They include people of all ages: newborn babies, children and adults. Some have a diagnosis and others may never receive one because their condition is so rare.

Government strategies, such as the Future of UK Clinical Research Delivery, Genome UK and Life Sciences Vision, will all support the new work to improve patients' lives.

Action plan goals

The key goals in the new action plan will include helping patients to get a final diagnosis quicker, coordinating care more efficiently, increasing awareness of such conditions among healthcare professionals and improving patient access to specialist care, drugs and treatment.

The National Health Service will liaise with service providers and the pharmaceutical industry, including all companies developing medical devices, to ensure everyone understands the impact of the internal strategic approach.

More engagement will be offered to patients living with rare diseases, so they better understand the available treatment options.

How is the project being funded?

In the October 2021 Budget, the government pledged more than £5 billion in funding, over three years, for health-related research and development. The England Rare Diseases Action Plan is part of this funding.

The aim is to create a solid partnership across the government, NHS, research funders, medical research charities, regulators, industry and academia to create a more efficient research and treatment system.

The Northern Ireland Rare Diseases Action Plan, setting out 14 actions to take treatment options forward over the next 12 months, has also been launched. Similar initiatives are being developed for Scotland and Wales.

What changes are going to be made?

The action plan will largely focus on using new technology, such as digital tools, to enable faster diagnosis. Technology will also improve the quality of virtual consultations, so patients will be able to see multiple specialists at the same time via video links.

A new digital tool, GeNotes, will enable healthcare professionals to find information on rare diseases quickly to help support a faster and improved diagnosis. The aim is for patients to receive the care they need as soon as possible, reducing waiting times.

The digital resource will also give easier access to the NHS Genomic Test Directories and improve learning opportunities for medical specialists. Pilot schemes for these new treatment options, such as virtual expert multidisciplinary teams, are in the design stages.

Pharmaceutical industry

The pharmaceutical industry will maintain its usual high standards to meet the increased demands of the Rare Diseases Action Plan.

Coruba's high-quality pharmaceutical products are at the forefront of the industry: with hygiene standards in the pharmaceutical industry being exceptionally high, the rubber materials combine to protect against disease transmission and contamination.

Almost 40% of the new medicines currently in development are to treat rare conditions, including gene and cell therapies, according to the Association of the British Pharmaceutical Industry.

The organisation has welcomed the plan to help patients get rapid access to the treatments they need and urges all delivery partners to work together to make the plans a reality.