Making patient data life changing: how LifeArc uses data to accelerate impact for people with rare diseases

At LifeArc, we see patient data as far more than numbers in a dataset. For us, data is a lens through which we can glimpse fragments of patients' experiences: the challenges they face, the treatments they receive, and the opportunities that innovation can unlock. That is why we are proud to support the UK's first National Patient Data Day, a moment to celebrate the power of data in improving lives, and to highlight the importance of patient partnership at the centre of all that we do.

LifeArc is a self-funded, not-for-profit medical research organisation that exists to translate science into life-changing treatments, for people living with rare diseases and those affected by global health challenges. Making life science life changing is our mission, and patient data sits at the very heart of that work.

Rare diseases and the power of data

People living with rare diseases face distinct challenges. By definition, each rare condition affects relatively few people – yet collectively, rare diseases impact the lives of over 3.5 million people in the UK alone. This creates an imperative to think big and collaborate widely. Small numbers mean we need to draw on data that crosses borders and silos – linking patients, clinicians, researchers, and industry partners to generate insights that no single dataset could provide alone.

Patient data gives us opportunities to streamline clinical trials by identifying potential participants faster and with greater precision, helping trials reach patients who need them most. This can make trials quicker, more cost-effective, and more inclusive – giving more patients a chance to access emerging treatments and benefit from innovation. For rare diseases, this is crucial, as patients can't wait. Without rich, accurate, and detailed data, patients risk remaining invisible to researchers and trialists. At LifeArc, we convene and collaborate to ensure that does not happen.

Partnership is at the core of our data approach

Making patient data life changing requires partnership at every step. We collaborate closely with patient charities, many of whom have built invaluable datasets and deep understanding of their communities' lived experiences. These partnerships ensure that our work remains grounded in what matters most to patients. For example, we have partnered with the Cystic Fibrosis Trust to leverage technology like machine learning to predict exacerbations earlier and develop novel treatments, all powered by data.

We also work alongside national research cohorts, like Our Future Health and Genomics England, as well as tapping into the wealth of routinely collected data from our National Health Service. By convening partners to make these different data assets work together, we can ensure that rare diseases are recorded at an appropriate level of detail to capture patients' experiences and that data is findable, accessible, interoperable, and reusable (FAIR). Our goal is for patients to be visible for research and trials, no matter how rare their condition.

One example of this is our leadership in developing infrastructure for rare disease innovation across the UK. Our network of Translational Centres for Rare Diseases and Lung Health Innovation Hubs all incorporate data-driven approaches to unlock new tests, treatments and technologies. These initiatives not only generate new data but also ensure that insights can be rapidly shared and translated into patient benefit. Importantly, we have embedded public involvement throughout these programmes to ensure that they are directly shaped by people with lived experience of rare diseases.

Patients as partners in data-driven research

Throughout all this, we never forget that behind every dataset is a person. Our support of National Patient Data Day, and our commitment to patient engagement, reflect our belief that patients must be equal partners in how their data is used. We are dedicated to ensuring that data is handled securely, ethically, and transparently – with clear benefits that are communicated back to the patient community. You can read more about our Shared Commitment to Public Involvement here.

We know that patient data can drive life-changing discoveries, but only if we use it wisely, collaboratively, and in ways that serve the needs and interests of those who share it. National Patient Data Day is a welcome opportunity to shine a light on how that happens and to celebrate the partnerships that make it possible.

We will continue place patients at the centre of our work to make life science life changing for people with rare diseases.