

Monitoring the rare diseases landscape

Mapping rare diseases research to drive future policymaking decisions

Client need: detailed data on current research and funding

The UK's Rare Disease Research Landscape Steering Group - a working group representing government, industry, and charities - needed to better understand the current rare disease research landscape in the UK and provide an evidence base to support future policymaking decisions on rare diseases.

To capture the full picture the researchers needed data for all rare disease research, whether funded by government, charities, or industry.

Solution: granular and reliable intelligence

The Steering Group leveraged government research funding portfolios and the Association of Medical Research Charities members' charitable expenditure portfolios to gain an understanding of the non-industry funded research.

To explore industry funded research, the Association of the British Pharmaceutical Industry (ABPI) and the BioIndustry Association (BIA), who represent organizations involved with the life sciences, pharmaceutical and biotech sectors across the UK, turned to Clarivate for detailed insights sourced from [Cortellis Competitive Intelligence](#) on R&D pipeline volume analyses of rare diseases.



Outcome: defining future directions based on reliable data

The Steering Group published a research landscape report and accompanying datasets that have provided a starting point for productive discussions with the rare disease community to:

- Better understand the research needs of the rare disease community.
- Identify gaps, priorities, and levers for change for future rare disease research.
- Promote stronger networks and collaboration across the rare disease research community.
- Quantify and analyse the rare disease research landscape funded and supported by government agencies.

Access the full report

Rare Disease Research Landscape Steering Group and Bainbridge K. Rare Diseases Research Landscape Project Report [version 1; not peer reviewed]. NIHR Open Res 2023, 3:45 (document) (<https://doi.org/10.3310/nihropenres.1115214.1>)

The results of the Cortellis search that represent industry research and development (R&D) projects on rare diseases in the UK are available as [Dataset 5 via NIHR OpenData](#).

Elements of success

Cortellis Competitive Intelligence is a broad *and* deep source of global pipeline and competitor intel, covering:

90K+

drugs, including 11K+
drugs linked to rare
diseases

3K+

indications, including
480 rare diseases

283K+

company profiles

Make critical portfolio decisions backed by
accurate, comprehensive pipeline and
competitive intelligence.

[Cortellis Competitive Intelligence](#)

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