

Orphadata Products : Services & Tailored Dataset Catalogue

2026

WHO ARE WE

Orphanet-AISBL is a non-profit spin-off of Orphanet, transforming the world's most trusted rare disease data into reliable, ready-to-use knowledge to address the needs of pharmaceutical companies, researchers, policymakers, consultancies, CROs, and patient communities worldwide.

Built on over 25 years of Orphanet (www.orpha.net) expertise and more than five million expert-curated data points in the Orphanet knowledge base, we connect and equip all stakeholders to make evidence-based decisions, accelerate innovation, and drive measurable impact across the rare disease ecosystem.

The funds raised through the services and datasets proposed by the Orphanet-AISBL contribute to the sustainability of the Orphanet network and thus ensure that we can continue to provide the community with quality, curated data on rare diseases and orphan drugs to the community both through www.orpha.net and www.orphadata.com.

HOW CAN WE HELP YOU TURN RARE DISEASE DATA INTO ACTIONABLE KNOWLEDGE

Orphanet AISBL's services are designed to transform existing, expert-curated rare disease data from the Orphanet knowledge base into actionable insights. Our services are principally based on the exploitation and interpretation of data that already exist within the Orphanet knowledge base, for example:

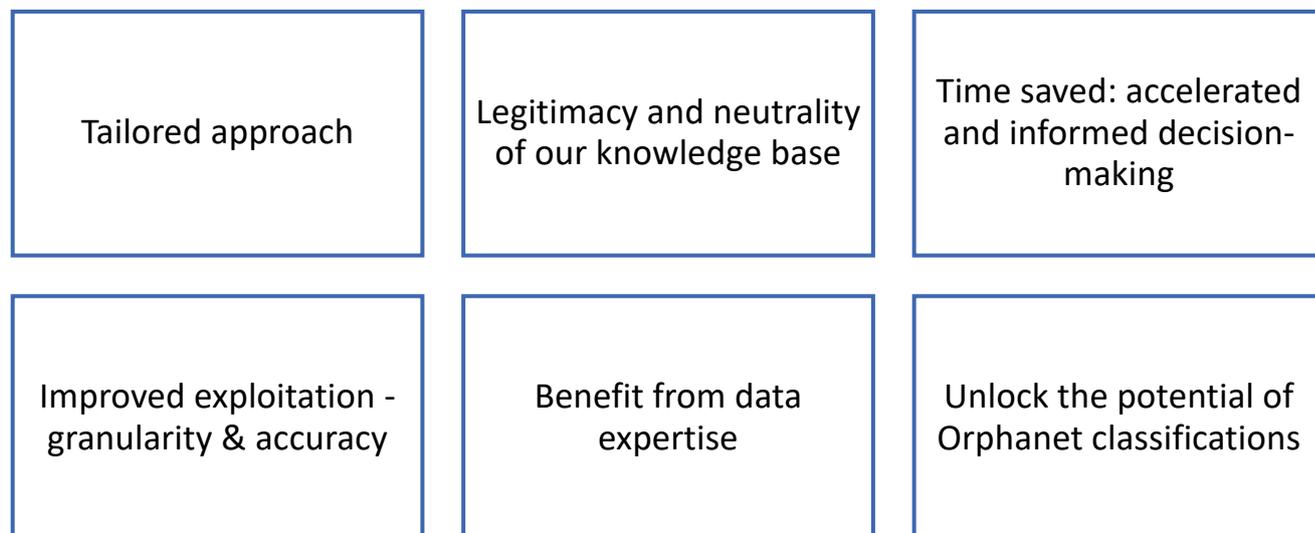
- Rare disease nomenclature & classifications
- Disease-gene relationships
- Disease-phenotype relationships
- Epidemiological & age of onset data
- Functional impact of diseases/ disabilities data
- Textual information
- Expert centres & networks of expert centres data
- Patient organisations & alliances/federations of patient organisations data
- Research activities data
- Orphan drugs and designations data

We also provide services that leverage the policy and literature review database, collected by the [OrphaNews](#) team, that can be combined with data from the Orphanet knowledge base to provide powerful insights on the rare disease landscape and trends in the ecosystem.

Although the Orphanet knowledge base does not contain patient data, the Orphanet – AISBL is exploring collaborations with European Reference Networks to provide services integrating patient data from ERN registries in the future.

We also remain open to developing additional services, tools, or solutions in response to emerging needs and strategic partnerships, complementing the standard services listed in this catalogue.

ADDED VALUE IN WORKING WITH THE ORPHANET-AISBL



HOW DO WE WORK

You can get in contact with the Orphanet-AISBL at flaminia.macchia@orphanet-aisbl.com to discuss your specific rare disease-related use case. During this exploratory meeting we will work with you to find a solution to best suit your needs and provide you with pricing information. Fees are evaluated considering the scope and volume of data to be provided, in addition to hours of work necessary to deliver the data and/or service, and the complexity of the request, as well as any updates. Prior to the delivery of the data and services you will sign a service contract with the Orphanet-AISBL which includes a detailed order form with full-service specifications.

Our team will be available at every step of the way to accompany you in the definition of your needs, the delivery of the data/service, and for any follow-up questions.

SERVICES & TAILORED SERVICES CATALOGUE

CUSTOMISED DATASETS AND TAILORED FORMATS

If our standard datasets are not adapted to your needs, we can provide you with extractions of Orphanet data tailored to your specifications, in a structured format either as a file, an API, or a custom data visualization service.

The complexity of this service will vary according to the number of parameters requested, whether classifications are queried, frequency of update, volume of requests (for APIs) and the format of the data delivery. During the specification of the service requested, we will also consider whether the data needed is associated with one or many individual diseases and whether it would be pertinent to explore interactions within our disease classifications, for which our expertise will be necessary.

Tailored formats, such as APIs, will help you automate access to our data, and so saving you time when integrating our data into your internal systems, reducing the need for manual processing of the files, and optimising your update cycle.

Use case example

Client's need:

Launch of a product in a number of countries in Europe, need for a better understanding of the rare disease population and expertise, for example epidemiology by country, centres of expertise by country, medicinal products in development, state of the play of research by country, patient organisations by country, clinical practice guidelines by language.

How we can help:

Orphanet-AISBL can provide tailored, structured files of Orphanet data for a range of parameters, so that you can explore Orphanet data concerning the country/countries and/or disease/diseases/groups of diseases of interest. This can be for one type of data (e.g. epidemiological data, research activities data) or for multiple types of data, depending on the scope of your use case. This data can also be provided as an API if this format is better suited to the client's needs, for example if the data needs to be integrated into an internal tool. We can also provide tailored data visualisation tools for the data of interest.

TECHNICAL ASSISTANCE FOR IMPLEMENTATION & INTEGRATION

You may require our technical support and expertise to help you implement, integrate and exploit Orphanet data effectively and make the most of what the data can offer. Our support can help you save time in reaching the results you want as well as improving the accuracy of outcomes.

We can explore your needs together and suggest a plan tailored to your needs, with dedicated support from the Orphanet-AISBL.

Use case example

Client's need:

Support in optimising the integration of Orphanet data into existing internal digital platforms, for example, in best utilising our classifications.

How we can help:

We determine a dedicated support plan provided by our team, with advice on most adapted approaches and data formats, as well as trouble-shooting sessions.

RARE DISEASE DATA EXPERTISE: CURATION, ANALYSIS & INTERPRETATION

You may want more than just access to our data as you may need Orphanet's rare disease expertise to provide you with specific insights. By coupling our knowledge base with our rare disease and data science expertise, we can help you save time by providing you with interpretation and tailored insights into your specific questions.

We will explore your use case together to determine the pertinent lines of inquiry, the level of complexity (descriptive analysis of Orphanet data vs. multi-source interpretation) and how you would like the results presented, for example as a report with or without supplementary files, or as a data visualization.

Use case example

Client's need:

Assessing trends in research activity, the distribution of expertise across Europe and/or disease groupings (i.e. state of play of research activities).

What we can provide:

A report providing the state of play of research activities and expertise in the countries that interest you over time, with insights on disease groupings/medical specialties, with supplementary detailed datasets in case you wish to explore further.

DASHBOARDS

You may need a more visual and interactive representation of Orphanet data, with custom filters and views allowing you to explore and draw insights from our data. This solution will allow you to have access to the most up-to-date and easy to explore data insights leveraging the power of the Orphanet database.

We will explore your specific use case together during the specification process to create the solution that works the best for you in terms of scope, granularity, and update frequency of data input.

Use case example

Client's need:

Explore trends in research activities and rare disease clinical expertise across disease categories and countries over time.

What we can provide:

Tailored data visualization dashboards, designed to your specifications by our team, which enable you to apply a range of filters to compare, visualize and explore datasets for specific research questions.

EVIDENCE-BASED REPORTS

You may need analytical reports combining Orphanet data and available evidence, focused on a defined policy, research or strategic question.

We will explore your specific use case together to specify the solution best adapted to your needs and that encompasses the sources most pertinent to your area of interest, and the format best adapted to your end use.

Use case example

Client's need:

Understand trends in diagnostics over the past 10 years in Europe, and detect future trends that could influence the client's R&D strategy.

What we can provide:

Analysis of trends based on a specific literature review, leveraging the power of the OrphaNews knowledge base, and augmented by data from the Orphanet database on diagnostic tests, with our data curation and policy review insights.

CONSULTANCY

Our team has wide, historic expertise in the rare disease field on a range of aspects, making us a powerful advisory partner in your strategic planning. Let us provide you with the data and advice that will best support your decision-making and planning.

Use case example

Client's need:

Disease or policy landscaping exercises to inform strategic positioning or health/research programme design.

What we can provide:

Virtual and/or in-person consultancy sessions with identified key opinion leaders / experts / data scientists in the Orphanet network.

TRAINING MODULES

You may need our help in training your staff and/or colleagues on rare diseases and/or the exploitation of Orphanet data. We can deliver custom-tailored training sessions according to your learning needs on a range of subjects, such as general training on rare diseases, Orphanet nomenclature, data use and interpretation, and/or Orphanet website use.

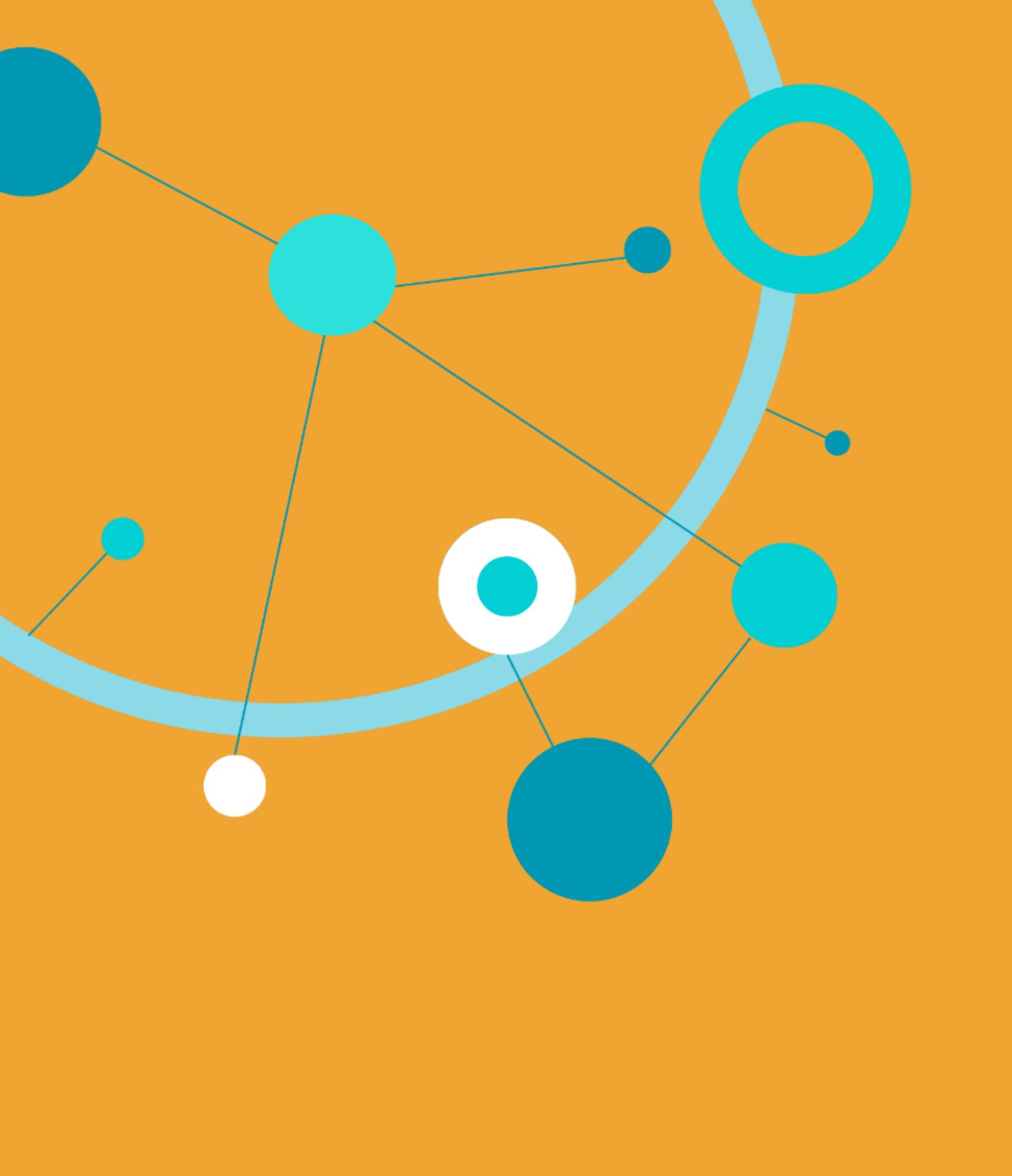
Use case example

Client's need:

Capacity building in a specific areas, for example improving codification of rare disease data, for institutions, industry, researchers or patient organisations to improve internal data analysis.

What we can provide:

Once we have discussed your learning needs and targets, we can deliver custom-made training sessions and training materials best adapted to your needs, either virtually or on site.



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ORPHADATA PRODUCTS – ORPHANET-AISBL Service Catalogue 2026

https://www.orphadata.com/docs/CatalogueServiceAISBL_Orphadata.pdf