

ABOUT ECRIN

The European Clinical Research Infrastructure Network (ECRIN) is a public, non-profit organisation that links scientific partners and networks across Europe to facilitate investigator-led, multinational clinical research.

Activities

ECRIN's main activity is the provision of services for the management of multinational clinical trials. Support is also provided for trial preparation and protocol evaluation.

In addition, ECRIN is involved in activities to enhance the ability of European institutions to successfully conduct multi-country clinical research (e.g. tools/ database development, data centre certification).

Moreover, ECRIN takes part in 'infrastructure development' projects to further develop the European clinical research community and facilitate multinational trials.

Members and Organisation

ECRIN has nine member countries (Czech Republic, France, Germany, Hungary, Ireland, Italy, Norway, Portugal and Spain) and three observer countries (Poland, Slovakia and Switzerland). ECRIN's management office is located in Paris, France.

ECRIN began in 2004 as a consortium and was awarded the legal status of a European Research Infrastructure Consortium (ERIC) end 2013.

ECRIN's Data Sharing Activities

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ECRIN supports the optimisation of clinical trial data sharing. The goal is to improve evidence in healthcare and, ultimately, to enhance public health policies and outcomes.



ECRIN is committed to promoting and enhancing the sharing of individual participant data from clinical trials for secondary analyses (e.g. new research questions, meta-analyses).

CLINICAL TRIAL DATA SHARING

Within the 'Coordinated Research Infrastructures Building Enduring Life-science Services' (CORBEL) project¹, ECRIN has been involved in the following data-sharing activities:

- **Developing principles and guidelines for clinical trial data sharing (2017)**

A multi-stakeholder taskforce developed 10 principles and 50 recommendations, representing the requirements of any framework used for the sharing of clinical trial data²

- **Classifying processes involved in sharing individual participant data from clinical trials (2018)**

ECRIN identified individual processes involved in data sharing in order to develop a generic framework and architecture for the sharing of clinical trial data³

- **Developing quality criteria for data repositories and assessing existing repositories (2019)**

ECRIN assessed 25 repositories that enable storage, sharing, 'discoverability', and re-use of individual participant data, as well as associated documents from clinical studies using a pre-defined set of quality criteria⁴

- **Providing a pilot repository for clinical trial data (2019)**

A pilot repository for clinical trial data based on DSpace was developed and assessed using quality criteria (paper under review by *BMC Medical Informatics and Decision Making*)

- **Reviewing the impact of data sharing of clinical trial data (2019)**

ECRIN, along with an International Expert Group, has performed a 'landscape analysis' to evaluate the impact of data sharing on research and medical care (paper expected end 2019)

- **Providing a toolbox for data sharing (ongoing)**

Based on the above activities, ECRIN is developing a toolbox for data sharing, including templates for standard operating procedures (SOPs) and data sharing agreements. The toolbox will be continuously updated and made available on the ECRIN website.

ADDITIONAL ACTIVITIES

ECRIN is also involved in other pan-European collaborative projects addressing important issues in data management for health research. Main activities include:

- **Developing policies for using medical care data for clinical research (ongoing)**

Within the 'EOSC-Life' project⁵, policies and recommendations for using research and medical care data (e.g. electronic health data) for health research will be developed

- **Creating a metadata repository for clinical trial objects (ongoing)**

In the eXtreme DataCloud ('XDC') project⁶, a metadata repository is being developed to improve accessibility of clinical studies and their related data objects (e.g. publications, study protocol, individual participant data, data management plan, statistical analysis plan, web pages, social media). A demonstration repository will be available end 2019.

NOTES



1. CORBEL has received funding from the European Union's Horizon 2020 (H2020) research and innovation programme under grant agreement number (GA no.) 654248. corbel-project.eu

2. bmjopen.bmj.com/content/7/12/e018647

3. f1000research.com/articles/7-138

4. trialsjournal.biomedcentral.com/articles/10.1186/s13063-019-3253-3



5. EOSC-Life has received funding from H2020 under GA no. 824087. www.eosc-portal.eu/eosc-life



6. XDC has received funding from H2020 under GA no. 777367. www.extreme-datacloud.eu

