



## Patient Registries & Biobanks – Important web-links

# Patient Registries

- Patient registries are organised systems that use observational methods to collect uniform data on a population defined by a particular disease, condition, or exposure, and that is followed over time. Patient registries can play an important role in monitoring the safety of medicines. The European Medicines Agency (EMA) has set up an initiative to make better use of existing registries and facilitate the establishment of high-quality new registries if none provide an adequate source of post-authorisation data for regulatory decision-making.

<https://www.ema.europa.eu/en/human-regulatory/post-authorisation/patient-registries#inventory-of-registries-section>

- Linking up rare disease research across the world

<http://catalogue.rd-connect.eu/web/guest/catalogue>

# Biobanks

- Biobanks collect biological samples and associated data for medical-scientific research and diagnostic purposes and organise these in a systematic way for use by others. The collection of samples and data for research purposes has a long history in the educational and medical systems. In the past, biorepositories were relatively uncontroversial, residing largely in the seclusion of pathology institutes. With recent technological advances, the potential to open up these existing collections for new uses is starting to be realized, but also new biobanks are being established.

<https://www.coe.int/en/web/bioethics/biobanks>

<http://www.eurobiobank.org/>