

6.2 Release of Data

1. Only the Project Leader has the authority to release data on approval of the Steering Committee. The Project Leader is responsible for correct procedures being followed in the event of data release.
2. Customised tables (according to user needs) indicating prevalence, public health indicators, perinatal mortality and prenatal diagnosis rates derived from aggregate data of congenital anomalies in the member registries, are available on the web at www.eurocat-network.eu, and will be updated twice yearly. A full publications list is available on the EUROCAT website and copies of publications published by Central Registry can be obtained from Central Registry.
3. Further information and data requests for research or policy purposes are welcome and Central Registry will endeavour to process requests in as timely a fashion as possible subject to resources. Enquiries should be addressed in the first instance to the EUROCAT Administrator (currently Barbara Norton). Information requests may concern (i) aggregate numbers of cases according to specified case characteristics where these are not available in EUROCAT publications or on the website or (ii) a request for a data file of individual records. See Requesting EUROCAT Data at <http://www.eurocat-network.eu/aboutus/requestingeurocatdata>.
4. Please note that access to data cannot be permitted if a EUROCAT member has already been given approval for the area of study under question.
5. A data contract must be signed to indicate agreement with EUROCAT terms and conditions. The details are available at <http://www.eurocat-network.eu/aboutus/requestingeurocatdata>.
6. All requests for access to Central Registry data should be completed on the appropriate application form (<http://www.eurocat-network.eu/aboutus/requestingeurocatdata>) and sent by email to the Administrator, Barbara Norton. The completed application form will then be considered by the Steering Committee. After approval from the Steering Committee, written permission will be requested from registries for use of their data.
7. Data will not be released until ethical approval, where necessary, has been obtained.
8. The Steering Committee may recommend that one or two EUROCAT staff or members collaborate in the proposed research, in order to advise on analysis and interpretation of EUROCAT data.
9. The formula for acknowledgement and/or authorship, is outlined in the terms and conditions of the contract (<http://www.eurocat-network.eu/aboutus/requestingeurocatdata>).
10. A draft of any intended publication of EUROCAT data should be submitted to the EUROCAT Steering Committee for comment. This will be advisory only, except

where factual inaccuracies are seen. Approval for the paper should be sought from each contributing registry, and registries have a right to withdraw their data from an intended publication if they consider it to be factually inaccurate, in accordance with the terms and conditions of the contract (<http://www.eurocat-network.eu/aboutus/requestingeurocatdata>).

11. Advance notification of the acceptance of a manuscript for publication based on EUROCAT data should be notified to the Administrator at Central Registry as soon as possible. A copy of the subsequent publication/s should be sent to the Administrator at Central Registry.