

BIND Data Access Policy

BIND research data are available as a resource for the scientific community to maximize the value of the data for research and eventual patient and public benefit.

- BIND Data Access governance falls under the remit of the BIND Dissemination and Exploitation Board (DEB) during the lifetime of the BIND project.
- After the BIND project end, and for a duration of three years, Data Access will be overseen by the Duchenne Data Foundation and a member of relevant BIND partners. After the three-year grace period, the data in repositories can be made freely available to the community unless protected by IP clauses.
- Only deidentified aggregate patient data may be shared and the dataset to be shared will be determined by the agreement with the external party, DEB or BIND data manager requirements, and any national restrictions.
- Data shared with an external party is limited to internal use by that party and cannot be shared otherwise with a third party or used for commercial purposes without the specific approval of the DEB.
- Requests for data can be made informally in the first instance to the BIND PI. Formal requests will be submitted via a Data Access Request form (below) and be evaluated by the DEB.
- Approval for sharing of patient-specific and aggregate data may be considered on a case-by-case basis depending upon the nature of the request.
- Data will be released subject to a signed Data User Agreement form (below).
- Individual BIND partners will not share patient-specific data generated by the BIND consortium with an external party without approval from the DEB. Data otherwise collected by a partner independent of BIND research may be shared with other parties without approval being obtained from the DEB.
- Data recipients will not attempt to identify individual human research participants from whom the data were obtained.
- Data recipients will acknowledge the “BIND Consortium” in all oral or written presentations, disclosures, or publications arising from analysis of the shared dataset.

BIND Data Access SOP

