



National Birth Defects Prevention Network
Surveillance · Research · Prevention

Surveillance Data Committee Charter

- **Mission:**
 - Facilitates the use of state birth defects surveillance data.
 - Develops and disseminates multi-state pooled data analyses.

- **Responsibilities:**
 - Maintain and share knowledge about the latest data and analytic resources in the birth defects field.
 - Provide opportunities for researchers new to the field to gain knowledge, experience, and mentorship in the analysis of birth defects surveillance data
 - Promote, encourage, and support an inclusive and diverse committee membership and involvement and engagement in the committee and collaboration in the use of state birth defects surveillance data by all its diverse members.
 - Evaluate/review proposed multi-state projects and provide feedback.
 - Track/disseminate information from the Annual Birth Defects Survey compiled by CDC.
 - Coordinate the peer review, clearance, and IRB processes as appropriate.
 - Evaluate/review other materials being proposed for publication and provide feedback.
 - Identify opportunities to leverage its data reports and manuscripts to unveil health disparities based on race, ethnicity, or other demographic and socio-economic factors.
 - Identify opportunities to disseminate birth defects prevention and prevalence findings to the within and outside of NBDPN; and coordinate with the Communication and Health Promotion Committee and with publishers for materials approved by Board of Directors (BOD).

- **Deliverables:**
 - Biennial Data Reporting
 - Facilitate state-based data tables of birth defect prevalence from any state program.
 - Facilitate summary of features for each birth defects monitoring programs (whether submitting data or not).
 - Data Reports and Manuscripts, which are stand-alone papers in the NBDPN special issue *Birth Defects Research*.
 - Multi-state projects related to the epidemiology of birth defects.
 - Data repository (future).

- **Organization:**
 - Review of Charter:
 - This Charter shall be reviewed and assessed by Surveillance Data Committee at least annually and any proposed changes shall be submitted to the Board of Directors for approval.

- Workplan:
 - The committee shall develop an annual workplan for the committee and submit to the Operations Committee Chair (Board Vice-Chair) by the 15th of first month of the organization's fiscal year.
 - Workplans will be reviewed and approved by the Operations Committee.

- Membership/Structure/Quorum:
 - Committee chair(s) shall be appointed by the Board of Directors and will serve on the Operations Committee.
 - This committee shall consist of at least 15 members.
 - Committee members should have general knowledge of definitions and trends in birth defects prevention. Committee members should have analytical skills, knowledge of trending birth defects data standards and data assets and writing abilities.
 - Committee members serve for a term of three years with no maximum number of terms served.
 - Committee workgroups may be organized by or assigned based on the annual workplan.

- Meetings:
 - The committee shall convene monthly. A quorum of any meeting shall consist of at least 5 members. Meetings will be conducted on Zoom and recorded as needed.

- Agenda, Minutes, Reports
 - The committee chair shall be responsible for:
 - Establishing the agendas for meetings.
 - An agenda, together with relevant materials, shall be sent to committee members at least 3 days in advance of the meeting.
 - Minutes for all meetings shall be drafted by the designee, reviewed by the committee chair and co-chair (if applicable) and approved by committee members at the following meeting.
 - Agendas and meeting minutes shall be uploaded to the NBDPN Box online site and available for review by the Operations Committee and the Board of Directors.



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Surveillance Data Committee
Workplan, FY 2024

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|--------------------------------------|---|
| Chair/Co-Chair: | Adrian Michalski / Eirini Nestoridi |
| Workgroups/Lead(s): | |
| 2025 Spotlight | Eirini Nestoridi, Adrian Michalski, Jennifer Isenburg, Erin Stallings |
| Space-Time Monitoring | Peter Langlois |
| Rare Syndromes | Eirini Nestoridi |
| Multi-state Projects | Wendy Nembhard (Mortality), A.J. Agopian (Defect Coding Comparison) |
| Data Housing, Management, & Analytic | TBD |
| Key Members: | |
| | |

| Deliverable | Workgroup | Schedule | Interim Deadline | Launch Date | FY2024 Workplan |
|---|---------------|-------------------------|------------------|--------------|--|
| D1) Facilitate Major Birth Defects Data from Population-based Birth Defects Surveillance Programs | Annual Report | Biennially (even years) | November 2024 | January 2025 | <ul style="list-style-type: none"> Begin the planning process to identify spotlight paper ideas, coordinate with CDC partners, SGSC toward the preparation for the 2025 data call. |
| D2) Facilitate Update to State Birth Defects Surveillance Program Directory | Annual Report | Biennially (even years) | November 2024 | March 2025 | <ul style="list-style-type: none"> Facilitate feedback and piloting of newly developed Annual Performance Summary |
| D3) Data Reports and Manuscripts | Annual Report | Annually | September 2022 | July 2023 | <ul style="list-style-type: none"> Topic development (Jan-March) Call for data (March-June) Analysis and writing (June-July) Manuscript review (July-August) |

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|--|---|---------------|--------------|-----------|---|
| | | | | | <ul style="list-style-type: none"> • Submission to BDR (September) • Publication NBDPN Special Ed (January) |
| D4) Promote real-time exchange of ideas | Presentations | Monthly | January 2024 | | <ul style="list-style-type: none"> • Encourage members to share their work and projects during meetings |
| D5) Multi-State Project Analyses & Manuscripts | Multi-State Projects / Individual sub-committees | Annually | | | <ul style="list-style-type: none"> • Facilitate & support special multi-state projects focused on specific topics outside of annual reports. • Disseminate resulting publications in collaboration with Communications & Health Promotions committee. • Share documentation/resources on inclusive language for manuscripts. • Diversity and Inclusion Committee can review manuscripts to ensure manuscripts produced and disseminated publications use inclusive language and can present on the use of inclusive language. |
| D6) NBDPN Annual Meeting Planning | Annual Meeting | 2024 | Sept 2024 | June 2025 | <ul style="list-style-type: none"> • Plan SDC breakout sessions for 2025 NBDPN Conference • Plan in person SDC meeting |
| D7) Cross Committee Work | | Begin in 2024 | | | <ul style="list-style-type: none"> • Collaborate with SGSC to assist with feedback and piloting of the new NBDPN Annual Performance Summary |
| Concepts/Future Goals | | | | | |
| C1) Data Housing, Management, & Analytic portal for multi-state projects | Data Housing, Management, & Analytic | Begin in 2024 | July 2024 | | <ul style="list-style-type: none"> • Identify possible options for housing multi-state data in a secure cloud forum which would allow analysis by multiple authorized NBDPN members. |
| C2) NBDPN resource repository | Guidelines Revision/Chapter Workgroups, Space-Time Monitoring | Begin in 2024 | | | <ul style="list-style-type: none"> • To support surveillance program staff training; this would include webinars, guidance documents, and other materials. • Guidelines Revision and Space-Time Monitoring will develop tools that can be stored/accessed on this member only area platform in new website. |