



National Birth Defects Prevention Network  
Surveillance Research Prevention

**Guidelines and Standards Committee Charter**

- **Mission:**

To develop and promote the use of standards and guidelines for birth defects surveillance data programs in the United States and increase the quality, consistency, and reliability of birth defects surveillance data.
- **Responsibilities:**
  - Develop and disseminate NBDPN's birth defects surveillance data standards and guidelines.
  - Provide training on the NBDPN's data standards and guidelines.
  - Collaborate with external partners to revise standards/guidelines, create new standards/guidelines, and evaluate resources for electronic birth defect reporting.
  - Monitor standards/guidelines for birth defects surveillance disseminated by others (e.g., World Health Organization).
- **Deliverables:**
  - Birth Defects Surveillance Data Guidelines and Standards Manual
  - Data Quality Tool
  - Data Utility Measure Tool
  - Training webinars for abstractors
  - Share up to date information on data modernization
- **Organization:**
  - Review of Charter:
    - This Charter shall be reviewed and assessed by Guidelines and Standards 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 15<sup>th</sup> 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.
    - Committee members should have a general knowledge of or interest in definitions and trends in birth defects prevention and birth defects surveillance methods.
    - Committee workgroups may be organized by or assigned based on the annual workplan.

- Meetings:
  - The committee shall convene on a bimonthly (every other month) basis. A quorum of any meeting shall consist of at least 5 members. Meetings will be conducted online 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 Guidelines and Standards Committee (SGSC)  
Workplan, FY 2024**

<b>Chair/Co-Chair:</b>	Jodi Snow/Washa Liu
<b>Workgroups/Lead(s):</b>	
Abstractor Technical Tools	Jodi Snow
Standards Development & Evaluation	Stephanie Robinson/Suzann Beauregard
EHR / HL7 Standards	Laura Pabst
Surveillance Guidelines Manual (reactivating)	Carol Stanton
<b>Key Members:</b>	

Deliverable	Workgroup	Schedule	Interim Deadline	Launch Date	FY2024 Workplan
D1) Start working on organizing the updates the document Guidelines for Conducting Birth Defects Surveillance to provide technical assistance and promote the adoption of evidence-based, national standards for birth defect surveillance programs.	Surveillance Guidelines	5-year plan Year 1	September 2024	January 2024	<ul style="list-style-type: none"> <li>Program Director (PD) begins as lead of project, reviews project activities.</li> <li>Recruit revision leadership groups, Steering, Advisory, Consults, Technical Editor, Chapter Lead, and Chapter Teams (Summer 2024)</li> <li>Develop revision plan and reference guide that includes detailed description/instructions of the components of the revision process</li> </ul>
D2) Updated Data Quality (DQ) Assessment Tool	Standards Development & Evaluation	Biennially (Odd years) or as needed	2024	March 2023	<ul style="list-style-type: none"> <li>Distribute DQ assessment tool results to programs</li> <li>Post summary results to NBDPN web site</li> </ul>
D3) Updated DQ Indicators	Standards Development and Evaluation	As needed	December 2024	2024	<ul style="list-style-type: none"> <li>Continue review and updates to DQ Indicators</li> <li>Complete Template</li> <li>Post to NBDPN web site</li> </ul>

D4) NBDPN Crosswalk Tool	Standards Development and Evaluation	Biennially (odd years) or as needed	2024	TBD	<ul style="list-style-type: none"> <li>• Complete review of NBDPN Crosswalk to replace Directory submitted with biennial data submissions</li> <li>• Determine submission guidelines</li> <li>• Determine data analysis and reporting for new Directory</li> </ul>
D5) Abstractor Training Webinars	Abstractor Technical Tools	As needed	December 2024	January 2024	<ul style="list-style-type: none"> <li>• Pre/post abstraction training webinar, to be broken down and re-recorded (Completed by Summer 2024)</li> <li>• Congenital Heart Defects training webinar (Completed by 12/2024)</li> <li>• Include closed captioning options for webinars</li> </ul>
D6) Abstractor Birth Defect Guides	Abstractor Technical Tools	As needed	December 2024	January 2024	<ul style="list-style-type: none"> <li>• Complete 2-4 abstractor birth defect guides (12/2024)</li> </ul>
D7) Review ICD Coding Changes	None	Yearly	November 2024	December 2023	<ul style="list-style-type: none"> <li>• Review CMS website for ICD-10-CM updates (November 2023)</li> <li>• Prepare document with changes/revisions (e.g., Q21.1) and share with NBDPN (December 2023)</li> </ul>
D8)	SGSC	Ad hoc	January 2024	December 2024	<ul style="list-style-type: none"> <li>• Record 2+ organ system webinars</li> <li>• Save recorded webinars to NBDPN website</li> </ul>
D9)	EHR/HL7 Standards	Ad hoc			<ul style="list-style-type: none"> <li>• Share up to date information on data modernization</li> </ul>
<b>Concepts/Future Goals</b>					
C1) Discover new needs of SGSC members regarding abstracting, standards, EHR/ HL7 or technological changes.	SGSC	Begin 2024			<ul style="list-style-type: none"> <li>• TBD</li> </ul>