
Introduction

In January of 1999, the National Birth Defects Prevention Network (NBDPN) established a Surveillance Guidelines and Standards Committee (SGSC) in order to develop and promote the use of standards and guidelines for birth defects surveillance programs in the United States. This set of guidelines is designed to serve as an important first step in the documentation of this process and as the vehicle for dissemination of the committee's findings.

The Guidelines for Conducting Birth Defects Surveillance (henceforth referred to as *The Surveillance Guidelines*) were developed with three major long-term objectives in mind:

- To improve the quality of state birth defects surveillance data, including accuracy, comparability, completeness, and timeliness.
- To enhance the utility of state birth defects surveillance data for research on the distribution and etiology of birth defects.
- To encourage and promote the use of state birth defects surveillance data for the purposes of linking affected children with services and evaluation of those services.

The technical guidelines that make up this document provide a way of improving the quality of birth defects surveillance data, which in turn enhances their use in support of the latter two objectives. Fundamental to quality is ensuring that procedures for all aspects of data definition, collection, management, and analysis are established and followed. Because state-based surveillance systems operate with different objectives and data needs, it is clear that, with respect to procedures and standards, "one size does not fit all." It is also clear, however, that common guidelines can provide a basis for the development of system-specific operating procedures and supporting manuals.

Variation among surveillance programs is manifest along several dimensions. These include:

- *Objectives*, which can be very diverse but commonly include:
 - Providing baseline data on occurrence
 - Identifying populations at increased risk
 - Monitoring changes in occurrence
 - Investigating clusters
 - Collaborating with research
 - Estimating service needs
 - Referring affected children to services
 - Evaluating prevention programs
- *Case ascertainment methods*
 - Active – case finding
 - Passive – case reporting
 - Combined

➤ *Organizational location*

- Health department
- University
- Other

The first two dimensions – objectives and case ascertainment methods – are of particular significance in attempting to develop guidelines that have the breadth to be useful (i.e., universality), while at the same time making clear that there is not necessarily a common denominator across programs. Thus most of the guidelines in this volume are phrased as *recommendations* or “shoulds,” as opposed to *standards*, which could be interpreted as “musts.” The exception to the latter is Chapter 10, which refers the reader to information on how data are to be reported to NBDPN for the Annual Report. The relevance of organizational location to the guidelines is probably restricted to legislative issues, which are addressed in Chapter 2.

The Surveillance Guidelines consist of a series of chapters covering the fundamental aspects of developing, planning, implementing, and conducting surveillance for birth defects and using the resulting data. Although the focus is on birth defects, most of the principles described are relevant and applicable to surveillance for any health outcome. Just as the methods and strategies developed for birth defects in the Metropolitan Atlanta Congenital Defects Program provided a blueprint for the subsequent development of the Metropolitan Atlanta Developmental Disabilities Surveillance Program, the information included in these guidelines can provide a blueprint for the development of surveillance for developmental disabilities among the states.

On reviewing the guidelines, the reader will note that a number of the chapters are supported by appendices. In many instances these appendices are designed to provide additional information on technical issues considered. In some cases they provide extensive detail on procedures that are currently being used by surveillance programs. Because of their size, three documents cited as appendices will only be available in electronic format. These are the NBDPN Abstractor’s Instructions (Chapter 3, Appendix 3.2) and the Texas Disease Index and the CDC Six-digit Codes (Chapter 5, Appendices 5.1 and 5.2, respectively). Information on how to access the electronic format is included in each appendix.

The Surveillance Guidelines are being published in two formats: as print copy and through the NBDPN website. The Surveillance Guidelines and Standards Committee anticipates updating and revising the guidelines over time. Whenever a revision is published, a revision date will appear in the chapter header to distinguish that page or pages from previous versions. Because we anticipate this will be a living document, we encourage comments, suggestions, and corrections. If you have such, please submit them through the link to the Surveillance Guidelines and Standards Committee on the NBDPN website.

This set of guidelines represents a great deal of work by a large number of individuals. The development of the document was carried out by the NBDPN Surveillance Guidelines and Standards Committee. A working group for each of the chapters did most of the writing. When chapters were completed in draft form, they were submitted to the SGSC Steering Group for review and suggested revisions. When a draft was considered acceptable to the Steering Group it was sent to Dr. Lowell Sever of Battelle Centers for Public Health Research and Evaluation, the editorial consultant for the reference manual. Dr. Sever then edited the chapter, returning it to the Steering Group, and working groups when necessary for clarification and acceptance of his revisions. Several of the chapters were also sent to specially assembled “Focus Teams” for review and assessment of the technical content. When the final content was agreed upon, the chapter was submitted to a Battelle technical writer and editor for finalization of structure and format.

We have compiled all of the contributors to this intensive process into a single acknowledgements page. *The Surveillance Guidelines* represent a significant and complex undertaking that could not have been accomplished without the contributions of this large number of individuals, and we thank them all.

We dedicate this milestone document to Larry Edmonds of the Centers for Disease Control and Prevention in recognition of his strategic vision, inspiring leadership, and steadfast commitment – both to the National Birth Defects Prevention Network and to the enhancement of birth defects surveillance generally – throughout the remarkable process of developing *The Surveillance Guidelines*.

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