



Summary of Focus Group and Survey Findings

In December of 2005, the Surveillance Guidelines and Standards Committee released a survey designed to measure user impressions of the Guidelines. In January of 2006, a focus group was interviewed at the annual meeting of the National Birth Defects Prevention Network (NBDPN). Here is a summary of the results:

Overall Impressions

- Overwhelmingly, the Guidelines are viewed positively by respondents.
- According to the survey, the most helpful chapters are Case Definitions, Classification and Coding, Case Ascertainment Methods, and The Whys and Hows of Birth Defect Surveillance. This was largely consistent across active, passive, and hybrid programs.
- The focus group was basically in agreement with this, although those participants did not think Case Definitions were as helpful. It was suggested that the Case Definitions chapter is not as helpful for established programs.
- The Data Collaboration chapter was least helpful.
- Passive programs used the minimum and recommended data variables more often than other programs. Active and hybrid programs used the abstractor instructions more often than passive programs.
- Respondents who do field work refer to the guidelines more often than administrators.
- Most people use a paper version of the Guidelines.
- There is a lot of interest in a chapter on prenatal diagnosis and surveillance.
- Common uses of the Guidelines include: program development and evaluation, justification (e.g., for grant money, cooperation from Vital Records), staff training, as an “authority”.

Suggestions for improvement/additions (from focus group)

- Supplement the Guidelines with a web page that includes more fluid information.
- Include appendices on software, contact info for people who can serve as resources.
- Include chapters on electronic submission of records, data linkage, referral and prevention, working with community groups.
- Include training materials.

- Create an index/hyperlinked version.
- Create a “Cliff Notes” version.

Standards vs. Guidelines (from focus group)

- Most people seemed very receptive to having standards.
- It was hoped that clear standards could help programs “make the case” for certain resources.
- There was much discussion about types of standards, including standards for completeness and core variables.
- Differing standards for different types of programs (active, passive, etc.) was also discussed. “Levels” of standards (similar to gold and silver cancer registries) was also discussed.
- There was no resolution on which specific standards that should be adopted.

Action Steps

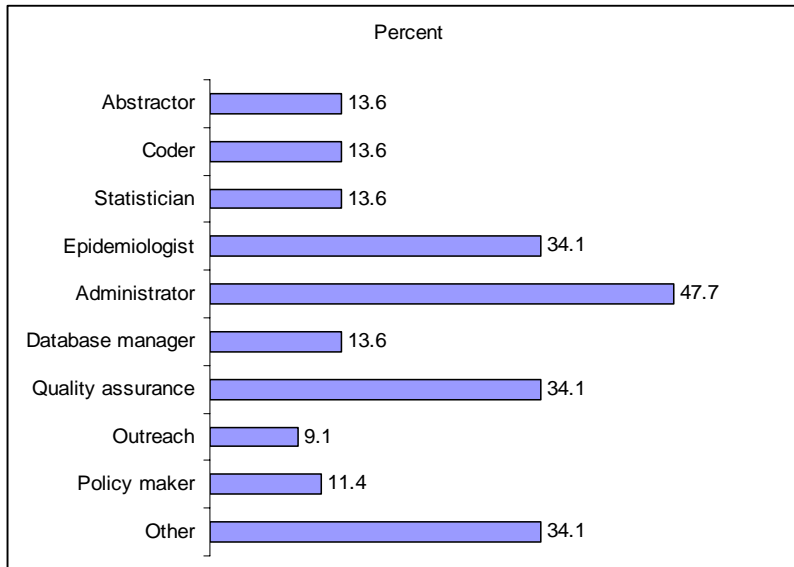
Thank you to everyone who filled out the survey and participated in the focus group! The Committee is taking several steps that reflect the suggestions/concerns of the participants. Specifically:

- There is a currently a chapter on prenatal surveillance under development.
- Two workgroups have started examining what is involved with developing program and abstractor standards.
- There is a “members only” section under development for the NBPDP web site. It is planned to include technical tools and other resources available for birth defect surveillance.

Please remember that you do not have to wait for a survey or a focus group to provide your input on the Guidelines. Feedback is always welcome, and we are also looking for people who would like to join the Committee. E-mail Ann Phelps, the chair of the Surveillance Guidelines and Standards Committee, at Ann.Phelps@dshs.state.tx.us. If you have any questions or concerns about the survey and focus group results, e-mail Brad McDowell at bradley-mcdowell@uiowa.edu.

Gory Details

Forty-five people responded to the survey. There was good representation across active, passive, and hybrid programs (33%, 24%, and 43% of respondents, respectively). A variety of roles were also represented in the survey results (see figure).



Percentage of respondents claiming various roles. Respondents were allowed to select more than one option, so percentages add up to greater than 100%.

Between 15 and 20 people from a wide variety of programs participated in the focus group at the NBDPN meeting. The participants were asked questions about their impressions of the Guidelines, how they used the Guidelines, and how they would improve the Guidelines. They were also asked if the NBDPN should move from “guidelines” to “standards”.

Basic findings from the survey and focus group are presented here. No significance tests were performed, but some responses were examined separately based on certain demographic questions. To preserve confidentiality, no individual responses are presented here.

Results Summary

[Export...](#)
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Filter Results

To analyze a subset of your data, you can create one or more filters.

[Add Filter...](#)
Total: 45

Visible: 45

Share Results

Your results can be shared with others, without giving access to your account.

[Configure...](#)
Status: Enabled

Reports: Summary Only

1. Page 1

1. Indicate for each Guidelines chapter listed below whether it was helpful, not helpful, or that you have not read it.

| | Helpful | Not Helpful | Have not read this chapter | Response Total |
|--|--------------------------------|-------------|----------------------------|----------------|
| Chapter 1: The Whys and Hows of Birth Defects Surveillance | 86% (36) | 2% (1) | 12% (5) | 42 |
| Chapter 2: Legislation | 55% (23) | 10% (4) | 36% (15) | 42 |
| Chapter 3: Case Definition | 91% (40) | 2% (1) | 7% (3) | 44 |
| Chapter 4: Data Variables | 84% (37) | 7% (3) | 9% (4) | 44 |
| Chapter 5: Classification and Coding | 86% (37) | 7% (3) | 7% (3) | 43 |
| Chapter 6: Case Ascertainment Methods | 86% (37) | 5% (2) | 9% (4) | 43 |
| Chapter 7: Data Quality Management | 71% (30) | 7% (3) | 21% (9) | 42 |
| Chapter 8: Statistical Methods | 63% (27) | 9% (4) | 28% (12) | 43 |
| Chapter 9: Data Management and Security | 69% (29) | 5% (2) | 26% (11) | 42 |
| Chapter 10: Data Collaboration and Dissemination through the NBDPN | 49% (21) | 12% (5) | 40% (17) | 43 |
| | Total Respondents | | | 44 |
| | (skipped this question) | | | 1 |

2. Please check the box by each Guidelines tool that you have used. If you have not used any of them, leave all boxes unchecked and go to the next page.

| | | Response Percent | Response Total |
|--|--------------------------|------------------|----------------|
| Sample legislation | <input type="checkbox"/> | 15.8% | 6 |
| Case definitions of birth defects | <input type="checkbox"/> | 97.4% | 37 |
| Abstractor's instructions | <input type="checkbox"/> | 68.4% | 26 |
| Descriptions of minimum and recommended data variables | <input type="checkbox"/> | 73.7% | 28 |
| Texas Disease Index | <input type="checkbox"/> | 36.8% | 14 |

| | | | |
|--|-------------|-------|-----------|
| 6-Digit CDC codes | <div></div> | 52.6% | 20 |
| Descriptions of data sources (vital records, hospital data sets, service logs, genetic services) | <div></div> | 60.5% | 23 |
| Data sources descriptive assessment tool | <div></div> | 31.6% | 12 |
| Total Respondents | | | 38 |
| (skipped this question) | | | 7 |

2. Page 2

1. On the average, how often do you refer to the guidelines?

| | | Response Percent | Response Total |
|--------------------------------|-------------|------------------|----------------|
| Once per week | <div></div> | 22.7% | 10 |
| Once per month | <div></div> | 43.2% | 19 |
| Once every six months | <div></div> | 20.5% | 9 |
| Once a year | <div></div> | 9.1% | 4 |
| Less than once a year or never | <div></div> | 4.5% | 2 |
| Total Respondents | | | 44 |
| (skipped this question) | | | 1 |

2. When you refer to the Guidelines, do you refer to... (check all that apply)

| | | Response Percent | Response Total |
|--|-------------|------------------|----------------|
| A paper version | <div></div> | 95.3% | 41 |
| An electronic version saved on your computer | <div></div> | 23.3% | 10 |
| The version on the NBDPN web site | <div></div> | 23.3% | 10 |
| Total Respondents | | | 43 |
| (skipped this question) | | | 2 |

3. Of the following topics, which would you like to see addressed in future versions of the Guidelines? (Check all that apply)

| | | Response Percent | Response Total |
|--|-------------|------------------|----------------|
| Prenatal diagnosis and surveillance | <div></div> | 85% | 34 |
| Data presentation | <div></div> | 62.5% | 25 |
| Research methods | <div></div> | 47.5% | 19 |
| Abstractor technical skills | <div></div> | 50% | 20 |
| <div>View</div> Other (please specify) | <div></div> | 27.5% | 11 |
| Total Respondents | | | 40 |
| (skipped this question) | | | 5 |