

Appendix 11.3 Data Users Matrix

Sample Questions Asked	Information Needs/Data Presentation Suggestions
Surveillance Program Staff	
<p><i>This group is likely to require process indicators useful for management. Members of this group may notice possible clusters. This audience also needs additional information about denominator issues and data quality.</i></p>	
<ul style="list-style-type: none"> ▪ How many abstracts were completed per field staff person? ▪ We have noticed more cases of birth defect x in this hospital; is that unusual? 	<ul style="list-style-type: none"> ▪ Data on labor hours and abstracting rates. ▪ Data on birth prevalence, usually in comparison to some standard, such as the entire state. ▪ Internal exhibits in terms of surveillance parameters: Completeness/Ascertainment, Case Processing Times.
Researcher	
<p><i>This audience is likely to be interested in:</i></p> <ul style="list-style-type: none"> ○ <i>Descriptive epidemiology (describing occurrence of birth defects by person, place, and time).</i> ○ <i>Analytic epidemiology (finding causes of birth defects).</i> ○ <i>Obtaining birth defect cases for related studies.</i> ○ <i>Methodological issues.</i> ○ <i>Availability of data on individual types of birth defects and on cases, both identified and de-identified, for ecologic studies and etiologic research.</i> 	
<ul style="list-style-type: none"> ▪ What are the patterns of birth defect occurrence by person, place, and time? ▪ What is associated with risk of birth defect x? ▪ How many cases of specific birth defects are represented in the database of the surveillance program? ▪ How do I get access to records for persons included in the surveillance program for research studies? 	<ul style="list-style-type: none"> ▪ Printed and web reports and charts with routinely tabulated results allow for quick response to many inquiries. ▪ Specially tabulated results ▪ Line item data with and without confidential information. ▪ Interactive web-based tool for custom queries allows for easy access and reduces staff time in responding to simple routine and non-routine aggregate data requests. See, for example, http://soupfin.tdh.state.tx.us/bdefdoc.htm

Sample Questions Asked	Information Needs/Data Presentation Suggestions
Physician and Other Health Care Providers	
<p><i>This audience is often interested in outcomes (pregnancy, how does the child do, survival/treatment), as well as birth defect prevalence. Members of this group may notice possible clusters. This audience also needs additional information about denominator issues and data quality. Statistical output for this audience may well run more detailed in terms of clinical detail. Allow for the presentation of small cases series. Members of this group often have the skill to interpret tabular data, but do not assume they will necessarily have the statistical sophistication that may be lacking in other audiences.</i></p>	
<ul style="list-style-type: none"> ▪ Which defects are most common? ▪ What are the trends in birth defects over time? ▪ Are there unexpectedly high rates in my area or facility? 	<ul style="list-style-type: none"> ▪ Printed reports. ▪ Web-based data.
Social/Education Service Provider	
<p><i>Needs from this audience are usually geographic in nature. Birth defects programs can promote use of data among this group by providing maps and other data that respond to these information needs.</i></p>	
<ul style="list-style-type: none"> ▪ Describe the population we serve in terms of location, income, other variables. ▪ How many babies with complex congenital heart defects do you estimate will be born during the next five years in the area for which our children’s hospital provides clinical care? 	<ul style="list-style-type: none"> ▪ Mapping location of clinics compared to appropriate birth defect cases. ▪ Time series analyses with projections (e.g., how many children with x syndrome will be born in x county for the next five years in order to project needs for special education teachers, etc.?).
Local Health Department	
<p><i>This audience tends to be interested in epidemiological data. Members of this group may also want to link your data with data they have on environmental concerns (e.g., factories, toxic waste sites). There is a risk of misuse of data if users do not understand the unique aspects of birth defects data.</i></p>	
<ul style="list-style-type: none"> ▪ What are our rates? ▪ How do we compare with the rest of the state? ▪ How do we compare with the nation? ▪ Are there links between birth defect clusters and local environmental concerns? ▪ What clusters (in our area) are you dealing with? ▪ What are the trends in birth defects over time? 	<ul style="list-style-type: none"> ▪ Epidemiologic data provided by zip code, city, county, region. ▪ Case characteristic summaries as tables, as well as rate tables and graphics, including trends. Consider also the presentation of rate ratios. ▪ Reports of cluster investigations; maps of clusters investigated. ▪ Have a document written in language accessible to the lay person explaining some of the finer points of interpreting birth defects data.

Sample Questions Asked	Information Needs/Data Presentation Suggestions
Maternal and Child Health Programs	
<p><i>Members of this group might be professionals in Women Infants, and Children (WIC) or Title V programs. They tend to be interested in trends over time, rates, outcomes, and surveillance operations.</i></p>	
<ul style="list-style-type: none"> ▪ Do you have any information on folic acid education programs that can be targeted to our Hispanic clients? 	<ul style="list-style-type: none"> ▪ Items here will likely address racial disparities and the demographics that underlie differences in race, including cultural health practices and SES. ▪ GIS/spatial analysis may be relevant here.
Family of Child with Birth Defect(s)	
<p><i>This audience tends to like information about known causes and risk factors for particular birth defects. Members of this group are interested in seeing birth defects data linked with potential teratogens or environmental concerns and the outcomes. They may desire information on educational, social, and clinical services available for children with specific types of birth defects.</i></p>	
<ul style="list-style-type: none"> ▪ I have a child with a cleft lip. What information do you have on the causes of this condition? ▪ I just had a baby with spina bifida. What information can you give me about this condition and where can I get specialized care for her? ▪ Do you have any information on support groups in my community for parents of children with Down syndrome? ▪ What caused my child’s birth defect? ▪ Have there been clusters investigated in my area? 	<ul style="list-style-type: none"> ▪ Literature summaries. ▪ Maps of cluster investigations. ▪ Charts comparing local/state rates to other areas. ▪ Be sure to explain the difference between individual- and population-level information
Students (public health, medical, nursing, allied health, or other college/university)	
<p><i>Needs among this audience might include:</i></p> <ul style="list-style-type: none"> ○ General education (e.g., lectures to a class) ○ Specific education (e.g., practicum placements) ○ Research (e.g., data and guidance on papers, theses, dissertations) <p><i>You might present to these types of students during Grand Rounds or at local seminars or conferences. They may also submit specific requests as a result of papers or projects they are working on.</i></p>	
<ul style="list-style-type: none"> ▪ Can you provide me with information about changes in the occurrence of neural tube defects in ___ following the fortification of cereal grains with folic acid? 	<ul style="list-style-type: none"> ▪ Printed reports. ▪ Copies of manuscripts. ▪ Interactive web-based tool for custom queries allows for easy access and reduces staff time in responding to simple routine and non-routine aggregate data requests. ▪ Raw data.

Sample Questions Asked	Information Needs/Data Presentation Suggestions
News/Media Person	
<p><i>Media personnel are generally interested in comparative rates region/state/nation. Also, they will likely need information about causes and risk factors. Their questions may or may not relate to a specific community concern or cluster. They tend to request large amounts of data and use very little of it.</i></p>	
<ul style="list-style-type: none"> ▪ What is the cause of x birth defect? ▪ Are the cases of x birth defect linked with the toxic dump, military base, factory, vaccine, etc? 	<ul style="list-style-type: none"> ▪ Printed and web reports and charts with routinely tabulated results allow for quick response to many inquiries. ▪ Have a document written in language accessible to the lay person explaining some of the finer points of working with and interpreting birth defects data.
Legislator/Policy Maker	
<p><i>This type of information request usually comes from higher up in the agency or from advocacy groups. Top information needs include cost of program, cost of birth defects to the state, number of people served by the program, and staffing data. This audience would be interested in surveillance data connected to other information such as regional variation or costs. Members of this group may also request administrative data—improvements in program efficiency, budget information, increases in caseload (live births, hospitals).</i></p>	
<ul style="list-style-type: none"> ▪ How many staff (FTEs) does the surveillance program employ? ▪ What is the cost of the program? ▪ How many babies with birth defects are born each year in my legislative district? ▪ What are the estimated lifetime costs of caring for a child with spina bifida? ▪ What is the impact of this policy? (e.g., decrease in rates of NTDs after fortification of food supply with folic acid) 	<ul style="list-style-type: none"> ▪ Narrative reports. ▪ Graphs of birth prevalence over time (for before/after comparisons) or comparing communities with different policies. ▪ Statistical exhibits intended for this audience should address not only descriptive aspects, but also the quantitative burden of disease.
Advocacy Group	
<p><i>The needs of this group will vary depending on what they are advocating for. This audience will need exhibits at two levels—exhibits for the lay public and exhibits for policy makers—and the distinction needs to be clear.</i></p>	
<ul style="list-style-type: none"> ▪ What are the rates in z location for birth defect x? ▪ Why are you not collecting data on birth defect x? ▪ What is the cost to y unit of government for treating birth defect x? 	<ul style="list-style-type: none"> ▪ Cost, magnitude, impact. ▪ Birth defects data linked with environmental data.

Sample Questions Asked	Information Needs/Data Presentation Suggestions
Other Community Members	
<p><i>Members of this group usually contact the registry to report concern of a possible cluster. They are frequently interested in environmental exposures and birth defects.</i></p>	
<ul style="list-style-type: none"> ▪ What are the rates of birth defects in my community? ▪ Are birth defects higher here than elsewhere? ▪ If higher, can the excess birth defects be linked to environmental concerns? 	<ul style="list-style-type: none"> ▪ Data on occurrence, usually in comparison to some standard, such as the entire state.