Appendix 3. Additional Resources.

To address connections between environmental contamination and residents' health in the Great Lakes' Areas of Concern (AOCs), public health researchers must identify and evaluate detailed environmental contamination and human health data. Initially, associations between environmental toxins and health are evaluated by conducting descriptive assessments of ecologic (grouped) data. This involves the use of environmental contamination and health outcome data from large populations within a geographic area such as an AOC or AOC county. These initial assessments use readily available, population-based datasets and are useful for hypothesis generation, monitoring of general trends, and identification of specific scenarios that merit further analytical evaluation.

Grouped analyses depend on summary measures of both an exposure and a health outcome for each geographic area in the analyses. Analyses of grouped data can sometimes provide useful information that generate further research questions. However, we did not feel that the data available for use in this report supported these types of analyses. First, much of the exposure to pollutants in this area is localized and does not apply to a whole AOC or AOC county, making summary measures of exposure potentially misleading. Second, the available health data does not necessarily measure outcomes of greatest interest relating to exposure to IJC-critical contaminants.

Regardless of whether grouped analyses are appropriate for particular research questions, they are generally followed by more refined, individual analyses. To conduct individual-level analyses that further evaluate relationships between environmental contaminants and health effects within AOCs, public health researchers must identify or collect specific, linkable, individual-level data on environmental contaminants and potential health effects. Unfortunately, linkable environmental contamination and health data at the individual level are not readily available. Relevant data on environmental contaminants include concentrations, spatial distribution within different environmental media, and the time frames associated with their presence in environmental media. For health effects data, necessary elements include information on the persons at risk (that is, who lived in AOCs during periods of significant contamination) and the adverse health effects experienced by those people.

Many limitations are associated with the current methods used to collect health data and the utility of this information for evaluating associations with the environment. A primary limitation is the dearth of health data for many adverse effects potentially associated with low-level, environmental contaminants. Consider residents who suffer from the broad range of behavioral, reproductive, developmental, neurologic, endocrinologic, and immunologic conditions. These conditions are all associated with the myriad of contaminants contained within the AOCs, yet most of these health effects are not captured by public health surveillance systems. Individual-level data for the majority of these conditions, such as a patient's medical records, reside with a patient's doctors, medical care facilities, or insurers. This makes uniform collection and assessment of this data prohibitive.

When quality data are available, the task is still difficult. Cancer registries have existed in most of the Great Lakes states since the 1990s. In terms of data quality and completeness, cancer incidence data collected by state cancer registries are considered a gold standard for chronic disease surveillance. Yet, even with available cancer data, environmental health research is hampered by data gaps in equally important areas such as the ability to link the cancer data with information on the person's exposure history or the measurement of other lifestyle characteristics that could confound or modify a potential association.

Similar to the inherent difficulties in evaluating health effects data, no comprehensive data source describes contaminant levels, their location in space and time, and their potential interface with human populations. Many separate environmental data sources describe industrial facilities and their environmental releases or historically contaminated sites and their associated impacts. However, none of these sources provide sufficient information on the contaminant, the process by which the contaminant was released, the geographic location of the release, or the duration of the release. As a result, researchers struggle to link disparate health and environmental data while also recognizing and considering other important influences such as disease latency, residential in and out migration, and lifestyle.

While no single comprehensive source of environmental or health data exists within the Great Lakes states, some examples of data sources provide quality information on specific causes of morbidity and mortality. This is true for environmental contamination as well. A few of these health and environmental datasets even overlap in time and space. However, proximity to environmental contamination does not imply exposure or effect. Exposure assessment is the process that uses environmental and health data, along with other important predictor variables, to determine a person's likelihood and level of exposure. The exposure assessment process provides a quantitative interface for evaluating environmental contamination and health data. This interface may use assumptions on water consumption, air inhalation, or soil contact to model the estimated exposures for persons or specific populations. Preferably, it will include more robust evaluations of exposure via biomonitoring.

The process of collecting, analyzing, and interpreting information for the AOCs should be clear and transparent. When relying on disparate datasets across the eight states containing the 26 U.S. AOCs, the task of evaluating and linking environmental and health data for these unique locations is a considerable challenge. In most cases, the contaminants are many, the current threats varied, and the potentially exposed population difficult to identify. Combined with the numerous, potentially associated health effects that are broad in their own characteristics, this becomes a daunting task.

When prioritizing public health research projects and applied public health actions, the primary decision criteria often relate to data quality, availability, and accessibility. Data quality refers to both the systematic collection procedures used to obtain the information as well as the specific details captured in this process. Systematic collection may include environmental and health data grouped at some geographic level within an AOC such as a county or zip code, or it may consist of more specific information describing persons with an adverse health effect or detailed environmental sampling results. The specific minutiae captured in this process must somehow be linked to each other through

geographic location and time. Availability and accessibility of data bespeak the presence of systematic collection procedures and to the degree in which a researcher can obtain this information in a useable and timely fashion. Preferably, these data are representative of the population at risk. Only by identifying or collecting quality data, can researchers make substantial progress in making the connection between the environment within each AOC and the health of the area residents.

ATSDR has compiled a list of data sources or datasets that are potentially useful in evaluating AOCs on a broad scale (Annex 1). The list includes both sources of health and environmental data. Some health data, including birth and death data as well as cancer incidence, are available for all AOCs. Other health data are specific to only some AOCs, such as birth defects and hospital admissions or discharge data. Similarly, some environmental data sources provide data for all AOCs while some are specific to AOCs or smaller units within these areas. Refer to Annex 1 for specific sources and a description of data that they capture.

While there are numerous health and environmental data sources listed, this is not an exhaustive list. It is likely that there are other health and environmental data sources, particularly for specific AOCs or smaller areas within an AOC, which could further assist in any evaluations. This list identifies only some of the more relevant data sources available across most areas. The methodology and limitations of each data source are varied and are important issues to consider prior to intended use.

It is evident that linking environmental and health data in a meaningful way, even when both are collected at the same time and in the same place, is a difficult task. But it is a necessity if we are to evaluate effectively the relationships between them. Most environmentally mediated health effects are chronic conditions that take years to develop following low-level exposures. In light of such challenges, public health researchers must address the disparate nature of these data sources. The CDC's National Environmental Public Health Tracking Program is leading the initiative to address many of the problems encountered in the evaluation of environment and health data, such as those seen in the Great Lakes region. The program's goal is to create a nationwide network of integrated health and environmental data—the National Environmental Public Health Tracking Network. Information from this network will increase the effectiveness of government agencies and academic researchers in evaluating public health actions and in preventing environmentally mediated diseases.

Annex 1.

Health Data

Birth Defects Statistics –
- State health departments collect data on the frequency of children born with adverse pregnancy related outcomes, including birth defects.
- The following state health departments collect this information.
  - IL - http://www.idph.state.il.us/about/epi/apors.htm
  - MI - http://www.michigan.gov/mdch/0,1607,7-132-2944_4670---,00.html
  - MN- http://www.health.state.mn.us/divs/eh/birthdefects/
  - NY- http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm

Birth and Death Statistics –
- National birth and death data are compiled by the National Center for Health Statistics and are publicly available via the Centers for Disease Control and Prevention (CDC) Wonder http://wonder.cdc.gov/
- State vital statistics offices also house this information.
  - IN - http://www.in.gov/isdh/19096.htm
  - IL - http://www.idph.state.il.us/vitalrecords/death_research.htm
  - MI - http://www.michigan.gov/mdch/0,1607,7-132-2944_4669---,00.html
  - MN- http://www.health.state.mn.us/stats.html#birthstats
  - NY- http://www.health.state.ny.us/vital_records/death.htm
  - OH- http://www.odh.ohio.gov/healthStats/vitalstats/deathstat.aspx
  - PA - http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=175&Q=201638
  - WI - http://dhs.wisconsin.gov/deaths/index.htm
    http://dhs.wisconsin.gov/births/index.htm

Cancer Statistics –
- National cancer statistics are compiled by the National Center for Health Statistics and are publicly available via CDC Wonder http://wonder.cdc.gov/
- State health departments collect cancer incidence data from (at least) 1997 onward.
  - IN - http://www.in.gov/isdh/23456.htm
  - IL - http://www.idph.state.il.us/cancer/statistics.htm
  - MI - http://www.michigancancer.org/resources/CancerData.cfm#midata
  - MN- http://www.health.state.mn.us/divs/hpcd/cdee/mcss/index.html
  - NY- http://www.health.state.ny.us/statistics/cancer/registry/
  - OH- http://www.odh.ohio.gov/odhPrograms/svio/ci_surv/ci_surv1.aspx
  - PA - http://sedac.ciesin.org/ozone/regs/pennsylvania.html
  - WI - http://dhs.wisconsin.gov/wcrs/index.htm
- National cancer incidence data are available from the Surveillance, Epidemiology (SEER) database through the National Cancer Institute. SEER collects information on incidence, survival, and prevalence from specific geographic areas representing 26 percent of the U.S. population and compiles reports on these measures as well as cancer mortality for the entire U.S. http://seer.cancer.gov/canques/

Hospital, Health Care, and Public Health Clinic Statistics –
- These data describe hospital admissions and discharges and contain information on the reason for the hospital visit, treatment obtained, and services rendered.
- The following state health departments collect this information.
    - IN - http://www.in.gov/isdh/20624.htm
    - IL - http://app.idph.state.il.us/emsrpt/hospitalization.asp
    - MI - http://www.michigan.gov/mdch/0,1607,7-132-2944_5324---,00.html
    - NY - The Statewide Planning and Research Cooperative System collects patient level data on patient characteristics, diagnoses and treatments, services, and charges for every hospital discharge, ambulatory surgery patient, and emergency department admission in New York State. http://www.health.state.ny.us/statistics/sparcs/operations/overview.htm
    - WI - http://dhs.wisconsin.gov/provider/hospitals.htm

NHANES –
- The National Health and Nutrition Examination Survey (NHANES) assesses the health and nutritional status of adults and children in the United States. An interview and physical exam are conducted. The NHANES interview includes demographic, socioeconomic, dietary, and health-related questions. The examination consists of medical, dental, physiological measurements, and laboratory tests. http://www.cdc.gov/nchs/nhanes.htm

BRFSS –
- Behavioral Risk Factor Surveillance System collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. http://www.cdc.gov/brfss/

Environmental Data

ATSDR Health Assessments and Consultations –
- The Agency for Toxic Substances and Disease Registry (ATSDR) conducts health consultations and health assessments to provide information on the health risks associated to a specific site, a chemical release, or the presence of a hazardous material. A health assessment is conducted for every proposed National Priorities List site. http://www.atsdr.cdc.gov/hac/PHA/index.asp

Fish Advisories –
- Fish advisories provide information on contaminants in fish. The U.S. Environmental Protection Agency (EPA) maintains a database of fish advisories reported by states, tribes, territories and Canada. http://www.epa.gov/waterscience/fish/advisories/index.html

EPA Great Lakes Environmental Database –
- The Great Lakes Environmental Database (GLENDA) includes regional environmental data on a wide variety of constituents in water, biota, sediment, and air. http://www.epa.gov/glnpo/monitoring/data_proj/glenda/index.html

EPA Air Data Sources –
- Ambient Air Monitoring Program. Collects air quality samples for one or more of the following purposes: judge compliance in meeting ambient air quality standards, activate emergency control procedures that prevent or alleviate air pollution episodes, observe pollution trends throughout the region. http://www.epa.gov/air/oaqps/qa/monprog.html
- Air Data. AirData presents annual summaries of air pollution data from two EPA databases. Air Quality System database provides data on ambient concentrations of criteria and hazardous air pollutants at monitoring sites. The National Emission Inventory database provides estimates of annual emissions on criteria and hazardous air pollutants from all types of sources. http://www.epa.gov/air/data/index.html

EPA Toxic Release Inventory (TRI) Program –
- TRI is a publicly available EPA database that contains information on toxic chemical releases and waste management activities that are voluntarily reported annually by certain industries and federal facilities. http://www.epa.gov/tri/

EPA Remedial Investigations –
- A remedial investigation is conducted for all National Priorities List sites. The investigation characterizes the site; determines the nature of the waste; assesses risk to human health and the environment; and conducts treatability testing. http://www.epa.gov/superfund/cleanup/rifs.htm
- Reports for specific sites can be viewed at:
  - Region V states - http://www.epa.gov/region5/superfund/index.html
  - NY - http://www.epa.gov/region02/cleanup/sites/nytoc_sitename.htm
  - PA - http://www.epa.gov/reg3hwmd/super/pa.htm

EPA Safe Drinking Water Information System –
- The Safe Drinking Water Information System contains information about public water systems and their violations of EPA's drinking water regulations. http://www.epa.gov/enviro/html/sdwis/index.html
- EPA provides drinking water quality reports by states annually. http://www.epa.gov/ogwdw/ccr/whereyoulive.html?OpenView#map

EPA National Pollutant Discharge Elimination System –
- The National Pollutant Discharge Elimination System (NPDES) permit program controls water pollution by regulating point sources that discharge pollutants into U.S. waters. http://cfpub.epa.gov/npdes/
- Information on NPDES compliance and enforcement are available through EPA's Enforcement and Compliance History Online system. http://www.epa-echo.gov/echo/

USGS Real-time Water Retrieval Data –
- The Real-time water data retrieval map is a portal to all U.S. Geological Survey (USGS) hydrologic monitoring stations that transmit data in real- or near real-time, including surface water, ground water, and water quality sites. http://water.usgs.gov/waterwatch/uvmap/

Potable Groundwater Data –
- The USGS provides water-quality data for both surface and ground water. Examples of water-quality data collected are temperature, specific conductance, pH, nutrients, pesticides, and volatile organic compounds. http://waterdata.usgs.gov/nwis/
- Some states may also have useful ground water data
  - MN- http://www.health.state.mn.us/divs/eh/cwi/
  - PA - http://www.dcnr.state.pa.us/topogeo/groundwater/PaGWIS/help.aspx#Intro
  - WI - http://wi.water.usgs.gov/gwcomp/find/vilas/index.html

National Response Center –
- National Response Center is the sole national point of contact for reporting all oil, chemical, radiological, biological, and etiological discharges into the U.S. environment. http://www.nrc.uscg.mil/