Legislative report on recommendations for improvements in the intraoperability and interoperability of technology

Submitted by: Iowa Department of Public Health
Prepared by: Bureau of Communication and Planning
Date: December 9, 2013

The Iowa Department of Public Health was charged by the legislature to submit a report recommending improvements for the intraoperability and interoperability of technologies that communicate data under the purview of the department. The 2013 Iowa Acts, Chapter 138, Section 3.9 states:

The department of public health shall submit a report to the individuals specified in this Act for submission of reports by December 15, 2013, providing recommendations for improvements in the intraoperability and interoperability of communications technology under the purview of the department to improve efficiency and reduce costs.

Iowa Department of Public Health's approach to ensure intraoperability and interoperability of technology

Data collection and management are core functions of the Iowa Department of Public Health (IDPH). Requirements to capture and communicate information for many different reasons over time have created isolated systems and databases at IDPH and in other state agencies. These systems were developed in isolation because the requirements and funding were from different sources such as the State Legislature, Centers for Disease Control and Prevention, Center for Medicare and Medicaid Services or other public entities.

The department is increasing its efforts to eliminate duplication, consolidate systems and data storage, and create interfaces among systems. IDPH uses a collaborative approach to the construction and enhancement of its data technologies. Systems are occasionally in need of revision or enhancement, if not complete replacement, or a new system. The initiative to address technology may originate from a number of sources. Oftentimes, the department has to develop or align data systems as required by federal and other grants; at times system development is driven by legislative request or ongoing requirements in Iowa Code or Iowa Administrative Code.

There are three primary types of technology system changes- revision or enhancement of an existing system, replacement of an old system, or construction of a new system. When a request to develop a new data system is received, the department first assesses whether an existing system might be modified to meet that need. For example, vision screening legislation was passed in the 2013 session and will require monitoring of child vision screening. The Iowa Immunization Registry Information System (IRIS) was evaluated for integration of these records, and was identified as the best fit for receiving vision screening information. As a result, a vision-specific module will be added to IRIS instead of developing a new system for vision screening.

Technology systems have finite lives and must be completely replaced at times. IDPH attempts to maximize the use of every system, often beyond the point of being able to secure external technological support, which can jeopardize the stability of the system. Typically staff from the Bureau of Information Management (IM) and/or program managers decides when a system must be replaced. As with the development of a new system, IDPH usually determines whether an existing system could be modified

instead of doing a complete replacement. An example of this is the effort to interoperate various systems within the Bureau of Family Health. The bureau uses multiple systems to track information on services provided to women, infants and children. The users of these systems, both internal and external to the department, greatly need a single point of data entry. Instead of replacing multiple systems with an expensive new one, the bureau is integrating the systems starting with two next year-newborn screening and early hearing detection. This integration will save staff time spent on data entry and analysis, is much less expensive than replacing those systems with a new one, and will result in the department having to maintain one system instead of two.

Requests for new data systems are infrequent; however, there are occasions when new systems are needed. The development of a new system involves extensive assessment and evaluation. The Public Health Tracking portal is the most recent technology system build by the department. When the Public Health Tracking portal was developed, funding from three bureaus was secured to maximize the investment and create efficiency by merging three projects into one. In addition, improving technological infrastructure was a key component of the tracking project, and provides a solid and sustainable base for future systems to be built on. At present, the portal has an extensive amount of health information, but is not comprehensive. The portal was built in such a way that data may be added incrementally, and with minimal expense and effort.

Recommendations for improved efficiencies
1. Continue creating detailed catalogs of data systems and their contents, datasets and other data resources. The goal of cataloging is to determine exactly what the department holds, how information is being stored, and most importantly how data are being used and disseminated. This effort has proved invaluable. When a need for any technological effort is identified, these catalogs are used to assess whether integration, interoperability or modifications may be made instead of replacing or building a new system.

2. All future IDPH technology requests will be reviewed by key staff in data management and IM. As previously stated, the requests will be evaluated for interoperability with existing systems. If replacement or a new system is needed, the department will conduct an assessment of potential costs within the limitations of the request for proposals guidelines. The department will continue to leverage requests for information and knowledge gained from other state partners to determine the most efficient and cost-effective way to develop or replace a technology system.

3. Implement the data-related goal of the IDPH Strategic Operational Plan, Fiscal Year 2014-2016. http://www.idph.state.ia.us/common/pdf/strategic_plan/FY2014-2016_strategic_plan.pdf. Goal 4 of the plan, "Improve the ability to manage, analyze, and act on data to improve operations and health outcomes" includes strategies to integrate IT projects; identify and document risks/benefit of centralized data collection, management and reporting; and developing a department wide data management blueprint.

IDPH is focused on creating efficiencies and reducing costs associated with technology as evidenced by efforts to improve infrastructure, catalog data systems and their content, and interoperate existing systems. The benefits of these projects are becoming apparent and the department will continue to prioritize this work in future years.

Attachments

IDPH dataset catalog- A comprehensive list of databases and systems including legal references for collection, use and dissemination of data, years of available data, data owner, storage location, etc.

Research Agreement and Research and Ethics Review Committee Policy- This policy addresses research use of department data, and the purpose and responsibilities of the research and ethics review committee.

Policy for the Release of Confidential Public Health Records- This policy provides detailed guidance on the appropriate use and release of public health data including legal references, examples of use and direction on the suppression of data.

Dataset name	Dataset acronym	Dataset description
Adult Blood Lead Data		Results of all blood lead testing conducted on Iowa residents who are 16 years and older.
Barriers to Prenatal Care	Barriers Survey	Barriers to Prenatal Care is a surveillance project supported by IDPH. Barriers survey's are distributed at all Iowa Birthing Hospitals. New mothers are encourage to complete the survey prior to discharge from the hospital. Barriers collects population-based data on maternal access to prenatal care, maternal attitudes and experiences before birth and shortly after the birth of her infant. Data from Barriers help to inform policy in women' health, family planning and maternal and child health.
Behavioral Risk Factors Surveillance System	BRFSS	Adult phone-based sample survey of health-related behaviors, risk factors and disease incidence and prevalence.
Breast and Cervical cancer early detection program	BCCEDP	Breast and cervical cancer screening, diagnostic and treatment referral data.
Care for Yourself (CFY) Database	CFY	The Breast and Cervical Cancer Early Detection (BCCEDP) program are integrated with WISEWOMAN. From Oct. 2012, the data system became web-based online data collection.
Census Bridged-Race Population Estimates		Intra-Censal county-level population estimates by age, sex, race, ethnicity.
Central Data Repository	CDR	The CDR contains federally and state required client data for licensed Substance Abuse Treatment in Iowa. There are five tables in the CDR (Client, Admission, Services, Discharge, Follow-up). The CDR can receive data electronically or through use of I-SMART. Data is monitored by IDPH and its sub-contractee, Magellan, to manage the performace of the provider network to assure cost-efficient and quality substance abuse assessment and treatment services. CDR data is also used for grant applications, outcomes reporting, gap analysis, unmet treatment needs. Data from the CDR allows IDPH to meet the federal reporting requirements for the Treatment Episode Data Set (TEDS) and National Outcome Monitoring System (NOMS).
Child and Adolescent Reporting System	CAReS	CAReS provides the official clinical record for all children who receive child health services, regardless of funding source

Dataset name	Dataset acronym	Dataset description
Child Care Nurse Consultant Encounter Data	CCNC Encounter	Captures the services and activities of CCNC, date, county, time spent, topic, child care provider, type of provider, community partners involved, number of people contacted, and some minimal outcomes.
Childhood Blood Lead Testing		Results of all blood lead testing on Iowa residents who are under the age of 16 years.
EMS Patient REGISTRY		EMS run dataset includes demographic data for EMS provider, and all relevant data for run, patient, patients care, transport destination as entered by EMS providers.
Environmental Surface Sampling Study (No longer collected)	EHS-net	Environmental Health Specialists Network (EHS-Net) study sampling sanitized food contact surfaces or cleaned non-food contact surfaces for surface contamination in Cerro Gordo County. The project was conducted 2005-2008 and focused on the surface contamination including: adenosine triphosphate (ATP), Salmonella, E.coli, Staphylococcus aureus, and total and fecal coliform bacteria. Data elements include inspection and sample results. To improve environmental health, specifically related to food safety and food handling to prevent foodborne illness outbreaks. This data is the result of a research project and will not be included in the Data Warehouse.
EPHT - Air Quality Monitored		This dataset is a requirement of the Tracking Program. The data will be obtained from CDC/EPA through the Tracking Program. The dataset includes air quality monitoring data.
EPHT - Air Quality Modeled		This dataset is a requirement of the Tracking Program. The data will be obtained from CDC/EPA through the Tracking Program. The dataset includes ozone and Particulate Matter concentrations modeled data.
EPHT - Air Quality: Particulate Matter Concentrations		This dataset is a requirement of the Tracking Program. The data will be obtained from CDC/EPA through the Tracking Program. The dataset includes particulate matter concentrations monitoring data and modeled data. Due to revisions to the EPHT Ozone Concentration file this file is no longer needed as a distinct data set
EPHT - Birth Defects		This dataset is part of the Tracking program. It will be obtained from the Univ of Iowa Registry for Congenital and Inherited Disorders under a data sharing agreement. The dataset includes County level counts of 12 different birth defects.
EPHT - Cancer		This dataset is a requirement of the Tracking Program. The data will be obtained from the National SEER Program under a data sharing agreement with the U of I Cancer Registry. The dataset will include counts rates for multiple cancer sites by year, age, sex, race, cancer site, stage, grade, and geographic area.

Dataset name	Dataset acronym	Dataset description
EPHT - Community Drinking Water Quality: DNR Water Quality		This dataset is required by the Tracking Program. The dataset will be obtained from the Iowa Department of Natural Resources through a data sharing agreement. The dataset includes information on Community Water Systems in Iowa and water quality results for multiple indicators.
EPHT - Community Drinking Water Quality: Drinking Water	SDWIS	This dataset is required by the Tracking Program. The dataset will be obtained from the Iowa Department of Natural Resources through a data sharing agreement. The dataset includes information on Community Water Systems in Iowa and water quality results for multiple indicators.
Gambling Treatment Reporting System	GTRS	Base data collection at admission and services
Hepatitis C Database		Epi-Info was a database that was used by the hepatitis C program to record patient demographics and lab test results. This dataset is no longer used on a regular basis. An assessment of what to do with this data set is needed. This will involve the Hepatitis C program area (Randy Mayer, Shane Scharer). At one time, there was some minimal interst in migrating some of this data to the IDSS system. There are no plans to start this project at any point in the near future.
HIV Care and Support Services	CAREWare	Dataset for both the AIDS Drug Assistance Program and client services.
HIV Prevention Programs	Evaluation Web	Data about HIV and Hepatitis C (HCV) counseling, testing, and referral (CTR) services; and data about HIV health education risk reduction program (HERR) services. To document and monitor HIV and Hepatitis C CTR and HERR participation.
HIV/AIDS Reporting System	e-HARS	HIV/AIDS data are collected to track the endemic in the state of Iowa, per Iowa Code 141A. Iowa's eHARS has information on all persons reported to have been diagnosed or treated for HIV disease in the state of Iowa. It also has data on persons reported to reside in Iowa but who are recieving HIV treatment in other states. The data include all reportable HIV test results and dates, as well as demographics and other characteristics of persons diagnosed. eHARS is a CDC-developed software that is used by surveillance programs in all 50 states plus U.S. territories. eHARS is actually two datasets, a document dataset and a person dataset. The person dataset is generated by eHARS from the document dataset. All HIV-related lab results are entered or imported into eHARS as new documents. Adult case report forms, pediatric case report forms, death documents, and birth documents are other document types that are entered or imported into eHARS.
Iowa Adult Tobacco Survey	IATS ir	The Iowa Adult Tobacco Survey (ATS) is a statewide survey conducted with the purpose of measuring adult tobacco use and tobacco-related attitudes.
Iowa Brain & Spinal Cord and Farm & Agricultural Injury Registry	BSFI - Brain, Spinal, Farm Injury	currently data reported by Iowa trauma facilities not utilizing the Trauma Registry Collector software but data from hardcopy reports received. As more of the trauma facilities have converted to electronic reporting (Collector), this data set has become less complete. Data purpose historically was to provide surveillance data specific to programs specializing in the areas specified in the name.

Dataset name	Dataset acronym	Dataset description
Iowa Community Water Fluoridation Program		Contains information on current status of fluoride in Public Water Systems including data on water samples, operation reports, and fluoride systems.
Iowa Disease Surveillance System	IDSS	IDSS is an electronic disease surveillance system. Required reportable acute conditions are reporting directly into the system by healthcare providers, hospital infection preventionists, laboratorians, local public health agencies or by IDPH. IDSS contains individual patient records, or events, for patients. Each event indicates a reportable infection for the patient. Various reports are available for download directly from IDSS, but secure access requires a token. Data in raw, non-aggregated format is exported from IDSS by use of SQL or SAS quesries (available to only select state staff).
Iowa Family Planning Data System	Ahlers	Information from the Iowa Clinic Visit Record about medical services provided in family planning clinics. To monitor usage, demographics, and characteristics of family planning services provided. To monitor progress toward performance measures. Reports can be generated for use by IDPH and contractors. Family Planning Annual Reports are generated for submission annually to the Office of Population Affairs.
Iowa Household Health Survey	HHS	The IHHS is a comprehensive, statewide effort to evaluate the health status, access to health care, and social environment of children and families in Iowa.
Iowa Immunization Registry Information System	IRIS	Immunizations
Iowa Registry for Congenital and Inherited Disorders	IRCID	Active surveillance of birth defects, stillbirths, and confirmed inherited metabolic disorders.
Iowa School and Child Care Audits	Immunization Audits	School and childcare immunization audits
Iowa Service Management and Reporting Tool	I-SMART	A web-based client management system and data reporting tool that allows the State of Iowa's licensed programs to provide information to the state related to the provision of substance use disorder evaluation and treatment. I-SMART can be used by providers as a full clinical record system or as a data entry tool to report the state required data elements. I-SMART as a full clinical system, provides the ability to manage and provide cost efficient and quality substance abuse assessment and treatment services. Use as a full clinical system places Iowa's substance abuse treatment providers in a more competitive standing and assists in outcome monitoring, quality assurance, facilitating identification of cost efficient services and positive treatment outcomes, gaining government recognition, and funding needs. I-SMART contains all the state required data elements that are automatically incoporated into the Division's Central Data Repository (patient profile/demographics, evaluation, admission, discharge, follow-up and services provided). It allows for the gathering of information to meet the federal government requirements for National Outcome Monitoring System (NOMS).

Dataset name	Dataset acronym	Dataset description
Iowa State Inpatient Database	SID	Inpatient hospitalization discharge records from Iowa hospitals, exclusive of mental health and federal hospitals.
Iowa Trauma Registry		The goal of Iowa's Trauma System is to match the patient's medical needs to the existing medical resources.
Iowa WIC Information Network	IWIN	The data found in IWIN represents all of the information that is collected by our local agency staff during participant clinic appointments.
Iowa Youth Survey	IYS	Students in the 6th, 8th, and 11th grades across the state of Iowa answered questions about their attitudes and experiences regarding alcohol and other drug use and violence, and their perceptions of their peer, family, school, and neighborhood/community environments.
Iowa Youth Tobacco Survey (Currently collected in IYS)	IYTS	Sample survey of tobacco use among middle and high school students in Iowa.
Pediatric Nutrition Surveillance System	PedNSS	The Pediatric Nutrition Surveillance System (PedNSS) is a child-based public health surveillance system that describes the nutritional status of low-income U.S. children who attend federally-funded maternal and child health and nutrition programs. PedNSS provides data on the prevalence and trends of nutrition-related indicators. Discontinued in 2012.
Pesticide Poisoning Surveillance Database	Occupational exposures are in SPIDER.	Records of Iowa residents who have been exposed to pesticides. Most of these records are from the Iowa State Poison Control Center
Pregnancy Risk Assessment Monitoring System	PRAMS	PRAMS is a surveillance system of selected maternal behaviors and experiences
Pregnancy Nutrition Surveillance System	PNSS	The Pregnancy Nutrition Surveillance System (PNSS) is a program-based public health surveillance system that monitors risk factors associated with infant mortality and poor birth outcomes among low-income pregnant women who participate in federally funded public health programs. Discontinued in 2012.
School Dental Screening Requirement		Annual school audit report including: student compliance with requirement, student treatment needs, types of providers who provided screenings/exams.
Sexually Transmitted Disease Management Information System	STD*MIS	Archived database (through 2009) of STD patient data received from labs, providers, clinics, disease intervention specialists (DIS), etc. Includes patient demographics, conditions (chlamydia, gonorrhea, syphilis, HIV partner services), risk factors, testing, social history, interview comments, and investigation plans. For Epidemiologic Study of reportable STDs and HIV and for Quality Assurance of STD and HIV Public Health Programs and Investigations.

Dataset name	Dataset acronym	Dataset description
State Health Registry of Iowa	SEER	SEER cancer registry data for state of Iowa. Estimated cancer incidence and mortality; plus special study reports/updates.
State Hygienic Laboratory Neonatal Metabolic Screening Database	INMSP	Reporting data system for results of newborn screening testing and short term follow up activities.
State Outpatient Database	SID	Patient billing records containing demographics (age, gender, race), residence (state and county), diagnosis fields, procedure codes, hospital charges and disposition (outcome: death and discharge location)
State-Certified Outpatient Diabetes Education Program Summary Data (IAC 641-9.10)		State-Certified Outpatient Diabetes Education Program Summary Data (submitted annually according to Iowa Administrative Code 641-9.10)
Substance Abuse Reporting System	SARS	SARS electronic data was collected from all licensed substance abuse treatment providers. SARS officially became a static/closed data base on October 1, 2011 (contains data through June 30, 2011). The data contained in SARS includes client demographics, admission, discharge, follow up, service data, and client outcome data related to abstinence, arrests, employment, hospitalizations, and several other variables. This data was used to meet the requirements for federal Treatment Episode Data Set.
Vital Records - Birth Certificate Data		Birth Certificate Records
Vital Records - Death Certificate Data		Death Certificate Records
Vital Records - Fetal Deaths		Fetal Death Records
Vital Records - Marriages Data		Marriage Certificate Records
Women's Health Information System	WHIS	This is a program specific file to capture the services received by pregnant women in Title V funded Maternal Health program

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Environmental Health	Bureau of Lead Poisoning and Prevention		Rita.Gergely@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health	IDPH POC = Stephanie Trusty	stephanie.trusty@idph.iowa.gov	
Tobacco Division	Tobacco		dshepherd@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Chronic Disease Prevention and Management	Housed at the University of Iowa College of Public Health Statistics	jolene.carver@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Chronic Disease Prevention and Management	Housed at the Center for Public Health Statistics, College of Public Health, University of Iowa	Suning.Cao@idph.iowa.gov	
Tobacco Division	Tobacco		Joann.muldoon@idph.iowa.gov	
Behavioral Health	Substance Abuse Prevention and Treatment	The CDR is hosted by FEi in Maryland. Fei provides by FTP a refresh of the CDR data set each Monday.	eric.preuss@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		jenni.rowley@idph.iowa.gov	

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Health Promotion and Chronic Disease Prevention	Family Health		analisa.pearson@idph.iowa.gov	
Environmental Health	Bureau of Lead Poisoning and Prevention		Rita.Gergely@idph.iowa.gov	
Acute Disease Prevention and Emergency Response	Emergency Medical Services	Med-Media is the data repository	terry.smith@idph.iowa.gov	
Environmental Health	Environmental Health Services		timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services		timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services		timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services		timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services	U of I Registry	timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services	U of I Registry	timothy.wickam@idph.iowa.gov	

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Environmental Health	Environmental Health Services		timothy.wickam@idph.iowa.gov	
Environmental Health	Environmental Health Services	Iowa DNR	timothy.wickam@idph.iowa.gov	
Behavioral Health	Office of Problem Gambling Treatment and Prevention	Office of Problem Gambling Treatment and Prevention	mark.vanderlinden@idph.iowa.gov	
Acute Disease Prevention and Emergency Response	Center for Acute Disease Epidemiology		john.satre@idph.iowa.gov	
Behavioral Health	HIV, STD, and Hepatitis		holly.hanson@idph.iowa.gov	
Behavioral Health	HIV, STD, and Hepatitis		Patricia.Young@idph.iowa.gov	
Behavioral Health	HIV, STD, and Hepatitis	The dataset is not housed in IDPH. Test and production servers are at DAS-ITE.	Jerry.Harms@idph.iowa.gov	
Tobacco Division	Tobacco		Joann.mudoon@idph.iowa.gov	
Environmental Health	Bureau of Lead Poisoning and Prevention		Julie.jones@idph.iowa.gov	

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Environmental Health	Environmental Health Services		randy.lane@idph.iowa.gov	
Acute Disease Prevention and Emergency Response	Center for Acute Disease Epidemiology	CADE, TB, STD, Hepatitis B Maternal & Perinatal & Hepatitis C (both part of Immunization), and Environmental Health Services use IDSS	john.satre@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		denise.wheeler@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		peter-damiano@uiowa.edu	
Acute Disease Prevention and Emergency Response	Immunization and TB		kimberly.tichy@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		Kimberly.Piper@idph.iowa.gov	
Acute Disease Prevention and Emergency Response	Immunization and TB		Donald.Callaghan@idph.iowa.gov	
Behavioral Health	Substance Abuse Prevention and Treatment	ISMART is hosted by FEi in Maryland	eric.preuss@idph.iowa.gov	

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Administration and Professional Licensure	Health Statistics	Vital Records and Tobacco Division	Jmuldoon@idph.iowa.gov	
Acute Disease Prevention and Emergency Response	Emergency Medical Services		terry.smith@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Nutrition and Health Promotion		jill.lange@idph.iowa.gov	
Behavioral Health	Substance Abuse Prevention and Treatment		TBD	
Tobacco Division	Tobacco		JMuldoon@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Nutrition and Health Promotion		jill.lange@idph.iowa.gov	
Environmental Health	Bureau of Lead Poisoning and Prevention		Rob.Walker@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		sarah.mauch@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Nutrition and Health Promotion		jill.lange@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Oral and Health Delivery Systems		saralyn.schlievert@idph.iowa.gov	
Behavioral Health	HIV, STD, and Hepatitis		George.Walton@idph.iowa.gov	

Division where the dataset is housed	Select the bureau where dataset is housed	Comments- select bureau	Data Owner Email	Legal authority to collect and disclose data set
Health Promotion and Chronic Disease Prevention	Chronic Disease Prevention and Management	University of Iowa/State Health Registry	Charles-Lynch@uiowa.edu	
Health Promotion and Chronic Disease Prevention	Family Health		Stanton-Berberich@uiowa.edu	
Administration and Professional Licensure	Health Statistics		Joann.muldoon@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Chronic Disease Prevention and Management		laurene.hendricks@idph.iowa.gov	
Behavioral Health	Substance Abuse Prevention and Treatment		Elizabeth.Schaller@idph.iowa.gov	
Administration and Professional Licensure	Health Statistics		Jill.France@idph.iowa.gov	
Administration and Professional Licensure	Health Statistics		Jill.France@idph.iowa.gov	
Administration and Professional Licensure	Health Statistics		jill.france@idph.iowa.gov	
Administration and Professional Licensure	Health Statistics		Jill.France@idph.iowa.gov	
Health Promotion and Chronic Disease Prevention	Family Health		stephanie.trusty@idph.iowa.gov	

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Text		1992	2010		Yes		Internal to IDPH
Text, PDF		1998	2011	data updated each July	Yes		External to IDPH
Excel, Delimited (csv, etc), SAS, Text		1988	2011	2012 will be available soon	Yes		Internal to IDPH
Text		1995	2010		Yes	Part of the CFY Data Dictionary	External to IDPH
	Online website generate reports for review	2009	Up-to-date	Receive data monthly from UI contractor	Yes	Provided from CDC	External to IDPH
Excel, Delimited (csv, etc), SAS		1980	2010		Yes		Internal to IDPH
Excel, Delimited (csv, etc), Text		2009	2013	Through current date	Yes		External to IDPH
Excel, CSV file		2001	2012		Yes		Internal to IDPH

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Unknown	It was sent and collected from CCNCs in Google Docs from 2008-2010. From 2005-2008 it was collected in Excel files and emailed to IDPH.	2005	2010		Yes		External to IDPH
Excel, PDF		1991	2010		Yes		Internal to IDPH
Access tables		2004	2012		Yes		External to IDPH
Unknown	A summary report of the data was provide to Cerro Gordo County at the completion of the study	2005	2008		No		Internal to IDPH
EPHT Dashboards, Data Mart File		2001	2011		Yes		External to IDPH
Unknown		2001	2005		Yes		External to IDPH
Unknown		2001	2008		Yes		External to IDPH
Unknown	To be determined with the Registry	2001	2008	Most recent available from Registry	Yes		External to IDPH
Unknown	To be determined with Registry	2001	2010	Most recent year available	Yes		External to IDPH

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Unknown	To be determined with IDNR	1996	2011	Most recent year available	Yes		
Unknown	To be determined with IDNR	2001	2012	Most recent year available	Yes		External to IDPH
Unknown		2005	2011	Same years as I-SMART	No	Not it's own data dictionary, but it is part of the I-SMART	Unknown
Excel, PDF		Unknown	2008		Yes		Internal to IDPH
Unknown		2009	2012		Yes		Internal to IDPH
Unknown		2000	2010		Yes		External to IDPH
Comma-delimited, tab-delimited, and SAS datasets can be exported from eHARS.	De-identified	1982	2012	We do not consier a year of data to be "final" until March of the following year. We consider the current year's data to be "provisional".	Yes	The Person dictionary has over 600 data elements. The Document dictionary has over 300 data elements.	External to IDPH
Excel		2002	2010		Yes		Internal to IDPH
Delimited (csv, etc)	TAB delimited	2003	2010		Unknown		Internal to IDPH

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Excel, Delimited (csv, etc), Access database, Text, PDF		Unknown	2011		Yes		Internal to IDPH
Excel, Delimited (csv, etc), SAS, Text		1993	2011		Yes	Business requirements	Internal to IDPH
Unknown	We do not release data from the data set except in report (aggregrate) style. When a request for raw data was received, a data sharing	2003	2012		Yes	Manual for data entry	External to IDPH
		2000	2010		Yes		External to IDPH
Excel, Delimited (csv, etc), Text		2001	2012		Yes	User Manual, available at https://iris.iowa.gov/docs/CompleteUserManual.pdf	External to IDPH
Text, PDF		1983	2011	preliminary	Yes		External to IDPH
Excel, Text, PDF		Unknown	2012		No	List of Data Fields	Internal to IDPH
Unknown	Data is released as part of the CDR. For providers using ISMART specific reports can be pulled from the report engine in ISMART	2005	2013	Data is current	Yes		External to IDPH

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Excel, Delimited (csv, etc), SAS, Access database		1990	2010		Yes		Internal to IDPH
CSV		2005	2012		Yes		Internal to IDPH
PDF		2006	2012	Data reported on a monthly basis	No	We have policies that describe what each report contains and suggestions for use.	Internal to IDPH
PDF		1999	2012		Yes		Internal to IDPH
Excel		2000	2008		Yes		Internal to IDPH
PDF		1990	2011	Reports discontined by CDC	Yes	CDC website contains this information.	Internal to IDPH
Text, PDF	Occupational data are sent to NIOSH as an extract of the SPIDER database.	2002	2008		Yes	There is for SPIDER.	Internal to IDPH
Varies	Depends on data request - can export to whatever file format is requested	2012	2013	Data collection is ongoing. Started November 2012.	No	Will be available soon	Internal to IDPH
PDF		1995	2011	Report will no longer be available.	Yes	Definitions can be found on the CDC website.	Internal to IDPH
Excel		2008	2010		No	Audit Report	Internal to IDPH
Excel		1990	2009		Yes		Internal to IDPH

Format for release of data	Comments- format for release of data	First year of available data	Last year or most recent year of available data	Comments- last year	Data dictionary available	Comments- data dictionary	Data housed within or outside of the department
Text, PDF	Can query state cancer registry for county specific data; unsure of database format.	1973	2011		Yes		External to IDPH
Access database		1993	2012		Yes		External to IDPH
SAS, Access database		2000	2010		Yes		Internal to IDPH
Excel, Text		2006	2013		No		Internal to IDPH
Excel, Text, PDF	Magellan provides these reports	1995	2011	Now Closed	Yes	User Manual	Internal to IDPH
Unknown		Unknown	2012		Unknown		Internal to IDPH
Unknown		Unknown	2012		Unknown		Internal to IDPH
Unknown		Unknown	2012		Unknown		Internal to IDPH
Unknown		Unknown	2012		Unknown		Internal to IDPH
Excel		1999	2011		Yes	Field List	Internal to IDPH

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
	No		Yes	The STELLAR software has been updated numerous times since 1992.
At UNI - Mary.Losch@uni.edu (data custodian)	Unknown	Contract with UNI	Yes	
	Yes		Yes	
	Yes	Contract for maintenance of the data	Yes	
We have a data contract with the University of Iowa	Yes	DSA with Cancer Registry at UI for semi-annual data linkage	Yes	
	No		No	
	Yes		Yes	
	Yes	One with Medicaid for client demographic information and eligibility. One with the Board of Medicine and Dental Board for a monthly import of providers.	Yes	The system was upgraded with data element changes in 2009 and 2011, and a major upgrade was made in 2012. Other data element changes have been made on an ad hoc basis.

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
Google Docs	No		Unknown	
	No		Yes	
	Yes	NEMSIS, Iowa DOT, University of Iowa Injury Surveillance	Yes	
	No		No	
	No	Referred to in IDPH DSA with DNR to consult with DNR on appropriate use of data	No	
	No		No	
	No		No	
	Yes	DSA explicitly lists allowable uses, need to consult with IRCID for determination of additional appropriate uses, and need to suppress data based on small counts in any presentation	No	
	Yes	DSA explicitly lists allowable uses, and need to suppress data based on small counts in any presentation	No	

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
	Yes		No	
	Unknown		Unknown	
	Unknown		Unknown	
	Unknown	As the need arises, data sharing agreements will be put in place	Yes	Periodic upgrades to collect new data elements required for reporting to HRSA.
	Yes		Yes	
Test and production servers housed at DAS-ITE. Data accessed via secure internet connection.	Yes	there is a data agreement in place for the portion of the data derived from vital records	Yes	CDC has made some modifications as they have introduced new builds of the software
	Yes		Yes	
housed by IT	Unknown		Unknown	

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
	Unknown		Unknown	
	Yes		Yes	All changes are made in the application
	No	We contract with them to store and manage our data	Yes	
Housed by UI	Unknown			
Iowa contracts with Hewlett Packard Enterprise Services (HPES) for hosting IRIS application	Yes	IRIS has a data sharing agreement with Vital Records	Yes	
University of Iowa College of Public Health Department of Epidemiology	Yes		Yes	
	No		Yes	
	Yes		Yes	Most enhancements funded by IDPH have been made, however with the commencement of the Gambling module, additional modificaitons have been made.

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
	Yes		Yes	
	Yes	University of Iowa Injury Surveillance	No	
The data is found in IWIN so is housed internal to the department. Local agencies also have access to most of the reports.	No	The WIC program has very strict requirements related to data sharing.	Yes	
	Yes	With several requestors of the dataset	Yes	
	Yes		Yes	
CDC processes and cleans our data extract	No		Yes	
	No		Yes	SPIDER cannot be modified. The Excel Spreadsheet has been modified.
	Yes	Internal DSA with WIC & IRIS and external DSA with CDC	No	
CDC processes and cleans our data extract.	No		Yes	
	No		No	
	No		No	

Comments- data housed within or outside of department	Data sharing agreement	Comments- data sharing agreement	Have modifications ever been made to the data elements (options for responses within individual fields)	Comments- modifications to data elements
	Yes	with Vital Records, not my program specifically	Unknown	
	No		Yes	
	Yes		Yes	Race was changed to address ethnicity
	No		Yes	
	Yes		Yes	
	Yes		Unknown	
	Yes		Unknown	
	Yes		Unknown	
	Yes		Unknown	
	Yes	HIPPA Business agreement with SoftForce our contractor.	Yes	

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
No		Unknown	Yes	Maintained (provide network resources), but not supported (they cannot make changes to the database).	Yes	Yes
Yes		Once a year	No		No	No
Yes		Only a few times a year	No		No	No
Yes		Only a few times a year	No		Yes	Yes
Yes		Less than once a year	No		Yes	Yes
Yes		Less than once a year	No		No	No
Yes		Once a year	No		Yes	Yes
Yes	The system was upgraded with data element changes in 2009 and 2011, and a major upgrade was made in 2012. Other data element changes have been made on an ad hoc basis.	Changes are made on an ad hoc basis, when needed			Yes	Yes

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
Unknown		Unknown	No		No	Yes
Yes	We only use specific fields for our report, and we create additional fields that are populated by existing data.	Daily	Yes	The STELLAR program is not supported by IM. However, IM maintains network space, etc., for the program.	Yes	Yes
Yes		Unknown	No		Yes	Yes
No		Unknown	No		No	No
No		Unknown	No		No	No
No		Unknown	No		No	No
No		Unknown	No		No	No
No		Unknown	No		Unknown	Unknown
No		Unknown	No		No	Yes

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
					No	No
No		Unknown	No		No	No
Unknown		Unknown	Unknown		Yes	Yes
Unknown		Unknown	Yes		Yes	Yes
Yes	Custom fields are created, deleted, or altered periodically to conform to the current needs of contracted agencies.	As often as needed	Unknown		Yes	Yes
Yes		Once a year	No		No	Yes
Yes	CDC has made some modifications as they have introduced new builds of the software	Less than once a year	No	Servers maintained at DAS-ITE. Program has remote access to servers to install new builds of eHARS on test and production servers - also for rare troubleshooting missions.	Yes	Yes
Yes		Less than once a year	No		No	No
No	I don't believe changes are an option at this time, although it needs updating	Unknown	Yes		Yes	Yes

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
Unknown		Unknown	Yes		No	No
Yes	Disease-specific forms are modified periodically; historical data is preserved in the context of historical forms if the changes are disease specific. For changes that are not disease-specific, historical data is moved to	Only a few times a year	Yes		Yes	Yes
Yes		Less than once a year	No		No	Yes
					Yes	Yes
Yes		infrequently; every other year	No		Yes	Yes
Yes		Less than once a year	No		Yes	Yes
Yes	Different vaccine requriements	Less than once a year	Yes		No	No
Yes	Titles of fields may change on the user side, and internally there also may be changes made by FEi when enhancements are made. ISMART is WITS based and is used by at least 22 other states/entities across the USA, with each entity capable of making enhancements that Iowa can sometimes choose to not turn on.	Less than once a year	No		Yes	Yes

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
Yes		Once a year	No		No	Yes
Unknown		Unknown	Yes		Yes	Yes
Unknown		Unknown	Yes		Yes	Yes
Yes		Less than once a year	Yes		No	Yes
Yes		Less than once a year	No		No	No
Unknown		Unknown	Yes		Yes	Yes
Yes	SPIDER cannt be modified. The Excel Spreadsheet has been modified.	Once a year	Yes	IM maintains the network, but they do not support SPIDER or our Excel spreadsheet.	Yes	Yes
No		Unknown	Unknown		Yes	Yes
Unknown		Unknown	Yes		Yes	Yes
No		Unknown	No		No	No
No		Unknown	Yes		Yes	Yes

Are changes made to the field elements- add, delete, alter existing fields	Comments- changes made to field elements	How often are changes made to the field elements	Dataset custodian IDPH IM	Comments- dataset maintained	Contains patient names	Contains other individual identifiers
Unknown		Unknown	No		Yes	Yes
Yes		Less than once a year	No		Yes	Yes
No		Unknown	Unknown		No	Yes
Yes		Once a year	Unknown	To 2011 - unlikely in future	No	No
No	no longer as data base is static/closed.	Unknown	Yes		Yes	Yes
Unknown		Unknown	Unknown		Yes	Yes
Unknown		Unknown	Unknown		Yes	Yes
Unknown		Unknown	Unknown		Yes	Yes
Yes	changes made to the certificate in 2009	Unknown	Unknown		Yes	Yes
Yes		Once a year	No		Yes	Yes

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Confidential Data	No		No	
	Non-Confidential Data	Yes	Annual report and county reports are posted to IDPH website each year	Unknown	Contractor has data set
	Non-Confidential Data	Yes		No	
	Confidential Data	No		Yes	
	Confidential Data	Yes	Cancer Registry at University of Iowa	Yes	
	Non-Confidential Data	No		No	
	Confidential Data	No		Yes	IDPH uses SSRS for generating reports for the CDR. IDPH continues to receive the data set by FTP site each Monday. Data set is also sent by FTP site to Magellan and OMS. Both Magellan and The Consortium have access to SSRS.
Contains Birth Date, Social Security Number and Title XIX number for child and parent(s)/guardian(s)	Confidential Data	Yes	Child health contract agencies and their child health sub-contractors have access to data.	Yes	

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Implied Confidential Data	Yes	CCNCs only have access to their own	Yes	Each sheet was created and shared with the CCNC who would input her data. The data was then downloaded to a disk or hard drive at IDPH at the end of the month and removed from the web and new month's sheet created.
	Confidential Data	Yes	Each local childhood lead program has a STELLAR datase (it is PC-based).	Yes	Passwords only.
	Confidential Data	No		Yes	
	Non-Confidential Data	No		No	
	Non-Confidential Data	Yes		No	
	Non-Confidential Data	Yes		No	
	Non-Confidential Data	Yes		No	
For the purpose of Tracking the dataset does not need to have identifying information	Non-Confidential Data	Unknown	Only indicators calculated from the dataset	No	
Does not need to for Tracking	Confidential Data	Yes		No	

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Non-Confidential Data				
	Non-Confidential Data	Yes		No	
Part of I-SMART system	Confidential Data	Unknown		Unknown	
	Confidential Data	No		No	
	Confidential Data	Yes	The CAREWare server is a central server located at IDPH. Access is only given to external uses contracted by IDPH who require access to data for their work.	Yes	
	Implied Confidential Data	Yes		Yes	Password protected; administrative rights/users determined here
Addresses, SSN, MRN	Confidential Data	No		Yes	Token not required, but access is restricted and administered by HIV Surveillance Coordinator.
	Non-Confidential Data	Yes		No	
	Confidential Data	No		Unknown	permission granted by IT, sign in using network password

Iowa Department of Public Health Dataset Catalog

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Non-Confidential Data	Yes		Unknown	
Street addresses, date of birth, alias name, physical description, parent/guardian name, and phone # (does NOT contain information such as Drivers Liscense #, SSN etc)	Confidential Data	Yes		Yes	
	Implied Confidential Data	Yes	Only to Title X family planning contractors, and only data specific to their agency	Yes	
	Confidential Data				
	Confidential Data	Yes		Yes	does not require a token; has restrictions for access – requires a three-part login
	Confidential Data	No		Yes	
	Non-Confidential Data	No		No	
	Confidential Data	Yes		Yes	Access is by Internet (HTTPS) and is protected by user id; password; and pin. Agencies can only see their specific data.

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Implied Confidential Data	No		No	
	Confidential Data	Unknown		Yes	
Each family has a family i.d. and each participant has a participant i.d.	Confidential Data	Yes	Local WIC agencies are able to access the reports we have available. Upon request we also provide them with ad hoc reports.	Yes	
demographic info per survey responder	Implied Confidential Data	Yes	Given dataset if DSA in place	Unknown	
	Non-Confidential Data	Yes		No	
	Confidential Data	Yes	PedNSS Reports are created without identifiers	No	
	Confidential Data	No		No	
birth dates, addresses, birth certificate numbers etc	Confidential Data	Yes	only by request and with a DSA	Yes	Restrictions placed on who has access
	Confidential Data	Yes	PNSS is reports are created without identifiers.	No	
	Non-Confidential Data	Yes		No	
	Confidential Data	No		Yes	No token, but has restricted access

Comments- other identifiers	Data Confidentiality Type	Accessible to external users (outside of IDPH)	Comments- external access	Requires token or has restrictions for access	Comments- requires token access
	Confidential Data	No	County-specific data is available to all Iowans by visiting their website	Yes	only certain data i.e. what's mentioned above is available to the public.
	Confidential Data	No		Yes	
medical record number and demographics information, such as gender, race and county of residence	Implied Confidential Data	Yes		Unknown	
	Non-Confidential Data	No		No	
	Confidential Data	No		Yes	SARS access is available to select individuals in the division and IM.
	Confidential Data	Unknown		Unknown	
	Confidential Data	Unknown		Unknown	
	Confidential Data	Unknown		Unknown	
	Confidential Data	Unknown		Unknown	
	Confidential Data	No		Yes	

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
Iowa Surveillance of Notifiable and Other Diseases	IDPH website		State	
Barriers to Prenatal Care County reports	IDPH website		Unknown	zip code
Health in Iowa Annual Report From the Behavioral Risk Factor Surveillance System Iowa 2009 Iowa Department of Public Health	IDPH website, non-IDPH website		State	Data available for selected MSAs and large central counties
Rescreening reports and data entered reports to contracted local programs on a monthly basis. Minimum Data Elements reported to CDC on a semi-annual basis (individual identifying information removed).	Email		Census tract	County level is most common
BCC MDE Report, WISEWOMAN MDE Report	Paper report, email	Bureau network		
Not available			County	
CDR data is used for Substance Abuse Treatment program profiles, ODCP Annual Report, and IDPH Fact Book. Magellan provides monthly/quarterly provider and aggregate system performance reports. CDR data requst are received from LSA, stakeholders, providers, media, etc	IDPH website		County	
Various grant applications, including the Title V MCH block grant (typically only report state numbers, not by county)	IDPH website		County	County of Service and County of Residence

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
Not available			County	by CCNC
Iowa Surveillance of Notifiable and Other Diseases. We provide data to Bureau of Family Health on a regular basis for reports. I do not know if these reports are released outside of IDPH.	IDPH website		County	
Not available	Non-IDPH website		Unknown	
Not available			Unknown	None
Not available			County	
Not Available			County	
Not Available			County	
Not available			County	
Not available			County	

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
Not available			County	
Not available			Unknown	
Not available			Census tract	
Not available			Unknown	
HIV, STD, and Hepatitis Epidemiological Profile; Slide sets	IDPH website		State	
State of Iowa End-of-Year HIV and AIDS Surveillance Report; Epidemiological Profile for Iowa (HIV, AIDS, and Sexually Transmitted Diseases); Annual slide set is also created; various fact sheets and special reports	IDPH website, email		Census tract; some ZIP code data	for thematic maps
20XX Iowa Adult Tobacco Survey Report	IDPH website, paper report		State	
Not available; farm injury data evaluated in 2008-2009, report not published because of gaps identified; unsure if TBI/TSCI data has been used to report			Unknown	

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
Web page based search link	IDPH Website	Data submitted to CDC	County/City	
Notifiable Diseases Annual Report Various reports are available based on user role	IDPH website	Downloaded by user	Unknown	Individual patient address
Released in aggregate to federal funder and any other data is summarized and presented per powerpoint. Program Profile available through the IDPH.		grant applications	City	Zip code
provider-specific, , Immunization Information System Annual Report (IISAR), Immunization Program Annual Report	IDPH website, CDC		County	
Annual report	IDPH website, non-IDPH website		State	
K-12 Immunization Summary 2010-11 Licensed Child Care Immunization Summary 2010-11	IDPH, Immunization Program website		County	
Providers have the ability to run various reports in the I-SMART report engine.	IDPH website		County	

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
asthma, diabetes, chronic disease reports	IDPH website, paper report		County	
Trauma Service Summary report	IDPH website		State	
Not available		We do not publish reports found in IWIN.	County	County and zip code
State of Iowa Youth Survey Report, County Youth Survey Report, Judicial District Youth Survey Report, DECAT Cluster Youth Survey Report, DHS Region Youth Survey Reports, DPH Substance Abuse Prevention Planning Regions Report, DPH Substance Abuse Service Area Youth Survey Reports, Area Education Agency (AEA) Youth Survey Reports, Trend Reports by State, County and AEA	IDPH website		County	
Iowa Youth Tobacco Survey Report	IDPH website, paper report		State	
Pediatric Nutrition Surveillance System	IDPH website, email		County	
Annual Pesticide Poisoning Surveillance System Report	IDPH website		County	
			State	
Pediatric Nutrition Surveillance System	IDPH website, email		County	
School Dental Screening Audit Report	IDPH website		Unknown	School
Bureau HIV, STD, and Hepatitis epidemiological profile; CADE epidemiological profile	IDPH website		County	

List the titles of reports that publish this data (released by IDPH)	Location of published reports	Comments- location of published reports	Lowest geographic level data is presented	Comments- lowest geographic level
Cancer in Iowa 2011; also reflected in reports (state cancer plan, cancer disparities report, etc.)	IDPH website, non-IDPH website, paper report		County	
System generated reports available to authorized users.		Not released outside of data system	Unknown	
Traumatic Brain Injury in Iowa: An Analysis of Core Surveillance Data 2006-2008	Paper report		County	
Not available		To be put on website when finalized	Unknown	Program level
IDPH does not release reports specifically from SARS (prior to 2005, yes).		Data is in aggregate form in Magellan Reports	City	
Vital Statistics Annual Report	IDPH Website		Unknown	
Vital Statistics Annual Report	IDPH Website		Unknown	
Not available			Unknown	
Not available			Unknown	
There are hundreds of report the system can generate most are use by the agencies some by IDPH those used by IDPH are used to report program data in our Title V grant application.			Region	Reports by agency service area

Is similar data collected by other states	Comments- similar data collected by other states
Yes	
Yes	Most state collect Prenatal Risk Assessment Monitoring System (PRAMS) data. Now Iowa has both PRAMS and Barries we feel they will complement each other Barries collect data 2 days after the birth of the infant and PRAMS is four to six month later so there are differences based on the passage of time.
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	All states have Title V child health programs that require data collection. This data may be similar, but is not standardized across states.

Is similar data collected by other states	Comments- similar data collected by other states
Unknown	
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	

Is similar data collected by other states	Comments- similar data collected by other states
Yes	
Unknown	
Unknown	
Unknown	
Yes	
Yes	CDC funds all states to conduct HIV surveillance. All surveillance jurisdictions must run the current eHARS version and submit de-identified data to CDC at least monthly
Yes	
Unknown	

Is similar data collected by other states	Comments- similar data collected by other states
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	
Yes	

Is similar data collected by other states	Comments- similar data collected by other states
Yes	
Yes	
Unknown	States do gather similar WIC data but due to the differences in data systems it is unknown what type of data is specifically gathered and how it is available.
Unknown	
Yes	
Yes	
Yes	
Yes	40 states and NYC are participating in PRAMS. There is a set of core questions that all states collect and are pooled into a national dataset. There are criteria for being included in the national dataset, including a minimum of 65% weighted response rate
Yes	
Yes	
Yes	

Is similar data collected by other states	Comments- similar data collected by other states
Yes	
Yes	
Yes	
Yes	Several states have certified programs
Yes	
Yes	
Yes	
Yes	
Yes	
Unknown	

Research Agreement and Research and Ethics Review Committee (RERC) Policy #AD 07-12-004

Purpose
The purpose of this policy is to outline the procedures for the review and approval of applications submitted to the department for access to department data for use in a research project as allowed by statute or Administrative Code.

Definitions
Research: A systematic investigation designed primarily to develop or contribute to scientific, medical, public health or psychosocial disciplines and generalized knowledge and not for personal gain. Examples of "research" are included in **Appendix A**.

Data sharing agreement (DSA): A legal contract between IDPH and any external entity (including other departments within state government and Reagent's institutions) in which parties agree to exchange specified variables within a dataset, or in some cases paper files, at identified intervals of time, and use of the data does not meet the conditions of initiating a research agreement.

Data Owner: The IDPH employee who is in the position that is responsible for the dataset, as designated by the director or director's designee or as indicated by statute. The data owner may authorize or deny access to certain data within IDPH, and is responsible for accuracy and integrity of the data and timely response to data inquiries.   However, the decision for release of data for the purpose of research is finalized by the Research and Ethics Review Committee.

Data Custodian: The IDPH employee who is in the position responsible for the safe custody, transport, and storage of the data; also responsible for the technical environment and database structure that hosts data. The custodian for IDPH data may be indicated by statute (i.e., State Registrar of Vital Records); however, the physical custodian for the majority of IDPH data is the Bureau of Information Management and Bureau of Health Statistics.

Data Steward: The IDPH employee who is in the position responsible for data content, context, and associated rules for interpretation of each data source. The data steward(s) serves as an intermediary between the data owner and data custodian. Data stewards have the responsibility of ensuring that the appropriate steps are taken to protect the data and that respective policies and guidelines are being properly implemented. Data Owner and Steward might be the same person.

Institutional Review Board (IRB): Also known as an independent ethics committee or ethical review board is a committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans. IDPH does not have an internal IRB; therefore, an external IRB approval may be sought by the researcher depending on the project partners.

Personal gain: Efforts by any employee that benefit an IDPH employee personally or professionally and where the "effort" is outside of the scope of normal job duties. Examples of efforts qualifying as "personal gain" include, but are not limited to: using department data for a dissertation or other graduate work, using department data in consulting work or in other supplemental employment.

Primary Investigator (PI): The individual conducting the research. The PI is responsible for the management of the research agreement. The PI is the point of contact for all communication with

IDPH related to the review of the application and is also responsible for non-IDPH individuals who are authorized to access data received through the research agreement.

Research agreement: A contract between IDPH and any external entity (including other departments within state government and Reagent's institutions) in which IDPH agrees to release specific variables within a dataset that includes parameters of time and geography as requested in a research application. A research agreement is required when the receiving entity intends to use the requested dataset for the purpose of research and is bound by the confidentiality requirements in the research agreement.

Research and Ethics Review Committee (RERC): The Research and Ethics Review Committee (RERC) is responsible for evaluating and approving or denying requests for IDPH-owned data. The committee composition, roles and responsibilities are outlined in this policy.

Policy
All applications for access to department data requested for the purpose of research must be reviewed and approved by the Research and Ethics Review Committee (RERC). The RERC is also responsible for assuring documentation is sufficient to meet the requirements for committee review.

The duties of the RERC do not include review or approval of <u>data sharing agreements</u> where research is not the basis for the request.

The duties of the RERC do not include review or approval of Open Records requests. Open Records requests must be processed according to the procedures outlined in department Policy# IM 11-04-015.

Procedures

Employee
If an employee receives a request for IDPH data from someone **outside** of the department, the employee should attempt to assess whether the requestor will be using the data for the purpose of research.

- **If the employee believes the request is research-related**, then the requester should be referred to the RERC Coordinator at rerc@idph.iowa.gov.
- **If the employee is not sure whether the request is research-related**, then the requester should also be referred to the RERC Coordinator at rerc@idph.iowa.gov.
- **If the request is unrelated to research**, then the request should be filled according to IDPH data access and release policies and procedures.

Employee Requests for Access to Data
IDPH employees requesting access to confidential department data must submit a request to the Bureau of Information Management via the Help Desk's Self-Service Portal, unless they are the Data Owners, Stewards, or Custodians with routine and job-related access to the data.

Request for access to confidential data by an employee must include a description of how the data will be used, dataset needed, variables within the dataset that are needed, and date range. In some instances paper files may be provided. The request will be submitted to the Data Owner for approval.

Research and Ethics Review Committee (RERC)
Duties of the RERC
The RERC is responsible for receiving and processing all applications for research agreements and research-related requests for IDPH data. This includes applications from IDPH staff and

2

non-IDPH staff. The following sections detail the procedure for processing research agreement applications and research-related requests.

All applications will be placed in queue for RERC review upon receipt of necessary documentation from the PI. After receipt of the complete application, the documents will be reviewed and a response provided to the PI typically within one month, but no more than three. The timing of reviews and final decisions is dependent on completeness of the application, PI responsiveness to comments or questions from the RERC, and the number of applications under review at that time.

Composition of the RERC
The committee will have four permanent members designated by Executive Team:
    A. Bureau Chief for the Bureau of Health Statistics (Vital Statistics)
    B. IDPH Medical Director/State Epidemiologist (Deputy State Epidemiologist may serve in the absence of the Medical Director)
    C. RERC Coordinator (Office Manager for the Bureau of Health Statistics)
    D. Data Management Coordinator or other comparable individual in a position with duties that include department data management.

The committee may have two additional members meeting the following criteria:
- One new member per month; each serving two months at a time; and
- Must have work experience and/or academic training in health statistics, research methodology or epidemiology of acute or chronic disease.

The RERC Coordinator will be responsible for selecting and scheduling additional meeting members.

Optional committee member
- The committee may include a temporary subject matter expert (e.g., data owner, steward, custodian or in some cases a bureau chief or other administrator).

Quorum criteria
- Decisions are made by consensus, where at least two permanent members must agree.

Criteria for IDPH Employee Use of Research Agreements when the IDPH Employee is the PI
(See Appendix B for a process checklist)

There are situations where IDPH employees must submit an application to the RERC for the use of IDPH data; however, there are also exemptions. Explanations for both are listed below:

    1) *Situations where an IDPH employee <u>MUST</u> submit an application for access to department data to the RERC*

        a. Data requested are being used for a research project outside of the scope of the employee's work or is not required to complete department assigned duties,

        OR

        b. Data requested are being shared with an outside person or entity for use in a research project,

        OR

    c. Data requested will be used to draft a manuscript for publication in a peer-reviewed journal, unless data release follows the department's data release guidelines.

       OR

    d. Data requested will be used outside the normal scope of job duties and for personal gain of any kind.

   2) Situations in which an IDPH employee is <u>EXEMPT</u> from submitting an application for access to department data to the RERC:

    a. Data requested are "owned" or kept within the department,

       AND

    b. Data requested are part of an IDPH employee's scope of work or is required to complete department assigned duties.

The RERC is available to IDPH employees for consultation on release concerns and guidance when an application is needed or not necessary.

Any data release to an external entity that has not been approved via this process must follow the department's Policy for the Release of Confidential Public Health Records (#ES 06-13-002).

Application Requirements for IDPH Research Agreements- *New and Continuing*
(See Appendix B for a process checklist)

All <u>NEW</u> applications submitted to the RERC for consideration must include the following documents:
- Checklist for application for new research agreement
- Application for research agreement
- List of requested variables or files
- Copy of IRB application (all documentation required)*
- Conflict of interest statement

*Conditional project approval may be granted when IRB approval is pending; however, no data will be released until IRB approval is obtained and submitted to the Department.

After approval of the **<u>NEW</u>** application, the PI will be asked to complete the following:
- Research agreement between IDPH and PI, including additional signature page for other persons involved in the project
- Destruction of data agreement

All applications submitted to the RERC for consideration for <u>CONTINUATION</u> must include the following documents:
- Checklist for application for continuation of an existing research agreement
- Current Research Agreement #, date current Agreement was effective, and a description of any changes in the research project
- Updated application for research agreement
- List of requested variables or files
- Copy of updated IRB application (all documentation required)*
- Conflict of interest statement

Revised 09-2013

*Conditional project approval may be granted when IRB approval is pending; however, no data will be released until IRB approval is obtained and submitted to the Department.

After approval of the **<u>CONTINUATION</u>** application, the PI will be asked to complete the following:
- Research agreement between IDPH and PI, including additional signature page for other persons involved in the project
- Destruction of data agreement

In addition to providing the necessary documentation, the RERC will assess whether proposals meet the following requirements:
- The department possesses the legal authority to release or withhold the data requested.
- Knowledge gained from this research agreement must contribute to the understanding of health conditions or to an issue related to public health and be of intrinsic value to the people of Iowa. Must be bona fide research and not conducted for personal gain[1]. The application of this requirement also applies to health statistics data[2].
- Data requested must be used **for research purposes only**. The data may not be transferred or reused by the Primary Investigator (PI) without seeking explicit and additional approval of the RERC. IDPH data may never be given or sold by a PI or other person(s) or entities, unless authorized by the original agreement
- Research must include ethical and legal considerations within the study design.
- Research must include realistic outcomes or goals.
- PI must verify the means to compensate the department for any charges resulting from the fulfillment of the research agreement (e.g., data retrieval fees).
- PI must submit all required documentation for review by the RERC (see application checklist for list of documents).
- PI must provide documentation of their application to Institutional Review Board (IRB) and the decision of the IRB, if applicable.
- PI must adhere to contract data security standards outlined in the research agreement.
- PI must provide drafts of any public presentation (e.g., manuscripts, presentation) containing IDPH data for pre-approval by the RERC Coordinator. PI is responsible for oversight of any public presentation of IDPH data. IDPH data may be presented without RERC authorization within the data release guidelines outlined in the research agreement. Questions surrounding pre-approval of data presentation may be submitted to the RERC at any time.
- PI must agree to submit a continuation request, if needed
- PI must confirm destruction of data, which may include confirming data destruction by an uninvolved or impartial third party.

The RERC reserves the right to request documentation outside of the parameters listed in the policy.

Consultation with the RERC prior to submission of application may be appropriate under certain circumstances. The RERC is available for consultation on release concerns and guidance when an application is needed or not necessary.

Any data release to an external entity that has not been approved via this process must follow the department's data release policy.

---

[1] 641.175.10(2)(b)

Oversight for the RERC

Oversight of the function and composition of the RERC is the responsibility of Executive Team. The RERC will provide annual updates of activities, at a minimum, to Executive Team.

Division/Bureau Responsibilities

The Bureau of Health Statistics is responsible for the coordination of the RERC and all applications received.

Responsibility for fulfilling the data requests approved by the RERC is that of the data owner and custodian. The data owner and data custodian will receive approval in the form of a copy of the research agreement from the RERC. If there is not a data owner or custodian identified for a dataset, the RERC will identify the appropriate contact to fulfill the request. Requests for data will be managed by the RERC Coordinator in the Bureau of Health Statistics.

Policy/Procedure Violations

For IDPH employees- violations of the policy are grounds for disciplinary action, up to and including discharge.

For all persons and entities participating in a research agreement with IDPH - the department has the authority to employ penalties for misuse of data. Penalties for violations of the research agreement may include, but are not limited to:

- Revocation of the research agreement and notice to the immediate supervisor of the violating PI.
- Notice of revocation of the research agreement to the entity's director.
- Immediate destruction of data confirmed by independent third party, and may need to be verified by IDPH.
- Future requests by the violating PI and other implicated investigators may be denied.
- Other sanctions as authorized by federal or state law.

The PI is responsible for all violations of the research agreement for all co-signatories of the agreement under the supervision of the PI.

Appendix A- Policy #AD 07-12-004

Examples of Research and Non-Research Requests
The following are examples of situations when requests for access to data, either from outside the Department or from Department staff, <u>MUST be reviewed by the RERC</u>.

Example A
A researcher from the University of Iowa is requesting access to five years' worth of birth certificate data. The data requested does not contain patient-identifying information, but will be used as part of a research project.
Explanation A
Data are being used for a research project. It does not matter whether the data will contain identifying information. All requests for data used in a research project must be routed through the process for approval through the RERC.

Example B
A staff person at IDPH is pursuing a doctoral degree. As part of her dissertation, the staff person needs access to data from the Trauma Registry. This person has access to Trauma Registry data due to her normal job duties, but needs to extract a dataset from the registry for use on her dissertation project. The dissertation project is not part of her normal job duties and is worked on outside of IDPH hours and on a personal computer.
Explanation B
Even though this staff person had access to the data, the dissertation project is outside of her normal scope of duties. That is reason alone to warrant RERC review. In addition, she intends on analyzing data on a computer outside the department. This person must submit an application to the RERC.

Example C
The Iowa Department of Human Services (DHS) is conducting a study to determine the percentage of low-income Iowa residents who are eligible for Medicaid that enroll in Medicaid either through IDPH or DHS. DHS is requesting the list of Iowa residents enrolled in Medicaid-sponsored maternal and child health programs, including patient names. DHS plans to publish the results of this study in a professional health journal with the intent to increase physician awareness of Medicaid enrollment statistics.
Explanation C
Even though the requestor of data in this example is another state agency, the agency is using the data for a research project. Anytime IDPH data might be used for research or publication, the request for data must go through the RERC.

Example D
A staff person at IDPH works routinely on situations involving infectious disease. This person began working with a statistician at a local university to determine if there were demographic patterns linked to the incidence of infectious disease. The statistician needed access to department infectious disease data that had potentially-identifying information. The outcomes of the analysis for the project were submitted to a health journal for publication.
Explanation D
The work of this project is within the scope of the IDPH employee's normal job duties; however, the data is being shared with someone external to the department and for the purpose of

Revised 09-2013

research. This project and permission to share data with the statistician should be requested through the RERC.

The following are examples of situations when requests for access to data, either from outside the Department or from Department staff, <u>Do NOT need to be reviewed by the RERC</u>.

Example E
The National Marrow Donor Registry has requested that IDPH match the list of eligible Iowa donors to Iowa residents who have died in the past year. The Donor Registry is making this request so that the Registry has a current list of donors.

Explanation E
This request does not involve use of the data for research; however, a data sharing agreement must be in place before data may be shared.

Example F
The Iowa Department of Human Services (DHS) is evaluating the percentage of low-income Iowa residents who are eligible for Medicaid that enroll in Medicaid either through IDPH or DHS. DHS is requesting the list of Iowa residents enrolled in Medicaid-sponsored maternal and child health programs, including patient names. The results of the evaluation are being used to assess DHS programs and will not be released outside of their department.

Explanation F
Other state agencies may request data from IDPH for use internally. A data sharing agreement is sufficient as long as the data is not released outside of the agency and is not used as part of a research project.

Example G
A statistician at a local university agreed to contract with IDPH as a consultant for non-research purposes. As part of the contract, the statistician needed access to large files of outpatient data with patient names and other identifiers.

Explanation G
A data sharing agreement should be part of the contract with the statistician, but since the work is contracted and not part of a research project, review by the RERC is not necessary.

Revised 09-2013

Appendix B- Policy #AD 07-12-004

Research Agreement Applications

<u>NEW APPLICATION CHECKLIST- IDPH</u>
All <u>NEW</u> applications submitted to the RERC for consideration must include the following documents:

☐ Checklist for application for new research agreement

☐ Application for research agreement

☐ List of requested variables for the dataset(s) included in the research agreement

☐ Copy of IRB application (all documentation required)*, *if applicable*

*Conditional project approval may be granted when IRB approval is pending.

After approval of the <u>NEW</u> application, the person serving as the PI will be asked to complete the following:

☐ Research agreement between IDPH and PI, including additional signature page for other persons involved in the project

☐ Destruction of data agreement

<u>CONTINUATION APPLICATION CHECKLIST- IDPH</u>
All applications submitted to the RERC for consideration for <u>CONTINUATION</u> must include the following documents:

☐ Checklist for application for continuation of an existing research agreement

☐ Updated application for research agreement

☐ List of requested variables for dataset(s) included in the research agreement

☐ Copy of updated IRB application (all documentation required)*, *if applicable*

*Conditional project approval may be granted when IRB approval is pending.

After approval of the <u>CONTINUATION</u> application, the person serving as the PI will be asked to complete the following:

☐ Research agreement between IDPH and PI, including additional signature page for other persons involved in the project

☐ Destruction of data agreement

Revised 09-2013

Disclosure of Confidential Public Health Records
Policy #ES 06-13-002

I. PURPOSE AND SCOPE OF POLICY

The Iowa Department of Public Health (IDPH) is governed by Iowa's Open Records law and generally provides public access to all records it maintains (Iowa Code chapter 22). In addition, IDPH is committed to providing information, data, and records to the public and the media to promote and protect the health of the population.

However, Iowa law also provides that certain information, data, and records maintained by IDPH are confidential and may not be disclosed to the public. For purposes of this Policy, a "confidential public health record" includes a record, certificate, report, data, dataset, or information which is confidential under federal or state law the above-cited provisions or other provision of federal or state law.

The purpose of this policy is to outline the legal status of confidential public health records, and to provide guidance to IDPH employees regarding the disclosure of confidential public health records.

These guidelines are generally applicable to all confidential public health records within the IDPH. However, certain confidential public health records are governed by additional regulations as well as specific exemptions. Information on additional regulations and exemptions are listed in Appendix A. Additional specific guidelines for the release of reportable disease information can be found in the *Policy for Disclosure of Reportable Disease Information* on IDPH Center for Acute Disease Epidemiology website.

II. CERTAIN PERSONALLY IDENTIFIABLE INFORMATION IS CONFIDENTIAL
As a general rule, public health records which contain personally identifiable information of a health-related nature are confidential under Iowa law.

For example, IDPH is required by law to generally maintain the confidentiality of the following records:
1. Hospital records, medical records, and professional counselor records of the condition, diagnosis, care, or treatment of a patient. Iowa Code § 22.7(2).
2. Personal information in confidential personnel records. Iowa Code § 22.7(11).
3. Records pertaining to participants in the gambling treatment program. Iowa Code § 22.7(35).
4. Medical examiner records and reports, including preliminary reports, investigative reports, and autopsy reports. Iowa Code § 22.7(41).
5. Personally identifiable medical information provided for the purpose of studies to reduce morbidity or mortality. Iowa Code §§ 135.40, 135.41.
6. Social security numbers. 42 USC 405(c)(2)(C)(viii)
7. Personally identifiable information and business identity related to a reportable disease or condition. Iowa Code § 139A.3; Iowa Code §§ 139A.30 - 32.
8. Personally identifiable information related to HIV/AIDS. These reports are maintained as

1

"strictly confidential medical information" and specific provisions prevent disclosure of this information except under very limited circumstances. Iowa Code §§ 141A.6, 141A.9.

9.   Personally identifiable information contained in IDPH registries, including the Statewide Trauma Registry, Immunization Registry, Central Registry for Brain or Spinal Cord Injuries, and Congenital and Inherited Disorder Registry. Iowa Code §§ 147A.25, 147A.26; 641 IAC 136.2(5); Iowa Code section 22.7(2); 641 IAC 7.12; Iowa Code § 135.22; Iowa Code § 136A.7.

10.   Professional licensing board information, including EMS. All complaint files, investigative files, investigative reports, and all other investigative information of a licensing board or its employees or agents which relates to licensee discipline are confidential. Iowa Code § 272C.6(4). However, the statement of charges, notice of hearing, and the final decision of a board, whether after hearing or through a settlement agreement, are public.

11.   Vital statistics records. Iowa Code § 144.43.

12.   Substance abuse program patient information and some licensing information. Iowa Code § 125.37; Iowa Code sections 22.7(2), 22.7(18), or 125.37; 641 IAC 155.16(5).

13.   Iowa Domestic Abuse Death Review Team and Iowa Child Death Review Team records pertaining to a specific death. Iowa Code § 135.111; Iowa Code § 135.43(3).

14.   Records which contain identifiable information related to a child's newborn hearing screening, rescreening, and diagnostic audiologic assessment. 641 IAC 3.10.

15.   Perinatal program surveys and reports. Iowa Code § 135.11(28).

16.   All medical, health and nutrition information collected regarding WIC program participants. 7 CFR 246, Iowa Code section 22.7(2), 641 IAC 73.7(7).

III. STATISTICAL, AGGREGATE OR TABULAR DATA MAY BE RELEASED IN ACCORDANCE WITH THE FOLLOWING GUIDELINES

IDPH is generally authorized to release data from a confidential public health record to the public so long as such release could not result in the identification of a person. Identifiable information (or identifiers) includes information that can be used to directly establish the identity of a person, such as a name, address, or unique identifying number. Identifiable information also includes information that can be used to indirectly establish the identity of a person by linking such information or data with external information that allows for identification of the person, such as obituaries, newspaper articles, or information on public websites.

 IDPH may therefore generally release information or data in an aggregate or a tabular format.

The determination of whether the release of aggregate information or tabular data would result in the identification of a person may be straightforward.

>   ***Example:*** *IDPH can report that the state experienced 29,066 deaths in 2013 without violating confidentiality provisions.*

>   ***Example:*** *IDPH cannot report that a 58 year old African American female residing in Adams County died from a stroke, if there is only one 58 year old African American female residing in Adams County, as such release would result in identification of this individual.*

Oftentimes, the determination of whether the release of information is consistent with confidentiality restrictions is complex and may require additional analysis and consultation with these guidelines including the department's legal counsel and data use advisors.

In determining whether release of aggregate information or tabular data would result in the identification of a person, IDPH will generally follow the Centers for Disease Control and Prevention's (CDC) scientifically acceptable principles for confidentiality protection. IDPH has relied upon selected guidelines from the CDC's Staff Manual on Confidentiality, the National Center for Health Statistics Staff Manual on Confidentiality, and the CDC-CSTE Intergovernmental Data Release Guidelines Working Group Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-Release of State-Provided Data, in preparing this policy. In addition, IDPH relied in part upon the Washington State Health Department's Guidelines for Working with Small Numbers in developing this policy. These sources can be found on agency specific web-sites.

In general, the following guidelines apply to the release of confidential public health records by IDPH:
Please note that all examples used in this policy are fictional.

Disclosure of Personal Identifiers Prohibited.

- IDPH shall not release information which directly identifies a person named in a confidential public health record, including name, address, telephone number, social security number, medical record number, exact date of subject's birth, or other direct identifiers.

    Example: On March 1, 2013, a physician reports to IDPH that Jane Doe, medical record number 7654321, a female living at 100 Main Street in Cedar Rapids, Iowa has been diagnosed with HIV. Jane Doe's name, medical number, and address are confidential and cannot be released by the health department. However, her case will be added to the total number of HIV cases in the state for the year, and that total number may be released.

- IDPH shall <u>not</u> knowingly release information which can be used to indirectly establish the identity of a person named in a confidential public health record by the linking of the released information or data with external information which allows for identification of such person.

    Example A: Bobby Smith, a 2 month baby boy from Ringgold County, dies of a congenital heart defect on January 30, 2013. An obituary in the local paper states his age at death and the date of his death. If IDPH releases information that a 2 month baby from Ringgold County died on January 30th from a congenital heart defect, that information could easily be linked with the obituary to establish his identity. For this reason, IDPH and local boards of health and health departments should not release all of these identifiers about Bobby Smith, but instead should broaden one or more of the identifiers to prevent the identification of Bobby Smith. See how to broaden identifiers below.

Certain media outlets have expressed an interest in receiving information about (1) county of residence, (2) age range in the general categories of child, young adult, adult, or elderly, (3) time frame identifier, and (4) health status. In some cases it will be appropriate to release information from all four categories as requested. However, one or more identifiers may need to

be broadened to ensure that the information provided cannot be linked with external information

3

to allow for identification of such person. **See section VI concerning release of data to the media.**

> *Example A (continued): The county of residence could be broadened so that the release provides that a child in Southwest Iowa died of a congenital heart defect on January 30, 2013. **See section VI concerning release of data to the media.***

> *Example A (continued): The time frame identified could be broadened, so that the release provides that a child from Ringgold County died of a congenital heart defect in 2009 - 2013. **See section VI concerning release of data to the media.***

> *Example B: A seven year old black male in Taylor County has sickle cell anemia. This type of anemia is most commonly found in African-Americans. Since there are few African-Americans in Taylor County, IDPH and local boards of health and health departments should not publicly disclose that a seven year old in Taylor County has sickle cell anemia, as doing so could lead to the identification of the child. **See section VI concerning release of data to the media.***

> *Example B (continued): The age group and gender could be broadened so that the release provides that a child aged 0-17 years in Taylor County has sickle cell anemia. **See section VI concerning release of data to the media**.*

- IDPH shall not respond to inquiries about a confidential public health record which include direct personal identifiers in a manner which confirms an inquiry.

> *Example C: An employer contacts IDPH concerned about the health status of their employee Jane Smith. When told that this is confidential information; he then asks whether his business has an employee enrolled in a gambling treatment program. IDPH cannot release any information regarding the health status of any individual employee to the employer, nor can IDPH confirm if an employee participates in any treatment programs.*

> *Example D: A soccer coach at the Prairie Ridge Recreation Center wants to know if the members of his team have received their influenza vaccines. IDPH and local boards of health and health departments cannot disclose directly to the coach, any information that would confirm if any of the soccer players had received their influenza vaccines.*

Aggregate Data Values.

- When releasing information from confidential public health records, IDPH must expand or broaden the identifier fields as needed in order to prevent identification. Common methods for preventing identification include:

4

o <u>Redacting</u> (removing) variables which directly identify a person, including name, address, telephone number, social security number, medical record number, exact date of case-patient's birth, or other direct identifiers.

o <u>Collapsing</u> continuous/interval data (ex: age, date of occurrence) into broad categories.

o <u>Collapsing</u> ordinal data (ex: location, geography) into broad categories.

o <u>Suppressing</u> of small numbers to ensure confidentiality

Definitions and Examples:

A <u>numerator</u> is the number on top and a denominator is the number on the bottom of a ratio. For example, if 13 of 62 people who attended a church supper became ill, 13 is the numerator, and 62 is the denominator.

A <u>line listing</u> is a row of data in which only one piece of information per category is available. For example, the number of cases per county is available in the line listing of reportable diseases in Iowa. (See example at www.idph.state.ia.us/adper/common/pdf/cade/decades.pdf).

Example:

	Polk	Story	Linn	Hamilton	Adair	Adams
Salmonella Cases	126	51	42	8	2	1

A <u>table</u> refers to the arrangement of descriptive or identifying data (for example age, sex, or race) in columns (vertical) and lines (horizontal), with the intersection of a column and a line referred to as a "cell", where several pieces of information are available per number. For example, the following hypothetical table of *Salmonella* cases in Polk County includes age and race. This sometimes referred to as "cross-tabs" when two pieces of identifying information (e.g., age and race) are used to arrange data in a table.

Example:

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	**Total**
White	22	16	13	11	10	72
Black	11	6	4	6	8	35
Asian	2	1	2	1	3	9
Pacific Islander	0	0	0	0	6	6
Total	35	23	19	18	27	122

<u>Use Numerator/Cell Size Rules for Data Aggregation or Suppression</u>.

■ When releasing information from confidential public health records, IDPH and local boards of health and health departments should use numerator/cell size rules to either guide selection of groupings of aggregated data values, or if aggregation is insufficient, to

suppress release of certain cells in a table. **IDPH should not release data if the numerator cell size is five or fewer: numerator cell size counts of one, two, three, four, and five should not generally be disclosed.** A count of no cases or events in the cell is not a threat to confidentiality and may be released, but a count of one, two, three, four, or five cases or events is a threat to confidentiality and should not be released.

> *Example:* A local health department is asked for information about teen pregnancy by age. The county has had one 14 year old, two 15 year old, two 16 year old, and four 17 year old teen pregnancies. Because there are fewer than 5 in each cell, the county should collapse the individual ages into one cell of teen pregnancies for seventeen years of age and under, so the release of information would state the county has had nine teen pregnancies of 17 years of age or younger (as long as denominator rules apply).

If data are released in a line listing, then the numerator suppression rules do not apply. The numerator suppression rules do not apply because only a single piece of information per category is being released in a line listing, therefore potential identification is not possible.

> *Example:* The number of trauma service cases in Iowa by year may be released.

Trauma service cases in Iowa				
	2009	2010	2011	2012
Trauma service cases	2,611	2,917	3,078	3,270

If data are released in table format, the following additional guidance should be followed:

☐ In no table should all cases of any line or column be found in a single cell.

☐ In no table should the total figure for a line or column of a cross-tabulation be five or fewer.

☐ In no table should it be possible to identify a person through subtraction or other calculation from the table or a combination of tables.

☐ Data released by IDPH or local boards of health and health departments should not permit identification of a person when used in combination with other external data.

Example: *The table below shows all of the Salmonella cases in Polk County. The table cannot be released to the public because single cell counts are below 6. All counts below 6 should be suppressed.*

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	**Total**
White	22	16	13	11	10	72
Black	11	6	4	6	8	35
Asian	2	1	2	1	3	9
Pacific Islander	0	0	0	0	6	6
Total	35	23	19	18	27	122

Example: *The table has been revised for numerator suppression. All counts, both single cell counts and total counts, of 5 or fewer have been replaced using an "S". However, the table still cannot be released to the public because cell values may be identified by simple calculations.*

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	**Total**
White	22	16	13	11	10	72
Black	11	6	S	6	8	35
Asian	S	S	S	S	S	9
Pacific Islander	S	S	S	S	6	6
Total	35	23	19	18	27	122

S= suppressed number

Example: *The table below can be released to the public.*

Salmonella cases in Polk County						
Race	Age 0-17	Age 18-40	Age 41-60	Age 61-80	Age 81+	**Total**
White	22	16	13	11	10	72
Black	11	6	S	6	8	S
Asian	S	S	S	S	S	S
Pacific Islander	S	S	S	S	6	S
Total	35	23	19	18	27	122

S= suppressed number

Use Denominator/Population Size Rules for Data Aggregation or Suppression.

■ When releasing information from confidential public health records, IDPH should use denominator/population size rules to either guide selection of groupings of aggregated data values, or if aggregation is insufficient, to suppress release of certain cells in a table. Prior to disseminating the information, IDPH should consider the size of the denominator (the population size represented in each cell of a table). Data should not be released if the total population from which the data are drawn is less than a certain size, based on the premise of a size sufficiently large enough that no subcell of the variables contained in the data would be expected to be smaller than a certain size. Generally, tabular data based on

denominations greater than 300 persons per cell present *minimal* risk for personal identification. Caution should be exercised if the cell's population size is between 100 and 300, and release should not occur if the population is less than 100.

> *Example: The table below shows all of the Influenza cases in Adams County. The table cannot be released to the public because the population sizes of Asians and Pacific Islanders for the specified age ranges are fewer than 100 counts in Adams County. Therefore, denominator suppression needs to be applied.*

Influenza **cases in Adams County**						
Race	**Age 0-17**	**Age 18-40**	**Age 41-60**	**Age 61-80**	**Age 81+**	**Total**
White	89	23	37	64	51	275
Black	47	16	19	25	33	140
Asian	22	6	8	14	24	74
Pacific Islander	15	7	6	16	16	60
Total	173	52	70	119	124	549

> *Example: Below is the version of the table as it can be released to the public. Although the race groups for Asians and Pacific Islanders were combined, not all of the age groups meet the guidelines for the denominator suppression rules. Therefore, to avoid count identification through calculations, all counts for both race and age group were suppressed.*

Influenza **cases in Adams County**						
Race	**Age 0-17**	**Age 18-40**	**Age 41-60**	**Age 61-80**	**Age 81+**	**Total**
White	S	S	S	S	S	275
Black	S	S	S	S	S	140
Asian/Pacific Islander	S	S	S	S	S	134
Total	173	52	70	119	124	549

S= suppressed number

> *Example: Assume there is an outbreak of Giardiasis in Ayrshire, Iowa, population 202, where seven ten year olds were infected with this disease. Public health authorities should not release that seven ten year old children in Ayrshire were infected with Giardia, because even though the numerator/cell size is over five, the denominator/population size is below 300. Because there are only a small number of ten year old children in this town, such a release may in effect be identifying every one of these children as infected with Giardia. The release should instead provide the relevant information for the county.*

Summary

☐ IDPH shall not release information which directly identifies a person named in a confidential public health record, nor respond to inquiries in a manner that confirms the identity of a person.

☐ IDPH should generally not report cells with counts of five or fewer.

☐ IDPH should be cautious when reporting rates or ratios based on denominators less

than 300 and should not disclose data based on denominators less than 100.

☐ IDPH should be cautious when reporting a specific disease in a minority population if a high proportion of the minority population has this disease, or if the disease is primarily found in a specific population.

☐ When producing tables, IDPH should be careful that users cannot derive confidential information through a process of subtraction.

IV. RELEASE OF DATA TO THE MEDIA

An important mission of public health is informing the public through the media about issues which impact the public's health. IDPH staff should collaborate with its public information officers and other appropriate staff to determine the content, nature, and scope of information to be released to the media.

When releasing demographic information regarding specific case-patients to the media, the following guidelines should generally be followed. In certain situations this level of detail may not be appropriate for release as described in this policy, and if there is a question about the specificity of information which should be disclosed consultation should be sought from legal counsel prior to release of the information.

Age Range:
The following age ranges should generally be used to report both illnesses and deaths. In press releases, the age ranges should be included in parenthesis within the text as demonstrated below.

☐ Child (0-17 years of age)
☐ Adult (18-40 years of age)
☐ Middle age (41-60 years of age)
☐ Older Adult (61-80 years of age)
☐ Elderly (81+ years of age)

Gender: The gender of the case patient should generally be released.

Geographic information: The smallest geographical area as appropriate should generally be released.
 1) County (release name of county of residence)
 2) Region - five regions will be used for the state:
    a. Northeast (NE)
    b. Southeast (SE)
    c. Central
    d. Northwest (NW)
    e. Southwest (SW)
 3) State (as a whole)

Ethnicity and Race: The ethnicity and race of a patient will not generally be disclosed in a press release.

Example: A 16 year old girl from Clay County dies from suicide and her obituary is posted in the local paper and on the local funeral home's website. Because an obituary is in the public domain, children deaths are rare and Clay County has a relatively small population, the following would generally be appropriate for release – "a female child (0-17 years of age) in Northwest Iowa died from suicide".

Example: A 57 year old woman in Linn County is diagnosed with breast cancer, but she is treated and does not die. Since she survived her illness, there is no information in the public domain, such as an obituary. In addition, this diagnosis is not rare and Linn County has a relatively large population – hence the following would generally be appropriate for release –"a middle age adult (40-60 years of age) woman in Linn County was diagnosed with breast cancer".

In unusual situations, or when unexpected information is in the public domain, the above standardized guidelines may need to be modified. These modifications should be consistent with other sections of these guidelines and consultation with public information officers and legal counsel may be appropriate.

V. LIMITED EXCEPTIONS WHICH AUTHORIZE RELEASE OF PERSONALLY IDENTIFIABLE INFORMATION

In addition to those disclosures of information authorized above, Iowa law also allows IDPH to disclose confidential information under the following circumstances:

☐ Confidential public health records and information may be shared by and between IDPH employees and local board of health and health department employees who have a need for the information in the performance of their duties. (641 IAC 175.10(2)"a" & "e", 641 IAC 1.17(3)"a" & "b", Iowa Code 141A.9(7)). Hence, IDPH and local health department employees may share any information necessary to effectively conduct a disease investigation.

☐ Confidential public health records and information may be shared with public health departments in other states or the CDC or other federal agencies when necessary for the other entity to perform their duties or as necessary to conduct the investigation. (641 IAC 175.10(2)"e", 641 IAC 1.17(3)"d", Iowa Code §§ 141A.9(8)). Confidential information provided to other departments
retains its confidential status and shall not be re-released by the receiving entity. In general, however, CDC and other federal agencies do not receive or retain individual identifying information.

> *Example: An Illinois resident is hospitalized in Davenport, Iowa, and is reported to Iowa public health officials as being ill with Lyme disease. This information, including name, address, and phone number of the resident, may be shared with Illinois public health officials (both the state and the case's local health department) as this information is needed by them to conduct the investigation and perform their job duties.*

☐ Public health records and information may be shared with other state governmental entities when necessary for those entities to perform their job duties. However, this information must be kept confidential by the receiving agency. In some situations, a Data Sharing Agreement

may be required. Please consult the Research and Ethics Review Committee in these situations. (641 IAC 175.10(2)"d" & "e", 641 IAC 1.17(3)"d").

> **Example:** *A city planning agency requests birth and death records, including street addresses, to conduct a population forecast for both city and public health planning. The data are required in order for them to perform their job duties. A data sharing agreement is required. The data released is only for their residents.*

> **Example:** *A local public health agency requests a list of children eligible for Medicaid for their county. This data will be used to confirm participants and services for entitlement programs. The data are required in order for the local public health agency to perform their job duties.*

☐ Public health records may be released to the subject of the record upon receipt of a written authorization for release from the subject or the subject's legal representative. (641 Iowa Administrative Code 175.12, Iowa Code §§ 141A.9(2)"a"). IDPH should exercise caution to ensure that other confidential information (i.e. reference to other ill individuals) contained in the report is redacted prior to release to the subject.

☐ Public health records may be released in response to a court order or subpoena. (641 IAC 175.9(2)"g", Iowa Code §§ 141A.9(2)"g"). Review shall be performed by the IDPH's legal counsel or local board of health and health department's legal counsel prior to release.

☐ IDPH may share personally identifiable information regarding diseases, health conditions, unusual clusters, or suspicious events that may be the cause of a public health disaster with the department of public safety, the homeland security and emergency management division of the department of public defense, and other appropriate federal, state, and local agencies and officials. (Iowa Code § 135.145(2)). The sharing of such information must be restricted to only that information necessary to prevent, control, and investigate the public health disaster. (Iowa Code § 135.145(3)).

VI. PENALTIES FOR UNAUTHORIZED RELEASE OF INFORMATION

A person who knowingly violates the confidentiality statutes and administrative rules cited above may be subject to criminal prosecution for a simple misdemeanor and may be subject to disciplinary action under IDPH or the relevant county's personnel policies, up to and including discharge from employment. A person who releases HIV/AIDS information is subject to criminal prosecution for an aggravated misdemeanor and is subject to civil action and civil penalties, and may be subject to disciplinary action under IDPH or the relevant county's personnel policies, up to and including discharge from employment. (Iowa Code §§ 139A.25, 141A.11).

In addition, while IDPH is not a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), local boards of health and health departments generally are covered entities, and may therefore be subject to an enforcement action under HIPAA if the local board of health or health department releases protected health information in violation of that regulation. Local boards of health and health departments should seek advice from their legal counsel to ensure their compliance with the federal law.

VIII. QUESTIONS AND EXEMPTIONS REGARDING APPLICATION OF THE GUIDELINES

All legal exemptions and additional regulations are listed in Appendix A. Questions regarding these guidelines and any specific circumstances may be directed to the following individuals:

Meghan Harris, MPH, MPA
Public Health Tracking Coordinator
Iowa Department of Public Health
(515) 725-2179
Meghan.harris@idph.iowa.gov

Patricia Quinlisk, MD, MPH
Medical Director/State Epidemiologist
Iowa Department of Public Health
(515) 281-4941
Patricia.quinlisk@idph.iowa.gov

Heather Adams, JD Assistant
Attorney General Iowa
Attorney General's Office
(515) 281-3441
Hadams@ag.state.ia.us

Jill France
Bureau Chief, Bureau of Health Statistics
Iowa Department of Public Health
(515) 281-4944
Jill.france@idph.iowa.gov

Appendix A: Legal exemptions and additional regulations for the release of confidential public health records.

- Reportable diseases – please reference the *CADE Policy for Disclosure of Reportable Disease Information* for additional regulations and exemptions.

Effective 09-2013