

COLOR CODE:		CCHF Public Health Databases Survey Information - the Raw Data.													2013 Policy Insights Report: "Patient Privacy and Public Trust" (www.bi.ly/HealthSurveillanceReport)													Citizens' Council for Health Freedom				
Red text: 2005 BIRTH RATE Black Text: Information provided by survey respondents Blue Text: Information discovered through CCHF research		General Database Information													Patient Consent Requirements			Parent/Guardian Notification	State Laws- Privacy		Notes of Interest											
		Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N) When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	Notes of Interest								
ALABAMA																																
BIRTH DEFECTS	1-Oct-06		AL	Alabama Birth Defects Surveillance and Prevention Program	1994; Population based 1998	4,581	60,453 - AL	Y	Y (No identifiers of the infants are released by the University except to the Vital Statistics Department of ADPH)	BD	State Public Health Department Authority; 45CFR-164.512(b) of the Privacy Rule	N	N	on a secure LAN line	100% University	N		N	N	N/A		AL										
CANCER	19-Sep-06		AL	Alabama Statewide Cancer Registry	1996	219,314		Y	Y	CA	Alabama Law 95-275	N	Required to file incident report with the Office of Legal Counsel	???	100% public (state & federal dollars)	N		N	Y	Healthcare providers issue information to patients through Notice of Privacy Practices	Y	AL										
IMMUNIZATIONS	18-Oct-06		AL	ImmPRINT (Immunization Provider Registry with Internet Technology)	1996	2,049,490		Y	Y	IM	Acts 1995, No. 95-530; Alabama Administrative Code: CHAPTER 420-6-2	N	N	N/A	100% public	N		N	N	N/A	N	AL										
NEWBORN SCREENING	29-Nov-06		AL	Neometrics (Newborn Screening Only)	1992	I do not know this information. 410,929 live births tested 2001-2007 (NNS)		Y	Y	NBS	No Ala. Code § 22-20-3 (1991)	N	I do not know this information	I do not know this information	Federally Funded	N		N	N/A	I do not know this information		AL										
ALASKA																																
BIRTH DEFECTS	23-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/7/2006	AK	Alaska Birth Defects Registry	Jan-96	Approx 6,192 (516/yr)	10,459 - AK	Y	Y "Surveillance Update: The Alaska Birth Defects Registry 1996-2002"	BD	NO LAW FOUND. Alaska Administrative Code 7 AAC 27.012. Birth defects registry					N						AK										
CANCER	21-Dec-05		AK	Précis-Central, developed by IMPAC Medical Systems, used by the Alaska Cancer Registry	1996	16,164 reportable cancer cases (Diagnosis Years 1996-2003, with 2003 not complete at this time)		Y	Y	CA	Public Law 102-515, "Cancer Registries Amendment Act"	N	N	None done	100% public (federal and state)	N		N	N	N/A	Y	AK										
IMMUNIZATIONS	23-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/7/2006	AK	Alaska Immunization Registry	pending			Y		IM	NO SPECIFIC STATUTORY CREATION OF REGISTRY. *7 AAC 05.931. Disclosure to immunization registries. Authority: AS 18.50.020 (Rule adoption), AS 18.50.310 (Vital Stats), AS 18.50.320 (confusing copies from Vital Records)					N						AK										
NEWBORN SCREENING	20-Sep-06		AK	Not named; Newborn Metabolic Screening Program (NBMS)	??	It is just a follow-up spreadsheet. 71,971 tested 2001-2007; Approximately 10,000 infants per year		Y	Y	NBS	Alaska Stat. §18-15-200, 210; AS 18.15.200. Screening For Phenylketonuria	N	??	None	It's just a spreadsheet!	N	Opt out	Only to opt out of NBS (informed dissent)	It is just a follow-up spreadsheet. There is just a spreadsheet kept for follow-up purposes to track outstanding presumptive positives through to diagnosis or a normal screen?	Yes for all mandated programs		AK	*... a person attending a newborn or infant whose request for appropriate specimens from the newborn or infant is denied by the parent or guardian is not guilty of a misdemeanor.*									
ARIZONA																																
BIRTH DEFECTS	27-Oct-05		AZ	Arizona Birth Defects Monitoring Program	1986	approx. 40,000	96,199 - AZ	Y	Y found 1,500 children a year. - http://www.cdc.gov/nbddd/bd/states/arizona.htm	BD	ARS sec. 36-133 (enacted 1988), AZ Administrative Code, Title 9, Chapter 4, Articles 1 & 5. Adopted effective 1991.	N	Y	not provided	100% CDC funding NCBDDD grants; (2005 Directory 40% CDC, 3 MCH, 27% genetic screening; 30% state)	N				N (specified access)		AZ	no documentation/survey received - completed by intern from phone interview									
CANCER	27-Oct-05		AZ	Arizona Cancer Registry	1980	approx. 375,000		Y	Y	CA	A.R.S. §36-133; Arizona Administrative Code Title 9, Chapter 4, pages 179-190	N	Y	not provided	100% public	N					N (specified access)		AZ	no documentation/survey received - completed by intern from phone interview								
HIV/AIDS	17-Nov-05		AZ	HARS	1985	Approximately 12,000		Y	Y	HIV	Arizona Revised Statutes	N	N	NR	100% public	N		N	NA	N												
IMMUNIZATIONS	1-Nov-05		AZ	Arizona State Immunization Information System	1998	2.6 million (21 - 25 million shots)		Y	Deidentified names	IM	A.R.S. §36.135; AZ Admin. Code R9-6-706-708	N	N: Not under HIPAA rules - misdemeanor	annual	State/federal		Opt out	Form 1-11		don't know		AZ	phone call interview; no survey received									
NEWBORN SCREENING	23-Jan-08	We will not be participating in the survey. (email March 7, 2006)	AZ	Arizona Newborn Screening Program - 29 conditions	1993	654,099 live births tested 2001-2007		Y	Y	NBS	Ariz. Rev. Stat. Ann. § 36-694 (1993); AZ Administrative Code - Sections R9-13-101 through R9-13-110 (NB Hrg) and R9-13-201 through R9-13-205 (Genetic/Metabolic)				Fees (100%??)	N	N					AZ										
OCCUPATIONAL INJURY	19-Jan-06		AZ	Census of Fatal Occupational Injuries	1992	NA		Y	Names are stored in a confidential database only in the State. They are not stored centrally.	OCC	OSH Act 1972	N	N	No external audit	50/50 Federal Government/State	N		N	N	NR	Unknown											
OCCUPATIONAL INJURY	19-Jan-06			Survey of Occupational Injuries & Illnesses	1992	Not disclosable		Y	Y	OCC	OSH Act 1972	N	N	No external audit	50/50 Federal Government/State	N		N	N	NR	Unknown											
ARKANSAS																																
BIRTH DEFECTS	23-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/4/2006	AR	Arkansas Reproductive Health Monitoring System (ARHMS)	1980 (pilot)		39,208 - AR	Y		BD	Senate Bill Act 214 - 1985				2/2007: 100% general state funds (http://www.statefanta.org/ComM2007/QuestFeb07.htm) 2005 BDS Directory: 100% state general funds							AR										
CANCER	21-Nov-06		AR	CancerCore Arkansas Central Cancer Registry	1996	138,181		Y	Y	CA	AR Dept of Health and Human Services Subchapter 2, 20-15-201 to 205	N	N	Mar-05	100% Federal CDC/National Program for Cancer Registries	N		N	N	N/A	Y	AR										
IMMUNIZATIONS	no date on survey		AR	Immunization Network for Children (INC)	2005	2,000,000+		Y	Y	IM	State Law Ark. Code Ann. § 20-15-1201 - 1203 (Arkansas Act 432 of 1995, as amended)	Not that we are aware of	It has never come up	Not ever that I am aware of	90% federal and 10% state	Y	Y	No, it's built into the INC	No because it a state law that the information be supplied [sic] to the Division of Health	NR	Not through the INC	AR										

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IMMUNIZATIONS	1/24/08	"My apologies, but I am not able to participate in your survey at this time. Thank you." (email April 18, 2006) NO RESPONSE TO CERTIFIED LETTER 12/4/2006	CO	Colorado Immunization Information System	Dec-95	"The system was disconnected in January 1999. After three years of operation, it had collected information on approximately 210 thousand children and 1.6 million shots." - Wesley Webb (http://webbware.com/colorado.htm) *CIS receives regular downloads of demographic information for all children born in Colorado and immunization information directly from health care providers. CIS currently has immunization records for 78% of all children under the age of six in Colorado. CIS is now a life long immunization information system for residents of Colorado." - http://www.coloradoimmunizations.info ____ Denver began a registry in 1995, which had 275,000 patients registered by 2001 - Successes Related to Implementation of an Immunization Registry in an Integrated Health System PPT		Y	Y	IM	25-4-2403. Department of public health and environment - powers and duties - immunization tracking system (amendment on April 2007) Colorado Immunization Act - HB1347 makes updates and changes to the immunization laws, including those governing the immunization registry. It allows the registry to include adult immunization records and to include newborn screening results, broadening its use as a public health information system. Concerns were raised about whether or not parents are appropriately and adequately notified of their option to be excluded from the registry. HB1347 also authorizes the Department of Public Health and Environment to explore several additional avenues for improving Colorado's immunization system and to make recommendations about needed policy changes. HB1347 was signed into law during Immunization Month in a signing ceremony at The Children's Hospital and HB1301 was signed into law on May 30 in Grand Junction." - http://www.coloradopublichealth.org/documents/2007_Legis_Wrap_Up_Report.pdf					The primary address of funding for the development and operation of CIS are federal (the annual immunization grant from the Centers for Disease Control, through a contract with the Colorado Department of Public Health and Environment), grants from private foundations, and in-kind contributions from the University of Colorado Health Sciences Center, integrated health plans and health care providers. The Colorado Legislature appropriated \$250,000 in 2005, \$386,400 in 2006 and \$470,060 in 2007 to support expansion of CIS to additional providers and recall of children who have not received recommended immunizations. - http://www.coloradoimm	N	opt-out					CO	The system is operated by the University of Colorado Health Sciences Center on behalf of the Colorado Department of Public Health and Environment.
NEWBORN SCREENING	1/24/08	"We are declining to do this survey..." (email March 16, 2006) NO RESPONSE TO CERTIFIED LETTER 12/4/2006	CO	Colorado Newborn Screening Program	1989	483,557 live births tested 2001 - 2007 Live Births: 100,000 (63,000 Colorado babies, 30,000 military/gov babies, and 6,000 Wyoming babies) http://www.cdphs.state.co.us/ps/genetics/geneticsplan.pdf - accessed 1/24/08; 70,000 babies a year (http://www.cdphs.state.co.us/ps/hcp/nbms/index.html)		Y	Y	NBS	Colo. Rev. Stat. §25-4-1001 to 1006; 25-4-1001. Short title... 25-4-1004.5. RULE: 5 CCR 1005-4 (http://www.cdphs.state.co.us/regulations/labreg/00504newbornscreening.pdf)					On June 20, 1987, the Colorado State Legislature passed an Act that provided funding for newborn screening programs across the state. That funding was for over \$250,000. - http://www.colorado.edu/colconflict/full_text_search/AIICRCDocs/95-4.htm	N	Opt-out (religious/personal) BROCHURE: "Your doctor will tell you how to get the testing your baby needs. Your baby might need to see a specialist. Get any additional testing State law requires that all babies born in Colorado have a newborn screening test. Parents have the right to refuse screening."					CO	

CONNECTICUT

BIRTH DEFECTS	25-Jul-05		CT	CT Birth Defects Registry	around 2002	1,600	41,718 - CT	Y	NR	BD	19A-53 and 19A-56; 19a - 56a, 19a.54, 19a.53. - 1991 enacted	N	Yes, but hasn't happened	Doesn't know	Fed. Funding = Mature (sic) and Child Health Program; 2005 BDS: 100% MCH funds)	N								CT	
CANCER	31-Mar-06		CT	Connecticut Tumor Registry	1935	767,886	(cases?) Online site says 475,000	Y	Y	CA	Conn. GS 19a-74; Regulations of the Dept. of Public Health sections 19a-17-1 through 19a-17-7 inclusive	N	N	N/A	100% public	Not for inclusion in database, but for some studies	See previous answer	N	N	N	Statutes are very broad; apply "need to know"			CT	
COMMUNICABLE DISEASES	31-Mar-06		CT		maybe 1980's or 1990?	100,00 [sic]		Y, but only in certain cases	NR	CD	not aware of any	N	Yes, but not sure	Doesn't know	State and Federal funding	Depends on age		NR	Doesn't know	NR	Doesn't know				
IMMUNIZATIONS	31-Jan-06		CT	CT Immunization Registry and Tracking System (CIRTS)	1993 Pilot Project in Hartford, 1996 - enrolled all Medicaid children back to 1995. 1998 - went statewide	371,497 (as of 2/1/2006)		Y	Y	IM	In 1994, Public Act 94-90, Section 19a-7h of the CT General Statutes authorized the establishment of CIRTS	N	N	Not applicable	Federal funding 100%	No...Automatic enrollment	Opt out.	Yes. CIRTS Enrollment Form and CIRTS Brochure (if they wish to refuse enrollment.)	Yes. CIRTS Enrollment forms and CIRTS Brochures notifies them of their automatic enrollment, and gives them an opportunity to refuse.	CIRTS Enrollment Form is given to all new moms in the birthing hospitals. & CIRTS Brochure is mailed to all new parents at their home address taken from birth certificate address.	No. We only request immunization record & demographics, that we are authorized to seek by state law, what is minimally necessary to perform our statutory mandates.)			CT	
NEWBORN SCREENING	25-Jul-05		CT	Newborn Screening Registry	mid-90's	2,149 (abnormal results)	298,091 live births tested 2001 - 2007 (estimated 2006-2007) - http://www2.uhhsa.edu/ncsis/	Y	NR	NBS	19A-55 Connecticut Statute [sic]; Conn. Gen. Stat. Ann §19a-55; 19A-55 (http://law.justia.com/connecticut/codes/title19a/sect19a-55.html)	N	NR	Doesn't know	State Funding	N		NR	Yes,	a brochure before testing	Doesn't know		CT		
OCCUPATIONAL INJURY	9-Feb-06		CT	Census of Fatal Occupational Injuries	1992	527 (1992-2004)		Y	Y	OCC	Names stored in confidential state database not stored centrally	N	N	No external audits	50/50 Federal/State	N		N	N	NR	Y	CT			
OCCUPATIONAL INJURY	1-Feb-06		CT	Survey of Occupational Injuries and Illnesses	1992	Not disclosable		Y	Y	OCC		N	N	No external audit	50/50 Federal/State	N		N	N	NR	Y	CT			
SEXUALLY TRANSMITTED DISEASES	31-Mar-06		CT		late 1990's	over 200,000		Yes	NR	STD		N	Doesn't know	Doesn't know	Federal funding	Depends on age		NR	Doesn't know	NR	N	CT			

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GEORGIA																								
BIRTH DEFECTS	2-Aug-05		GA	Birth Defects Georgia Birth Defects Reporting and Information System (GBDRIS)	2003	10,000	142,200 - GA	Y (names collected/indicated in one copy, not the other)	Y (no names in analytical database)	BD	OCGA 31-12-2 and 31-13.2 and Chapters 290-5-3.02 and 290-5-24 (Rules)	N	Y	end of 2004	no funding specifically for the database - state funds provide for salaries 2005 BDS Directory: 100% "other federal funding"	N			N		Complete access, no law for blanket access, health care providers encouraged to provide information	GA		
BIRTH DEFECTS	23-Jul-08		GA	Metropolitan Atlanta Congenital Defects Program	1967			Y	Y	BD	OCGA 31-12-2				100% public	N						GA	The Metropolitan Atlanta Congenital Defects Program was established in 1967 by CDC, Emory Univ, and the Georgia Mental Health Institute.	
CANCER	29-Jul-05		GA	Georgia Comprehensive Cancer Registry (GCCR)	1995	290,000		Y		CA	312.1-2	N	N	none	federal/state	N						GA	phone interview; no survey form	
IMMUNIZATIONS	1-Aug-05		GA	Georgia Immunization Registry of Transactions and Services (GRITS)	2003	approx. 3.5 million		Y	Y	IM	don't know OCGA 32-12-3.1 Newborn Screening statute	N		mid 2004	CDC and GA Dept Immunization funds	N	Opt Out	Y	N		Y	GA		
NEWBORN SCREENING	1-Aug-05		GA	Newborn Screening Program	1999	approx. 2 million (135,000 annually)		Y (imported records from state lab)	Y	NBS	Effective January 1, 2007, Georgia law (OCGA 31-12-6 & 31-12-7) and Rules and Regulations (Chapter 290-5-24) requires that every live born infant have an adequate blood test for 28 disorders - Ga. Code 831-12-5 to 71MCS1	N	Y (no written requirement - assume we would notify if it did happen)	none	state funded appropriations	N			N				GA	phone interview; no survey form
OCCUPATIONAL INJURY	no date on survey		GA	Survey of Occupational Injuries and Illnesses	1992	Not disclosable		Y	Y	OCC	OSH Act of 1972	N	N	No external audit	50/50 Federal Government/State	N			N	NR	N	GA		
HAWAII																								
BIRTH DEFECTS	12-Jan-06		HI	Hawaii Birth Defects Program Database	1986, but data collected retrospectively back through 1986	44,025 abstracts on 19,196 cases/individuals (1986 - 2003 complete), 2004 being collected	17,924 - HI	Y	Yes, but strict confidentiality maintained	BD	Act 252 (2002), Hawaii Revised Statutes Chapter 321 and 324	N	N	Never, as it would give outsiders access to confidential patient information. The Program does 7% re abstraction by another individual	Currently State of Hawaii Birth Defects Special Fund. Have had federal, state and private money. 2005 BDS Directory: 54% state, 31% CDC, 5% federal funding, 4% private foundations, 6% Special Fund funding	N			N	N/A	Yes, for birth defects	HI		
CANCER	19-Jan-06		HI	Central Registry Information System Product (CRISP) - Hawaii Tumor Registry	1973	158,460 as of 1/17/06		Y	Y	CA	Y	N	N	No external connectivity/internal database	Federal and State	N			N	N/A	Y	HI		
COMMUNICABLE DISEASES	27-Oct-05		HI	Infectious Diseases Database	Electronic records began in 1991	45,000 to 47,000 individual (about 4,000 new each year)		Y	Y	CD	Chapter 156 of Hawaii law/code	N	Unknown	cannot comment	unknown	unknown				NR	NR	Unknown	HI	phone call interview; no survey received
IMMUNIZATIONS	6-Oct-06	"The State of Hawaii Department of Health, Immunization Branch is currently in the process of developing an immunization information system, therefore, responses to all survey questions at this point are "not Applicable." (email (October 6, 2006)	HI	Immunization Information System - being developed but NOT in operation at this time						IM												HI		
NEWBORN SCREENING	25-Jan-08	"I have decided NOT to participate in this survey. The Chief of CSHNB concurs with my concerns regarding the use of this survey data. (email February 9, 2006); "The Hawaii State Department of Health has some serious concerns about the use of the data from this survey and has made a decision to decline to participate." (letter, December 18, 2006) RESPONSE TO CCHC November 30, 2006 fax to Department	HI	Hawaii Newborn Metabolic Screening Program (NBMSP)	1986 screening began	126,227 live births tested 2001 - 2007 (estimates 2006 - 2007) - http://www2.uhscsa.edu/nmsis/ - 32 conditions tested		Y		NBS	In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs. The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003.			A 3-state collaboration involving the Hawaii newborn screening program, the Oregon Public Health Laboratory, and the California GDS was formed to screen newborns from Hawaii. Beginning March 2002 and continuing through middle June 2003, staff members at the Hawaii newborn screening program offered NBMS supplemental screening to newborns born at Kapiolani Medical Center for Women and Children, with an informed consent process similar to the California protocol. - http://pediatrics.aappublications.org/cgi/content/full/117/5/S1/S261a...[supplemental screening pilot project: http://hawaii.gov/health/family-child-health/genetics/newspdf/tandem/asstructure.pdf] "The estimated duration of the supplemental testing is March 1 - December 31, 2002. Participation in the study will be voluntary and informed consent will be obtained for both the testing of specimens."			N	opt-out (religious)	To refuse			HI		
OCCUPATIONAL INJURY	12-Jan-06		HI	Survey of Occupational Injuries & Illnesses	1992	Not disclosable		Y	Y	OCC	OSH Act of 1972	N	N	No external audit	50/50 Federal/State	N			NR	N	NR	Unknown. Please contact Hawaii State Department of Health	HI	

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IDAHO

BIRTH DEFECTS	24-Jul-08		ID	NO SURVEILLANCE SYSTEM			23,062 - ID		BD														ID	
CANCER	22-Nov-05		ID	Cancer Data Registry of Idaho	1969	159,000		Y	CA	Idaho Code (57-1703-57.1707) and Public Law 102-515	Never	N	We have an IT consultant who ongoing monitors security	50% federal, 50% state	N		N	N	NR		Only health records containing data pertaining to a cancer diagnosis or treatment	ID		
IMMUNIZATIONS	23-Jan-06		ID	IRIS (Idaho's Immunization Reminder Information System)	1999	303,044 as of (1/5/06)		Y	IM	Y IDAPA 39-4803. Immunization Registry.	N	Not according to statute but it is a misdemeanor offense to disclose registry information without authorization and civil liability	Aug-02	100%public	Yes IRIS is an OPT-IN Registry	Y	Yes, but providers can utilize their own form but they must comply with the exact language.	Y	The IRIS consent form or statement serves as the mechanism by which parents/guardians or patients are notified that their records will be entered into the IRIS database.	Yes, the Idaho Dept. of Health and Welfare has complete access to these records. Local Health Departments have access to their jurisdictions records but only the counties within their jurisdictions.	ID			
NEWBORN SCREENING	7-Mar-06		ID	"We contract with Oregon State lab to do our NBS. They maintain the database and send us a report of positive cases only."	"?"	153,276 live births tested 2001 - 2007 (estimates 2006 & 2007) - http://www2.uhscsa.edu/nmsi/		Y	NBS	Idaho Code §39-909 to 91-NCSL; 39-909. TESTS FOR PHENYLKETONURIA AND PREVENTABLE DISEASES IN NEWBORN INFANTS. & 39-910. DUTIES OF DIRECTOR IN ENFORCING ACT. http://www3.state.id.us/cgi-bin/newidst?scid=39090010.K & 39-912. EXEMPTION BECAUSE OF RELIGIOUS BELIEF - The provisions of this act shall not apply to any child whose parent or guardian objects thereto on the grounds that it conflicts with the tenets or practices of a recognized church or religious denomination of which said parent or guardian is an adherent or member.	N	"?"	"?"	"?"	"?"	"?"	"?"	"?"	"?"	"Parent consents to test. I do not know that they consent to a Database collection of results. HCFA Regs. Are the basis of Database Development" (1st survey 3/7/06); "Idaho parents can opt out [sic] of testing per Idaho Practitioner Manual" (2nd survey 9/20/06)	"The lab contacts a genetic specialist at OHSU and he contacts the P."	N	ID	
OCCUPATIONAL INJURY	19-Jan-06		ID	HP Reflections	1989	441,932		Y	OCC	IDAHO LAW TITLE 72 (Chapter 5 - http://www.legislature.idaho.gov/ledat/Title72/72.CH5SECT72-516.htm)	N	N	Never	100% public - The Commission is funded from a 2.5% workers' compensation insurance premium tax	N		N	N	N/A	N	ID			

ILLINOIS

BIRTH DEFECTS	3-Nov-05		IL	Adverse Pregnancy Outcomes Reporting System (APORS) Illinois Health and Hazardous Substances Registry	1986 preliminary; 1989 - 2002 available data	approx. 20,000	179,020 - IL	Y	BD	Health and Hazardous Substances Act (410 ILCS 525) - enacted 1986	N	N	N	State funding and some CDC funding current CDC funding NCSDDD grantee; 2006 BDS Directory; 73% general state funds, 27% CDC grant	N		N	N	N	N	IL	phone interview; no survey form
CANCER	3-Nov-05		IL	Illinois State Cancer Registry	1986	approx. 1 million		Y	CA	Health and Hazardous Substances Act (Admin rules - Subchapter P - Haz & Poison Subst. - 77 Ill. Admin 840) (410 ILCS 525)	N	N	No outside audits - rely on own server; access is limited by administrator	State/CDC	N		N	N	N	Y - not broad authority but for specific things	IL	phone interview; no survey form
COMMUNICABLE DISEASES	8-Nov-05		IL	Illinois Disease Surveillance	2004	30,000+		Y	CD	Reporting rules	N	N	internal audit a month ago	Fed money and CDC ep. Grant	N - reported by physician; law requires						IL	phone interview; no survey form
IMMUNIZATIONS	3-Oct-06		IL	TOTSII-CARE Tracking Our Toddler's Shots	mid-1990's; full year production 12/2000	approx. 3 million 12 million shot record, 12/18/08		Y	IM	"TOTS, or Tracking Our Toddler's Shots, is an immunization record sharing system developed by the Illinois Department of Public Health (IDPH). The system allows public and private health care providers to share the immunization records of Illinois residents. Currently, the system contains more than 12 million shot records." http://www.idph.state.il.us/health/infect/tots.htm , accessed 1/25/08	N	Y	Depends on if you are an IT audit or a Physical audit. Our last OAG IT audit which includes IT security was 9/2005	100% CDC Federal on a Immunization Grant	Y "A patient, or a child's parent or guardian, must give consent to be included in the statewide registry. If consent is not given to participate in the statewide registry, the patient can still be included in your local TOTS system. However, this patient's information will NOT be shared outside your local system." http://www.idph.state.il.us/health/infect/tots.htm	NR	Yes - We have a state form	Y	It is stated in the CONSENT FORM	N	IL	

COLOR CODE: CCHF Public Health Databases Survey Information - the Raw Data. 2013 Policy Insights Report: "Patient Privacy and Public Trust" (www.bit.ly/HealthSurveillanceReport) Citizens' Council for Health Freedom

Red Text: 2005 BIRTH RATE	General Database Information														Patient Consent Requirements			Parent/Guardian Notification	State Laws- Privacy		Notes of Interest		
	Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N)- When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt in or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	
NEWBORN SCREENING	25-Jan-06		IL	Genetics/Newborn Screening System	1984	1 million plus records. (some have multiple records due to multiple specimens "This really only reflects testing done since the database was established, around 1992 or 1993 I believe [sic]. We had been doing centralized screening for several years prior to that. We do not have electronic records of the test results for those infants, only hard copy paper reports." (email, March 22, 2006) 1,239,595 live births tested 2001 - 2007 (estimates for 2006-2007). http://www2.uhscsa.edu/nmsis/		Y	Y	NBS	IL General Assembly, PKU Testing Act (410 ILCS 240) Administrative Code Part 651 Newborn Metabolic Screening and Treatment Code; 410 ILCS 240.01 to .03-NCSL	Don't Know	No	don't know	Newborn Screening Fee collected from hospitals	N		N	N	N/A	No	IL	phone interview; no survey form
VITAL STATISTICS	3-Nov-05		IL	Vital Statistics	1916	25 - 30 million records		Y	Y	VS	Vital Records Act 410 ILCS 535	Not sure - mainframe system - no exposure to hackers; not web based		Maintained by state data agency - periodic maintenance	state money/general revenues	No, state law - consent for release; not storage		Parents would know - birth certificate		N	IL	phone interview; no survey form	

INDIANA

BIRTH DEFECTS	24-Jan-06		IN	Indiana Birth Defects and Problems Registry	2002	28,119 (born from 2002-2005); 87,193 - IN	Y	Y	BD	IC 16-38 IC 16-38-4-7 and IBPR Rule 410 IAC 21-3	Not to our knowledge	Based on circumstances - legal opinion is required	Jun-05	100% public 2005 BDS Directory; 25% Genetic Implementation Grant; 75% MCH funds	N		N	NR	Yes, for children identified with a birth defect	IN		
CANCER	23-Nov-05		IN	Indiana State Cancer Registry	1987	514,000+	Y	Y	CA	Indiana Code 16-38-2; Public Law 102-515; Public Law 107-260	N	N	N/A	100% public (state & federal government funding)	No (because State law requires reporting)		N	N/A	No (not complete access)	IN		
IMMUNIZATIONS	13-Feb-06		IN	CHIRP (Immunizations)	2002	2,433,863	Y	Y	IM	IC 16-35-5	N	Y	Nov-05	100% Federal Grant	N	Opt-out	State Form 52308 (09-05) To opt out of the registry.	N	NA	N	IN	
NEWBORN SCREENING	24-Jan-06		IN	Newborn Screening	2003	Unknown, requires special run (can find out, but would require a special charge for programming) 612,455 live births tested 2001-2007 (estimates 2006 & 2007). http://www2.uhscsa.edu/nmsis/	Y	Y	NBS	Y IC 16-41-17 IC 16-41-17-8; The bill - http://www.in.gov/isdh/programs/nbs/PDFFiles/nbs1aw.pdf ; NB Hrg Law: IC 16-41-17-2.	Not to our knowledge	Requires legal opinion based on circumstances	Jun-05	100% public	Y brochure says all babies, doesn't mention consent	Opt out religious only	Yes for opt out	N	N/A	N	IN	

IOWA

BIRTH DEFECTS	17-Apr-06		IA	Iowa Registry for Congenital and Inherited Disorders (RCID) Iowa Birth Defects Registry	1983	40,000+ "Tammy has meetings set up to finalize the plans for follow up. She reported that she will be calling all families who have children who are listed within the birth defects registry; approximately 1650 families per year." - Iowa Birth Defects Advisory Committee Minutes January 17, 2003 - http://www.idph.state.ia.us/genetics/comm/pdf/minutes_011703.pdf	39,311 - IA	Y	Y	BD	Iowa Code 136A, Iowa Administrative Code 641-4.7. Enacted 1986, Revised 2001, 2003, 2004.	N	N	7/2 0 0 5	100% public 65% CDC grant; 35% general state funds	N		N	Y	Letter	Y	IA	
CANCER		NO RESPONSE TO CERTIFIED LETTER 12/4/2006	IA	State Health Registry of Iowa, Iowa Cancer Registry	1973				CA	135.4											IA		
IMMUNIZATIONS	24-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/4/2006	IA	Immunization Registry Information System (IRIS)	1993-ADIOS-IIS; 2001 IRIS	Currently, there are 750,000 patient records and 5,000,000 vaccination records in IRIS. - http://www.idph.state.ia.us/adper/commo/npdf/immunization/irs_what_is_irs.pdf		Y	Y	IM	Rule 641-7.11 (22) Iowa's Immunization Registry				The Centers for Disease Control and Prevention and other entities fund registries in all 50 states.							IA	
NEWBORN HEARING SCREENING	25-Apr-06		IA	eSP (e-Screener Plus) is the database used for Early Hearing Detection and Intervention	2004	Approx. 48,842				NB Hrg	Statutory authority for reporting	N	Unknown	1 1/2 years ago	100% public - CDC	Screening is the law, except if a child is born with a condition incompatible with life. Parents can refuse (active refusal)	opt-out	There is a refusal form for the parent to sign if they do not want their children screened	No. It is required that parents are notified of the screening results, not that the results are placed in the database, except for individual hospitals that choose to do so	NA for data. Letter for screening results	Unknown - it may be program specific	IA	
NEWBORN SCREENING	24-Apr-06		IA	Iowa Neonatal Metabolic Screening Database (located at the University of Iowa Hygienic Laboratory) (NS Metabolic)	Approximately 1992	Over a million specimens for example, 271,285 live births tested 2001-2007 (estimates 2006-2007) - http://www2.uhscsa.edu/nmsis/		Y	Y	NBS	Iowa Code Chapter 136A "Birth Defects Institute," (Iowa Code §136A.1 to 7 - NSCU) and Iowa Administrative Rules 641.4.	N	No policy to contact families, but University requires any security breach to be reported to the Police and FBI.	Annual external audits by the University	100% public	Y	Opt out	Yes. A waiver form is provided by the State.	Y	Health care providers provide brochure with information to parents before testing	Y	IA	

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Black Text: Information provided by survey respondents	Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N)/ When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Parent/Guardian Notification Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	Notes of Interest	
KENTUCKY																								
BIRTH DEFECTS	27-Apr-06		KY	KY Birth Surveillance Registry	1996	58,201	56,444 - KY	Y	Y	BD	902 KAR 19.010, KRS 211.651 - 211.670 - enacted 1992 - http://chfs.ky.gov/dph/ach/ckckr.htm	N	N	Not answered	100% state funds 100% MCH funds 2007	N		N	N	Not answered	Y	KY	"Each health care provider of newborn care shall provide an infant's parent or guardian with information about the newborn screening tests required under subsection (2) of this section." - state statute	
CANCER	23-Jan-08	"The data base you refer to, Cancer - Tom Tucker - is not in this Cabinet nor do we have responsibility for it. This registry is located at the University of Kentucky, but is a state resource... We will assist in any way we can to get you the information you require" - 12/1/06 email from Charles Kendall, Cabinet for Health and Family Services in response to 11/30/06 fax from CCHF. CCHF never got the data. Unclear why. Sent certified letter	KY	Kentucky Cancer Registry	1986			Y		CA	214.556 Kentucky Cancer Registry - Cancer patient data management system - voluntary in 1986, mandatory in 1991;				"CDC funding for the state cancer registry began in 1994. The first diagnosis year for which cancer cases were reportable to CDC was 1995. This registry also receives funding from the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program." - http://apps.nccd.cdc.gov/cancercontacts/pccr/contact.asp?ontactid=199							KY		
IMMUNIZATIONS?	14-Sep-06		KY	KY Electronic Public Health Record System	The registry has not yet been deployed	N/A		They will be.	They will be	IM??	KRS 214.015	N/A	N	N/A	100% public	N	Opt-Out	N	N	N/A	Y - KRS 205.177	KY		
NEWBORN SCREENING	27-Apr-06		KY	Newborn Screening Follow-up	2005	800	abnormal results?: 378,128 live births tested 2001-2007 1,533,435 (estimates 2006-2007) - http://www2.uhcasu.edu/nmsi/	Y	Y	NBS	Ky. Rev. Stat. §214.155 - http://www.lrc.ky.gov/KRS/214-00/155.PDF - Effective: July 12, 2006 History: Amended 2006 Ky. Acts ch. 190, sec. 1, effective July 12, 2006. - Amended 2005 Ky. Acts ch. 66, sec. 1, effective March 11, 2005, and ch. 99, sec. 450, effective June 20, 2005. - Amended 2001 Ky. Acts ch. 31, sec. 1, effective June 21, 2001. - Amended 2000 Ky. Acts ch. 457, sec. 3, effective July 14, 2000. - Amended 1998 Ky. Acts ch. 426, sec. 397, effective July 15, 1998. - Amended 1990 Ky. Acts ch. 369, sec. 35, effective July 13, 1990. - Amended 1988 Ky. Acts ch. 277, sec. 1, effective July 15, 1988. - Amended 1986 Ky. Acts ch. 447, sec. 2, effective April 11, 1986. - Amended 1982 Ky. Acts ch. 39, sec. 1, effective July 15, 1982. - Amended 1974 Ky. Acts ch. 74, Art. VI, sec. 107(2) - Created 1966 Ky.	N	N	Not answered	100% state general funds Law calls for federal grants and state fees	N	Yes - religious	N	N	Not answered	N	KY		
LOUISIANA																								
BIRTH DEFECTS	3/14/06		LA	LBDMN (Louisiana Birth Defects Monitoring Network) Birth Defects Registry	2005	243	60,937 - LA	Y	Y	BD	L.A.R.S. 40:31.41 - 31.48 enacted in 2001; LAC 48: V. Chapters 161 and 163.	N	Y	N/A (haven't had one yet)	100% public (Title V Block Grant CSHCN (child with special health care needs) funds) Received \$100,000 MCH grant in 2005 in part to begin data collection on birth defects at 25 major hospitals in six parishes in Louisiana." - https://perfddata.hrsa.gov/MCHB/mchreports/tvierports/Abstracts/Abstract.asp?AbstractIndex=21&MCHBranch=inst-structure&FY=2005	N		Consent is not required, but there is an "after-the-fact" opt-out clause in the legislation.	N	N	N/A	Y	LA	
CANCER	3/21/06		LA	Louisiana Tumor Registry	Began statewide in 1980	350,410 cancer cases		Y	Y	CA	"Statutory authority: Reportable by Louisiana law" RS 40:1299.80 and LAC 48: V.8501-8513	Never	Currently there is no such policy where confidentiality is strictly enforced (eg. suppression of small number, no linkage with other files to identify patients, etc.)	2005. University conducts "audit" yearly on security procedures such as enforcement of password, change of password every 45 days, firewall, confidentiality agreement, etc.	98% public (federal and state) and <2% private		No, it is mandated by law and the Louisiana revised statutes are accessible to public	Not applicable	Louisiana registry law allows access to its data by the Environmental Epidemiology Section of the State Health Depart for investigation of potential cancer clusters that might be related to environment. Their staff has sign confidentiality agreement. All findings and reports using Registry data must be reviewed by registry staff to ensure confidentiality and accurate interpretation.	LA				

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HOSPITAL DISCHARGE	4/17/06		LA	Louisiana Hospital Inpatient Discharge Database	1998	500,000 discharge records per calendar year		Y	Y (however, to protect confidentiality, access to these data is restricted)	HD	Louisiana Revised Statutes 40:1300.111 - 1300.114 AND Louisiana Administrative Code 48:15101 - 15125	N	N	Not Applicable	100% public	N		N	Not answered	N	LA										
IMMUNIZATIONS	3/14/06		LA	Louisiana Immunization Network for Kids Statewide (LINKS)	July 2 001	1.8 million		Y	Y	IM	State Law RS 40: 331.13	N	N	On going	100% public	Opt-out	Y	Y	"At the time of vaccination, parent must sign Vaccine Administrative Record form"	N	LA										
NEWBORN SCREENING	3/14/06		LA	Newborn Screening and Follow Up System (includes separate patient tracking programs for each disease in the newborn screening battery)	1987 - With many modifications through the years	30,000 ("The 30,000 represents a cumulative total over about 5 years of sickle cell, hypothyroidism and metabolic suspects and cases." - March 23, 2006 email) 443,999 live births testes 2001-2007 (estimates 2006-2007) - http://www2.luhscsa.edu/nmsis/		Y	Y	NBS	RS 40:1299.1 and LAC 48: V.6303	N	N	Unknown	Mix of revenue 63% Medicaid, 10% self generated, 27% State	N		N	Not answered	Re newborn screening, allows for records necessary in ensuring that a child is provided proper follow-up care	LA										
SEXUALLY TRANSMITTED DISEASES	9/13/06		LA	Louisiana STD Database (LA STD)	Began Approx. 1995 Restructured in: 1998	Over 500,000 record		Y	Y	STD	"Although the data is required to be reported in accordance with Article 51 of Louisiana's Administrative Code, there is no mandate as to how manage the data"	N	N	Not answered	100% State Funded	N		Not relating to the database	N	N/A	Y	LA									
MAINE																															
BIRTH DEFECTS	3-Mar-06		ME	ChildLINK Maine Birth Defects Program	2003	Approximately 400	14,112 - ME	Y	Y	BD	N 22 MRSA c. 1687	N	Y	Ongoing 24/7 security	2005 BDS Directory - "Currently, MCH funds pending additional funding sources"	N		N		Y	ME										
CANCER	4-Jan-07		ME	Maine Cancer Registry	1983	approx 140,000		Y	Y	CA	State Law Title 22 Chapter 255	N		Security breach is reported to Division Director and Privacy Officer for investigation and mitigation	100% public (state and federal)	N		N/A	N	N/A	Y	ME									
HOSPITAL DISCHARGE	17-Apr-06		ME	Hospital Inpatient	1980	N/A - Average 160,000 discharges per year		N		HD	State Legislature 22 M.R.S.A Sections 8708 & 8711	N		Security audits are conducted by the state Bureau of Information Services. Whereas my IS support person is on vacation I cannot answer this question at this time.	Assessments on hospitals, providers and insurers plus fees for the data	To release data to this organization? NO		Not answered	Not answered	Not answered	This organization is NOT part of the state department of health or bureau of health. (answers to questions came from the Maine Health Data Organization)	ME									
IMMUNIZATIONS	22-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/7/2006	ME	NR - Found - Maine ImmPact (plus integrated system- Public Health Information System)	1998 - IMM Pact	NR - Annual birth cohort, 13,720 (1998 preliminary) All Kids Count project brief, n.d. http://www.allkidscount.org/pdfs/project_briefs/brief_maine.pdf ; "ImmPact2 receives weekly birth and death data from the state's Vital Statistics database. New births are generally loaded into ImmPact2 within two to three weeks. ImmPact2 also contains all birth data from January 1, 1995, to the present." https://immact2.maine.gov/R/help/TheImmPact2_Immunization_Registry.htm		Y	Y	IM	20-A MRSA §6355??: "Maine state comprehensive infant immunization surveillance program," Northole AS Jr., J Maine Med Assoc. 1969 Feb;60(2):47-8; "The Maine and New Hampshire Immunization Programs co-developed an immunization registry called ImmPact. This is a lifetime (i.e. not just childhood) immunization registry that will recommend vaccines and schedules for all populations"; "Immunization Policies and Funding in Maine, n.d.; http://immact2.maine.gov				DC NIP (70%) and Maine Medicaid (30%) - All Kids Count project briefs, n.d. http://www.allkidscount.org/pdfs/project_briefs/nier_maine.pdf					"ImmPact2 can give parents the option to participate or not." - "Imm Policies and Funding in Maine"			ME								
NEWBORN HEARING SCREENING	13-Mar-06		ME	Newborn Hearing Screening (CHILDLINK)	2003	43,000		Y	Y	NB/Hrg	Y	Y	N	Ongoing monitoring Symantec 24/7	100% public	N		N	N	N	N	ME	Privacy Breach was reported but no details included.								
NEWBORN SCREENING	13-Mar-06		ME	Newborn Bloodspot Screening	2000	100,000 98,457 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.luhscsa.edu/nmsis/		Y	Y	NBS	Me. Rev. Stat. Ann. tit. 22 §1531 to 1533; Me. Rev. Stat. Ann. tit. 24-A, § 4238 (1995) - addresses metabolic formula and food. Me. Rev. Stat. Ann. tit. 22, § 1533 (1983)- addresses genetic services.	N	N	2004	100% public	N		N	N	N	N	ME									
MARYLAND																															
BIRTH DEFECTS	21-Sep-05		MD	The Birth Defects Reporting and Information System (BDRIS) (THIS IS NOT A PUBLIC DATABASE, IT IS FOR PATIENT CARE and Epidemiologic purposes)	1984	20,441 at the moment	74,980 - MD	Y	Y	BD	Not specific to the database - Statute --Health-General Article, Title 18, § 206, sets the guidelines for the program and requires hospitals to report and the Department to follow up by sending the parents a letter offering information and referrals to services. Annotated Code of Maryland - enacted 1982.	N	N	Do not understand what this means - We do not have outside people come in and audit this type of database.	100% from MCH Block Grant [sic] funds - there is no specific budget to the database - it is homedated - the only budget is the salaries of the nurse doing newborn screening follow up who computerized our follow up paper files and some occasional programmer assistance	2005 BDS Directory, 100% general state funds			No, there is no consent form but there is a standard data collection form and parents help fill it out most of the time -	No - Not specifically that their baby is in the database. However, to [sic] we are required to write the parents, offering information and referrals and we tell them that the baby's birth defect was reported to us by the hospital of birth as required by law in the letter -	None specific to the database but all parents get a letter from the program about their baby's results and about any necessary follow up	Yes, under certain circumstances - However, lack of ability to enforce access records is a particular problem in this program because, although we send them the statute and the CDC materials on how public health surveillance programs are exempt from the privacy provision of HIPAA, hospitals resist giving us any data that wasn't entered on the form in the hospital including required lab results that weren't back by discharge. We ascertain additional cases from birth certificates, fetal death certificates and infant death certificates...The aggregate anonymous data may be used by academic partners for IRB approved research. Informed consent is not required. It should be clear that it is not possible to operate a birth defect surveillance program without a database	MD								
CANCER	13-Sep-06		MD	Maryland Cancer Registry	1982	900,000+		Y	Y	CA	MD Code Annotated, Health General § 18-204	N	N	Jun-06	100% Public	N		N/A	N	N/A	Y	MD									
IMMUNIZATIONS	11-Sep-06		MD	Immunet	Jun-04	4,000,000 plus		Y	Y	IM	Y	N	Not answered	Daily	100% Public	N	Opt Out	N	N	Not answered	N	MD									

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		14-Sep-06		MA	Newborn Screening for Treatable Disorders	1999	approx 1,035,999 555,667 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nhsis/		Y	Y	NBS	M.G.L. c.111 ss.4E and 1 0A, 105 CMR 270 Mass. Gen. Laws 111 §3, 4E, 5, 6, 24A, 110 - NCSL	Not to our knowledge	Y	2004	fees	Unable to answer as question does not specify consent for what. Religious exemption - 10 mandated; 19 optional plus CF - http://www.uma-samed.edu/grade/ade/fields/nbs_9ng.pdf			N	Not answered	105 CMR 3000.191 with respect to diseases dangerous to the public health	MA									
		14-Sep-06		MA	Registry of Vital Records and Statistics	1620 at city and town level and 1842 statewide	Approximately 20 million records from 1915 to present		Y	Y	VS	M.G.L.c.111 ss.2 and 24B	Not to our knowledge	Y	2004	state appropriations, user fees, and federal cooperative agreements	Unable to answer as question does not specify consent for what						MA									
MICHIGAN																																
		4/6/06		MI	Michigan Birth Defects Registry	1992	160,000	127,706 - MI	Y	Y	BD	Act 48 of 1987 Public Act 236 of 1988	N	N	Auditor General Reviewed the Program Area in 2004	100% public CDC funding NCBDDO grantee; 2005 BDS Directory; 25% CDC Grant; 75% general state funds.	N	N	N	N	Not answered	Access is limited to information on the reportable condition and its management	MI									
		4/6/06		MI	Michigan Cancer Surveillance Program	1985	app 1 million		Y	Y	CA	Act 82 of 1984	N	N	Auditor General Conducted a Program audit in 2004	100% public	N	N	N	N	Not answered	To those portions of the record that relate to the reportable condition	MI									
		1/23/08		MI	Michigan Childhood Immunization Registry	1987	9,383 children reported to registry in 2003 (http://www.mdch.state.mi.us/PHA/OSR/BirthDefects/Birth%20Defects%20Annual%20Report%2006.pdf); The Michigan immunization registry (MIR) has achieved remarkable success. 71% of the state's providers use the registry to access up-to-date information on the immunizations of 2.2 million children. - AIRA Snapshots, January 2002. IN 200, audit lists 1.2 million children (http://audgen.michigan.gov/comprp/docs/sr3964299.pdf)				IM	Act 48 (Public Act 368)				*Annual operation costs are \$2.4 million dollars, which is obtained through the Healthy Michigan Fund and Medicaid. Making the direct link from the MIMS and MCIR will be cost shared with Medicaid. This will be done in conjunction with the development of a Web interface for MCIR. The estimated cost to develop this, along with adding additional fields such as race/ethnicity and a mechanism for processing adoption records, is \$2 million.* All Kids Count project brief, 7/1/01, http://www.allkidscount.org/pdfs/project_briefs/brief_michigan.pdf							MI									
		7/22/08		MI	Michigan Newborn Screening Program		126,020 screened in 2006 (2006 report); 698,159 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nhsis/ ; AND... *The Newborn Screening Program began in 1965, when the state began screening infants for phenylketonuria. Ten additional disorders have been added to the screening panel since that time, and over five million infants have been screened through the statewide program. (Newborn Screening in Michigan, 2004 Annual Report.) Also...populated with electronic birth certificate of every child born since Jan 1, 1994. *Collection of data for long-term tracking of infants identified through newborn screening is imperative. As a result, clinical databases have been developed by the NBS follow-up program at the Endocrine, Metabolic, Sickle Cell and Cystic Fibrosis Centers (see below). - 2006 annual report		Y	Y	NBS	LAW: <a *<="" additional="" as="" blood="" conduct="" consumer="" defined;="" department="" detroit="" for="" future="" hardship="" href="http://www.legislature.mi.gov/(S/ggzc2in5du04ad46xsa04245)/mileg.aspx?page=getobject&objectname=mi-333-5431&query=on&highlight=newborn; Mich. Comp. Laws §333.5431 - NCSL; Public Act 14 of 1987 (See Appendix A: NBS legislation)
mandated further expansion of screening with the addition of three disorders: biotinidase deficiency, maple syrup urine disease (MSUD), and hemoglobinopathies such as sickle cell disease. The act also designated the state laboratory as the sole testing site, mandated a fee to fund the program, and added comprehensive programs for follow-up, medical management, and quality assurance. *The newborn screening program is legislatively mandated through Public Health Code Act 368 of 1978 with additional amendments from 1986 through 2003. The specific enabling legislation is written as follows:

333.5431 Testing newborn infant for certain conditions; reporting positive test results to parents, guardian, or person in loco parentis; compliance; fee; " identification.="" index"="" misdemeanor;="" of="" pamphlet;="" price="" regarding="" specimen="" specimens;="" td="" violation="" waiver;=""> <td></td> <td></td> <td></td> <td>found - "The Newborn Screening Program is funded through fees generated from the purchase of the initial blue screening card. Hospitals and birthing attendants purchase the cards to have available to complete after a birth. The revenue collected from sale of the cards allows the state to offer laboratory, follow-up, and medical management services to all Michigan families." Michigan 2004 annual report</td> <td>found - "The informed consent requirements of sections 17020 and 17520 do not apply to the tests required under subsection (1) - state statute have opt-out form only for optional pilot test; 11 mandatory tests; total of 49 tests including CF, Mich annual report 2006</td> <td>Must consent for research; http://www.michigan.gov/docu/ments/michfinal_NBS_2006_Report_22219_4_7.pdf - 2006 Annual report has consent form - page 43.</td> <td>Y - for research</td> <td>Y</td> <td>Pamphlet: "S) The department shall rewrite its pamphlet explaining... (a) The nature and purpose of the testing program... (b) The purpose and value of retaining a blood specimen... (c) The department's schedule for retaining and disposing of blood specimens... (d) That the blood specimens...n.(1) may be used for medical research pursuant to subsection (7)(b)." - statute 2003</td> <td>LAW ON SPECIMENS - 7) The department shall do all of the following in regard to the blood specimens taken for purposes of conducting the tests required under subsection (1): (a) By April 1, 2000, develop a schedule for the retention and disposal of the blood specimens used for the tests after the tests are completed. The schedule shall meet at least all of the following requirements: (i) Be consistent with nationally recognized standards for laboratory accreditation and federal law. (ii) Require that the disposal be conducted in compliance with section 13811. (iii) Require that the disposal be conducted in the presence of a witness. For purposes of this subparagraph, the witness may be an individual involved in the disposal or any other individual. (iv) Require that a written record of the disposal be made and kept, and that the witness required under subparagraph (iii) signs the record. (b) Allow the blood specimens to be used for medical research during the retention period established under subsection (a), as long as the medical research is conducted in a manner that preserves the confidentiality of the test subjects and is consistent to protect human subjects from research risks under subpart A of part 46 of subchapter A of title 46 of the code of federal</td> <td>MI</td> <td></td> 				found - "The Newborn Screening Program is funded through fees generated from the purchase of the initial blue screening card. Hospitals and birthing attendants purchase the cards to have available to complete after a birth. The revenue collected from sale of the cards allows the state to offer laboratory, follow-up, and medical management services to all Michigan families." 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MINNESOTA																								
BIRTH DEFECTS	21-Jun-07		MN	Minnesota Birth Defects Information System	2005	1,632	70,919 - MN	Y	Y	BD	Minn. Statutes Section 144.2215 - 2219 - enacted 2004	This info is non-public security info under Minn. Statutes sec. 13.37	Notification requirements are as stated in Minn. Stat. Sec. 13.055	This info is nonpublic security info under Minn. Stat. Sec. 13.37	100% public CDC funding NCBDOD grantee		Persons can opt-out; see Minn. Stat. sec. 144.2216	Y	Y	Letter	Access is as stated in Minn. Stat. Sec. 144.2216	MN	Process to define use and access if data is disclosed to Non-MDH entities: "The process in Minn. Stat. Secs. 144.2215 - 2219 and 13.05, subd. 7."	
CANCER	12-Jul-07		MN	Minnesota Cancer Surveillance System	1988	500,000+		Y	Y	CA	Minnesota Stat. Secs. 144.671-144.69	This info is non-public security info under Minn. Statutes sec. 13.37	Notification requirements are as stated in Minn. Stat. Sec. 13.055	This info is non-public security info under Minn. Statutes sec. 13.37	100% public	N	N	N	n/a	No Access is as stated in Minn. Stat. Sec. 144.68 and Minn. Rules parts 4606.3303 and 4606.3304 (reports)	MN	Process to define use and access if data is disclosed to Non-MDH entities: "The processes contained in Minn. Rules parts 4606.3307 - .3309"		
IMMUNIZATIONS	1-Jul-07		MN	Minnesota Immunization Information Connection	2002	3.8 million 492,554 live births tested 2001 - 2007 (estimates for 2006-2007). http://www2.uthscsa.edu/nmsis/		Y	Y	IM	MN Statutes Sections 144.05 and 144.3351	This info is non-public security info under Minn. Statutes sec. 13.37	Notification requirements are as stated in Minn. Stat. Sec. 13.055	This info is non-public security info under Minn. Statutes sec. 13.37	100% public 2005 BDS Directory, 80% CDC grant, 5% general state funds; 5% March of Dimes in kind match to CDC grant. *Our thanks to the State of Wisconsin for making the MIC application available to Minnesota at no costs. Financial support for operating the MIC application was provided by Medical Health Plans (Minnesota Immunization Information Connection, login page, https://mic.health.state.mn.us/micsecurity_login.shtml , Accessed June 1, 2007)		Persons can opt out	N	Y	pamphlets and mailed notice	N	MN	Process to define use and access if data is disclosed to Non-MDH entities: "The processes in Minn. Statutes Sec. 144.5531 and 13.05, subd. 7"	
NEWBORN SCREENING	1-Jul-07		MN	Newborn Screening	1986	1,423 million		Y	Y	NBS	Minn. Statutes Section 144.125	This info is non-public security info under Minn. Statutes sec. 13.37	Notification requirements are as stated in Minn. Stat. Sec. 13.055	This info is non-public security info under Minn. Statutes sec. 13.37	100% public		Persons can opt out; see Minn. Statute Sec 144.125	Y	Y	brochures; web; orally by health care providers	N	MN	Process to define use and access if data is disclosed to Non-MDH entities: "The processes in Minn. Statutes Sec. 13.3805 and 13.05, subd. 7"	
MISSISSIPPI																								
BIRTH DEFECTS	14-Mar-06		MS	MS Birth Defects Registry	2000	16,652	42,395 - MS	Y	Y	BD	Section 41-21-205 of the MS Code of 1972 enacted 1997....	No	Follow Agency HIPAA guidelines	N/A	2005 BDS Directory, 90% genetic screening revenue, 10% MCH funds	N		N	N	N/A	N	MS		
CANCER	2-Mar-06		MS	MS Cancer Registry Database	1996	Unknown - we do not count individuals. We count cancer cases. The number of cases is unknown because of duplicate entries due to a software conversion that we are working to correct.		Y	Y	CA	Y	None that I am aware of. The MCR was located at the MS Department of Health until June 2004. The data was relocated to the University of MS medical Center in December 2004. No breach has occurred since the move.	N	There has been none that I am aware of.	Both federal and state funds	N	N	No, unless they request to view their medical record and then by HIPAA inclusion in this database should be recorded in the medical record	Note in the medical record	Y - The registry is located at the University of Mississippi Medical Center not the State Health Department	MS			
IMMUNIZATIONS	10-Mar-06		MS	Patient Information Management System (Immunizations) [found - Mississippi Immunization Registry, started in 1994]	1994	1,970,000 found "The Immunization Registry operates statewide in all 105 public health clinics throughout nine districts. We currently have approximately 600,000 clients on file and five and a half million shot records. The target age groups consist of two, 0-2 years of age and the extended group of 0-18 years of age." - http://www.msdc.state.ms.us/msdshsite/static31_395_136.html accessed 1/22/08		Y	Y	IM	Y	"The Mississippi Child Immunization Act of 1994 established a centralized registry to be operated by the Department of Health for health care providers to report all childhood immunizations given in the state. The goal of the Mississippi State Department of Health, Immunization Program is to insure that accurate and valid immunization data is available to health care providers, parents, and others who have a legitimate and tangible interest in immunization information." - http://www.msdc.state.ms.us/msdshsite/static31_395_136.html accessed 1/22/08.	N	N	8/2005 - new audit in progress	Medicaid Recovery Funds	Y	NR	Y	N	NR	N	MS	
OCCUPATIONAL INJURY	14-Feb-06		MS	Survey of Occupational Injuries and Illnesses	1992	Not Disclosable		Y	Y	OI	OSH Act of 1972	N	N	No external audit	50/50 Federal Government/State%	N	N	N	NR	Not known	MS			

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	14-Mar-06	MS	MS Newborn Screening Database	1982	167,745 - this is the number of screens(which) are done by Pediatric Screening and the blood spots are kept by them. Prior to June 2003, our screens were done by the Tennessee Department of Health Lab and blood spots are kept by them - April 21, 2006 email 288,654 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uthscsa.edu/nsis/		Y	Y	NBS	The statute is section 41-21-205 of the Mississippi Code, as amended by the 2001 Mississippi Legislature. Title 15 - Mississippi Department of Health Part IV - Office of Health Services Subpart 01 - Division of Genetics CHAPTER 38 RULES AND REGULATIONS GOVERNING NEWBORN SCREENING AND BIRTH DEFECTS REGISTRY 38 AUTHORITY 38.01 Statutory Authority Sections 41-21-201 and 41-21-203 of the Mississippi Code of 1972, Annotated, authorizes the State Department of Health to adopt rules and regulations to carry out the Newborn Screening and Follow-up Program for hypothyroidism, phenylketonuria (PKU), hemoglobinopathy, congenital adrenal hyperplasia (CAH), galactosemia, and other such conditions as specified by the State Board of Health as stated herein below in section B. Section 41-24-1 of the Mississippi Code of 1972, Annotated, authorizes the State Department of Health to adopt rules and regulations to establish a program of testing to determine the presence of sickle cell trait or sickle cell anemia.	No	Follow Agency HIPAA guidelines	N/A	Other/Fees	No, testing is mandated by state law	No, only if refusal of newborn screen and this is done at the hospital of birth	No, screening is mandated	N/A	N/A	MS							
MISSOURI																											
BIRTH DEFECTS	9/29/06	MO	Missouri Birth Defects Registry	1985	approx 1,725,000 total; approx 92,000 with defects	78,618 - MO	Y	Y	BD	General authority to collect public health data	N	N	None known	100% (2006 BDS Directory; 54% service fees; 37% MCH fund; 9% private foundations)	N	N	N	NR	N	MO							
CANCER	10/4/06	MO	Missouri Cancer Registry	1972 voluntary; 1984 mandatory					CA	FOUND - (RSMo 192.650, 192.653, 192.655, 192.657 and CSR 70-21.010)										MO							
IMMUNIZATIONS	1/22/08	MO	Missouri Immunization Registry	Jan 1 1994 - MOHSAIC presentation brief	1,117,022 (6,424,313 doses of vaccine recorded) per PPT presentation MO Dept of Health "Immunization registry Targeted Research Project, Grant #U1WCCU714725, NANCY L. HOFFMAN, DIRECTOR, CENTER FOR HEALTH INFORMATION MANAGEMENT AND EPIDEMIOLOGY.		Y	Y	IM	"Where do I go to receive a copy of my immunization records? There are a number of sources that may have an individual's immunization records, but the best way to have access to those records is to keep a copy of your own record and your child's records, if you received your immunizations at a local health department, your records will probably be on file there. Your doctor's office may also have your records. Schools and child care facilities require proof of immunizations and are another good source of information. The Missouri Department of Health and Senior Services maintains an immunization registry. Staff members who work with immunizations will gladly look up records for people with a need to know this information. However, participation in this system is voluntary. Most Missourians are not in the system, and most of the people in the system are young children. No agency or professional is required to keep these records, so it is always best to keep your own record in a safe place." - http://www.dhsas.mo.gov/FrequentlyAskedQuestions					voluntary									MO			
NEWBORN SCREENING	9/21/06	MO	Missouri Health Strategic Architecture and Information Cooperative (MOHSAIC)	2002	78,213 (the number of babies born in 2005. This number includes both normal and abnormal newborn screen results." (9/25/2006 email) "Of the 75,530 Missouri live births reported in 2003, 99.9 % of the babies received newborn screening. - "Newborn Screening in Missouri Program Overview and Test Addition" http://www.dhsas.mo.gov/NewbornScreening/WI_mems.pdf [550,192 live births tested 2001 - 2007 (estimates for 2006-2007) -		Y	Y	NBS	NO	N	Y	Jul-06	General revenue, federal funds do not know the percentage as this database is used by other programs (WIC, immunizations, Childhood lead program, etc.) and they have to financially contribute to the maintenance.	N	N	N	Yes, letter	N	MO							
"MULTIPLE DATABASE SYSTEM"	9/25/06	MO	Missouri Health Strategic Architecture and Information Cooperative (MOHSAIC) - includes databases for newborn screening, WIC, Immunization, Childhood lead, Breast & cervical cancer. Only staff designated to have access to the particular database can access the information.	1996	3,336,288 as of 9/25/2006		Y	Y		N	Y	Network security audit done accomplished in July 06.	100% Federal	N	N	N	NR	N	MO								

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	Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N)/ When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	Notes of Interest

MONTANA

BIRTH DEFECTS	22-Jan-08		MT		2000 (2007 report to CDC)		11,583 - MT			BD	NONE - received CDC Birth Defects grant in 2000 and again in 2002 (Report to CDC 2007). According to a "MT State Genetics Profile", Gold Systems is a software company that collect, manages, and refers data on children with birth defects. http://depts.washington.edu/genpol/docs/SIGenProfiles/Montana.pdf (Summer 2005)					"The Birth Defects Registry is no longer funded. It therefore needs to be revamped...Birth defects can still be entered into the CHRIS system so we can access the birth defects electronically." (Advisory Sub-Committee Current Minutes, CSHS Advisory Committee Meeting, February 3, 2006. mt.gov. http://www.dphhs.mt.gov/vPHSD/family-health/cshs/cshs-advisory-current-minutes.shtml)								MT	There was agreement that there needed to be improvement in how children with metabolic conditions are found. Dr. Schiesinger suggested better benchmarks for metabolic clinic patients as well as a plan for doctor education on the clinics. There was discussion about whether it was money, referrals, lack of diagnosis or all three. There was discussion of the birth defect registry tracking of metabolic disease, but the state ran out of funding for the registry...The Birth Defects Registry is no longer funded. It therefore needs to be revamped. John Johnson and MaryLynn Donnelly expressed interest in this. Birth defects can still be entered into the CHRIS system so we can access the birth defects electronically. As part of this discussion, MaryLynn asked if the birth defects registry is reactivated, would it be within CSHS mission to send out a letter to families of children with birth defects giving them direction to appropriate resources including our department. It was agreed this was appropriate. http://www.dphhs.mt.gov/PHSD/family-health/cshs/cshs-advisory-current-minutes.shtml FEB 3, 2006 minutes		
CANCER	11-Sep-06		MT	Montana Central Tumor Registry	1979	125,500		Y	Y	CA	Y	N	Unknown	Never done	20% State, 80% Federal	N		N	N	None	Y	MT					
"MULTIPLE DATABASE SYSTEM"	10-May-06		MT	Children's Health Referral and Information System (CHRIS); "The MPHIL is a population-based db in which all babies born in MT are screened. If they have a condition that qualifies them as a child with special health care needs, they go into the CHRIS system; "The birth defects registry is a module within CHRIS and contains the 46 CDC-reportable conditions for babies born in calendar years 2000 through 2004. CHRIS contains medical specialty clinic services provided to each child in the Special Health Services module of CHRIS. These data go back to 1988"; "We're not going to be able to give you a clear unduplicated count. Many of the babies are in both [birth defects module and Special Health Services module] because the nature of their conditions make them eligible for the Special [sic] Health Services clinics and other services. The inclusion criteria for the BDR are much stricter than for SHS, but it is not very likely that there are children in the BDR that are not also in SHS. You're just going to have to go with the 27K." (email)	1999 "CHRIS Oracle system was spec'd in 1998 and operational in 1999. Old Special Health Services data from 1988 was imported into the CHRIS system"	27,196		Y	Y	BD/NBS	N	N	N	2006	100% federal	Y	opt-out	Y	Y	Consent form	N	MT					
IMMUNIZATIONS	25-Sep-06	"Thank you, however, Montana will not be taking part in this survey" (email September 25, 2006) NO RESPONSE TO CERTIFIED LETTER 12/4/2006	MT	Montana State Immunization Registry						IM	NR found - WIZRO (Web-based Immunization Registry Database) is used to access the state immunization registry - http://www.dphhs.mt.gov/PHSD/ph-informatics/PH-informatics-PHDS-wizrd.shtml												MT				
NEWBORN SCREENING	22-Jul-08	See "MULTIPLE DATABASE SYSTEM" above	MT	The Genetics Program (SF 275 - signed by Gov 4/26/2005)		80,244 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nmsi/		Y	Y	NBS	Mont. Code Ann. §§50-19-201 to 211- NCSL "Mont. Code Ann. §§ 50-19-201 to - 211 These provisions require testing of all newborns less than 28 days old for inborn metabolic errors and authorize the State Department of Health and the Montana Developmental Center to administer the testing program and assist in providing services. They also establish a voluntary statewide genetics program to provide education; counseling and genetic testing, counseling, and education to parents and prospective parents. Specified services include follow-up programs for newborn testing, especially with respect to phenylketonuria; comprehensive genetic services; educational programs on diagnosing and treating genetic disorders; and counseling and testing programs to diagnose and manage genetic and metabolic disorders. Last updated: 17-Nov-04* - genome.gov														2005 - "voluntary" stricken from law	MT	

NEBRASKA

BIRTH DEFECTS	19-Sep-06		NE	Nebraska Birth Defects Registry	1973	33,000	26,145 - NE	Y	Y	BD	Both [Statutory or Regulatory Authority] Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646, §71-647, §71-48, §71-649) - enacted 1972.....and RULE: TITLE 186	None known	N	Annual completed fall of each year. Also ongoing security examination.	PHHS Block grant and State funds; 2005 BDS Directory; 100% MCH funds	N	N	N	NR	N	N	N	NE	N - We have access to medical records only if a disease is reportable; birth defects are reportable
CANCER	19-Sep-06		NE	Nebraska Cancer Registry	1987	164,830 TUMORS; We track tumors, not people		Y	Y	CA	Both [Statutory or Regulatory Authority] Neb. Rev. Stat. §§ 81-642 to 81-650 & RULE: TITLE 186 - HEALTH REGISTRIES AND RELEASE OF INFORMATION; CHAPTER 5 - RELEASE OF MEDICAL RECORDS AND HEALTH INFORMATION	None known	N	Annually, completed fall of each year. Also ongoing security examination.	NPCR & state funds	N	N	N	NR	N	N	NE	N - We have access to medical records only if a disease is reportable; all cancer is reportable	

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Blue Text: Information discovered through CCHF research																												
IMMUNIZATIONS	22-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/7/2006	NE	ImmuNet Nebraska		"The purpose of the program is to implement, operate, and maintain a computerized immunization tracking and recall system for providers in Douglas County and the State of Nebraska. ... Over one million immunizations administered to nearly 180,000 children served by the public clinics since 1993, are entered into the system." - http://www.douglascountyhealth.com/livnglimmunet.php				IMM	Can't find law or rule (12/5/08). FOUND: "Linda Ohry of the Nebraska Immunization Registry Coalition said Nebraska was one of the first states to initiate a public registry, but it has only been available for public providers and has not been modernized over the years. The state currently has two registry systems in place which contain records for only 20 to 30 percent of children in the state, she said." (Statewide immunization registry proposed." Unicameral Update Online, January 23-26, 2006)														NE			
NEWBORN SCREENING	21-Sep-06		NE	Pediatric Screening System	1-Jul-03	<85,000 183,687 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uthscsa.edu/nnsis/		Y	Y	NBS	Neb Rev. Stat. §§ 71-521 and 71-522 EFFECTIVE NEBRASKA DEPARTMENT OF 12/18/07 HEALTH AND HUMAN SERVICES 181 NAC 2 TITLE 181 SPECIAL HEALTH PROGRAMS CHAPTER 2 SCREENING OF INFANTS FOR METABOLIC DISEASES http://www.sos.ne.gov/rules-and-regs/research/Rules/Health_and_Human_Services/2007/181-0001-0002/181-0001-0002.htm	N	Not "required" but would recommend we do to our Policy Cabinet	August 2005; currently in the middle of another one to be completed by the end of September 2006	Private	N		N	N	N/A	No - only to the extent it is necessary for the purposes of tracking, monitoring, and referral relevant to newborn screening		NE					
NEVADA																												
BIRTH DEFECTS	16-Nov-06		NV	Nevada Birth Defects Registry	2002	3,093 BDR	37,268 - NV	Y, if parent/guardian allows	Y	BD	NRS 442.300-300; NAC 442 - enacted 1999	N	Only by ethics - no state law	None done to our knowledge	100% fees for BDR 2006 BDS Directory: 100% service fees	Y	Opt-out	Y if opting out	Y	Letter, or phone if need be	Y, for the BDR		NV					
CANCER	1-Sep-06		NV	Nevada Central Cancer Registry	1979	195,291		Y	Y	CA	NRS 457.230 Establishment and maintenance of system for reporting information; objectives; persons required to report information.	N	N	Unknown	85% federal grant; 14% client fees	N		N	N	N/A	Y		NV					
IMMUNIZATIONS	16-Nov-06		NV	Nevada WebZ: Immunization Registry	1994	1,000,000+ RWJF funding 1991 - State of Nevada doc	"Nevada WebZ currently contains over 111,000 records of children 0&6 5 years of age with two or more vaccinations. - http://health.nv.gov/index2.php?option=com_content&do_pdf=1&id=191	Y	Y	IM	We are working on it passed in 2007 (NRS 439.265)	Not to our knowledge	N	N/A	100% public	Y	Opt-out	Y	N	N/A	Yes; for disease surveillance		NV					
NEWBORN SCREENING	16-Nov-06		NV	Newborn Screening	older than 10 years	36,410 NBS abnormal results?? - 245,516 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uthscsa.edu/nnsis/		Y	Y	NBS	NRS 442.008	N	Only by ethics - no state law	None done to our knowledge	MCH Title V for NBS	Y	Opt-out	Yes if opting out	Y	Letter, or phone if need be	NR		NV	"We contract with Oregon State Lab. To run our newborn screening tests. They have a database to track results and follow-up on abnormal results. We don't keep a separate database." (email on September 14, 2006 from a different person than filled out our survey two months later)				
NEW HAMPSHIRE																												
BIRTH DEFECTS	4/14/06		NH	New Hampshire Birth Conditions Program	2003	255 infants in 2003. Please complete data request form available from http://www.dhhs.state.nh.us/DHHS/HSDMLIBRARY/Form/nonconf-data-request.htm	14,420 - NH	Y	Y	BD	RSA 132	N	There is no statute or rule addressing this.	Aug-04	100% Federal Funds CDC funding NCBDDO grantee; 2005 BDS Directory: 100% CDC grant	Based on individual facility policy		N	Based on individual facility policy	Varies per facility	Variable depending on the circumstances		NH					
CANCER	3/30/06		NH	New Hampshire Cancer Registry	Though established in 1986 the database starts from the year 1987	104,344		Y	Y	CA	New Hampshire State Statute-Title X-Chapter 141-B http://www.gencourt.state.nh.us/rsa/html/X/141-B/141-B-mrg.htm	None so far	Not Required under Present rules but the rules are in the process of being changed. ADDITIONAL COMMENT ON SURVEY: "The rules pertaining to Cancer registry (sic) would be updated in the fall or winter of 2006. So the rules planned would be covering more privacy issues etc."	In 2005	100% Public	Cancer is reportable disease as result there is no opt out for the patient.		N	N	N/A	Y		NH					
IMMUNIZATIONS	1/25/08	"NH does NOT have a registry. NH is not participating in a regional or other combined registry." (email September 20, 2006)	NH	ImmuPACT	1998	State registries that enroll children and record their vaccinations are another valuable tool for helping parents and providers identify immunization needs of individual children, assessing coverage in individual practices, and generating community wide estimates of immunization status. New Hampshire's immunization registry moved from pilot testing to provider enrollment in late 2000" - http://www.healthnh2010.org/immunization.htm		Y	Y	IMM	Chapter 141-C:20-f Immunization Registry, Aug 14, 1998 - http://www.gencourt.state.nh.us/rsa/html/X/141-C/141-C-20-f.htm(NO RULE YET - http://www.gencourt.state.nh.us/rules-he-p300.html)						Unclear - not required to participate						NH					
NEWBORN SCREENING	9/29/06		NH	Newborn Screening (database system held by regional screening lab contracted to do state screening)	1999	110,251 98,108 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uthscsa.edu/nnsis/		Y	Y	NBS	N.H. Rev. Stat. Ann. § 132:10-a (1999)	N	UMASS would notify NH (not sure what state of NH would do)	2004	Private??	N consent for data base; "informed dissent" for Newborn Screening found - 30 tests - http://www.nerg.org/brochures/NHEnglish.pdf	opt-out	N	N	NR	???		NH					

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Red Text: 2005 BIRTH RATE	General Database Information													Patient Consent Requirements			Parent/Guardian Notification		State Laws- Privacy			Notes of Interest	
Black Text: Information provided by survey respondents	Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N)/ When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	Notes of Interest
Blue Text: Information discovered through CCHF research																							

NEW JERSEY

BIRTH DEFECTS	15-Dec-06		NJ	New Jersey Special Child Health Services Registry	1983	approx. 170,000	113,776 - NJ	Y	Y	BD	LAW: P.L. 1983, c. 291 (N.J.S.A. 26:8 - 40 et seq. amended 2005, Chapter 176, Administration Rules., N.J.A.C. 8:20	Database is stored electronically on a device that is independent of any network. Access to the building and work area is protected by multiple layers of security. Database is protected by multiple levels of security. Data is stored in encrypted format	NA, see answer to H [Privacy Breach]	Ongoing	100% public	N	NA		The administrative rules (N.J.A.C. 8:20 et seq) require us to notify the parent/guardian of any child alive at the time of registration	We mail the parent/guardian a letter informing them of the registration; no information is included as to the nature of the medical reason the child is registered	Refer to N.J.S.A. 26:1-1 et seq. This New Jersey public health law covers a wide variety of programs, each having specific statutory authority described in detail.	NJ			
CANCER	23-Jan-08	The information that you are seeking for your survey is available to the public on our web site http://nj.gov/health/oes... the NJDHSS considers patient privacy essential and we take strong measures to ensure the privacy of all patients. ... (letter, December 19, 2006)	NJ	NR - New Jersey State Cancer Registry	1979	1.1 million (45,000 plus cases per year)		Y	Y	CA	Not found...but see: http://www.state.nj.us/health/oes/documents/oes_factSheet.pdf				"CDC funding for the state cancer registry began in 1994. The first diagnosis year for which cancer cases were reportable to CDC was 1995. This registry also receives funding from the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program."	N							NJ		
IMMUNIZATIONS	28-Nov-06		NJ	NJ Immunization Information System (Registry)	1994	700,000		Y	Y	IM	"New Jersey will have a registry to compile the immunization and health screening records of all children born in the state under a bill signed into law September 2, 2004, by Governor James E. McGreevey. "Law establishes immunization registry for children, Pharma Law Weekly, 9/21/04.	N	Y	Identify Theft Protection Act	Unavailable	100%Public	NJ's Registry Act 2004 provides an opt out provision for children born 1/1/98 and afterwards. Persons born prior to 1/1/98 consent to participate are required. (opt in)	both	Y	NJIS Consent To Participate Form Form-32	Persons born prior to 1/1/98, are required to sign an NJIS consent to participate.	Provider informs parent or patient and provides NJIS brochure, which outlines the purpose and benefits of Registry enrollment.	The Health Insurance Portability and Accountability Act 1996 (HIPAA) allows for public health purposes that health information can be provided to local, state or federal public health authorities, to prevent or control disease, injury or disability; to report child abuse or neglect; report domestic violence; report to Food and Drug Administration problems with products and reactions to medications; and report disease or infection exposure.	NJ	
NEWBORN SCREENING	25-Sep-06		NJ	MSDS (Metabolic Screening Database System)	1990 (in electronic form)	Approx. 1.7 million to date	[783,588 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.njdhssa.edu/main/]. Between 2001 and 2003, New Jersey	Y	Y	NBS	N.J.S.A. 8:18-1.1 Thru N.J.S.A. 8:18-1.13	N	N	N/A Confidential information: "The Department considers security procedures to be confidential information"	100% Public (Fee for Service)	N			N	NR	N	"The Department has the authority to review patient medical records in the facilities we license and regulate... However, DHSS does not regulate private practitioners."	NJ		

NEW MEXICO

BIRTH DEFECTS	3/8/06		NM	Birth Defects Registry New Mexico Birth Defects Prevention and Surveillance System (BDPASS)	1995 but being revised at this time. At this time, no data is going into the database.	We are currently in the process of revising the database. The original (Children's Chronic Conditions Register) was created with a vision of being accessible to health care providers, not conduct surveillance	28,835 - NM	Y	Y	BD	Birth defects have been reportable since 2000. NO LAW; Change in regulations, Jan 1, 2000.	No. The data is maintained on a computer that is a stand alone and not networked. Birth defects data is linked to the birth file. All identifiers are removed prior to analyzing the data for producing annual reports.	N	Unknown	100% public	N		N	N	NR	Y	NM	
CANCER	9/15/06		NM	New Mexico Tumor Registry	1966	Approximately 200,000		Y	Y	CA	New Mexico Administrative Code, Title 7, Chapter 4, Part 3	N	Unknown	2003	100% public	N		N	N	N/A	Y	NM	

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	Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N) When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State		
IMMUNIZATIONS	3/30/06		NM	NM Statewide Immunization Information System	2005	1.5 million		Y	Y	IM	Immunization Act of 2004 24-5-7. Immunization registry; creation: The department of health, in conjunction with the human services department, shall establish and maintain a state immunization registry. The registry shall be a single repository of accurate, complete and current immunization records to aid, coordinate and promote effective and cost-efficient disease prevention and control efforts. http://www.conwaygreene.com/nmsul/peet.dl?File=mplates&f=main-h.htm&2.0; HB 180 - PASSED *Chapered, Chapter No. 45, Relates to pharmacists; provides immunization reporting requirements for pharmacists; allows access to information in the immunization registry. 5-2006	N	N	None to date	100% Public	Y	Opt out	Y	N/A	NR	Y		NM	
NEWBORN SCREENING	9/20/06		NM	Access	1995*	>300,000 194,984 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhhsca.edu/tnss/		Y	Y	NBS	DOH	N	N	Unknown	public	N	Opt out	N	N	N		NM	"We do not have a registry for newborn genetic and hearing screening but plan to include them in the revision of the birth defects registry" (email March 9, 2006) BUT got survey 9/19/06	

NEW YORK

BIRTH DEFECTS	1/23/06	"in your letter, you identify several databases and information systems for which you had previously requested survey data. These particular databases and information systems are among the most sensitive data maintained by the Department of Health. The Department safeguards this information with a variety of technical and procedural controls, and does not release information regarding the nature of these controls. Consequently, the Department of Health will not be participating in the Citizens' Council national survey ..." (letter March 9, 2007) RESPONSE TO CCHC LETTER FAXED to Dept 11/20/2006	NY	New York State Congenital Malformations Registry	1982	1984 - 9,456 children (13,352 malformations) of 277,945 children live births in NY; 1995 - 271,042 live births and 10,282 children with 14,520 defects; 1996 & 1997 - 11,020 (1996) and 10,457 (1997) of 520,587 live births in 1996&1997 ("Virtually all reports are abstracted from inpatient hospital records, since malformations diagnosed on an outpatient basis are not well reported. Accurate hospital clinical recognition of malformations depends on clinical acumen and interest...") - 1996 Report; Congenital Malformations Report Summary Report Statistical Summary of Children Born in 1998 - 2001 and Diagnosed Through 2003 (Of 1,024,714 live births 1998 - 2001, there were 10,902 in 1998, 10,342 in 1999, 10,719 in 2000, and 10,294 in 2001); Congenital Malformations Registry Summary Report Statistical Summary of Children Born in 2002-2004 and Diagnosed Through 2006 (Of 503,799 live births in 2002 - 2004, there were 11,008 in 2002, 11,036 in 2003 and 11,678 in 2004). "This current report presents statistics for major anomalies only. Minor anomalies may cause problems in the determination of malformation rates because they are common and variably reported. They may not even be recorded in the medical chart." 2/20/07 2004 report	246,351 - NY	Y	Y	BD	Public Health Law Art. 2, Title 11, Sec 225(5)(i) and Art 2 Title 1, sec 206(1)(j); Codes, Rules and Regulations, Chap 1, State Sanitary Code, part 22.3 - enacted 1982.					CDC funding NCBDDO grants; 2005 BDS Directory; 45% CDC grant; 24% MCH funds, 16% other federal funding; 15% general state funds	N			N				NY		
CANCER	1/23/08	See above response	NY	R- New York State Cancer Registry (http://www.health.state.ny.us/statistics/cancer/registry/about.htm)	1997 - converted to new database (Population-based since 1976)	"The Cancer Registry receives almost two hundred thousand reports of invasive cancers per year, representing over 100,000 new tumors. "- http://www.health.state.ny.us/statistics/cancer/registry/about.htm		Y	Y	CA	New York State Public Health Law, Article 24, Title 1, Section 2401, Cancer: duty to report. "Reporting is not voluntary; Public Health Law, section 2401, requires it, and civil penalties can be levied for noncompliance with the law. The law specifies that reports should be submitted within six months of when the patient was seen." http://www.health.state.ny.us/statistics/cancer/registry/about.htm					N			N				NY			
IMMUNIZATIONS	7/21/08	See above response	NY	New York State Immunization Information System (NYSIIS)	1997 provider manual	"A statewide Web-based immunization information system (IIS) is currently under development. (http://www.health.state.ny.us/prevention/immunization/information_system/index.htm)		Y	Y	IM	Article 21, Title 6, of Public Health Law 2168. (http://www.health.state.ny.us/prevention/immunization/information_system/laws_and_regulations/public_health_law_section_2168.htm) was signed into law in August 2006 for all persons less than 19 years of age - Immunization Registry Law - "The goal of the new immunization information system is to establish a complete, accurate, secure, real-time immunization medical record that is easily accessible and promotes public health by fully immunizing all individuals appropriate to age and risk." (http://www.health.state.ny.us/prevention/immunization/information_system/index.htm); uses the Wisconsin Registry application, which has been used for adaptation and installation in 9 other states and territories. (http://www.health.state.ny.us/prevention/immunization/information_system/status.htm). NOTE: "... For the city of New York the commissioner of health and mental hygiene may include data collected in the citywide registry as provided in this					No, mandated except for persons 19 and older. There is an opt-in written consent form for individuals over age 18.				Y	one-page document providers will use to notify parents				NY	i) The commissioner may use the immunization registry for purposes of outreach, quality improvement and vaccine accountability, research, epidemiological studies and disease control; (ii) the commissioner of health and mental hygiene for the city of New York may use the immunization registry for purposes of outreach, quality improvement and vaccine accountability, research, epidemiological studies and disease control; (iii) local health departments shall have access to the immunization registry for purposes of outreach, quality improvement and vaccine accountability, epidemiological studies and disease control within their county; ...11. The commissioner may provide registrant specific immunization records to other state registries pursuant to a written agreement requiring that the foreign registry conform to national standards for maintaining the integrity of the data and will not be used for purposes inconsistent with the provisions of this section.

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	NEWBORN SCREENING	1/25/08	See above response	NY	NYS Newborn Screening Program (2002 -> 2.9 million tests - http://www.wadsworth.org/newbornphyguidelines.pdf)	Subcontract with Brooklyn Hospital Center - July 1, 2005 - May To create and maintain a comprehensive database of children diagnosed by the New York State Newborn Screening Program. - http://www.wadsworth.org/newborn/nymac/subcontracts.html - accessed 1/25/08	"The Newborn Screening Program in the Division of Genetic Disorders performs more than 11 million tests annually for more than 40 congenital diseases and the human immunodeficiency virus (HIV) which causes Acquired Immune Deficiency Syndrome (AIDS). The tests are conducted on the quarter of a million babies born each year in New York State. -" http://www.wadsworth.org/newborn/index.htm		Y	Y	NBS	Public Health Law 2500-a (http://www.wadsworth.org/newborn/law.htm) and NYCRR 10. Section 59-1 (02/01/1997) - http://www.wadsworth.org/newborn/regs.htm#D%2500-a... Testing, the recording of the results of such tests, tracking, follow-up reviews and educational activities shall be performed at such times and in such manner as may be prescribed by the commissioner. The commissioner shall promulgate regulations setting forth the manner in which information describing the purposes of the requirements of this section shall be disseminated to parents or a guardian of the infant tested.... (http://public.leginfo.state.ny.us/menugtf.cgi?COMMONQUERY=LAWS					Y	opt-out (religious)						NY			
NEW YORK CITY																											
	IMMUNIZATIONS	1/24/08	Didn't send NYC a survey. All info found online	NYC	New York Citywide Immunization Registry (CIR)	1997 (April 26, 1994 resolution). On July 7, 2005, an amendment expanding reporting requirements from age 7 and under to age 18 and under.		Y	Y	IM	City Health code section 11.04 and 11.07(d) - http://www.nyc.gov/html/doh/downloads/pdf/cir/whcode2005.pdf - Will stay separate from NYSIS, but can exchange data															NY	
NORTH CAROLINA																											
	BIRTH DEFECTS	21-Dec-06	"...We are concerned that your publication is likely to present this information in a biased framework that will undermine the interests of public health... Therefore, it is in the interest of public health that we resp2006ectfully decline to participate in your survey." (Letter, December 21, 2006) NO RESPONSE TO CERTIFIED LETTER 12/7/2006	NC	North Carolina Birth Defects Monitoring Program	1987	approximately 4,000-5,000 infants per year http://www.schs.state.nc.us/SCHS/bdmp - accessed 1/23/08	123,096 - NC	Y	Y	BD	NCGS 130A-131; RULES: North Carolina Administrative Code Title 10A- Chapter 47 Subchapter C - enacted 1995						The NCBDMP 2000 surveillance report reported funding from "State appropriation, the March of Dimes, and the [CDC]." The 2005 BDS Directory: 55% general state funds; 45% CDC grant	N							NC	
	CANCER	3-Jul-06		NC	Central Cancer Registry Database	Complete data back to 1990. Other data was reported prior to 1990.	480,000 estimated		Y	Y	CA	North Carolina General Statutes 130A-205; 130A-208 through 130A-215; associated Administrative Code, Chapter 26	Not that I'm aware of	N	None, that I'm aware of	100% public - almost 50% CDC, the rest State of North Carolina		Consent is not required to be in the database but it is required before participation in a research study	N	N	NR	N				NC	
	IMMUNIZATIONS	7-Jul-06		NC	North Carolina Immunization Registry (NCIR)	2005	4,054,937		Y	Y	IM	NC statutes, NC Information Technology Services, and Division of Information Resource Management REGISTRY NOT REQUIRED - 130A.152 - "Local health departments shall file monthly immunization reports with the Department. The report shall be filed on forms prepared by the Department and shall state, at a minimum, each patient's age and the number of doses of each type of vaccine administered. (c) Immunization certificates and information concerning immunizations contained in medical or other records shall, upon request, be shared with the Department, local health departments, and the patient's attending physician. In addition, an insurance institution, agent, or insurance support organization, as those terms are defined in G.S. 58-39-15, may share immunization information with the Department. The Commission may, for the purpose of assisting the Department in enforcing this Part, provide by rule that other persons may have access to immunization information, in whole or in part."	N	N	Uncertain	100% Public	N	N	NA	Y						NC	"Having the N.C. Immunization Registry in our clinic will be a dream come true! I cannot wait to be able to access all of our county's children with just a mouse click." - Carole Watson, RN, Forsyth Cty Dpt of Public Health - Immunization brochure (http://www.immunize.nc.com/images/PDFteaserBR_06.pdf)
	NEWBORN SCREENING	21-Dec-06	"...We are concerned that your publication is likely to present this information in a biased framework that will undermine the interests of public health... Therefore, it is in the interest of public health that we resp2006ectfully decline to participate in your survey." (Letter, December 21, 2006) NO RESPONSE TO CERTIFIED LETTER 12/7/2006	NC	North Carolina Newborn Screening Program - 20 conditions, specimen kept 2 years (2001NNSGRC)...then "indefinite" (2008 NNSGRC)	1965 PKU screening began; 1985 five conditions; 1997 MS/MS began	" Between 28 July 1997 and 28 July 2005, 344 078 infants were screened and 219 diagnoses were confirmed on newborns with elevated screening results(http://www.springerlink.com/conten/502760060h822577) PLUS.....372,904 births tested 2005-2007 (123,943 in 2005, and estimates for 2006-2007) - http://www2.uthscsa.edu/nnsjs/		Y	Y	NBS	N.C. Gen. Stat. §130A-125-NCSL; A filter paper blood spot sample is required by state law (GS 130A-125) - http://ajph.state.nc.us/Newborn/default.asp						N	Opt-out (GAO report): "Screening shall not be required when the parents or the guardian of the infant object to such screening." - § 130A-125.						NC		

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NORTH DAKOTA																									
BIRTH DEFECTS	7-Feb-06		ND	North Dakota Birth Defects Monitoring System	2004	2004 master list includes 2,746 individuals	8,390 - ND	Y	Y	BD	Health Statistics Act (Chapter 23-02.1) and Birth Report of crippled child (NDCC 50-10) address reporting but are not specific to birth defects monitoring.	N	Adhere to department's privacy and confidentiality policies. Any breaches are to be reported to supervisor and Department's risk manager for follow-up.	Unsure, although State's auditor's office provides periodic audits to state agencies.	100% public	2005 BDS Directory: "SSDI Grant"	N	Currently used for statistical purposes only.	N	N	NA	No. ND's birth defects monitoring system is passive. Medical records are not actively abstracted.	ND		
CANCER	15-Nov-05		ND	North Dakota Cancer Registry	1997	33,945		Y	Y	CA	Statutory	N	N/A	N/A	75% Federal, 25% State General Funds	N		N	N	N/A	N	ND			
IMMUNIZATIONS	15-Nov-05		ND	North Dakota Immunization Information System	1988	455,908		Y	Y	IM	North Dakota Department of Health	N	N	10/31/05	Public	N	Opt-out	N	Y	Vaccine administration record	N	ND			
NEWBORN SCREENING	25-Sep-06		ND	Excel Spreadsheet and Iowa (NMSP) Database	1964; started in 1992 with Iowa	134,552		Y	Y	NBS	Yes State of North Dakota N.D. Cent. Code § 25-17-04 [RULE?? - CHAPTER 33-06-16- http://www.legis.nd.gov/information/acdata/pdf/33-06-16.pdf]...History, Effective December 1, 1996; amended effective March 1, 2003; January 1, 2006; General Authority: NDCC 23-01-03(3), 23-01-03.1, 23-01-04, 23-01-15, 25-17-01, 25-17-02 Law Implemented: NDCC 23-01-03.1, 25-17-01(3), 25-17-02, 25-17-03, 25-17-05	N	Don't know	Don't know	Title V dollars for follow up and Fee for Service for NBS	No Consent Required	Yes there is a form, but no government form	N	NA	Y	ND				
OCCUPATIONAL INJURY	9-Jan-06		ND	Oracle database	Began collecting data with the first claim - Workers Compensation in ND became law in 1919	519,261 injury id's in the database		Y	Y	OCC	NDCC Title 65	N	NA	Audit conducted in December - report not yet finalized.	100% funded by employer premiums	N		N	NA	1 don't know. You would have to contact the state health department	ND				
SEXUALLY TRANSMITTED DISEASES	24-Feb-06		ND	STD/MIS	2000	Approximately 8500 individuals		Y	Y	STD	Statutory/regulatory authority for reporting of designated reportable conditions (ND Administrative Code 33-06-01, ND entry Code 23-07-01); no specific statutory/regulatory authority for us/maintenance of database	N	N	Fall 2005	100% public (federal funding via CDC)	N		N	NR	Y	ND				
OHIO																									
BIRTH DEFECTS	13-Feb-06		OH	Ohio Connections for Children with Special Needs	2005 - database still in development	0, still in development	148,388 - OH	Yes, when implemented	Yes, when implemented	BD	Ohio Revised Code 3705.31 ORC 3705.30 - 3705.36 (July 2000) and Admin. Rules June 3, 2005.	N/A	Unsure at this time	N/A	100% Public CDC funding NCBD00 grantee; 2005 BDS Directory: 100% CDC grant	Legislation does not require consent to collect information. Parents may request removal of child's personally identifying information.	Yes, currently in development	N	NR	Unsure at this time	OH	Contact number and email for person who did not actually fill out survey			
CANCER	19-Jan-06		OH	Ohio Cancer Incidence Surveillance System	1992	850,000		Y	Y	CA	Statutory	N	N	Annually	NPCR through the CDC and Ohio legislature	N		N	NR	Y	OH				
IMMUNIZATIONS	1-Dec-05		OH	IMPACT Statewide Immunization Information System, Keene press release March 1 2002	2/2002 (web); 1995 (previous)	2,939,000		Y	Y	IM	part of Healthy 2010 federal objective	N	audit logs - can see who had looked at records	Sept. 05	State and federal	N		Y	pamphlet handed out by providers	don't know	OH	phone interview only; no survey response form			
NEWBORN SCREENING	9-Feb-06		OH	MSDC (1993-2000), Lifecycle (2000 Present)	1993	2,807,513		Y	Y	NBS	OAC 3701-53-03(D), ORC 3701.501 and 3701.502	N	N	A full audit has not been performed; however, in January 2006 ODH IT developed an operational plan for the NBS software.	Other - the program is entirely fee-based	N		N	NR	Y	OH				
OCCUPATIONAL INJURY	9-Jan-06		OH	Census of Fatal Occupational Injuries	1992	Roughly 195 per year since 1992		Y	Names are store [sic] in a confidential database only in the state. They are not stored centrally	OCC	OSH Act of 1972	N	N	No external audit	50/50 federal/state	N		N	NR	Unsure	OH				
OKLAHOMA																									
BIRTH DEFECTS	23-Jan-08	NO RESPONSE TO CERTIFIED LETTER 12/4/2006	OK	NR-Oklahoma Birth Defects Registry	1992, statewide 1994	From 1994 - 1998 - 8,950 children reported (Annual Report).	51,801 - OK	Y	Y	BD	63 O.S. Section 1-550.2 - enacted 1992		Not required by law		CDC funding NCBD00 grantee; 2005 BDS Directory: 57% MCH funds; 30% CDC grant; 13% general state funds	N		Not required by law			OK	*Any person who, in violation of a written agreement to maintain confidentiality, willfully discloses any information provided pursuant to this section shall be deemed guilty of a misdemeanor, and upon conviction thereof shall be punished by a fine of Two Hundred Dollars (\$200.00) or imprisonment in the county jail for not more than thirty (30) days, or by both such fine and imprisonment.*			
CANCER	12-Sep-06		OK	Oklahoma Central Cancer Registry	1997	160,738		Y	Y	CA	Statutory [§631551.1. Tumor registry. A. The State Commissioner of Health shall establish and maintain an up-to-date tumor registry to ensure an accurate and confirming source of data concerning such carcinous, precancerous and inermous diseases as the State Board of Health may by rule specify. Such registry may include data necessary for epidemiological surveys and scientific research, and other data which is necessary and proper to further the recognition, prevention, control, treatment and cure of cancer, precancerous and inermous diseases.]	N	No, only OSDH privacy officer	2003	100% public (Federal and State)	N		N	N	N/a	N	OK			
IMMUNIZATIONS	25-Sep-06		OK	Oklahoma State Immunization Information System	1995	2,264,014		Y	Y	IM	None	N	N	2004	100% Public	No, however parent signs consent to release information to schools/day care/other facilities requiring immunization information		N	NR	No, (contingencies exist on what access is allowable)	OK				

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			OK	Newborn Screening - Neumetrics	1989	Lab database: 606,202; Follow-up database: 103,342 351,568 live births tested 2001-2007 (estimates for 2006-2007) - NNSGRCC		Y	Y	NBS	Indirectly - i.e. provide testing and follow-up; a database is needed to perform these activities Okla. Stat. §53-1-533, 53 - NCSL "Laws 1971, c. 18, § 1, emerg. eff. March 16, 1971. §53-1-533. Phenylketonuria, related inborn metabolic disorders and other genetic or biochemical disorders - Educational and newborn screening programs...D. The State Board of Health shall promulgate any rules necessary to effectuate the provision of this section. Added by Laws 1965, c. 252, § 1. Amended by Laws 2002, c. 463, § 1, eff. Nov. 1, 2002; Laws 2005, c. 452, § 1, eff. Nov. 1, 2005. §631534. Tests. The State Board of Health shall make such rules and regulations pertaining to such tests as accepted medical practice shall indicate, and is authorized to make such testing mandatory if sufficient evidence exists that the public has been negligent in accepting such practice and if the Board considers it in the	N	N	Unknown	100% public	N		N	N	NA	N	OK					
OREGON																											
		Responded in email on 3/6/2006 that they have no birth defects registry	OR	Birth Defects Surveillance Program - "Oregonians do not have the complete picture of birth defects rates in their state and communities because their state has not established a birth defects monitoring program. Approximately 46,000 babies born in Oregon in 2000 were not tracked for birth defects." - Trust for American's	Oregon Envir Council asks for registry in Feb 2008		45,922 - OR			BD												OR					
			OR	Oregon State Cancer Registry	1996	Approx 154,000		Y	Y	CA	ORS 432.500-432.900	N	N	N/A	100% public	N		N	Y	Letter	Y	OR					
			OR	Oregon Immunization ALERT Childhood Immunization Registry	1996	1.8 million		Y	Y	IM	Oregon Revised Statutes 433.090 to 433.102, Oregon Administrative Rules 333-049-0010 to 333-0049-0130	N	N - considering legislation on this topic for the next biennium	2004	Approximately 15% private funding, 85% public funding	N		N	N	No, however, notification is included in the Newborn Handbook given to all new parents. Clinics are also encouraged to distribute parent brochures that explain the registry.	Health Departments are authorized users of the ALERT registry	OR					
		NO RESPONSE TO CERTIFIED LETTER 12/4/2006	OR	Northwest Regional Newborn Screening Program		326,167 live births tested 2001 - 2007 (2006-2007 estimates) - NNSGRCC - accessed 1/26/08; "From 1996-2000, 190,814 Oregon newborns were screened for the panel of six disorders." - http://mchneighborhood.ichp.edu/pacnorsg/Oregonassessment2/NewbornMetabolicScreening.pdf ; "Each year the program tests more than 200,000 specimens representing more than 1,200,000 tests per year! The Newborn Screening Program is entirely supported by fees." http://www.oregon.gov/DHS/ph/nbs/about_us.shtml ; "Serving as the regional center for newborn screening, five states participate in the regional program (Alaska, Hawaii, Idaho, Oregon, and Nevada), along with military facilities in Washington State and Korea, and birthing facilities in Guam, Japan and Kwajalein." - Northwest Newborn Regional Screening Program		Y	Y	NBS	Oregon Revised Statute (ORS) 433.285, ORS 433.290, ORS 433.295, ORS 192.537, ORS 743.726 "Family Net - DHS is currently planning a client-based, integrated child and family health data system called the FamilyNet Data System. The purpose of such a system is to coordinate information about children and families receiving public health, social, and educational services. The system can be used to identify individual and family risks, monitor services to children and families over time, facilitate care coordination, and assess the public health service delivery system. Newborn Data Linking - The primary goal of newborn data linkage is to create a mechanism to identify and follow-up with children who have not received appropriate newborn screening tests or who have abnormal results. In early 2002 the Office of Family Health launched a pilot project with three hospitals, the Newborn Screening Program at the Oregon State Public Health Laboratory, and the Center for Health Statistics to link electronic birth certificates, metabolic screening, and newborn hearing screening data using the metabolic screening number as the unique identifier. Pilot testing of the linkage process has been successful and plans are emerging to expand linkage statewide and connect follow-up functions to the FamilyNet system." (http://mchneighborhood.ichp.edu/pacnorsg/Oregonassessment1aData-Surveillance.pdf)			100% Fees	N	Y - religious											"Religious Objections A religious exemption can be claimed from the requirement for the newborn screening tests. In this event, the person otherwise responsible for submitting the specimen for testing is responsible for submitting a copy of the Informed Dissent form to the state laboratory signed by the infant's parent; see page 27. Parental Refusal In the event a parent refuses the testing, the program strongly urges practitioners to obtain an "Informed Dissent" signed by the parent and placed in the infant's medical record. Suggested wording is provided on the next page." - http://www.oregon.gov/DHS/ph/nbs/nbspractmanual.pdf ; "In addition, representatives from Oregon's newborn screening program and state genetics program are participating in a Health Resources and Services Administration funded multi-state Maternal and Child Health Improvement Project that focuses on conducting research, identifying strategies, and developing materials which address ethical, legal, social, and financial issues surrounding the use of MS/MS for newborn screening of a culturally and ethnically diverse population." - http://mchneighborhood.ichp.edu/pacnorsg/Oregonassessment2/NewbornMetabolicScreening.pdf

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PENNSYLVANIA																						
BIRTH DEFECTS	1/19/2006 and July 22, 2008	PA	Pennsylvania Birth Defects Surveillance Database	2003	Source does not know. [*] In Pennsylvania, approximately 2% of births (2 out of 100 babies) or 2,761 had a birth defect reported on their birth certificate in 2002. http://www.dsf.health.state.pa.us/health/wpl/view.asp?a=179&q=242217	145,383 - PA	Y	Y	BD	("Current legislation or rule: not applicable") - 2007 BD Directory			Aug-06	State and Federal 2005 BDS Directory: 100% MCH funds	N	N	N	N	N	Y	PA	Birth Certificates - the only source of Birth Defects tracking they have (7/08 - "Pennsylvania Follow-up, Outreach, Referral and Education to Families (PA FORE Families) is a monitoring and outreach system that uses existing secondary data sources to identify infants and children with birth defects. PA FORE Families was developed to improve monitoring of the occurrence of birth defects and to identify more infants and children under the age of two with a birth defect so they can be linked to health care services and early intervention programs as quickly as possible...PA FORE Data Sources: Birth records from the Department's Bureau of Health Statistics and Research; and Outpatient/inpatient hospital discharge data from the Pennsylvania Health Care Cost Containment Council (PHCC). PA FORE Families Pilot: The initial PA FORE Families pilot project began on July 1, 2003, and continued through June 30, 2004. During this time, a statewide birth defects monitoring database was created by matching birth records and hospital discharge records." - http://www.dsf.health.state.pa.us/health/wpl/view.asp?a
CANCER	1-Aug-05	PA	Cancer Pennsylvania Cancer Registry	Phased in starting in 1962 statewide 1985	approx. 77,000 new cases each year [1988 - 58,220, 1989-58,665, 1990-60,953, 1991-63,469, 1992-66,090, 1993-67,232, 1994-66,665, 1995-67,210, 1996-68,306, 1997-70,512, 1998-71,655, 1999-68,873, 2000-69,065, 2001-72,645, 2002-72,102, 2003-71,291, 2004-70,837, 2005-71,788 - all invasive; in situ NOT included		Y	Y	CA	PA Cancer Control, Prevention and Research Act; Disease Prevention and Control law of 1955 (Reps exist in 28 Pa. Code Chapter 27)	N	N	There are yearly network vulnerability and penetration testing security audits performed. The last one was done in August 2004. Also in addition each year the State Auditor's General's Office, as part of the yearly GAAP audit and as part of the single audit for federal purposes, engages a 3rd party independent review of computer security and controls of all systems.	Federal and State	N		NR	There is no notification of the database	NR	"In Pennsylvania, there is no law that allows the Department of Health to have complete access to medical records of any individual at any time for any reason. There are, however, exceptions whereby the Department is permitted to gain access to some or all of an individual's medical record for a specific purpose. For example, in the case of a communicable disease outbreak, or in the case of individuals with tuberculosis, the department in carrying out its public health functions, would be able to access individual's medical records."	PA	
IMMUNIZATIONS	1-Aug-05	PA	Immunization Registry [Pennsylvania Statewide Immunization Information System (PA-SIS) - "The Statewide Immunization Information System (SIS) is a web-based immunization registry. In 2006, SIS was implemented in 206 provider sites including state health centers, county and municipal health departments (exclusive of Philadelphia), FQHCs, Rural Health Clinics, PPA sites and private provider practices. - http://www.dsf.health.state.pa.us/health/healthFinal_2006_Annual_Report1.pdf]	2000	"Pennsylvania birth records are electronically imported into the PA-SIS on a weekly basis. Patient records are currently created in the PA-SIS for all Pennsylvania births from 1996 to date. For patients born in Pennsylvania prior to 1996, providers create the patient record. For all patients born outside of Pennsylvania, providers create the patient record." - http://www.dsf.health.state.pa.us/health/wpl/view.asp?a=179&q=242237&PMH=H&e%20providers%20required%20to%20back-enter%20the%20records%20of%20existing%20patients?	240,000	Y	Y	IM	none	N	N	See above	Federal and State	N		NR	See above	NR	See above	PA	
NEWBORN HEARING SCREENING	1-Aug-05	PA	Newborn Screening/Hearing	1-Jul-02	Grand total of 514,186 screened to date for hearing loss, with the caveat that figures for the 2005 birth year are preliminary." (email April 27, 2005); 3,201 - "The 2021 is the number of newborns referred to DOH because they failed their hearing screening and needed DOH follow-up." (survey, August 1, 2005)		Y	Y	NBSHrg	Infant Hearing Education, Assessment, Reporting and Referral Act	N	N	See above	Federal and State	N		NR	See above	NR	See above	PA	
NEWBORN SCREENING	1-Aug-05	PA	Newborn Screening/Metabolic	1965	1,788,098 - "the number of newborns tested and in the metabolic newborn screening database."		Y	Y	NBS	The Newborn Child Testing Act of 1965 Penn. Statutes 28. Screening and Follow-up for Disease of the Newborn - http://www.pacode.com/secure/data/028/chapter28/chap28toc.html	N	N	See above	Federal and State	N	religious opt-out §28-12	NR	See above Prior to specimen collection, the health care provider shall provide the pregnant woman, prior to the infant's birth, or the mother or guardian, after the infant's birth, with a pamphlet supplied by the Department to explain the nature of the newborn screening blood tests for the diseases in § 28-2 (relating to newborn diseases listed)	NR	See above	PA	§28-57A health care provider, testing laboratory, the Department or any other entity involved in the newborn screening program may not release any identifying information relating to any newborn child screened in the newborn screening program to anyone other than a parent or guardian of the newborn child or the health care provider for the newborn child designated by a parent or the guardian except as follows: (1) As may be necessary to provide services to the newborn child. (2) With the consent of the newborn child's parent or guardian. (3) With the child's consent when the child is 18 years of age or older, has graduated from high school, has married or has been pregnant. (b) Only the Department will have the authority to release or authorize the release of nonidentifying information concerning the newborn screening

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TEXAS																							
BIRTH DEFECTS	7-Feb-06		TX	Birth Defects Registry Texas Birth Defects Epidemiology and Surveillance Branch	1994	92,905	385,915 - TX	Y	Y	BD	Chapter 87, Texas Health & Safety Code, Title 2, Subtitle D, Section 1, Chapter 87, (Texas Birth Defects Act of 1993	N	N	No external security audits have been completed	100% Public 2005 BDS Directory: 51% general state funds; 33% MCH Title V funds; 16% Preventive Health Block Grant - **Note: does not include CDC-funded Texas Center for Birth Defects Research and Prevention**	N		N	N	N/A	Y	TX	
CANCER	12-Jan-05		TX	Cancer Registry (Sand Crab)	1976 (only records 1995 forward now in database)	938,253 (as of 12/7/05)		Y	Y	CA	Chapter 82, TX Health and Safety Code	No	No - this HIPAA obligation does not apply since we are not a provider or clearing house	No external security audits have been conducted.	100% public	N		N	N/A	Y	TX		
HIV/AIDS	5-Jan-06		TX	HIV/AIDS Reporting System (HARS)	1985	95,379		Y	Y	HIV	CDC HIV/AIDS Surveillance Cooperative Grant. Texas Health & Safety Code Chapter 81, Texas Administrative Codes Chapter 97, Texas STD/HIV Reporting Guidelines. ** Additional Information in Comments	N	Breaches are immediately reported to the CDC, then await instructions from CDC	January 2005 by the CDC. Contracted sites have annual visits	CDC Surveillance Cooperative Grant	Per 45 CFR § 164.506 in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [sic] Privacy Rules, Patient consent is not required for use of information in the HARS database. ** See Comments for additional information.	For HIV testing only	Per 45 CFR § 164.520 in HIPAA [sic] Privacy Rules, adequate notification is required. ** See Comments for additional information.	Disease Intervention Specialists are assigned to notify	Per 45 CFR § 164.512(B) in HIPAA [sic] Privacy Rules, DSHS is provided access to medical records in Texas. ** See Comments for additional information.	TX	COMMENTS: ** Rules for Reporting and Confidentiality of Sexually Transmitted Disease Case Information are found in the Texas Register (25 TexReg 1977), under Texas Administrative Code, TITLE 25 HEALTH SERVICES, PART 1 DEPARTMENT OF STATE HEALTH SERVICES, CHAPTER 97 COMMUNICABLE DISEASES, SUBCHAPTER F SEXUALLY TRANSMITTED DISEASES INCLUDING ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) AND HUMAN IMMUNODEFICIENCY VIRUS (HIV); RULE § 97.132, RULE §97.133, RULE § 97.145, & RULE §97.146. For additional information or a full text version of the Texas Administrative Code, visit the Disease Reporting links on our website: http://www.tdh.state.tx.us/hivstd/reporting/ ** For additional information or a full text version of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [sic] Privacy Rule and Public Health Guidance from CDC and the U.S. Department of Health and Human Services, visit the HIPAA [sic] links on our website: http://www.tdh.state.tx.us/hivstd/reporting/	
HIV MEDICATION PROGRAM	20-Dec-05		TX	Texas HIV Medication Program (THMP)	1987	45,000		Y	Y	HIV MEDS	This is the State ADAP (AIDS Drug Assistance Program) for Texas, which was established in 1989 by Senate Bill 959	N	We would first consult with our General Counsel to determine an official response in the unlikely event of such an occurrence.	Specific date not known; IT staff are responsible for internal & external security issues	This is a state government program funded by Federal/RyanWhite and designated state dollars. [sic]	No, all applicants to the program must be entered into the database for processing.	Yes; each THMP Application for Assistance must be signed by the individual applicant.	No, all applicants seeking assistance must be entered into the THMP database	N/A	Unknown	TX		
IMMUNIZATIONS	22-Nov-06		TX	Houston-Harris County Immunization Registry	1992	1.1 million		Y	Y	IMM	State of Texas	N	N	NA	100% private	Y	Opt-in	Y	N	NR	Y	TX	
IMMUNIZATIONS	25-Sep-06		TX	ImmunTrac	Batch imports - 1995; user interface - 1996	5.3 million		Y	Y	IMM	Texas Administrative Code, Title 25, Part 1, Chapter 100	N	N	(decline to answer)	100% public	Y	Opt-In	Y	Y	letter	ImmTrac does not have complete access to medical records	TX	
NEWBORN SCREENING	14-Mar-06		TX	Newborn Genetic Screening (NBS) Laboratory Information Management System (LIMS)	1991	Approximately 5,300,000 2,700,321 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uthsca.edu/nhsis/		Y	Y	NBS	Tex. Code Ann. Health and Safety §33.001 to .038 NCSL	N	N	No external security audits have been completed	Paid for by collection of newborn screening fees	N	(a parent can opt out of NS for religious purposes, which would keep them out of the database)	N	N	N/A	N	TX	
SEXUALLY TRANSMITTED DISEASES	7-Mar-06		TX	STD*MIS	1997	997,686 (Feb 2006)		Y	Y	STD	Texas Health and Safety Code, Chapter 81, Texas Administrative Code, Chapter 97	N	N	None	100% public	N		N	NA	Yes, for Communicable Diseases	TX		
UTAH																							
BIRTH DEFECTS	4-Jan-07		UT	Utah Birth Defect Registry	1994	The number of individuals in the database is not public information	51,566 - UT	Y	Yes - However privacy is strictly guarded and this information is not accessible to the public	BD	Utah Administrative Code R398-5 under the authority of Title 26-1-30(2)(c), (d), (e), (g), (h), (i), 26-10-1(2), 26-10-2, 26-25-1 Birth Defect Rule, Utah Admin Code R398-5 (1999) - NO SPECIFIC LAW	N	Yes - By state law we are required to notify all persons in the database if there is a breach.	An RFP (request for proposal) for an external security audit will soon be in place with the audit taking place sometime in the next six months	100% Public 2005 BDS Directory: 80% MCH fund; 20% CDC grant	N	N/A Consent is not required	N	N/A	Utah administrative code allows for the limited access to medical records of children born with birth defects and their mothers	UT	"I spoke with my Director and she has stated that we are not going to participate in this project. Thanks." (email March 2, 2006) BUT the department responded after Governor received CCHF's December 21, 2006 certified letter requesting participation	
CANCER	8-Feb-06		UT	Utah Cancer Registry	1966	NR		Y	Y	CA	Cancer Reporting Rule: R-384-100, State of UT	N	N	2 0 0 4	NCI - Small appropriation from Utah Department of Health.	N		N	NR	**?	UT		
IMMUNIZATIONS	24-Mar-06		UT	Utah Statewide Immunization Information System	1995	1,595,103 as of December 2005		Y	Y	IM	UT State Rule R386-800	N	N	About 2003	50% public; 50% private	Y	Opt-out	Y	Y	Notice in birth packet at the hospital	Not sure	UT	
NEWBORN SCREENING	3-Oct-06		UT	Newborn Screening Oracle Database	Jan-06	41,000 362,716 live births tested 2001-2007 (estimates for 2006-2007) - NNSGRC		Y	Y	NBS	Regulatory Rule R398-1, Newborn Screening Authorizing, and Implemented or Interpreted Law: 26-1-6, 26-1-30(2)(a), (b), (c), 26-10-6	N	No (currently no policy)	Jan-06	Screening Card Fee for Service	N		N	N	NR	N	UT	"The hospitals and birthing centers buy the cards from us...so it is private. I assume they pass the cost on to the patient (and thus the insurance companies). We waive the cost of the card for about 1% of our patients. These are usually those that use an uncertified mid-wife and come from Utah's unique polygamous communities. They would not be tested otherwise." (October 3, 2006 email)

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VERMONT																																
BIRTH DEFECTS		23-Jan-08	CCHF likely sent a certified letter in December 2006 but unable to find USPS receipt	VT	Birth Information Network (BIN)	2006	??	6,295 - VT	Y		BD	Act 32 (Title 18 VSA §5087) - enacted 2003				100% CDC grant							VT	No birth defects registry at this time BUT found: "Vermont Birth Information Network" funded 2003 - 2008 by CDC because there is "no one system exists that tracks all birth defects. This project will develop a comprehensive surveillance system for the birth defects component of the Vermont Birth Information Network" - http://www.cdc.gov/ncbddd/birthdefects/vermont.htm - accessed 1/23/08 (site was updated Jan 3, 2008)								
CANCER		30-Jun-06		VT	Cancer Registry	1994	38,880		Y	Y	CA	18 VSA §§ 151-157 § 152. Establishment of cancer registry (a) The commissioner shall establish a uniform statewide population-based cancer registry system for the collection of information determining the incidence of cancer and related data. The secretary shall adopt rules necessary to effect the purposes of this chapter, including the data to be reported, and the effective date after which reporting by health care facilities and health care providers shall be required. (b) All cancers diagnosed or treated in the state shall be reported to the representative of the health department authorized by the commissioner to compile the cancer data, or any individual, agency, or organization designated to cooperate with that representative.	N	N	Dec-04	100% Federal	N	N	N	n/a	Y	VT	Additionally, the commissioner or his or her authorized representative shall have physical access to all records which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified cancer patient. Willful failure to grant access to such records shall be punishable by a fine of up to \$500.00 for each day access is refused. Any fines collected pursuant to this subsection shall be deposited in the general fund. (Added 1993, No. 90, § 2) § 155. Disclosure (a) The commissioner may enter into agreements to exchange confidential information with other cancer registries in order to obtain complete reports of Vermont residents diagnosed or treated in other states and to provide information to other states regarding their residents diagnosed or treated in Vermont. (b) The commissioner may furnish confidential information to other states' cancer registries, federal cancer control agencies, or health researchers in order to collaborate in a national cancer registry or to collaborate in cancer control and prevention research studies. However, before releasing confidential information, the commissioner shall first obtain from such state registries, agencies, or researchers agreement in writing to keep the identifying information confidential and privileged. In the case of researchers, the commissioner shall also first obtain evidence of the approval of their academic committee for the protection of human subjects established in accordance with part 46 of Title 45 of the Code of Federal Regulations. (Added 1993, No. 90, § 2)									
IMMUNIZATIONS		3-Aug-06		VT	VT Immunization Registry	2004	57,050		Y	Y	IM	1 - Vermont Statutes Title 18 Health Care Public Health Regulations/CHAPTER 21. COMMUNICABLE DISEASES/Subchapter 4. Immunization/§ 1129. Childhood immunization registry. "b) The department may use the data to create a registry of childhood immunizations. Registry information regarding a particular child shall be provided, upon request, to the child after the child reaches the age of majority and to the child's parent, guardian and health care provider. Registry information shall be kept confidential and privileged and may be shared only in summary, statistical or other form in which particular individuals are not identified. (Added 1997, No. 91)	N	N	Dec-04	100% public	N	N	N	NR	N	VT										
NEWBORN SCREENING		14-Jul-06		VT	VT Newborn Screening Program Database	1989	49,893 (VT only)	42,840 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/insie/ - in 2006 screening expanded to 36 tests. CF not included (http://www.slttrib.com/news/ci_8293862. Utah health officials want cystic fibrosis tests for newborns. 2/28/06)	Y	Y	NBS	RULE: "b. Screening tests shall be performed on newborn infants, except that after being informed of the reasons for and the costs of the tests, the parents, guardians, or custodians may refuse to have the tests performed. Documentation of such refusal shall be sent to the Vermont Department of Health, Vermont Newborn Screening Program." - http://healthvermont.gov/reg/newborn_screening_reg.aspx..... LEGISLATION??? Legislation: Genetic legislation may be clearly expressed in public health statutes. It may also be embedded in other regulations, administrative rules, or other less obvious statutes, e.g. labor law. Identifying and interpreting state genetics legislation is not necessarily straightforward. One example of genetic-related legislation in Vermont is: Click here for: Title 18: Health Chapter 217 - Genetic Testing	N	On as case by case basis	2004: plans are underway at NENSP to have this done more frequently	Approximately 45% private and 55% public	Only if family chooses to opt-out	Opt-out	Y	N	N/A	Not to my knowledge.	VT									
VIRGINIA																																
BIRTH DEFECTS		19-Jul-05		VA	Birth Defects Virginia Congenital Anomaly Reporting and Education System - VaCARES	1987	99,483 (email September 14, 2006)	104,555 - VA	Y	Y	BD	Code of VA 32.1-69.1,69.2 enacted 1985, amended 1986, 1988, 2006	No - secure system	No specific requirement in code. Notification if privacy breach	2002 - web based brought online	Federal Title 5 - state/federal funds 2002-2010 NCBDD (\$150,000 - \$180,000); 2005 BDS Directory; 70% MCH funds; 30% CDC grant	N						VA	phone call interview; no survey received								
CANCER		21-Jul-05		VA	Cancer	1970 - possibly earlier	550,000 individual case reports; # of people not the same		Y	N	CA	Code of VA 32.1-70, 71	N	No written procedure - state has sanction	No formal test of security arrangements; info technology maintains security; restrict access, only direct need, database NOT seen outside VDH, not connected to servers; separate independent review	State of VA - general funds and CD - National Program of Cancer Registries	No, law doesn't require consent		Yes	physician	Yes, Commissioner has complete access for purposes of surveillance and public health investigation	VA	phone call interview; no survey received									

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Red Text: 2005 BIRTH RATE		General Database Information													Patient Consent Requirements			Parent/Guardian Notification	State Laws- Privacy			Notes of Interest										
Black Text: Information provided by survey respondents Blue Text: Information discovered through CCHF research		Date Data Acquired	Survey Response - Only if No Response Received	State	Program Name	Start Year	Current # Individuals in Database	Birth Rate in 2005*	Indiv. Names Coll. (Y/N)	If Collected, are Names Included in Database? (Y/N)	DATABASE	Statutory and or Regulatory Authorization for Database	Privacy Breach (Y/N)/ When?	All Persons in Database Required to be Notified of Privacy Breach?	Most Recent Security Audit	Source of Funding	Required (Y/N)	If Consent Required, is it Opt In or Opt Out?	Specific Form Required/Type for Patient to Sign? (Y/N)	Required? (Y/N)	Form of Notification (F, PC, CN, PN, TC, O)	Full Access to Med Records? (Y/N)	State	Notes of Interest								
												specific legislation (March 2005)																				
		18-Jul-05		VA	Immunization	1994 - 1995	2.5 million (some duplication)		Yes - most cases; for purpose of electronic medical record, billing, contact provider	Yes, immunization records	IM	S.B. 1132 - "Chapter No. 684, Requires the Board of Health to establish a statewide immunization registry that consolidates patient immunization histories from birth to death may be made available to participating health care providers; releases of aggregate data without personal identifiers, and the use of the data in an epidemic or outbreaks of a vaccine preventable disease." www.bisccc.org	not to my knowledge	No law or regulation	Jun-05	grants through CDC; VFC and 317 funding	N		HIPAA exceptions	No - notified of disease, not that in database		N	VA	phone call interview; no survey received								
		17-Jan-06		VA	VISITS Virginia Infant Screening and Infant Tracking System	Sep-02	130, 899 708,004 live births tested 2001 - 2007 (estimated for 2006-2007) - NNSGRC		Y	Y	NBS	Statute 32.1-69.1 Screens for 28 conditions since March 1, 2006, 11 conditions prior to then - http://www.vahealth.org/pgs/news.htm - accessed Jan 25, 2006, Va. Code §32.1-65-69	N	N	02	Title 5 - State and Federal dollars	N	Religious objection	N	N	NR	Yes, We conduct our own record audits	VA	§ 32.1-67.1. Confidentiality of records; prohibition of discrimination. The results of the newborn screening services conducted pursuant to this article may be used for research and collective statistical purposes. No publication of information, biomedical research, or medical data shall be made that identifies any infant having a heritable or genetic disorder. All medical records maintained as part of newborn screening services shall be confidential and shall be accessible only to the Board, the Commissioner, or his agents. (1996 - 07-2006 - 312-731)								
		19-Jul-05		VA	STDs	Jun-05	3/4 of 1 million		Yes, most cases	Y	STD	Don't know statute	not to my knowledge	N	Jun-05	grants through CDC	N - state, federal law doctors report to local authorities which report to the state			No - notified if they have disease, not that they are in database		N	VA	phone call interview; no survey received								
		7-Jul-05		VA	Vital Records	1913	compiled over year at 100,000 births per year, 57,000 deaths, 26,000 induced terminations, and 8,000 natural fetal deaths					VA Chapter 32, Code - VA7-32.1-249	N		Contact state registrar	Generate own funds by sale of documents	NO - facilities required by law to submit documents					Can't reveal individual data; research purposes only; many restrictions	VA	phone call interview; no survey received								
WASHINGTON																																
		9-Aug-05		WA	Washington State Birth Defects Surveillance System	1986 active and 1991 - passive	not known	82,703 - WA	Y	Y	BD	WAC 246-101 - enacted 2000	N	not known	Jul-05	100% 2005 BDS Directory; 60% MCH funds; 40% general state funds	N							WA								
		9-Aug-05		WA	Cancer Registry	1992	approx. 35,000 cases per year		Y	Y	CA	RCW 70.54.230	Never, special server, control server, log on, work closely with IT people, password, anyone can be hacked	NR	work with IT people for security audit	National Program of Cancer Registries of CDC	N - exempt from HIPAA for reportable conditions			Provide brochures about cancer registry to doctors and medical offices	Y - complete paperwork sent in by facilities		WA	phone call interview; no survey received								
		2-Dec-05		WA	Washington Notifiable Conditions	1987	Tens of thousands		Y	Y	CD	Statutory Authority: RCW 43.20.050 and 70.104.030, 00-23-120, §246-101-001, filed 11/22/00, effective 12/23/00. Rules: Washington Administrative Codes WAC 246-100, WAC 246-101	N	Unknown	Within the past 12 months	100% public funds	N		N	N	n/a	Only as needed for public health investigation and intervention of notifiable conditions	WA									
		9-Aug-05		WA	Immunization Registry	1992 Web-based launched May 2004	approx. 4.5 million There are more than 15 million immunizations for 3.8 million individuals recorded in the registry. - http://www.doh.wa.gov/Public/2004_news/04-059.htm		Y	Y - doctors can look at data	IM	no statutory in WA Patient information from the public portion of the state birth certificate is automatically entered in the database. - http://www.childprofile.org/Providers/faqs.html	N	Y (as of July 1st)	none	federal funds, immunization grants, state dollars, Medicaid matching funds	Y	Opt out: "If you choose not to participate in... CHLD Profile Immunization Registry: If you do not want to have your child's immunizations entered into the Registry, talk with your child's doctor or clinic. If they use the Registry, they can keep your child's information out. You may also call CHLD Profile at 1-800-325-5599.			Y	mail	No law for complete access	WA	phone call interview; no survey received							
		4-Aug-05		WA	Newborn Screening	Current database has 7 years of data	75,000 times 7 years 652,488 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nbsis/ ; "In 2007, we performed over 2.4 million tests on more than 166,000 specimens for about 83,000 newborns." - http://www.doh.wa.gov/ehsph/phi/newbornscreen.htm ; Approximately 75,000 yr or 80,000 with military included - Debra Doyle, Jan 3, 2002 PPT		Y - lab specimens	Y - not all patient names, sometimes mother's name	NBS	(Chapter 70.83 RCW) and Specific requirements are described in Section 246-650-050 WAC.	N	No laws address database; not included under HIPAA; reasonable measures considered to notify; no law	within last year;	state law - fee collected for each child born in state	N	religious opt-out		Not about database but process of screening	Hospital supplies info to parents Brochure		WA	phone call interview; no survey received. Written parent consent is required for any research involving identifiable information and for most other purposes. Any release of specimens or other information must comply with the State's Uniform Health Information Act (Chapter 70.02 RCW) and the privacy and security provisions of Chapter 246-650 Newborn Screening. - http://www.doh.wa.gov/ehsph/phi/newborn/pubs/2007_en_brochure.pdf ; 70.02 RCW Health Information Act - Requires patient consent for most disclosures except: Between providers of care to the patient; Public health purposes; Research if - specific conditions are met - approved by IRB, Court order; ALSO, 42.48 RCW Research (Pub. Policy, DST 2006)								

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NEWBORN SCREENING	27-Sep-06		WV	Lab: MSDS (WV); follow-up is an in house created database in the Maternal & Child Health (where data is only entered on positives; personally entered by Tara)	Lab - 1993 & updated in 1996; F/U data started in 2001	MSDS 311,899; F/U database approx 7,000 148,825 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nmsis/		Y	Y	NBS	W.V. Code §16-22-1 to 6- NCSL; §16-22-3 of the Code of West Virginia, 1931 - amended and reenacted, March 10, 2007 - http://www.wvohr.org/nbms/HB2583_enr.pdf ; "a) The hospital or birthing center in which an infant is born, the parents or legal guardians, the physician attending a newborn child, or any person attending a newborn child not under the care of a physician shall require and ensure that each such child be tested..."; RULES - Title 64-91-1-1. Department of Health and Human Resources Bureau for Public Health Legislative Rule, "Newborn Screening	N	N	N (to best of her knowledge)	lab database state funded; F/U 100% funded by Title V	N		N	N	N/A	N	WV		
WISCONSIN																								
BIRTH DEFECTS	10-Mar-06		WI	WI Birth Defects Registry (WBDR)	2004	833	70,984 - WI	Yes, if parent permission is given, no if parent permission is not given	Yes, with/parent permission	BD	WI Statute 253.12 (enacted 2000); Rules: HFS 116 - effective 2003	N	N	The Wisconsin Birth Defects Registry is a secure website with three security layers. It is part of the public health information network which was audited in summer 2004.	Development was funded by CDC grant; ongoing maintenance is funded by state GPR funds - 2005 BDS Directory; 50% MCH; 50% general state funds	Yes, parents sign permission for their child	Opt-in	No, but we have developed a sample form for reporting facilities to use or modify	No further notification is given, other than the parent consent form that is signed	NR	N	WI		
CANCER	18-Sep-06		WI	Wisconsin Cancer Reporting System	1976	approximately 675,000 persons		Y	Yes, but names & other confidential identifiers are rarely released, and only per statutory authority	CA	Chapter 255.04, Wisconsin Statutes	No	No, the statute does not specifically require notification. However, we are required to notify patients of a breach if their record was sent to us from another central cancer registry in a different state; our data exchange agreements with those states require notification if a breach is ever identified.	20% State General Purpose Revenue funds, approx. 5% from multiple outside sources for customized data requests and 75% federal funds from the National Program of Cancer Registries, Centers for Disease Control and Prevention.	January 2005. The next one is scheduled for January 2007. (Full Department level, not just the cancer registry)	No	No	No	N/A	Yes, under Chapter 146.82(2)(a)5, Wisconsin Statutes	WI			
IMMUNIZATIONS	18-Sep-06		WI	WIR	1999	4.6 million		Y	Y	IM	NR	N	N	2003, although 10 other states & 2 US territories use the WIR software & probably have had their own audit done	100% public	No, it is an opt out	Opt-out	Yes, to opt-out, which is part of the birth certificate, immunization visit or upon request	N, but we ask that our providers ask	It is part of the Birth Certificate & Vaccine Administration Form	For continuity of care	WI		
NEWBORN SCREENING	23-Mar-06		WI	EPIC Software-COHORT (Underlying Database - CACHE)	1993	975,000 approximate 483,918 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nmsis/		Y	Y	NBS	NS Screening Statute [sic] - 253.13 Wis. Stat. Ann. §253.13-NCSL; "253.13 - 3) Exceptions. This section shall not apply if the parents or legal guardian of the child object thereto on the grounds that the test conflicts with their religious tenets and practices. No tests may be performed under sub. (1) or (1m) unless the parents or legal guardian are fully informed of the purposes of testing under this section and have been given reasonable opportunity to object as authorized in this subsection or in sub. (1m) to such tests.	Not to your knowledge	WI does not have a law requiring patient notification of database breaches. HIPAA regulations however require security to protect patient confidentiality and any breach would be evaluated by the HIPAA Officer on a case-by-case basis.	The WSLH is a government laboratory with approximately 25% of our total support from state tax dollars. The Newborn Screening Program charges a fee to that covers our testing costs.	No - Parents may opt out for religious reasons	No	No, however, the HIPAA Privacy Notice is posted on the WSLH website and explains how data may be used in our organization.	N/A	No - DPH may request records necessary to carry out their public health mission.	WI	253.13(4) (4) Confidentiality of tests and related information. The state laboratory of hygiene shall provide the test results to the physician, who shall advise the parents or legal guardian of the results. No information obtained under this section from the parents or guardian or from specimens from the infant may be disclosed except for use in statistical data compiled by the department without reference to the identity of any individual and except as provided in s. 146.82 (2). The state laboratory of hygiene board shall provide to the department the names and addresses of parents of infants who have positive test results. 146.82(2)(a)6: For purposes of research if the researcher is affiliated with the health care provider and provides written assurances to the custodian of the patient health care records that the information will be used only for the purposes for which it is provided to the researcher, the information will not be released to a person not connected with the study, and the final product of the research will not reveal information that may serve to identify the patient whose records are being released under this paragraph without the informed consent of the patient. The private pay patient may deny access granted under this subsection by annually submitting to the health care provider a signed, written request on a form provided by the department.			
WYOMING																								
BIRTH DEFECTS	29-Nov-05		WY	NONE			7,239 - WY			BD	2008 - found nothing in Wyo Stat. §35													
CANCER	13-Jul-05		WY	Rocky Mountain Cancer Data System	1967 1966 and collecting since 1963	84,774 cases		Y	Y	CA	State: Wyoming Statute 35-1-240(b); Federal: Public Law 102-615	N	N	Unsure	95% Federal (CDC) 5% State	N	N	N	N	NR	Yes, We get copies of medical records when we abstract cancer cases. However, some hospitals abstract their own cases and we do not see those records.	WY	DC uses a Rocky Mountain Cancer Data Systems along with 22 other state or regional registries: http://mcds1.med.utah.edu/about/about.htm	
COMMUNICABLE DISEASES	7-Dec-05		WY	NETSS	1992	1,298 for 2005		Y	Y	CD	Statute 35-4-107	N	Yes - per HIPAA	Have not had one yet. But they are planning one now	100% Federal	N	N	N	NR	Yes, Statute 35-4-107	WY			
IMMUNIZATIONS	9-May-06		WY	Wyoming Immunization Registry (WYIR)	Nov-01	270,837		Y	Y	IM	NONE - "Although there currently is no state statute requiring the use of the Wyoming Immunization Registry (WYIR), all providers that administer immunizations within the State of Wyoming are strongly encouraged to use the system...While the law does not require reporting immunizations, WYIR recommends doing so." - Wyoming Immunization Registry (WYIR), WYIR User Manual, January 2008, INCLUDES SSA	N	N	N/A	100% public	N	Reporting NOT required by law	Opt-out	Y	N	N/A	N	WY	

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		NEWBORN SCREENING	25-Jan-08	CCHC likely sent a certified letter in December 2006 but unable to find USPS receipt	WY	Newborn Screening Program	35 4 802. Rules and regulations. (a) The state department of health shall make all rules and regulations necessary for: ...Implementation of W.S. 35 4 801, as amended, not later than July 1, 1999.	45,227 live births tested 2001 - 2007 (estimates for 2006-2007) - http://www2.uhscsa.edu/nehss/		NBS	Wyo. Stat. §35-4-801 to 802. NCSL - "(a) Every child born in the state of Wyoming, within three (3) to five (5) days for full term children and five (5) to eight (8) days for premature children following birth unless a different time period is medically indicated, shall be given medical examinations for detection of remedial inborn errors of metabolism and for detection of major hearing defects. ... (c) Informed consent of parents shall be obtained and if any parent or guardian of a child objects to a mandatory examination the child is exempt from subsection (a) of this section. " - WY Statutes 2007. In effect om 1999 and including changes from 2008 session. "Under Wyoming law, newborns are initially screened between 24-48 hours after birth unless parents sign a waiver opting out of the program." - WY Dept of Health Press Release, June 30, 2006.		Consent required									Y, but does not appear to be happening		Consent Required			WY	
		OCCUPATIONAL INJURY	13-Feb-06		WY	Survey of Occupational Injuries and Illnesses	1992, but it was discontinued in mid 1990's and started up again in 2002	Not disclosable				Y	Y	OCC	OSH Act of 1972	N	N	No external audit	50/50 Federal Government/State	N		N	N	NR	You may contact the Health Department at 307-777-7656 for this information.	WY		
		**2005 CDC REPORT: http://wonder.cdc.gov/wonder/sci_data.html/detail/type_int.html/05/TechAppendix05.pdf											*Form of Notification abbreviations: specific form (F), postcard (PC), clinic notice taped to the wall (CN), physician notice (PN), telephone call (TC) or other (O)															