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Selected Federal Resources

**OMB Circular A-110** has been revised to provide access to research data through the Freedom of Information Act (FOIA) in certain circumstances. Data that are (1) first produced in a project that is supported in whole or in part with Federal funds and (2) cited publicly and officially by a Federal agency in support of an action that has the force and effect of law (i.e., a regulation) may be accessed through FOIA. NIH Grantees and Applicants: Notice Of Amendment To A-110. The amendment to OMB Circular A-110 applies only to data produced with Federal support that are cited publicly and officially by a Federal agency in support of an action that has the force and effect of law. [http://grants.nih.gov/grants/policy/a110/a110_guidance_dec1999.htm](http://grants.nih.gov/grants/policy/a110/a110_guidance_dec1999.htm)

**Federal regulations 45 CFR 46** require that applications and proposals involving human subjects research must be evaluated with reference to the risks to the subjects, the adequacy of protection against these risks, the potential benefits of the research to the subjects and others, and the importance of the knowledge gained or to be gained [http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm](http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm).


**Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule** [http://privacyruleandresearch.nih.gov/pr_02.asp](http://privacyruleandresearch.nih.gov/pr_02.asp)

**Office of Civil Rights**

**Hurricane Katrina and Privacy** [http://www.hhs.gov/ocr/hipaa/](http://www.hhs.gov/ocr/hipaa/)

Hurricane Katrina Bulletin #2: Compliance Guidance and Enforcement Statement


PHIN includes early event detection, routine public health surveillance, secure communications among public health partners, information dissemination and knowledge management, analysis and interpretation, and public health response systems. These activities will serve as part of an integrated and interoperable network critical in developing a more effective and response-oriented public health system.

**CDC BioSense** is being developed to support early event detection activities associated with a possible bioterrorism threat. Regional health data will be sent to authorized health officials detailing health trends that could be related to a possible bioterrorism attack. [http://www.cdc.gov/phin/component-initiatives/biosense/index.html](http://www.cdc.gov/phin/component-initiatives/biosense/index.html)

**CDC National Electronic Disease Surveillance System (NEDSS)** is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state and local levels. [http://www.cdc.gov/nedss/](http://www.cdc.gov/nedss/)

NEDSS supports routine surveillance activities associated with the rapid reporting of disease trends to control outbreaks. The NEDSS platform allows states to enter, update and electronically transmit demographic and notifiable disease data.

**CDC Health Alert Network (HAN)** - Ensures that each community has rapid and timely access to emergent health information; a cadre of highly-trained professional personnel; and evidence-based practices and procedures for effective public health preparedness, response, and service on a 24/7 basis. [http://www.phppo.cdc.gov/HAN/Index.asp](http://www.phppo.cdc.gov/HAN/Index.asp) HAN’s architecture upgraded the capacity of state and local health agencies to communicate different health threats such as emerging infectious and chronic diseases, environmental hazards, as well as bioterrorism related threats.

**CDC National Healthcare Safety Network (NHSN)** - A knowledge system for accumulating, exchanging and integrating relevant information on infectious and noninfectious adverse events associated with healthcare delivery. The NHSN allows entry (manual and electronic) of event and summary (denominator) data for each data-reporting module in the network. The data analysis features of the network range from simple reports and graphs to statistical analysis that compares the healthcare facility's rates with national performance measures. [http://www.cdc.gov/ncidod/hip/NNIS_members/nhsn.htm](http://www.cdc.gov/ncidod/hip/NNIS_members/nhsn.htm)

**CDC Epi-X technology** allows for the secure exchange of communications between participating public health partners via the web by providing up-to-the-minute information, reports, alerts, and discussions about terrorist events, toxic exposures, disease outbreaks, and other public health events. CDC Epi-X is the web-based communications solution for public health professionals. Through Epi-X, CDC officials, state and local health departments, poison control centers, and other public health professionals can access and share preliminary health surveillance information --- quickly and securely. Users can also be actively notified of breaking health events as they occur. Key features of Epi-X include unparalleled scientific and editorial support, controlled user access, digital credentials and authentication, rapid outbreak reporting, peer-to-peer consultation, and CDC-assisted coordination of investigations. Epi-X supports postings and discussions about disease outbreaks and other health events that potentially involve multiple jurisdictions. Since its inception in December 2000, health officials have posted over 4800 reports of disease outbreaks. Epi-X highlights include local and national responses to terrorism, West Nile virus surveillance, influenza surveillance leading to the discovery of a new strain, foodborne outbreaks and food recalls that affected residents in multiple states, and investigations of travelers with contagious illnesses. [http://www.cdc.gov/epix/](http://www.cdc.gov/epix/)

**CDC National Environmental Public Health Tracking Program.**
The program’s goals are to (1) build a sustainable national EPHT network, (2) increase EPHT capacity, (3) disseminate credible information, (4) advance environmental public health science and research, and (5) bridge the gap between public health and the environment. The ongoing collection, integration, analysis, interpretation, and dissemination of data on environmental hazards; exposures to those hazards; and related health effects. The goal of environmental tracking is to provide information that can be used to plan, apply, and evaluate actions to prevent and control environmentally related diseases. [http://www.cdc.gov/nceh/tracking/](http://www.cdc.gov/nceh/tracking/)

**NIH Cancer Informatics Grid (caBIG)** The cancer Biomedical Informatics Grid, or caBIG™, is a voluntary network or grid connecting individuals and institutions to enable the sharing of data and tools, creating a World Wide Web of cancer research. The goal is to speed the delivery of innovative approaches for the prevention and treatment of cancer. Over 800 people from more than 80 organizations are working collaboratively on over 70 projects. The infrastructure and tools created by caBIG™ also have broad utility outside the cancer community. caBIG™ is being developed under the leadership of the National Cancer Institute's Center for Bioinformatics. [https://cabig.nci.nih.gov](https://cabig.nci.nih.gov)

**Electronic Primary Care Research Network (ePCRN),** allows primary care practices to link with researchers conducting clinical research anywhere in the United States. This program is funded by the Roadmap Initiative of the National Institutes of Health, and administered by the Federation of Practice Based Research Networks (FPBRN). Integrating basic and clinical research, the ePCRN is one of the most promising infrastructure developments in primary care.

The principal aim of this proposal is to enable the development of an electronic infrastructure that facilitates the recruitment of subjects and the performance of RCTs in primary care practices anywhere in the United States, and that promotes the rapid integration of new research findings into primary care. The specific technical objectives of ePCRN are to provide a web-portal that enables primary care practices to link with researchers in academic centers or the NIH to facilitate recruitment, entry, and follow-up of multidisciplinary randomized controlled trials; to establish a clinic-based registry in primary care using distributed database technology that interfaces with the web portal solution in order to enhance the process of clinical trials recruitment and the translation of research findings into practice and finally to use Internet2 components for enhanced functionality and communication. [http://www.epcrn.org](http://www.epcrn.org)

The **NIH Patient-Reported Outcomes Measurement Information System (PROMIS)** initiative establishes a collaborative relationship between NIH and individual research teams through a cooperative agreement (U01) mechanism. PROMIS, a key project of the trans-NIH Roadmap Initiative, is a 5-year effort to improve assessment of self-reported symptoms and other health-related quality-of-life outcomes across many chronic diseases (e.g., cancer, asthma, arthritis, cardiovascular disease). PROMIS is beginning with core domains of physical functioning, emotional distress, pain, fatigue, social/role participation, and general health perceptions and includes both adult and pediatric populations. It is funded through a cooperative agreement between NIH and extramural investigators, including six primary research and data collection sites and a statistical coordinating center.

**Biomedical Informatics Research Network (BRIN)** [http://www.nbim.net](http://www.nbim.net)

**Models of Infectious Disease Agent Study (MIDAS)** [https://www.epimodels.org/ midas/about/do](https://www.epimodels.org/ midas/about/do)

**National Center for Biomedical Computing (NCBC)**