



## **New Jersey Integrated Population Health Data (iPHD) Project**

### **ACCEPTABLE USE GUIDELINES**

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**Table of Contents**

**1.0 INTRODUCTION ..... 3**

    1.1 Purpose ..... 3

    1.2 Authority ..... 3

    1.3 Background ..... 3

**2.0 GENERAL DATA GUIDELINES ..... 5**

    2.1 Acceptable Access ..... 5

    2.2 Acceptable Purpose ..... 5

    2.3 Aggregated Data ..... 6

    2.4 Limited Data Sets ..... 6

**3.0 SPECIFIC DATA GUIDELINES ..... 8**

    3.1 Sensitive Data ..... 8

## **1.0 INTRODUCTION**

### **1.1 Purpose**

This policy establishes the acceptable use of data collected, stored, and maintained in the Integrated Population Health Data (iPHD) Project operated by the Center for State Health Policy (CSHP), a unit of the Institute for Health, Health Care Policy and Aging Research within Rutgers Biomedical and Health Sciences at Rutgers, the State University of New Jersey.

### **1.2 Authority**

These acceptable use guidelines are authorized under P.L. 2015, c 193, an Act concerning the establishment of a process to integrate certain health data and other data from publicly supported programs for population health research and supplementing Title 30 of the Revised Statutes (“iPHD Project Law”).

### **1.3 Background**

By enacting the iPHD Project Law, the New Jersey Legislature and Governor established a process to integrate health and other data from publicly supported programs for population health research for the purpose of: (1) improving the public health, safety, security, and well-being of New Jersey residents; and (2) improving the cost-efficiency of government assistance programs. The iPHD Project Law establishes a Governing Board and oversight process and authorizes iPHD project operations within the Rutgers Center for State Health Policy (CSHP). The legislation requires that the iPHD project will be capable of securely receiving, maintaining, and transmitting data in accordance with the Act no later than 12 months following its effective date. The iPHD project shall comply with all applicable federal and state laws and regulations governing the privacy and security of personal health information and other data including, but not limited to, the Health Insurance Portability and Accountability Act of 1996 (HIPAA; Pub.L. 104–191, 110 Stat. 1936), 42 C.F.R. Part 2, and other laws and regulations applicable to data received or distributed by the iPHD project.

The iPHD Project Law recognized that the New Jersey administrative departments and agencies create and maintain individually identifiable data and aggregated data sets in performance of their functions. A process by which agencies or authorized researchers can access data will help improve the value of those data. The linkage of

multiple data sources and application of valid research methods can help identify population trends and individual and community determinants of the health, safety, security, and well-being of New Jersey residents.

The establishment of a secure, statewide iPHD project containing certain data from New Jersey departments and agencies relating to health and publicly supported programs will facilitate project-by-project approved analysis and research on the most effective strategies of improving the health, safety, security, and well-being of New Jersey residents and the overall cost-efficiency of government assistance programs. Rutgers CSHP has responsibility for the analytic and administrative operation of the iPHD project.

## **2.0 GENERAL DATA GUIDELINES**

### **2.1 Acceptable Access**

Access to de-identified data held by the iPHD project is subject to the approval of the Governing Board and state agencies contributing data, and in the case of generalizable research, the review and approval of an Institutional Review Board. The following individuals and organizations shall be eligible to apply for data access:

- a. Faculty or staff academic researchers, including students under the direct supervision of a faculty member or professional research staff member of a post-secondary educational research institution;
- b. Research staff from the Legislative branch, Executive branch, Judicial branch, or other governmental entity of New Jersey state or local government;
- c. Research staff from non-profit organizations;
- d. Research staff from organizations that provide services or engage in research projects determined by the Governing Board to further the mission and purpose of the iPHD project as declared by the Legislature at N.J.S.A. 30:4D-65.

### **2.2 Acceptable Purpose**

The acceptable access and use of de-identified iPHD program data will only be approved by the Governing Board if such access and use is in accordance with both of the following purposes:

- a. To (1) improve the health, safety, security, and well-being of the residents of New Jersey or, (2) improve the cost-efficiency of government programs; and
- b. To (1) perform research that is consistent with the iPHD project annual research agenda as published by the iPHD Project Governing Board and that has been authorized by an Institutional Review Board or (2) perform analyses that are not generalizable research but further the performance or operations of the iPHD project or New Jersey state or local governmental programs. Furthering the performance of the iPHD project or government programs includes, but is not limited to, informing or fortifying external grant making and funding requests and fulfilling federal, state, and other required reporting requirements.

### **2.3 Aggregated Data**

The iPHD project may release aggregated (i.e., grouped) data and de-identified Limited Data Sets (LDSs) only with the approval by the Governing Board and when such release is permitted within the guidelines listed in this policy and only in a manner that reasonably protects the privacy and confidentiality of individually identifiable information, as provided below:

- a. In order to protect the privacy and confidentiality of individual information, aggregated data may be released by the iPHD project only when the identity of individuals represented in the data are reasonably protected. CSHP will review requests for aggregated data and will not include information that must be kept confidential either by agreement with the data contributors or by federal or state law or regulation. The iPHD Board shall decline requests for aggregated data that do not reasonably prevent the disclosure of the identity of individuals represented in the data or that violate agreements with data contributors or applicable laws and regulations.
- b. A request provides reasonable potential to benefit the community, or the development and effective implementation of evidence-based practice or public policy; and
- c. When an identified group is smaller than a threshold of thirty (30) records, the report must display a placeholder (for example, -, \*, NA) with a disclaimer explaining what the placeholder means. Internal and external report authors shall be responsible for adhering to small group suppression rules.

### **2.4 Limited Data Sets**

The iPHD project may release de-identified individual data that could be used to identify an individual who is a subject in the data only with the approval of the Governing Board and in a manner that reasonably protects the privacy and confidentiality of the individual, as follows:

- a. The iPHD project may release data only when: (i) it has been de-identified in a manner that complies with the de-identification process required under HIPAA for protected health information at 45 C.F.R. 164.514(b), regardless of whether the data constitutes health information; or (ii) it constitutes a limited data set that excludes the direct personal identifiers set forth at 45 C.F.R. 164.514(e)(2) (e.g., name, social security number, program ID numbers);
- b. Because even de-identified data may carry risk of individuals being identified through statistical measures, CSHP will redact (remove) or recode (e.g., by grouping categories) data elements in de-identified datasets that, when used

- alone or in combination with other data elements, present a reasonable likelihood of enabling the identification of individuals represented in the data.
- c. Although de-identification of a limited data set, as described above, can minimize the risk that individuals are identifiable, the risk of disclosure cannot be fully mitigated through such measures. Thus, data users shall be responsible for ensuring that the iPHD project Acceptable Use Guidelines are applied appropriately to any reports that are created.

## **3.0 SPECIFIC DATA GUIDELINES**

### **3.1 Sensitive Data**

Various federal and New Jersey laws and regulations impose additional confidentiality protections on certain types of information (“Sensitive Data”), including, but not limited to, alcohol and drug treatment and prevention records protected by 42 C.F.R. Part 2 (“Part 2”); genetic information protected by the Genetic Information and Nondisclosure Act and State law; HIV/AIDS records; venereal disease records; psychotherapy notes as defined in HIPAA; and records maintained by certain State agencies and by certain healthcare professionals and facilities licensed by the State. For example, disclosure of Part 2 substance use treatment records generally may not be disclosed or re disclosed without prior written consent. Many of these federal and State laws and regulations include treatment, research, and public health reporting exceptions that permit their disclosure in limited circumstances detailed in the respective provisions of law. Disclosure of and access to such Sensitive Data in the iPHD must comply with these specific federal and State requirements.