

Reference Guide for Completion of the Iowa Department of Public Health Application for Access to Data for Research Purposes

Personnel Information

1. **Principal Investigator (PI):** Provide the contact information for the individual responsible for the management of the research. The PI is the point of contact for all communication related to the review of the research agreement application and also accepts responsibility for all those who are granted access to the data.
2. **Authorizing Contract Signatory:** Provide the contact information for the individual who will sign the research agreement on behalf of the principal investigator if the PI is not able to sign the agreement. An example would be a contact in a University Division of Sponsored Programs. The Authorizing Contract Signatory will serve as a secondary contact for this research agreement in the event that the Iowa Department of Public Health (IDPH) cannot make contact with the PI. IDPH may contact the Authorizing Contract Signatory for a variety of reasons, including for confirmation that data has been destroyed following the completion of a research agreement.
3. **Data Manager:** Provide the contact information of the individual who will receive the securely transferred data from IDPH. This individual will be named in the research agreement as the custodian of the data on behalf of the researcher and will be responsible for the conditions of use and for all security arrangements to protect against unauthorized data use. If this section is left blank, the PI will be considered the data manager.
4. **Additional Contact for Research Agreement (Optional):** If applicable, provide the name and email of a research support specialist or other staff member responsible for coordinating the research agreement application process.

Project Information

5. **Project Title:** List your project title as you would like it to appear on your research agreement. Please note that this title may be visible to the public on IDPH's website.
6. **Intended Start Date:** List the intended start date for your research. This refers to the intended start of the research project and does not include time spent on the IDPH research agreement application and approval process.
7. **Intended End Date:** List the intended end date for your research project. This date does not refer to the application process or IDPH Research Agreement (RA). An explicit date (month/day/year) is required. The entry "ongoing" is not an acceptable response for intended completion date.
8. **Overview of Project:** Provide an overview of your project that includes study aims and



hypotheses. The aims and goals of your research project must be realistic and reviewers should be able to understand from your description why all requested variables are necessary to complete your research. Your response should avoid jargon and be understandable to a non-technical reader.

9. Per Iowa law, all research completed with IDPH data must contribute to an understanding of health or an issue related to public health and must be of intrinsic value to the people of Iowa. Provide a description of how the knowledge gained from your research project will meet this requirement.
10. Describe how human subjects are selected for inclusion in this project.
11. Specify whether or not individuals under the age of 18 years will be included in this project.
12. Specify whether or not individuals will turn 18 years of age over the course of this project.
13. Describe data collection procedures and protocols.
14. Describe de-identification procedures and planned data analysis.
15. Specify whether or not informed consent will be required for participation in your research project. If individuals will be consented to their participation, all informed consent documents must be included with your research agreement application and they will be reviewed by the RERC. If you have received a waiver of informed consent for this research project, please submit that with your research agreement application. The informed consent documents, including any contact scripts, may be included as an appendix to the research agreement.
 - 15a. If participants will be consented to their participation, describe your informed consent processes and procedures. If you have received a waiver of informed consent, please leave this question blank.
16. Specify whether or not IDPH data will be used to identify individuals to be contacted by researchers for this project.
 - 16a. If IDPH data will be used to identify and make contact with individuals, please describe the contact protocols and procedures. Note that IDPH requires that individuals be informed that IDPH data were used for identification and contact. The following guidelines must be followed in accordance with the research agreement:
 - a. Submit all documentation for contact protocols, including contact letters and/or scripts, and the informed consent form to the RERC with your research agreement application.
 - b. Provide the RERC a detailed description of how the PI intends to make contact with potential subjects and conduct subsequent follow-up. Initial contact with potential subjects shall be through the issuance of a joint notification letter from the PI and



IDPH. In lieu of a joint letter, two letters may be provided (one from the PI and one from IDPH on official IDPH letterhead).

17. If you will not be using IDPH data to identify individuals to be contacted in this study, leave this question blank. Specify whether or not this research project has been reviewed and approved by an Institutional Review Board (IRB). IDPH will not issue a research agreement without IRB committee approval or exemption.

- If the project has been approved by an IRB, please submit a copy of your IRB approval letter. This IRB approval must be current.
- If the project has been reviewed by an IRB or an Institution Human Subjects Office and it was determined that this project is exempt, please submit a copy of your IRB exemption letter or determination document.
- If the project is exempt per state or federal statute, the statute that applies must be identified in question 17a.
- If the IRB application has been submitted and approval has not yet been given, please submit a copy of the IRB application. The RERC will review applications but will not provide approval until an IRB determination has been made and the required documents received.

17a. If this project is exempt from IRB based on state or federal statute, identify which statutes apply. If this does not apply to your research project, leave this question blank.

18. Specify whether or not you plan to release the results of this study. This could include, but is not limited to, peer-reviewed publications, student presentations (including informal presentations to a class or formal presentations such as dissertations open to the public), reports for internal use that will be viewed by individuals other than the research team, presentations (including those given at professional conferences), or any other papers or public release.

18a. If the results of this study will be released, IDPH review and approval of the document or presentation is required in accordance with the research agreement. IDPH does not comment on the content of research findings. The review is only to ensure compliance with the IDPH Disclosure of Confidential Public Health Information, Records, or Data Policy. This policy can be found here: <https://idph.iowa.gov/PublicHealthData/research-requests>

If the research agreement will be with an Iowa Regents University, the process for document review Universities effective March 15, 2017. The general conditions can be found here: <https://idph.iowa.gov/finance/funding-opportunities/general-conditions> will be followed as outlined in the IDPH General Conditions for Contracts with State



Data Request Information

19. Select the dataset(s) that contain variables you are requesting through this application. For each dataset that you are requesting, specify the data range and geographic area. If the requested dataset is not listed, specify as other. Note that legal constraints vary by dataset and all data for each dataset may not be available for research purposes. Additionally, note that fees are assessed for the receipt of vital records variables. For a fee estimate, please send an email request to RERC@idph.iowa.gov.

19a. If the applicant is an internal IDPH program AND the applicant is requesting vital records data, please provide the org code to be used for billing purposes. If the applicant is another state government agency AND the applicant is requesting vital records data, please provide the accounting string information for billing. Other agencies or organization should leave this blank.

20. For any dataset for which the geographic area requested is not statewide, please specify the regions/locations of interest for each data source. For example, provide the names of counties or the relevant ZIP codes. If the data requested is statewide, leave this question blank.

21. Specify whether or not you already have access to the data requested in this research agreement application for another approved purpose.

22. Provide a list of the variables that are being requested for each dataset. A form to select vital records variables is available at <https://idph.iowa.gov/PublicHealthData/research-requests>. Contact IDPH at rec@idph.iowa.gov for data dictionaries of other datasets.

23. Provide any additional information related to the data being requested. Examples of responses could include: only aggregate data is requested, data is needed for certain individuals and the researcher will provide a list to IDPH to match, a specific age range, a specific diagnosis as indicated through ICD-9 and/or ICD-10 codes, a specific gender, etc.

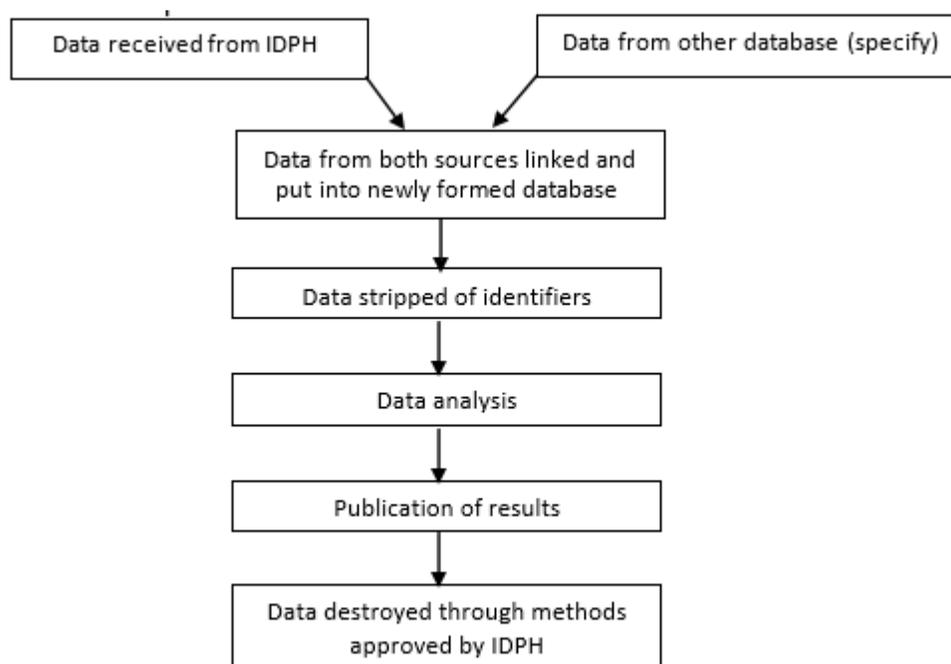
Data Linkage Information

24. Specify whether or not any of the data requested through this research agreement application will be linked to any other data. IDPH defines data linkage as the use of data from any other data source for comparison purposes, the creation of a combined database, matching, or extraction. This includes the use of a geographical area in comparison or matching. This does not include calculation of rates such as standardization and age-adjusted rates. Linkage is not limited to electronic databases. A selection of “no linkage” is not common.

25. If linkage to other datasets is intended, describe your data linkage process and the purpose of each data linkage. If no data linkage is intended, leave this question blank.



26. If data linkage will occur, a linkage flow chart is required as part of the research agreement application. This flow chart should illustrate what datasets will be linked, what new datasets (if any) will be created, and when confidential identifiers will be stripped. In some instances, confidential identifiers may be used to link data by data owners/stewards before the researcher receives the data file. A flow chart should be an easy to understand diagram that shows how the steps in your study fit together. It should display what happens to the data after they are obtained from IDPH until they are destroyed. The flow chart should be submitted as a separate document (for example, PDF, PowerPoint, or Word Document). Below is an example of a linkage flow chart:



Data Security Information

27. Please describe all mechanisms for data security. These mechanisms should be consistent with the Security Rules for IDPH Data, which can be found here: <https://idph.iowa.gov/PublicHealthData/research-requests>. Note that IDPH may conduct a security audit of the data at any time, per the research agreement. Answers to 27a – 27d are required for all applicants. An answer to 27e is only required if you are requesting permission through the research agreement application to share data with an individual external to your agency or organization. If you will not be transferring the data, leave 27e blank.
28. Describe how you will ensure confidentiality of the received data. This response should include information on any trainings or confidentiality agreements required of research project personnel.
29. Please state the name of the staff person who would take the lead on reporting and resolving any case of a suspected or actual data security incident. This person should be aware of who to contact and how to report an unauthorized disclosure of data.
30. Specify whether or not you are seeking approval through this application to share IDPH data outside of your organization. Note that if you answer yes to this question, you must also provide answers for questions 30a and 28e.
- 30a. If data will be shared outside of your organization, explain who will have access to the data, what data sharing agreements or data use agreements are in place, and all data sharing protections in place regarding this arrangement. Please note that IDPH may request to review data use agreements or other documentation of sharing.
31. Specify whether or not you discussed this research agreement application or acquiring IDPH data with any IDPH employee(s) prior to submission.
- 31a. If you discussed this research agreement application with an IDPH employee prior to submitting this application, please provide his or her name. Note that this information does not impact the approval of your application. The RERC may contact those specified for technical assistance regarding your request.
32. Specify whether or not your research project aligns with IDPH’s Research Agenda. For more information on the IDPH Research Agenda, please visit: <https://idph.iowa.gov/PublicHealthData/idph-research-agenda>
- The IDPH Public Health Research Agenda is presented as suggestions for researchers interested in pursuing objectives that are relevant to the Iowa Department of Public Health’s work to protect and improve the health of Iowans, and will be updated on a semi-annual basis. The research agenda consists of two parts:



- **Research Priorities** – general research topics and questions based on Department strategic priorities. IDPH will provide consultation on available data, assistance with the process for accessing these data, and limited access to subject matter experts. Researchers are expected to provide final publications, presentations, and other materials resulting from this research.
- **Research Projects (Not yet released.)**– defined projects or research questions identified by specific Department programs. IDPH has defined any incentives available, project goals, timeline, and staff time commitment for each research project. Researchers are expected to provide a finished product, such as a report or presentation of findings.

While the Department is extremely interested in these areas, this interest does not imply that results generated by research will be endorsed by the Department. This research agenda also does not imply that data requests for research purposes outside of the identified priorities and projects will not be approved. Requests for all data for research purposes, including those that align with IDPH’s research agenda, must be reviewed and approved by the Department’s Research and Ethics Review Committee, and an active research agreement must be signed. For more information about requests for IDPH data for research, please visit:

<https://idph.iowa.gov/PublicHealthData/research-requests>



Research Priorities Title:

Childhood Obesity

About this Topic: IDPH has identified obesity as a key priority in both the Healthy Iowans plan, and the IDPH Strategic Plan. The Department recognizes that life course approaches, which address health through the various stages of life including maternity, infancy, early and middle childhood, adolescence, early and middle adulthood, and older adulthood, are necessary to stem the growing obesity problem in Iowa. Funds have been earmarked for childhood obesity interventions, and innovative and timely research will help to inform Department activities related to these funds.

Research Questions:

1. What established and new measures based on current IDPH data provide the most valid, reliable, and feasible indicators of childhood obesity risk factors attributable to public health interventions?
2. What strategies are more effective in enhancing the adoption and diffusion of behaviors that promote healthy weight in childhood, specifically in low-income and rural areas of Iowa?
3. How do patterns of interaction within Iowa's health, education, and social service delivery systems impact the effectiveness, efficiency, and outcomes of public health strategies to reduce obesity and promote healthy weight in childhood?

Title: Prescription Monitoring Program

About this Topic: IDPH and the State of Iowa Legislature have identified substance abuse, and specifically opioids, as a major public health issue. Nationally, the opioid crisis has been declared a national emergency. Due to demographic factors, such as rurality, and access to services, Iowa shows unique patterns in the epidemiology of substance abuse. New trends in substance abuse require innovative uses of data in order to understand and address Iowa's substance abuse issues.

Research Questions:

1. What are the groups most at risk for prescription drug abuse, and how do risk factors vary among specific groups? What are predictive indicators of community risk factors for prescription drug abuse?
2. What is the relationship between prescription patterns of opioids, opioid-related deaths, treatment admissions for opioids, and medication-assisted treatment provider proximity and/or availability?
3. What is the current use of Iowa's Prescription Monitoring Program by pharmacists and providers, and what programming and policy changes can improve the quality and utility of these data?

Title: Rural EMS Systems

About this Topic: Emergency Medical Services (EMS) operate in an increasingly complex environment, particularly in rural areas. Iowa's EMS system exists within a unique landscape of large rural areas served by high numbers of Critical Access Hospitals (CAHs) and Level IV trauma facilities. IDPH seeks to better understand Iowa's EMS capacity and resource gaps, in order to improve effectiveness and efficiency of out-of-hospital services to Iowans.

Research Questions:

1. How can data from the AMANDA Licensing System and/or EMS System and Trauma System Registries (Image Trend Elite) be utilized to measure the impact of volunteer provider training and experience on patient care and outcomes?



2. How do governmental jurisdictions, and areas of overlapping responsibility, influence 911 (emergency scene) response, transfer, and patient outcomes, specifically in rural areas?
3. What is the minimum standard for dispatch, response, and on-scene response times for rural Iowa to assure the best outcomes for ST-Elevation Myocardial Infarction (STEMI), stroke, and trauma?

Title: The Impact of Health-Related Professional Licensure in Iowa

About this Topic: Licensing of health occupations can protect the public's health and safety by increasing the quality of professionals' services through mandatory requirements and restrictions. However, evidence shows that licensing of professions can create barriers to employment opportunities, and lead to higher costs to consumers. These benefits and risks can vary greatly from state to state due to the heterogeneity of what and how professions are licensed across the US. A better understanding of the impact of health-related professional licensure in Iowa will help to ensure public health benefit, and to avoid negative economic impacts.

Research Questions:

1. Are Iowa's health-related professional licensure regulations aligned with current skills needed in each licensed profession, and do these regulations adequately protect the health of Iowans?
2. How is Iowa's economy impacted by health-related professional licensure, including employment, access to jobs, and wages of licensees, including reimbursement rates?
3. What is the impact of health-related professional licensure regulations on consumers, and how does this impact vary?

Title: Older Adult Mental Health

About this topic: Both healthy aging and mental health care were identified as important issues in the Healthy Iowans plan. Cognitive decline and other mental health issues related to aging affects individuals across their life course, their families, and their communities. Additionally, recent policy changes in Iowa, including the creation of Mental Health and Disability Services regions in 2014, has changed the mental health services landscape. As the population of Iowa ages, particularly in rural areas, older adult mental health is an emerging issue with significant impacts on population health.

Research Questions:

1. How well do current IDPH data, including hospitalization and death data, estimate the prevalence of mental illness, including age-related cognitive decline in Iowa?
2. How are mental and physical healthcare providers with training in geriatric care geographically distributed in Iowa? What barriers exist for older adults to access these professionals? Who is providing caregiving to older Iowans, and how do roles and responsibilities vary across diverse groups? What are Iowa's caregivers' needs related to skills and support.

