



External Research Requests for City-Generated and Maintained Data: Overview

The Office of the Deputy Managing Director of Health and Human Services and its departments require departmental approval for external research requests. Each department that is contributing data to a project must provide authorization for the project.

Departments reporting to the Office of the Deputy Managing Director of Health and Human Services include the following:

- Department of Behavioral Health and Intellectual disAbility Services (DBHIDS)
- Department of Human Services (DHS)
- Philadelphia Department of Public Health (PDPH)
- Office of Supportive Housing (OSH)

All requests for data to conduct research involving human subjects will require a proposal review, department approval, IRB review¹ and approval, and a Data License Agreement (DLA) drafted and approved by the Law Department for the City of Philadelphia. If the data request incorporates human subject data from the Philadelphia Department of Public Health (PDPH) or the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS), the research project must be submitted to the Philadelphia Department of Public Health Institutional Review Board (PDPH IRB).

General Requirements

- The City of Philadelphia defines human subject data as all data that is maintained as a client-level record. This includes both identified and de-identified client-level information. If you have a research request for data maintained by the City aggregated at a level higher than the client level and in a manner that does not permit for re-identification of individuals, please contact the department for protocols for accessing the data.
- All state and federal laws regarding research and the use of data must be observed.

¹ All research requests for data involving human subjects maintained by the Philadelphia Department of Public Health (PDPH) and the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS) must be reviewed by the Philadelphia Department of Public Health Institutional Review Board (PDPH IRB). At the discretion of the Deputy Managing Director of Health and Human Services or her/his designee, research requests for data involving human subjects maintained by the Office of Supportive Housing (OSH) or the Department of Human Services (DHS) may be directed to the PDPH IRB.



- The transfer of data must be in alignment with the DLA, and data should only be transferred using secure protocols (secure file transfer protocol, encryption, password protection, etc). The investigator is required to destroy the data or maintain the data as outlined in the DLA.
- The investigator must notify the City, in writing, of any intent to submit a report or an article for publication or to present the data in a public forum. See attached list of department contacts.
- A copy of all final study documents must be provided to the City. Researchers may be asked to present findings to City staff. See attached list of department contacts.
- Reports or articles written based on the approved research project must include the following statement: *Opinions contained in this report reflect the opinions of the author and do not necessarily reflect those of the City of Philadelphia.*

The City will assist with the transfer of data. The City is not required to integrate data sets from multiple source systems. The City is not required to support the project through data validation, application of research methods, or the development of findings. The City maintains the right to decline a proposal if the request requires a substantial amount of city resources to fulfill the request. The City maintains the right to seek reimbursement for any administrative, data integration or data transfer activity associated with the project. The following link provides guidance on how the City will determine project-related costs:

- [Requesting Integration Services from the City of Philadelphia](#)

Review Process

The process requires departmental approval of the project concept to proceed. If assistance is needed to determine the involved departments, please contact the Director of the Data Management Office (see attached list of department contacts). If the proposed project requires data from more than one department, the Director of the Data Management Office in the Office of the Deputy Managing Director of Health and Human Services will coordinate the process across the departments.

Department of Behavioral Health and Intellectual disAbility Services (DBHIDS) and Philadelphia Department of Public Health (PDPH)

This process should also be followed for any research projects involving human subjects initiated through OSH or DHS that include DBHIDS or PDPH data.

1. Review the PDPH IRB instructions for submitting a proposal for review (<http://www.phila.gov/health/Commissioner/IRB.html>). All research requests for data at the client level must be reviewed by the PDPH IRB, even if the data request is for de-identified data². If the investigator is requesting de-identified data, the proposal should clearly identify that the request is for de-identified data and who from the participating city agency(s) will perform the de-identification procedures. If you have any additional questions regarding submission requirements, please contact Candace.Adams@phila.gov.
2. Following the guidance provided on the PDPH website, submit a complete proposal to the PDPH IRB for review. The PDPH IRB will review the proposal and contact the investigator if additional information is needed.
3. Concurrently with Step 2, submit a copy of the proposal to the contact(s) for the agency(s) that will provide data for the study. See attached list of contacts to find the appropriate contact information for your proposal.
4. The data contributing agency(s) will evaluate the proposal and provide a written response to the investigator indicating if the proposal has been approved or not and, if not approved, an explanation as to why the proposal has not been approved. If the project is approved, the data contributing agency(s) will submit documentation of the approval to the PDPH IRB.
5. The PDPH IRB will notify the investigator, the data contributing agency(s), and the Law Department of its decision to approve or not approve the project by sending a copy of the approval letter. If the project involves multiple data contributing

² If individually identifiable information is requested by the investigator, and the data is subject to the Health Insurance Portability and Accountability Act (HIPAA) rules, the IRB approval must include a waiver of the HIPAA requirement that a signed authorization must be obtained.



departments, a copy of the approval should also be submitted to the Director of the Data Management Office in the Office of the Deputy Managing Director of Health and Human Services.

6. The data contributing department will contact the Law Department and the investigator to develop and execute a Data Licensing Agreement (DLA). The data contributing department will need to send the formal project title, the PDPH IRB approval letter, the project scope, a list of data elements that will be shared, the proposed term, and a department contact for the project. The executed agreement will be sent to the investigator, the data contributing agency(s), and the PDPH IRB. If the project involves multiple data contributing departments, the Director of the Data Management Office in the Office of the Deputy Managing Director of Health and Human Services will contact the Law Department and the investigator to develop and execute the DLA.
7. Upon PDPH IRB approval and completion of a DLA, the following information will be sent electronically by the department to the Director of the Data Management Office:
 - a. The project name as referenced in the IRB application
 - b. The name and contact information for the principal investigator
 - c. The departmental approval
 - d. The approved proposal and approval letter from the PDPH IRB
 - e. The DLA as approved by the Philadelphia Law Department

Office of Supportive Housing (OSH) and the Department of Human Services (DHS)³

Note: if the proposed research study includes data from DBHIDS or PDPH, the review process outlined in the previous section must be followed.

1. Submit a copy of the proposal to OSH or DHS. See attached list of contacts for the appropriate contact for OSH or DHS.
2. OSH or DHS will evaluate the proposal and provide a written response indicating if the proposal has been approved or not with an explanation of any disapproval to the investigator. If the proposal is approved by OSH or DHS, and the investigator is requesting de-identified data, the investigator must identify in the proposal that the request is for de-identified data and who from the participating city agency(s) will perform the de-identification procedures prior to submission of the proposal to the home institution IRB.
3. Upon receiving a letter of support from OSH or DHS, the investigator(s) should submit the required documentation to their home institution IRB for review. All research requests for data at the client level must be reviewed by an IRB, even if the data request is for de-identified data⁴. At the discretion of the Deputy Managing Director of Health and Human Services or his or her designee, research requests for data involving human subjects maintained by OSH or DHS may be directed to the PDPH IRB for review. If you are directed to the PDPH IRB, please follow the review process guidance provided for DBHIDS and PDPH.
4. If the study is approved by the investigator's home institution IRB, a copy of the letter of approval or exemption and the final proposal must be forwarded to OSH or

³ All research requests for data involving human subjects maintained by the Philadelphia Department of Public Health (PDPH) and the Department of Behavioral Health and Intellectual disAbility Services (DBHIDS) must be reviewed by the Philadelphia Department of Public Health (PDPH) and Institutional Review Board (IRB). At the discretion of the Deputy Mayor for Health and Opportunity or her/his designee, research requests for data involving human subjects maintained by the Office of Supportive Housing (OSH) or the Department of Human Services (DHS) may be directed to the PDPH IRB.

⁴ If individually identifiable information is requested by the investigator, the IRB approval must include a waiver of the HIPAA requirement that a signed authorization must be obtained.

DHS and the PDPH IRB. A reliance agreement between PDPH IRB and the home institution IRB must be in place before the research can commence.

- a. A reliance agreement is not required for a study that receives an exemption. If you are not sure if the study meets the requirements for exemption, please contact the Data Management Office, department sponsor or PDPH IRB. See contact information on the final page of this document. The researcher is also required to submit documentation that the study has been exempted to the department(s) that provided unit approval.
5. For DHS research projects, DHS is required to submit the proposal to the Pennsylvania Department of Human Services (PA DHS) for approval.
6. Upon receiving confirmation of IRB approval, OSH or DHS will notify the Law Department to initiate work on a data license agreement and forward the IRB approval to the Law Department.
7. The Law Department will contact the investigator and OSH or DHS to develop and approve the DLA. The executed agreement will be sent to the investigator and OSH or DHS. The data contributing department will need to send the formal project title, the home institution approval letter, the project scope, a list of data elements that will be shared, the proposed term, and a department contact for the project. The approved agreement will be sent to the investigator, the data contributing agency(s), and the IRB.
8. OSH or DHS is responsible for submitting the following information electronically to the Director of the Data Management Office:
 - a. The project name as referenced in the IRB application
 - b. The name and contact information for the principal investigator
 - c. The departmental approval
 - d. The approved proposal and the approval letter from the IRB of the home institution



- e. For DHS involved projects, DHS will provide documentation of the PA DHS approval
- f. The DLA as approved by the Philadelphia Law Department



Contact Information

For any questions about External Research Requests, please contact the following:

James Moore

Director, Data Management Office (DMO)

Office of the Deputy Managing Director of Health and Human Services

Phone Number: 215.686.2158

Email Address: james.moore@phila.gov

Kai Chandler

Business Intelligence Analyst

Data Management Office (DMO)

Office of the Deputy Managing Director of Health and Human Services

Phone Number: 215.686.5246

Email Address: kai.chandler@phila.gov

For questions about the Institutional Research Board (IRB), please contact the following:

Candace Adams

Administrative Assistant, Institutional Review Board

Philadelphia Department of Public Health

Phone Number: 215.685.0856

Email Address: candace.adams@phila.gov

For department specific needs, please contact the following:

Suet Lim

Director of Research and Evaluation

Department of Behavioral Health and Intellectual disAbility Services

Phone Number: 215.413.7165

Email Address: suet.lim@phila.gov

Cynthia Schneider

Deputy City Solicitor, Child Welfare unit

Department Of Human Services

Phone Number: 215.683.5137

Email Address: cynthia.schneider@phila.gov



Caroline C. Johnson
Deputy Health Commissioner
Philadelphia Department of Public Health
Phone Number: 215.686.5206
Email Address: caroline.johnson@phila.gov

Nancy M. Guarino
Programmer Analyst Project Manager
Office of Supportive Housing
Phone Number: 215.686.7117
Email Address: nancy.m.guarino@phila.gov