Data-Sharing and Usage Policy

HIV Implementation Science Coordination Initiative

This policy establishes the terms and conditions under which the HIV Implementation Science Coordination Initiative (ISCI) can share and disclose data from National Institutes of Health (NIH)-funded Ending the HIV Epidemic (EHE) projects to other parties.

The Implementation Science Coordination Initiative provides high-quality technical assistance for Ending the HIV Epidemic funded implementation research teams and creates opportunities to share generalizable knowledge to help end the HIV epidemic in the United States.

The NIH funds implementation research projects conducted in collaboration with partners in the 57 jurisdictions prioritized in the EHE initiative. We refer to these as “EHE Projects”. These projects support research in geographic focus areas to strengthen research-community collaborations and enhance the implementation science knowledge needed for the EHE initiative. The projects involve partnerships between investigators, local health officials, and community groups in EHE priority areas.

The projects receive Implementation Science support and coaching from the Implementation Science Consultation Hubs. Hubs play a primary role in the EHE initiative by offering key services to an assigned group of projects throughout the year and enable harmonization of implementation outcomes to describe findings and lessons learned across contexts and settings involved in EHE activities. Hubs also support projects with progress reporting to the NIH.

ISCI collects data from Projects through periodic and systematic surveys to collect projects characteristics, progress, and outcomes to better assist and inform the EHE initiative. These quantitative data are reported at the project-level, in aggregate form and do not include client-level data. Project-level data, including study characteristics and publications, are publicly available on the EHE Dashboard (https://hivimpsci.northwestern.edu/ehe-supplement-projects/).

Our data sharing policy considers two different models of making data available to secondary users: (1) online open access through the EHE Dashboard (https://hivimpsci.northwestern.edu/ehe-supplement-projects/); (2) Request for data from ISCI’s data repository.
Data in the ISCI Repository

The data from ISCI is collected through a series of periodical surveys to collect information on project descriptors, progress/processes, and implementation characteristics.

The data available for request include (Additional details can be found here):

- Areas of consultation for the projects (e.g., Implementation theories, models and frameworks (selection, combination, adaptation, application);
- Common implementation measures and analytic strategies;
- Categories of research questions (e.g., Adapting theories, Collecting determinants, Piloting strategies, etc.);
- Project study design (e.g., Survey, Qualitative approach, Mixed Methods, Quasi-Experimental Trial, Cost analysis, etc.);
- Effects of COVID-19 pandemic on the projects (e.g., Collaboration with/involvement of implementation partners, Data collection, IRB approval, Engagement with IS Consultation Hub activities, etc.).
- Implementation Outcomes categorized by Proctor;
- Unit of analysis used by the projects;
- Data sources (e.g., Patients, Providers, Health Systems, Jurisdiction, etc.);
- Frequency of coaching sessions by the Hubs;
- Project Research and Dissemination activities (e.g., Publication, Townhall, Webinars, etc.);
- Strategies coded by Expert Recommendations for Implementing Change (ERIC).
TERMS AND CONDITIONS

These terms and conditions apply for data requirements pertaining to ISCI’s data repository of the EHE projects not available on our EHE Project Dashboard.

1. The confidentiality of data pertaining to individual projects will be protected as follows:
   a) ISCI will only provide project-level or aggregated data. ISCI will not provide unpublished outcome data nor research participant data.
   b) The data recipient will not release data to a third party without prior approval from ISCI.
2. Data transferred pursuant to the terms of this Agreement shall be utilized solely for the purposes set forth in the “Data Request” (see form below).
3. As part of the data request submission, the recipient must provide a justification for use, intention of analyses, final product (paper, conference presentation, internal use), and verify if that the data are not available on the EHE Dashboard [https://hivimpsci.northwestern.edu/ehe-project-dashboard/].
4. Data requests will be reviewed by members of ISCI’s Executive Committee, which includes representations from each IS Consultation Hub, and fulfillment of data request will be determined on a case-by-case basis, based on: availability of data, scope of proposed research question(s), and alignment with NIH, EHE, and ISCI guidelines. Additional information may be requested to make final determination.
5. A Data Use Agreement may be additionally requested depending on the type of data requested, and this policy does not replace that requirement.

DATA REQUEST

Provider: HIV Implementation Science Coordination Initiative at Northwestern University
Provider Scientist Name: Brian Mustanski, PhD and Nanette Benbow, M.A.S.

Email: isci@northwestern.edu

Recipient organization:

Recipient Scientist Name

Recipient Scientist Email:

Date of Request:

Type of Proposal:

☐ Paper
☐ Conference Presentation
☐ Internal use
☐ Other:

Conference (Where applicable):

Proposal Information

Primary Research Question(s) or Aims: Enter your research question or aims.

Variables (operationally defined): What variables/measures will be used to answer question?

Do you need identifiable data (for this dataset that would mean identifying the PI and the institution conducting the EHE supplement project).

Analytic Plan: If known, enter your analysis plan for answering question.

Data Request

Type of File: CSV, SPSS, SAS, etc.
Time Points: From what years are you requesting data?

Variables/Measures: Be specific. Contact data team for codebook or help as needed.

Data Team Support Requested: Support type: dataset preparation, analysis, writing, etc.?

Date Needed: When do you need this data? Allow for at least 7-10 business days for proposal review.