Obtaining Access to Arkansas Department of Health Data

The Arkansas Department of Health (ADH) welcomes collaborations with and use of data available at the ADH by researchers in academic institutions. The basic process may vary somewhat dependent upon the type of data requested, but generally includes four required steps:

1. Prepare protocol:
   Researchers are encouraged to collaborate with relevant ADH program staff for input on research protocols. This will help to ensure that the variables needed for research are available and reliable. A list of programs and contact information for program staff at the ADH can be found here.

2. Get IRB approval
   Researchers must receive approval from their institution's Institutional Review Board to obtain access to ADH data.

3. Complete data request form:
   The data request form can be found here.

4. Submit for Science Advisory Committee (SAC) review:
   The researcher and ADH program staff can work with the appropriate Associate Director for Science (ADS) to get on the SAC agenda. The SAC meets every 2nd and 4th Friday of each month at 2pm in the Director's Conference Room at the ADH. Agenda items should be sent to the ADS at least one week before the SAC meeting for review.

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<th>Associate Director for Science</th>
<th>Email</th>
<th>Dataset(s)</th>
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<tr>
<td>Howraa Al-Mousawi, Center for Public Health Practice</td>
<td><a href="mailto:Howraa.Al-Mousawi@arkansas.gov">Howraa.Al-Mousawi@arkansas.gov</a></td>
<td>Vital Statistics (Birth and Death), Hospital Discharge Dataset (Inpatient and Emergency Department), Trauma Registry, Cancer Registry, BRFSS, Pregnancy Risk Assessment Monitoring System</td>
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<td>Dirk Haselow, Center for Health Protection</td>
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<td>HIV/STI/Hepatitis C/TB Surveillance Dataset, Trauma Registry, Prescription Drug Monitoring Program</td>
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<td>Name</td>
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<td>Appathurai Balamurugan,</td>
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<td>Cancer Registry</td>
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<td>Richard McMullen,</td>
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<td>USAFOOD Safety Database</td>
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**Projects That Must Be Reviewed**

All research proposals asking for data or information from the ADH must be reviewed and approved by the SAC, including requests that are internally as well as externally generated. Published results from externally generated requests must include a disclaimer stating that “The Arkansas Department of Health does not guarantee the accuracy of the information, and the views expressed in this paper are not necessarily those of the Arkansas Department of Health.”

Examples of external projects or activities that require review and approval are:

1. Projects by researchers from outside ADH such as those from faculty and students of universities, colleges and research institutions.
2. Research or projects submitted by ADH staff to funding sources outside ADH.
3. Projects that require the use of data from the various registries, vital records and other data sources at ADH, unless these data have been previously published as ADH reports.

Data satisfying the appropriate conditions set out in the Guidelines for Request below may be released with the approval of the SAC.

Additional requirements for access to data from Arkansas Cancer Registry:

Data requests of the cancer registry are subject to review by the Arkansas Board of Health which meets on a quarterly basis. The researcher needs to provide the board with a synopsis of the research and purpose of data request.

**Expected timeframe for receipt of data:**

The timeframe for review and approval of data requests will vary depending on the source and nature of the data being requested, and the completeness of the application. The SAC meets twice a month and is usually able to review all requests at the time of each meeting. If external review is also needed, as in the case of Cancer Registry data, additional time will be required.
Guidelines for Requests for Research Data

The Science Advisory Committee will review requests for data and consider the following:

a. Will the data be used for a legitimate public purpose?

b. Has an Institutional Review Board approved the study?

c. Has the researcher provided documentation that the confidentiality of the data will be protected when in his or her possession, a list of persons having access to the data and a description of all safeguards to protect the data from unauthorized access?

d. Has the researcher provided documentation that the data will not be re-released in either electronic files or paper copy?

e. Are individual record data needed for the purposes of the study, or would aggregate data meet the researcher’s needs?

f. Does the researcher need the level of detail requested? For example, does the project really require mother’s date of birth, or would age suffice?

g. If individual identifiers are not included in the data files, has the researcher agreed that identification of individuals will not be attempted?

h. Unless specifically approved, has the researcher provided assurances that the data will not be linked with other datasets? Such linkages could easily identify individuals by name.

i. Has the researcher provided assurances that no data will be published or released in any form if a particular individual is identifiable? This must include cross-tabulations or aggregate data with cell sizes so small that the identity of an individual could be determined.

j. Are the data subject to HIPAA restrictions?

k. Is the researcher willing to provide a report of findings at the completion of the study?

l. Has the researcher given assurances that all data files will be returned to the office of origin or destroyed at the conclusion of the project?
Items to submit to SAC for review

1. Data request form
2. Research protocol to include but not limited to:
   a. Background and research question
   b. Methodology
   c. Results dissemination plan
   d. Data Protection Plan
3. IRB letter of approval or letter from the IRB indicating that the research does not involve human subjects
4. Any additional documents relevant to the project (e.g., surveys, collaborative agreements with other agencies)