**Data Access Request: PopData & HDP**

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| **Mandatory Document Checklist**  *Complete this checklist before submitting the DAR to PopData. DARs without all mandatory applicable attachments will be returned to the PI prior to PopData review* | | | | | | | | | | To be completed by PI | | To be completed by PopData |
| ✔ or N/A | | ✔ or N/A |
| 1. Principal Investigator **completed PopData privacy training** (if storing data on PopData Secure Research Environment) or **Health Data Platform privacy training** (if storing data on HDP Secure Environment) prior to submitting the DAR | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. **Project Overview** for proposed research project | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. **Ethics Application** for the proposed research project | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. **Valid Ethics Certificate** for the proposed research project | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. If **public funding** is in place, a copy of the **formal funding notification letter** from the funding body that includes **the expiry date of the funds** | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. In the case of **for-profit source(s) of funding,** allfunding contract letters and all agreements setting out the terms governing the relationship between the for-profit entity and the PI and/or research team | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. Supporting documents to provide proof that a **scientific peer review process** has been conducted for the research project | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. In the case of a **Student DAR**, their **academic supervisor’s curriculum vita and letter of support,** in lieu of peer review by public funding agency | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. In the case of a **Research Team Member without an academic affiliation or who is not employed by a recognized Canadian health authority, a letter from the relevant Institution confirming the contractual relationship between the Research Team Member and the Institution** | | | | | | | | | | Yes  N/A | | Yes  N/A |
| 1. In the case that the Principal Investigator proposes to place Researcher-Collected Data on the Secure Research Environment (SRE), the **consent form** that was used to collect the data and the **Consent Form Requirements – MOH Attestation** is required. | | | | | | | | | | Yes  N/A | | Yes  N/A |
| An executed **Declaration of Research Independence and Conflict of Interest** from the following members: Principal Investigator, Co-Investigators, and Project Team Members with data access | | | | | | | | | | Yes  N/A | | Yes  N/A |
| Part A.1: Safe People*Ensuring the Users Can be Trusted to Use the Data in an Appropriate Manner.* *MoH Policy Reference: Access to Health Data for Research Policy, Section 5 (a) i-iii.* | | | | | | | | | | | | | | |
| Identifying Information | | | | | | | | | | | | | | |
| Note to PI  * Consistency across all documents is essential * Ensure that the individual identified as the Principal Investigator (PI) /Student Applicant is also named across the Ethics and funding documentation * If the PI of this DAR is not the named Principal Investigator on ethics and/or funding, please provide rationale for the discrepancy * If the title of this DAR is not the same across the ethics and funding documentation, please provide rationale for the discrepancy | | | | | | | | | | | | | | |
| Principal Investigator’s Name | | | | | | | Phone | | | Primary Email | | | | |
| Primary Contact (if different than PI) | | | | | | | Phone | | | Primary Email | | | | |
| If this is a Student DAR, Student Applicant’s Name | | | | | | | Phone | | | Primary Email | | | | |
| Title of Research Project/Program | | | | | | | | | | | | | | |
| Name of person completing this form | | | | | | | Phone | | | Primary Email | | | | |
| If there are PI and/or Project Title differences between DAR, ethics and funding, provide rationale | | | | | | | | | | | | | | |
| 1. **Affiliation** | | | | | | | | | | | | | | |
| **Note to PI**   * PIs for data access for research purposes must fulfill the relevant legal criteria, and generally will include but not be limited to:   + Individuals with academic affiliation with a university in Canada, including supervisors acting on behalf of graduate students (see: <https://www.canada.ca/en/employment-social-development/programs/designated-schools.html>), OR;   + Health care professionals employed by a recognized Canadian health authority   + If you do not fall under the above two affiliations, please contact PopData to discuss your affiliation | | | | | | | | | | | | | | |
| 1. **Academic Affiliation** | | | The PI has a formal **academic affiliation** with a university or college in Canada, as above:  Yes  No | | | | | | | | | | | |
| University/College: | | | | | Position: | | | | | | |
| ***AND/OR*** | | | | | | | | | | | | | | |
| 1. **Student Applicant** | | | The Student Applicant is a **graduate student** currently enrolled at a Canadian university and the DAR is co-submitted with their **academic supervisor**, who is an eligible PI in their own right, as consistent with the policy guidance provided above:  Yes  No | | | | | | | | | | | |
| University/College: | | | | | | | | | | | |
| Academic Supervisor: | | | | | Academic Supervisor’s Position: | | | | | | |
| ***AND/OR*** | | | | | | | | | | | | | | |
| 1. **Health Care Professional** | | | The PI is a **health care professional** employed by a **health authority in Canada**  Yes  No | | | | | | | | | | | |
| Health Authority: | | | | | Position: | | | | | | |
| Supervisor: | | | | | Division and Branch | | | | | | |
| ***AND/OR*** | | | | | | | | | | | | | | |
| 1. **Alternate Affiliation** | | | The PI has an **alternate affiliation** | | | | | | | | | | | |
| Affiliation | | | | | | | | | | | |
| Please provide justification that the PI has the ability to conduct this research project independently with no conflict of interest or influence of for-profit organizations | | | | | | | | | | | |
| If you have multiple affiliations, **please list all affiliations** and indicate the affiliation that will be registered as the institution of record on the Research Agreement here: | | | | | | | | | | | | | | |
| 1. **Privacy Training**   Policy Reference: *Access to Health Data for Research Policy, Section 8.* | | | | | | | | | | | | | | |
| **Note to PI:**   * The PI must have completed PopData Privacy Training or HDP Privacy Training prior to submitting a DAR * This requirement is intended to ensure a consistent level of understanding regarding data security and privacy within the context of provincial legislation and PopData/HDP practice. It also will assist the PI to complete Part B, the Data Request. * The general privacy policy requires the PI and research team members to complete PopData Privacy Training refreshers every three years while they have access to the Research Extract * If a PI has completed training within the 3 years prior to submitting this DAR, the expiry date should be entered below. Refer to the my.popdata website (https://my.popdata.bc.ca) or contact PopData if you are not sure about the expiry date for your PopData Privacy Training. Contact the HDP if you are not sure about the expiry date for your HDP Privacy Training ([mohanalytics@gov.bc.ca](mailto:mohanalytics@gov.bc.ca)). | | | | | | | | | | | | | | |
| The PI has completed PopData Privacy Training prior to submitting a DAR  Yes  No | | | | | | | | | | | | | | |
| The PI has completed HDP Privacy Training prior to submitting a DAR  Yes  No | | | | | | | | | | | | | | |
| Privacy Training Expiry Date | | | | | | | | | | | | | | |
| 1. **The Research Team** | | | | | | | | | | | | | | |
| **Note to PI:**   * Identify ***all*** members of the Research Team, including the PI, in the Table A below * The Principal Investigator and all members of the Research Team must be the same as named on the Ethics Application, Certificate and Funding Letter * The Principal Investigator named on the DAR must be named on the Ethics Certificate and Funding Letter, or an explanation provided in Section 1. * In cases where a Research Team Member has multiple emails, their primary e-mail and academic affiliation for this project must be provided * If a Research Team Member has no academic or health authority affiliation, provide letter from the relevant Institution confirming the contractual relationship between the Research Team Member and the Institution * Provide “Declaration of Research Independence and Conflict of Interest” from the following members: Principal Investigator, Co-Investigators, and Project Team Members with data access * If there are any changes to the Research Team or their data access requirement, notify PopData within two weeks | | | | | | | | | | | | | | |
| If there are discrepancies between Research Team Members listed on the DAR, ethics and funding, provide rationale: | | | | | | | | | | | | | | |
| **Table A: Research Team Members** | | | | | | | | | | | | | | |
| **Name** | | **Position** | | **Emails** | **Affiliations** | **Role**  **(e.g. Principal Investigator, Co-Investigators, Project Manager)** | | | **Key Project Tasks**  **(e.g. analyze raw data, develop methodology, review statistical outputs, etc.)** | | | **Access to data**  **Y/N** | | |
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| **Part A.2: Safe Projects**  ***Ensuring the Use of Data is Appropriate.***  *MoH Policy Reference: Access to Health Data for Research Policy, Section 7.* | | | | | | |
| 1. **Academic Research**   *Policy Reference: Access to Health Data for Research Policy, Section 6 (a) ii.* | | | | | | |
| **Note to PI:**   * *“Research” means a systematic investigation designed to establish principles or other generalizable knowledge, and includes the development, testing and assessment of research* | | | | | | |
| The proposed project constitutes ***research*** consistent with the definition provided above.  Yes  No | | | | | | |
| 1. **Ethics Approval**   *Policy Reference: Access to Health Data for Research Policy, Section 5 (b).* | | | | | | |
| **Note to PI:**   * “Ethics approval” in this context means approval in writing of an application granted by the research ethics board or committee established at or recognized by a Canadian educational institution, hospital or health authority which has authority to provide that approval for that application * Canadian Education Institutions are listed here: <https://www.canada.ca/en/employment-social-development/programs/designated-schools.html> * A copy of the research project’s ethics application and certificate is required as part of the DAR. * The ethics certificate must be valid throughout the research team’s access to the data * It is the responsibility of the PI to renew ethics certificates and notify PopData of renewal. Renewals must be submitted to PopData prior to the expiry of the previous certificate. * Failure to maintain a current ethics certificate will result in termination of access to the SRE/HDP SE | | | | | | |
| The approved Ethics Application is included in DAR application  Yes  No | | | | | | |
| The relevant Ethics Certificate is included in DAR application  Yes  No | | | | | | |
| Research Ethics Board (e.g. BREB, CREB, etc.) | | | Ethics certificate number: | Ethics expiry date: | | |
| 1. **Funding and Peer Review**   *Policy Reference: Access to Health Data for Research Policy, Section 5 (c) and (d) (i-v).* | | | | | | |
| 1. **Projects with Public Funding** | **Note to PI**   * Before declaring 100% public funding, note that any contribution from a for-profit organization, including funding or in-kind contributions, provided either directly, indirectly, or through a third party such as an industry-funded patient group, is considered as a funding contribution * If you answer No to the following question, please also complete following section, “B. Projects with For-Profit Funding and Contributions” | | | | | |
| Project is 100% publicly funded  Yes  No | | | | | |
| List all public funder(s) in Table B below: | | | | | |
| **Table B**  **List of Public Funders** | | | | | |
| **Name** | **Type of Contribution/Funding**  **(e.g. grant, scholarship, award, in-kind, department, cash)** | | | **Amount** | **Expiry Date** |
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|  | A copy of the formal funding notification letter from the public funding body that **includes the expiry date of the funds** to be awarded is attached  Yes  No | | | |
| In the case of **funding by a university department**, a formal letter from that department that confirms the public source(s) of the funding and its expiry date is attached  Yes  No  **Note**: In the case where a donor to the university department wishes to remain anonymous, the request should be noted in the letter. This option is not available to industry/organization donors. | | | |
| Adjudication of the funding award process included **a scientific peer review process** conducted by the public funding body  Yes  No | | | |
| An **alternative peer review process** approved by the Data Stewards(s) has been conducted and the peer review requirements have been met  Yes  No | | | |
| In the case of a Student DAR, the **academic supervisor’s curriculum vita and letter of support** are attached to the DAR in lieu of peer review  Yes  No | | | |
| ***AND/OR*** | | | | |
| **B. Projects with For Profit Funding and Contributions** | **Note to PI:**   * In the case of an PI whose research is funded *either in full or in part by a for-profit organization*, all for-profit funders must be listed below, with the type and amount of funding provided * For profit funding / contributions include funding or in-kind contributions, provided either directly, indirectly, or through a third party such as an industry-funded patient group * In addition, all contracts, agreements, memorandums of understanding, or other instruments governing or outlining the relationship between the for-profit funder and the PI/research team must be provided * Failure to disclose such relationships and relevant governing instruments could result in suspension or revocation of data access | | | |
| List all **for-profit funders and contributors** in Table C below | | | |
| **Table C**  **List of For-Profit Funders/Contributors** | | | |
| **Name** | **Type of Contribution/Funding**  **(e.g. grant, scholarship, award, in-kind, department, cash)** | **Amount** | **Expiry Date** |
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|  | | An **alternative peer review process** approved by the Data Stewards has been conducted and the peer review requirements have been met  Yes  No | | | | | | | |
| 1. **Project Overview** | | | | | | | | | |
| **Note to PI:**   * Provide the research project overview as a separate attachment. * The project overview provides **the context for your data request** * The more complete and clear the information provided in the project overview, the more likely that PopData will be able to review and submit your request without delays * Your clarity and consistency also will assist PopData, the Health Data Platform, the Health Data Platform Council, The Data Stewardship Committee, or other Data Stewards to review and process your DAR with minimal questions and iterations * PopData and the HDP do not judge the methodology, but an understanding of the researcher’s intent increases the capacity of the HDP to provide the correct data | | | | | | | | | |
| The project overview must include the following 5 headings:   1. Key aims/objectives 2. Intended cohort (including date ranges) 3. Expected variables (including date ranges) 4. Basic methodology 5. Brief consideration of how the analysis will be eventually presented, communicated and utilized 6. Linkage strategy (to be completed by PopData or the HDP)      * All information provided must be consistent with the relevant Ethics Application and any information supplied in DAR: Part A * The project overview should not exceed two pages   **Prior to completing this section, please review section B, which sets out expectations for data access.** | | | | | | | | | |
| 1. **Analysis Overview** | | | | | | | | | |
| How often do you require data refreshes?  Quarterly  Yearly  No refreshes  If more frequent than quarterly or yearly, please indicate the refresh time frame and provide a justification: | | | | | | | | | |
| What software tools do you need for your analysis? Please check off the tools below. | | | | | | | | | |
| **PopData** [**SRE tools**](https://my.popdata.bc.ca/html/SRE/software.html)**:** | | | | | | | | | |
| ACG John Hopkins | | | | ArcGIS | | Epi Info | | | JoinPoint |
| GeoDa | | | | Gephi | | graphViz | | | MS Visio |
| MPlus | | | | MS Office | | MS Project | | | Rtools |
| Python | | | | R | | Rstudio | | | Stat Transfer |
| SAS | | | | SaTScan | | SPSS | | | Stata |
| WinBugs | | | |  | |  | | |  |
| **HDP** [**SAE tools**](file:///Users/meganengelhardt/Desktop/hdp_faqs_vol_2_20210401_res_final.pdf)**:** | | | | | | | | | |
| Anaconda | | | | R | |  | | |  |
| Python | | | | DataBricks | |  | | |  |
| Other software tools, please specify: | | | | | | | | | |
| Part B.1: Safe Data | | | | | | | | | |
| Core Data Sets – Data Request | | | | | | | | | |
| **Note to PI PI:**   * Some data available through PopData and the HDP are ‘Core Data’. Core Data are data identified by the Data Steward as 'Safe Data' and are eligible for pre-approved release, with the exception of PharmaNet data. * Core Data includes commonly-requested data columns, but not necessarily all of the columns available in a data set. For example, some Core Data fields, such as geography or organizational codes, have been suppressed for increased protection of privacy. * For the majority of DARs, requesting access to Core Data will expedite the data access approval process and reduce the wait time for data access. It may also reduce the need for time-consuming data amendments related to a request for additional data fields or changes to study populations, which cannot be self defined in non-core data. * Please note that the overall data access request is subject to meeting ALL of the Five SAFEs requirements, not just the Safe Data component * PIs can view all accessible data and thus have the flexibility to create their own study population/cohort and select their variables of interest * Providing the opportunity to see all available data will assist PIs to make informed decisions as to which data best suits their needs as well as decreasing the possibility of omission when selecting variables * Using the following list please identify the Core Data sets that are required to conduct the research. If you are unsure of which data sets you require, please contact a Data Access Coordinator at PopData for assistance. | | | | | | | | | |
| **Table D: Core Data Sets** | | | | | | | | | |
|  | COVID test lab data | | | | | | | | |
|  | COVID Case Data [HDP data] | | | | | | | | |
|  | Cardiac Service British Columbia (CSBC) [HDP data] | | | | | | | | |
|  | Transfusion Registry [HDP data] | | | | | | | | |
|  | Mortality Data – Vital Statistics | | | | | | | | |
|  | Fee for Service (MSP) data | | | | | | | | |
|  | Chronic Disease Registry | | | | | | | | |
|  | Discharge Abstract Database (DAD) | | | | | | | | |
|  | National Ambulatory Care Reporting System (NACRS) | | | | | | | | |
|  | Pharmanet | | | | | | | | |
|  | Consolidation File / Client Roster | | | | | | | | |
|  | 811 [HDP data] | | | | | | | | |
|  | Vital Statistics Births | | | | | | | | |
|  | Vital Statistics Stillbirths | | | | | | | | |
|  | Vital Statistics Marriages | | | | | | | | |
|  | Home and Community Care Minimum Reporting Requirements (HCC-MRR) | | | | | | | | |
|  | Resident Assessment Instrument (RAI) | | | | | | | | |
|  | | | | | | | | | |
| 1. **Non-Core Data Requests** | | | | | | | | | |
| **Note to PI:**   * In some cases, PIs may want Core Data as well as data not offered in Core, these projects are known as “Non-Core Data” projects * Non-Core Data include data that are NOT identified by the Data Steward(s) as 'Safe Data' and thus are NOT eligible for pre-approved release * PIs must provide additional detail and justification for requests to data sets/data elements that:   1. are not included in the list of data sets/data elements within the Core data offerings (**“Internally Managed Data”**)   2. data sets that are not internally managed by PopData (**“Externally Managed Data”**)   3. have been collected by the researcher (**“Researcher-Collected Data”**) * Access to Non-Core Data follows the usual processes and will not follow the expedited review procedures for Core Data * An additional charge for Non-Core Data will be added to the cost of data | | | | | | | | | |
| 1. **Internally Managed Data** | | | **Note to PI:**   * Internally Managed Data include:   + Data elements suppressed for privacy and excluded from Core Data (e.g. full date of birth from Consolidation File/Client Roster)   + Additional data sets internally managed by PopData but currently not offered as Core (e.g. BC Perinatal Data Registry) * To access Internally Managed Data you need to complete the relevant data checklist(s) and for data elements only you must also provide justification and rationale (where necessary) to explain why each data element is necessary to conduct your proposed research * Please ensure that all data requested are consistent with your Research Project Overview, including all date ranges * During review of the submitted DAR, PopData will review this information to ensure that it offers sufficient information to assist the relevant Data Stewards in their adjudication of risk associated with data release * PopData may contact the PI by telephone or email to request additional clarification or justification | | | | | | |
| **Table E**  **Non-Core Data Sets / Data Elements**  **(Internally Managed by PopData)** | | | | | | |
| **Data Sets** | | **Date Range**  **(Year - start date, end date)** | | **Data Elements** | **Rationale**  **(Describe why the data are required to achieve the research objectives)** | |
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| 1. **Externally Managed Data** | **Note to PI:**   * Externally Managed Data refers to data coming from other organizations, i.e. data that are not internally managed by PopData and are not collected by the researcher * Private databases, such as those maintained by private laboratories, are considered external data * If you are NOT using Externally Managed Data, you may proceed to the next section of this application * If you are requesting access to Externally Managed Data, please upload/attach the following:   + Applications and approvals (if available) for use of Externally Managed Data that will be linked to the requested data,   + If applicable, the consent form used by the external Data Steward to collect the data, * Plain-language description of all Externally Managed Data fields to be linked to the requested data and retained for analysis | | | |
| **Table F**  **Non-Core Data Sets**  **(Externally Managed by PopData)** | | | |
| **Data Sets** | **Date Range**  **(Year - start date, end date)** | **Data fields to be used for linkage**  **(e.g. PHN or other type of identifier, etc.)** | **Rationale**  **(Describe why the data are required to achieve the research objectives)** |
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| 1. **Researcher-Collected Data** | **Note to PI:**   * Researcher-Collected Data refers to data collected and governed by the researcher e.g. survey data * If you are NOT using Researcher-Collected Data, you may proceed to the next section of this application * If you are requesting access to Researcher-Collected Data, please upload/attach the following:   + Consent form used to collect the data,   + Plain-language description of Researcher-Collected Data fields to be linked to the requested data and retained for analysis | | | | |
| Please indicate if you intend to load your own research data (Researcher-Collected Data) onto the SRE, and if Yes, please complete Table G below  Yes  No | | | | |
| The consent form is included with the submitted DAR  Yes  No | | | | |
| ~~The consent form used to collect the data was pre-approved by the Ministry of Health~~  ~~Yes  No~~ | | | | |
| The Consent Form Requirements – MOH Attestation is complete and included with the submitted DAR  Yes  No | | | | |
| If no consent form is included, provide rationale: | | | | |
| **Table G**  **Researcher-Collected Data** | | | | |
| **Data Source** | **Data collection method (e.g. chart review, survey, etc.)** | **Data fields to be used for linkage**  **(e.g. PHN or other type of identifier, etc.)** | **Date Range**  **(Year – start date, end date)** | **Rationale**  **(Describe why the data are required to achieve the research objectives)** |
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| **Part B.2: Safe Setting**  ***Ensuring the Data Access Environment has Appropriate Safeguards and Limits Unauthorized Use.***  *Policy Reference: How Data are Accessed (S. 9).* | | | |
| **Note to PI**   * The PI is required to access the project data (as described in Part B) and perform their analysis using a secure environment (SE) that is deemed acceptable by the Health Data Platform Council, the Data Stewardship Committee, and/or other Data Stewards depending on the data requested * The two main secure environments include the Secure Research Environment (SRE) maintained and operated by PopData and the Health Data Platform Secure Environment * Determining which secure environment is to be used will depend on the type of data needed for the project and the tools needed to complete the data analysis * Use of an alternative SE must be approved by the Health Data Platform Council, the Data Stewardship Committee, and/or other Data Stewards depending on the data requested * In all but the most exceptional cases, use of an alternative secure environment **located outside of BC will not be approved** * The PI must comply with any requirements associated with the use of the designated environment and with any requirements that Data Steward(s) may direct | | | |
| Will data will be handled within the HDP SE or the PopData SRE?  Yes  No  If yes, proceed to Part B.3. If no, answer the questions below. | | | |
| If No, identify below which of the HDP Data Council approved SEs you propose to use:    Please answer the questions regarding physical location and security of data below. | | | |
| **Physical location and security of data** (if not using HDP SE or the PopData SRE) | | | |
| Note to PI:   * Indicate the physical locations(s) where research data will be used or accessed, including research sites, and storage sites (if different) * Indicate all general physical security measures in place at each location * Include measures taken to protect workstations, hard copy and source media * If data will be stored on a network or system to which individuals other than identified project personnel have access, or on a system connected to a public network (the internet), indicate and describe the network security measures in place * Describe how, and from where, any regular maintenance and backups of your network are conducted, where backup material is stored, and provide the backup retention schedule | | | |
| Site | | Organization name | |
| Street Address | City | | Province |
| Country | Postal code | |  |
| **NOTE:** All physical locations housing data must be locked, except when an individual authorized to access the data is present. If data will be stored on a network or system to which individuals other than identified project personnel have access, or on a system connected to a public network (the internet), indicate and describe the network security measures in place. | | | |
| Locked cabinet  Door keypad Other  Firewall  Password changed regularly, change interval (days)  Password rules (minimum length complexity)  Drives of folder with access restricted to specific research group | | | |
| **File encryption**  No encryption:  Security audit:  Access logs:  Describe how, and from where, any regular maintenance and backups of your network are conducted, where backup material is stored, and the backup retention schedule.  Backup | | | |

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| **Part B.3: Safe Output**  ***Ensuring the Output Process Protect the Data.*** |
| **Note to PI**   * PIs and their research teams are required to conduct project analyses within the HDP SE or PopData SRE * Only statistical products and non-data will be permitted as outputs from the HDP SE and PopData SRE * Statistical products are, generally, information dissemination products that describe, estimate, forecast, or analyze the characteristics of groups, customarily without identifying the persons, organizations, or individual data observations that comprise such groups (e.g. aggregated data tables, regression results, etc.) * All outputs will be reviewed |
| Will outputs be requested from this project?  Yes  No |
| What outputs do you intend to transfer out of the HDP SE and PopData SRE? Please be specific and outline your proposed output in detail (e.g. aggregated data tables) |
| Description of how small cell sizes will be managed to mitigate the risk of re-identifiability of the information disseminated |
| Describe for what reasons output is required, what the intention of using the data will be, and how it will be published |