Iowa's Integrated Data System for Decision-Making (I2D2): Governance Plan

September 2019

i2d2
Iowa's Integrated Data System for Decision-Making

Authorized by the I2D2 Data Stewardship Committee and Early Childhood Iowa State Board.

Summary

This document describes the governance plan for Iowa's Integrated Data System for Decision-Making (hereafter referred to as I2D2). The plan was created with the approval of the ECI State Board appointed Integrated Data System (IDS) Taskforce in 2019. Legislative authority comes from Iowa Code Chapter 256i, which provides support for an ECI-driven I2D2 to actualize the vision that Iowa will have a coordinated, comprehensive service system for young children and their families. This plan incorporates the goals of the ECI State Board's Strategic plan by promoting: (1) effective communication and coordination among multiple systems, (2) a systems-informed approach to policy and programming, and (3) evidence-based policies and services that reflect good stewardship of public investments.

The protocols, committees, and procedures described herein were developed by the ECI IDS Taskforce in consultation with national experts through the Training and Technical Assistance Program of the Actionable Intelligence for Social Policy Network (www.aisp.upenn.edu) and local data governance experts and documentation from existing state systems (e.g., EdInsight; IDPH Research and Ethics Review Committee).

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PART I: VISION, MISSION AND PRINCIPLES

I2D2 VISION:

Iowa's early childhood system will be effectively and efficiently ***coordinated*** among health, social service, and education agencies to support healthy and successful families. This work will be ***informed by actionable intelligence*** derived from a ***statewide integrated data system*** that comprehensively identifies and addresses the needs of Iowa's young children and their families.

I2D2 MISSION:

Ensure ethical integration and analysis of relevant, cross-system data to:

- identify priority areas for policy and program change to support young children and their families;
- advance a culture where applied and academic knowledge are effectively brought together to transform theory into practice;
- strengthen broad outcome assessment and improvement;
- promote a data literate community of researchers, practitioners, and policy makers;
- encourage the use of analytic findings in practice and policy decision-making; and
- foster an iterative inquiry process that builds, expands, and adapts to knowledge gained.

I2D2 PRINCIPLES:

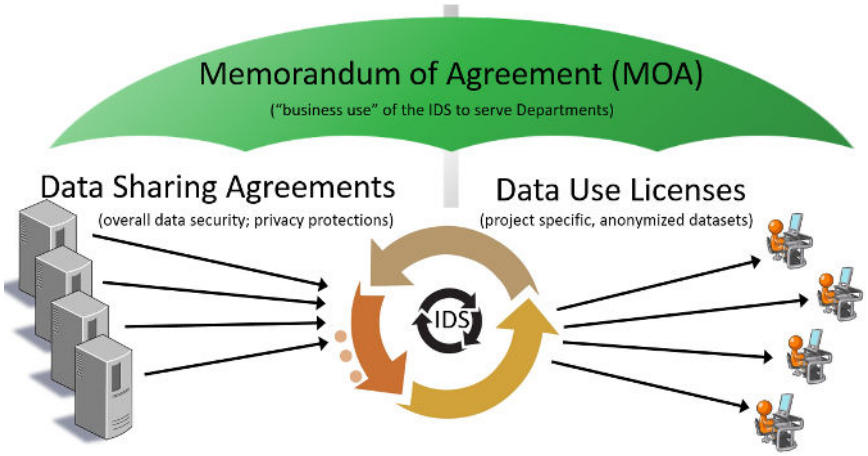
To fulfill the I2D2 Vision and Mission, the following principles serve as a foundation for the creation of our governance processes:

1) Act first and foremost in the service of improved public good and services.
2) Maintain high standards for data security that protect privacy and confidentiality.
3) Build mechanisms to ensure that all data meet standards for timeliness, accuracy, validity, and professional collection methods.
4) Minimize the costs associated with the actionable intelligence inquiry process, while maximizing the benefits to be derived from the data.
5) Engage the community of practitioners, policy makers, and researchers in the production and sharing of information generated from the inquiry process.

Part II: LEGAL STRUCTURES

I2D2 is authorized through three layers of legal protections that actualize the vision of I2D2 while maintaining strict confidentiality and privacy protections for the data contained within the system.

FIGURE 1: LEGAL AGREEMENTS



1. MEMORANDUM OF AGREEMENT

This is the umbrella agreement that authorizes I2D2 to exist in service of Early Childhood Iowa's mission. It is effective from the time of signatures and does not expire unless a written withdrawal of any party is amended to the agreement. It lists the key departmental units involved in the collaboration and refers to the current governance document as the implementation procedures for how I2D2 will operate. The MOA names the Governing Board, Data Stewardship Committee, and I2D2 Resource Hub as the operational groups for implementation.

2. DATA SHARING AGREEMENTS

One agreement between each data-contributing agency and Iowa State University is implemented to authorize sharing of data for use in I2D2. Data sharing agreements (DSA) will refer to the MOA for the overarching purpose and prioritizing of data sharing to support program and policy decision-making. DSAs will contain details about how data will be securely transferred, stored, managed, integrated, anonymized, and used only for approved projects that follow the protocols outlined below. DSAs will authorize data to be shared from the data-contributing agency with Iowa State University (as the IDRH) to be cleaned and stored in a "data lake". This "data lake" will be a secure, encrypted location where data will be stored and cleaned until projects are approved for use. DSAs will specify when and how data can be used, such that only projects that have been vetted and approved by the I2D2 Data Stewardship Committee will be authorized to use data contained in I2D2.

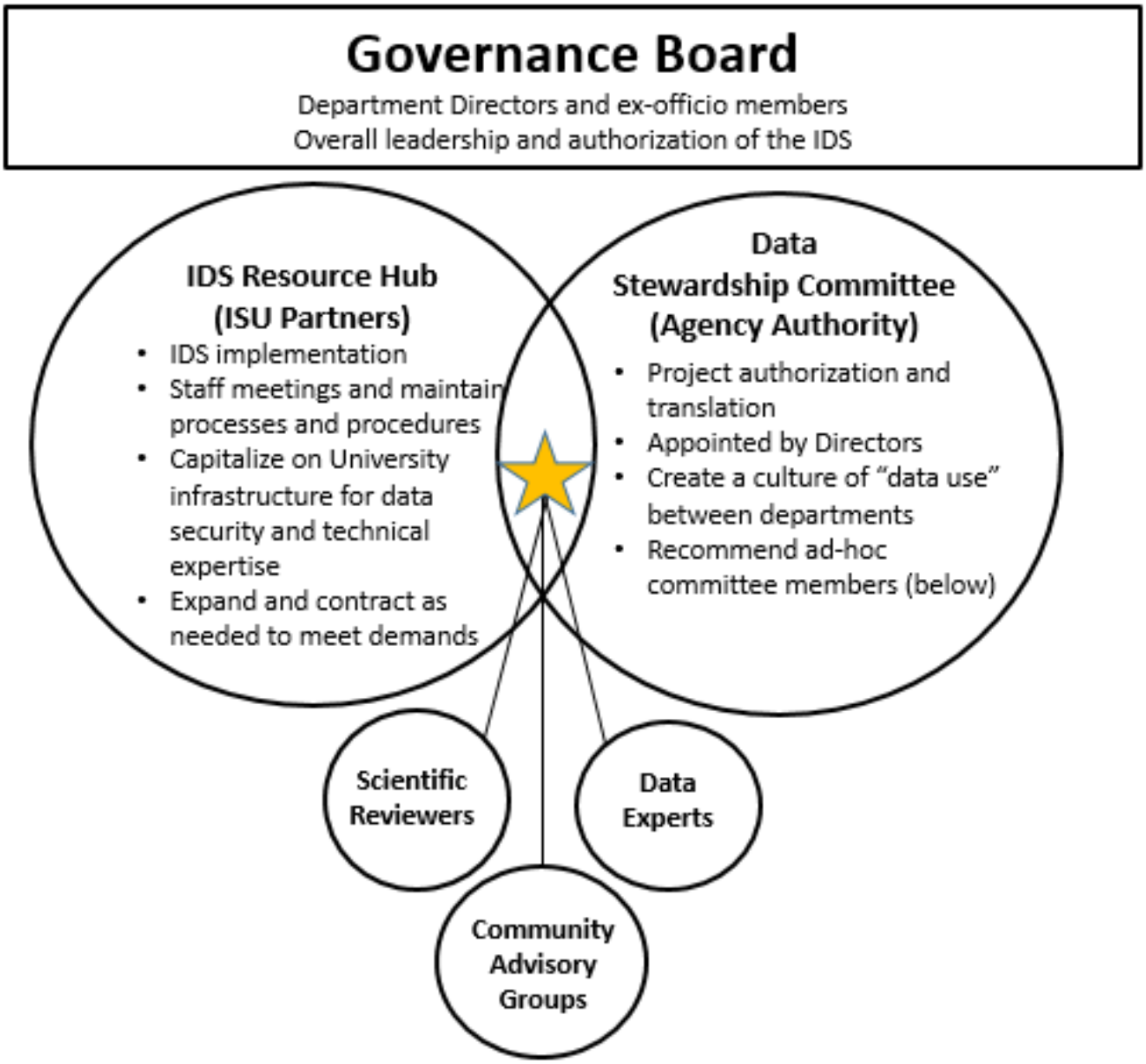
3. DATA USE LICENSES

One data use license (DUL) between each requestor and the IDRH will be generated every time there is an approved project that is authorized to use I2D2 data. The DULs are time-limited for access to anonymized/limited datasets for projects that have been formally approved by the I2D2 Data Stewardship Committee. DULs will reference the MOA, DSAs, and the specific project parameters that were approved for use including the datasets, variables, approved research questions, and timelines for a project. DULs will authorize the use of anonymized datasets that must be destroyed or returned to the IDRH upon completion of projects.

PART III: GOVERNANCE STRUCTURE AND FUNCTIONS

The success of a statewide longitudinal data system relies on the expertise and contributions of key leaders and stakeholders who are strategically engaged in the work. For I2D2, key working groups will facilitate this collaborative effort by fulfilling a requisite role in shaping and executing the vision and mission of I2D2. This governing body will include three standing workgroups (Governance Board, I2D2 Resource Hub, and Data Stewardship Committee) as well as three ad-hoc groups commissioned to support individual projects before and after their approval: Scientific Reviewers, Data Experts, and Community Advisory Groups.

FIGURE 2: I2D2 GOVERNANCE STRUCTURE



GOVERNANCE BOARD (GB)

Purpose and Function: EXECUTIVE LEADERSHIP

The objective of the Governance Board is to provide overall guidance and support for the scope and focus of I2D2. These chief decision makers are positioned to consider and resolve internal and external policy issues that surface as I2D2 develops, and go beyond the authority of the Data Stewardship Committee (DSC) or the I2D2 Resource Hub. Voting members will include Directors, or their designees, from all data-contributing departments/agencies. Ex-officio members will include the ECI office administrator, I2D2 Resource Hub director, and ECI Board Chair. Meetings of the GB will occur at least annually, or as needed, to provide direction and feedback on I2D2 activities.

Roles and Responsibilities of the GB:

- Champion the system within the various agencies and stakeholders, including executing strategic communication plans about the I2D2 mission, vision, purpose, and ongoing projects
- Authorize I2D2 through the establishment and renewal of the MOA
- Establish priority uses of I2D2
- Recommend representatives to serve on the DSC with decision-making authority to implement I2D2 and approve the use of I2D2 data for proposed projects
- Approve the policies and procedures created by the DSC for the implementation of I2D2
- Facilitate the establishment of legal data sharing agreements and memorandum of agreement to implement I2D2

DATA STEWARDSHIP COMMITTEE (DSC)

Purpose and Function: PROJECT AUTHORIZATION AND TRANSLATION

The objective of the DSC is to support the implementation of I2D2 and create a culture of data use between departments in service of the I2D2 mission. Members of this committee will be recommended by the GB to serve the role of "chief decision makers" for the use of I2D2, acting upon the recommendations of the I2D2 Resource Hub, Scientific Reviewers, Data Experts, and Community Advisory Groups. The DSC also ensures the operationalization and communication of findings in collaboration with data requestors and IDRH.

DSC will meet at least quarterly to discuss I2D2 policies and procedures, review and vote on project proposals, and consider findings from approved projects. DSC members are positioned to consider and resolve internal and external policy issues that surface as I2D2 develops, and ensure I2D2 reflects the overall objectives of the various state agencies and partners.

Roles and Responsibilities of the DSC:

- Understand the GB priorities for the use of I2D2, including the ECI Strategic Plan and the role of I2D2 in supporting the ECI mission;
- Understand specific Department priorities and needs as they relate to discussions about I2D2 priorities and proposed uses;
- Support the implementation of I2D2 procedures and policies regarding data sharing and use in the service of the ECI mission;
- Champion the system within the department and with external stakeholders to facilitate sustainability, including executing strategic communication plans about the I2D2 mission, vision, purpose, and ongoing projects;
- Adopt and communicate data governance policies, as needed, to ensure data integrity and usability

- Adopt and implement misconduct procedures in collaboration with the IDRH and under the authority of the GB;
- Provide recommendations to the IDRH regarding potential experts for Scientific Reviewers or Data Team members who will be designated to provide review and input on datasets and proposed project uses prior to a DSC vote;
- Review and vote on proposed I2D2 projects, including the solicitation of input from additional relevant departmental stakeholders as needed;
- Commission Community Advisory Groups to participate in I2D2 inquiry processes;
- Review project findings and provide recommendations for stakeholder communication plans, policy or program improvements, and/or future analytics;
- The DSC, or alternative representatives designated by the GB (which could also be the Community Advisory Group), will provide a pre-publication review of any products generated as a result of I2D2 analytics. Such a review will be completed within 30 days of submission, with input from the GB Directors as needed.

DSC Meetings:

The DSC should convene at least quarterly to deliberate I2D2 priorities, review proposed projects, consider findings from approved projects, and monitor processes and procedures. Additional meetings may be convened to address priority policy questions or review project proposals or findings that require attention between quarterly meetings. Individuals, other than agency directors or their designees, may be invited to participate in DSC discussions (though would not have a vote on matters of process or protocol).

I2D2 RESOURCE HUB (IDRH)

Purpose and Function: IMPLEMENT

The I2D2 Resource Hub will be housed at Iowa State University with the responsibility for implementing the work of the I2D2 according to the established Mission, Vision, and Principles and as directed by the Memorandum of Agreement and related policies. This team is responsible for, at minimum: (1) staffing the governance meetings and related activities including GB, DSC, SR, DE, and CAG; (2) executing and maintaining all legal agreements (MOA and DSAs to establish the system, and individual DULs to authorize I2D2 projects that are approved by the DSC); (3) screening and monitoring I2D2 projects from proposal through to dissemination; and (4) conducting data management and integration activities as approved by the DSC. The IDRH could also execute analytic projects as approved by the DSC in accordance with all other procedures outlined herein.

Staffing:

At minimum, roles including Director, Research Director/Project Manager, and Data Engineer must be covered by dedicated staff time. These roles could be covered by a few individuals in the short-term, with the understanding that personnel could be expanded and contracted over time depending on the scope and nature of I2D2 project demands.

Director. Responsibilities would include: Co-facilitate the GB, develop the overall plan and structure for implementing I2D2, maintain all required legal agreements, staff meetings, pursue and sustain funding in partnership with ECI leadership for the basic infrastructure of the IDRH (not including analytics, which would be budgeted on top of basic maintenance funding), and provide final “clearance” for any sharing of anonymized/limited datasets (i.e., serve as the Data Privacy Officer). The Director would also be responsible for maintaining relationships with stakeholders that are critical to the mission of I2D2 which includes, but is not limited to: I2D2 data contributors, ISU leadership, ECI Stakeholders Alliance and workgroups,

program/agency leadership who may be translating findings, analytic users, and the broader research community. This role includes facilitating a strategic communication plan with various stakeholders.

Research Director/Project Manager. This role includes managing I2D2 requests; providing initial reviews of analytic proposals; consulting with requestors; developing and maintaining timelines and budgets for projects; managing the work of the data engineers and analysts; and maintaining meeting minutes, notes, and documentation of all work completed.

Data Engineer(s) and Analyst(s). Data scientist(s) would be responsible for maintaining the "data lake" and all data documentation (original and project-specific integrations); routine data management and cleaning; development and implementation of data integration plans, and the de-identification of datasets.

SCIENTIFIC REVIEW TEAM (SRT)

Purpose and Function: RECOMMEND

The SRT is an ad hoc committee responsible for reviewing requests for I2D2 data and providing recommendations to the DSC for consideration. The SRT will be comprised of substantive and methodological experts who are recommended by the IDRH and DSC. It will comprise as many members as needed to cover the topic areas included in data requests. It will operate on an ad-hoc basis, where membership will be fluid and requests to review will be solicited according to members' expertise as projects are proposed. The goal is to ensure the membership includes a cross-section of various research specialties important to the I2D2 work, represent the geographic regions of the state, reflect as many of the Regent's universities as possible, and support data use for a variety of purposes (e.g., policy, programming, academic).

The reviews will focus on the following questions:

- How well does the proposal fit with existing literature on the topic?
- Are the scientific methods for the analysis sound, or are there other methods to consider?
- Are there limitations in proposed sample sizes or data quality that might render findings questionable to be used for decision-making purposes?
- Are there any concerns about variables used or not used that might confound the potential findings (i.e., are there available covariates left out that have known relations with the outcomes and need to be considered)?

DATA EXPERTS (DE)

Purpose and Function: DATA SUPPORT

The Data Experts committee serves as a specialized, ad-hoc committee that supports I2D2 data management, proposal reviews, data integration, and the interpretation of findings from analytic projects. A primary role of the Data Experts is to support the acquisition, integration, and use of data from departmental systems. This team will be comprised of one or more data experts from each data-contributing entity who are selected based on their expertise and area of data focus. Members will be expected to understand policy/program changes within their systems that may impact data availability and quality for I2D2 projects.

<u>Roles and Responsibilities of the Data Experts</u>:

- Meet on an as-needed basis

- Provide the DSC with the recommendations needed to adopt policies that ensure the quality, availability, security, and usability of data for purposes of I2D2. The group is the subject matter authority regarding data processes
- Identify the business rules required to ensure data are current, consistent, and accurate
- Help the IDRH maintain a log of critical data issues, including their status and resolution
- Manage the work of data acquisition when projects are approved and/or at regular intervals determined by the DSC to support the overall work of I2D2
- Provide documentation for all data provided to the IDRH
- Review research project proposals, as needed, to provide feedback on the feasibility of data use as proposed

COMMUNITY ADVISORY GROUPS (CAG)

Purpose and Function: SHAPE and TRANSLATE

A Community Advisory Group is a working group of program managers, practitioners, data experts, policy advocates, community members, and other stakeholders whose role is to help ensure that research questions, analytics, and the application of findings from analyses that use I2D2 are considered in light of program and community realities. Each CAG also helps ensure ECI principles including equity are infused within I2D2 projects. The CAG helps analytic teams understand the contexts in which administrative data are collected (e.g., the meaning of missing data or confusing/conflicting data values) and translate findings into action with a sensitivity to program challenges and realities. Members of the CAG will be recommended by the DSC for approved projects that use I2D2 data.

CAG meetings will occur approximately three times throughout a project, but this may be determined at the project outset and fluctuate as needed:

- First, the CAG will meet at the beginning of the project with the IDRH and the requestor to understand the scope of the project and anticipated timelines when sequenced findings could be considered. Preliminary discussions of the strategic communication plan for the project will be included.
- Next, periodic interim meetings will be held as findings are available through different phases of the approved project. The purpose of these meetings is to solicit discussion about the findings, deliberate potential implications, and discuss the strategic communication plan. Some implications could include identifying additional questions that require further analytics, or recruiting additional CAG team members with expertise that was not originally anticipated.
- At the conclusion of a project the CAG will meet with the analytic team to consider all findings, recommend what/how the findings will be communicated widely and with the DSC, and discuss the translation of the findings into program or policy recommendations. It is expected that (at minimum) a co-constructed final report will be prepared from all I2D2 projects that will include input from the CAG and DSC in addition to the presentation of analytic findings. The CAG may also recommend additional presentations for other stakeholder groups who would benefit from the findings to engage in further program or policy development work, and/or future cycles of inquiry stemming from project findings.

PART IV: PROJECT REVIEW PROCESS

Every project will follow a standard set of processes from the initiation of the idea through to the dissemination of results and either (a) termination of the project or (b) consideration of the next cycle of inquiry to build on the results. This section will outline these processes and discuss the different roles and responsibilities of each I2D2 governance group.

PHASE 1: CONSULTATION

- The Requestor (internal or external) consults with IDRH to understand the process and contents of I2D2. This consultation may include:
    - Discussing the data systems that are included and how they have been used in the past;
    - Understanding the limitations/boundaries around the use of I2D2 data (privacy/confidentiality, publication process, data destruction policy, required participation in DSC/CAG deliberations, etc.); and
    - Provision of general estimates of timelines and budgets for I2D2 projects.
- The IDRH may provide feedback to the Requestor as they prepare their application to ensure it is complete, follows all guidelines (including format of the proposal, checkboxes for data systems or elements requested, budget, IRB approval, etc.), and is likely to serve the priorities of I2D2 under the direction of the DSC.

PHASE 2: I2D2 PROJECT REVIEW

- The Requestor submits an application to the IDRH ***with at least one signed letter of support*** (LOS) from an agency or department represented on the signed MOA. The LOS must contain, at minimum:
    - Information about the relationship between the requestor and the supporting agency;
    - How the agency would benefit from the proposed analytic project; and/or how the agency is hindered in their current practice without the information that the project proposes to provide; and
    - What role the agency will have throughout the project, including involvement on the CAG and additional mechanisms to facilitate the translation of analytic findings into practice and policy decisions.
- IDRH provides a preliminary review to ensure the application follows protocol and includes all required components.
- IDRH solicits (at least) 2 independent reviews from the Scientific Review team with expertise about the content area. The reviews will include, but are not limited to, the following questions:
    - How well does the proposal fit with existing knowledge (empirical literature or state assessments/reports) on the topic?
    - Are the scientific methods for the analysis sound, or are there other methods to consider?
    - Was a proper power analysis conducted to determine if the sample size and proposed analytic approaches will be valid?
    - Are there any concerns about variables used or not used that might confound the potential findings? (i.e., are there available covariates left out that have known relations with the outcomes and need to be considered?)
- IDRH solicits reviews from Data Experts as needed to provide information and context regarding the data systems of focus for the proposal.

- IDRH summarizes the reviews and provides additional input as relevant (including but not limited to estimated project timelines and budgets, and/or implications of pursuing the project on the overall scope of work currently underway with I2D2). This summary and report will be provided to the DSC at least 1 week in advance of the DSC meeting where the proposal will be discussed.

PHASE 3: DATA STEWARDSHIP COMMITTEE MEETING

- DSC holds (at minimum) quarterly meetings to review project proposals, discuss findings from analytic projects, and also share departmental priorities that I2D2 might be able to help address or that they want help considering.
- At the DSC meeting, a Requestor may present a brief overview of their proposal – including the main purpose, proposed methods, and proposed implications.
- DSC and IDRH members ask questions and discuss the proposal – looking for opportunities to enhance the proposal to ensure it is relevant & scientifically rigorous (may suggest other data to consider, or other questions that would be of value to the DSC).
- Decisions regarding whether projects will move forward will follow a consensus model whereby all DSC members will have input. Consideration of the needs and concerns of those members whose data would be used for the project, however, should be weighed accordingly. In pursuit of consensus, it is likely that most proposals at this stage would receive a "revise/resubmit" decision where minor changes are recommended.
- Individual agencies can veto the use of their own data in any project. If that occurs, the group can discuss whether changes can be made to move forward without those data or revise the project to seek approval of the dissenting agency.
- If projects are approved, DSC will authorize with a signatory page that becomes an addendum to the proposal and includes what data and analyses are approved and for what time period.
- If project are approved, DSC will recommend members for a Community Advisory Group to follow the project, offer insight along the way, and consider findings while the research is being conducted to ensure they are translated and/or considered for use (see more details below about this process).
- If projects are not approved, the DSC will provide comments regarding questions and concerns.
- IDRH summarizes the discussion, decisions, questions and/or recommendations for revision and next steps in a written communication to the Requestor.

PHASE 4: DATA INTEGRATION (After projects are approved)

- IDRH consults with Data Experts to map out the data integration plan and generate revised timeline and budget estimates. Revised timelines and budgets are negotiated with the Requestor prior to execution of a Data Use License (DUL) and commencement of data integration work.
- IDRH generates the Data Use License (DUL) with the Requestor that outlines the project scope and legal limitations for data use. This DUL will include the approved proposal and the DSC approved signatory page in the appendix of the DUL.
- IDRH creates an integrated dataset following the plan, checking with relevant Data Experts members along the way to ensure the analytical variables are pulled and coded appropriately.
- IDRH anonymizes the dataset according to DSC approved deidentification protocols, leaving only the analytical variables and randomly generated I2D2 numbers to enable future linkages if they are pursued and approved by the DSC.
- IDRH submits to and receives clearance from the Data Security Officer that the dataset is sufficiently anonymized/limited.
- IDRH securely provides access to the anonymized/limited dataset for the Requestor.

PHASE 5: DATA ANALYTICS AND DISCUSSION

- Requestor begins preliminary analytics and coordinates with the IDRH to schedule Community Advisory Group meetings to consider interim results and help shape the study.
- Community Advisory Group meets regularly (at least 3 meetings) with the Requestor to discuss findings, shape additional analyses, ask questions, and consider the results for implications, and propose future cycles of inquiry. Together, the Requestor and CAG determine when and how to present findings to the DSC and develop a communication plan.

PHASE 6: DISSEMINATION AND NEXT STEPS

- At minimum, the Requestor presents findings to the DSC at the midpoint and the conclusion of the project. GB, DSC, and CAG have the right to the following from all Requestors:
    - Full Final written report detailing all analytic methods, findings, and the deliberations of the CAG in considering implications;
    - Requests for up to 2 presentations to additional stakeholders for input and ideas;
    - An opportunity to engage in future research (pending resources) – particularly if the analytic findings suggest new interventions or policy changes that would benefit from continued evaluation; and
        - Pre-publication review – I2D2 users must share any publications with IDRH for review to ensure confidentiality and alignment with DUL.
- IDRH is responsible for ensuring that all datasets are destroyed by Requestors upon completion of approved projects (or returned to I2D2 for warehousing in case future analytic needs arise that would benefit from using the archived datasets).
    - An amendment process will be allowed for Requestors who want to add data elements or answer additional questions with the datasets they have (and who have adequately addressed DSC and CAG needs such that they are granted permission to continue the work). This could also be allowed in the case where longitudinal studies wish to add new outcome data to their project over time.
    - Renewals of existing projects to extend timelines or substantially alter project scope would require DSC approval.

PART V: STRATEGIC COMMUNICATIONS PROCESS

Routine communications with ECI stakeholders about I2D2 priorities, procedures, and findings from I2D2 projects are critical to maintaining a strong data culture to improve understanding and "use" of data across ECI systems. The following guidelines will facilitate such communications in accord with ECI mission and Strategic Plan.

- IDRH Director will provide quarterly updates about I2D2 work for the ECI Administrator to include in the ECI Administrative Updates
- Routine meetings of the ECI State Board, Stakeholders Alliance, and component groups will include updates and/or discussion about I2D2 work
- Each CAG will work with Requestors of approved projects to develop a formal communication plan related to each specific project. This plan will be initiated at the project kickoff meeting to identify relevant stakeholders, and revisited and formalized near the end of the project once findings are ready to be shared.
- IDRH will establish standardized reporting guidelines and templates for Requestors to provide written and oral communications about projects with ECI stakeholders.
- All I2D2 products, reports, briefs, and presentations will be made available on the I2D2 website.