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Data Sharing for Demographic Research
ICPSR/ISR
From my experience...

1. How to best organize for reviewing applications and managing agreements
2. What are the features of a good online system to manage agreements
3. Don’t forget about the administrative costs
4. How best to handle security issues
5. How to help people avoid the pitfalls and common mistakes—how to make the process easier?
6. What are a few innovations that ICPSR is exploring
1. Organizing to review and process...

- Team based, collaborative model
  - Multiple staff members trained for project management
  - At least two reviewers per application
- Establish clear guidelines for applicants
  - Provide information upfront
  - Design system to efficiently collect information
    - Asking for the same information in different locations throughout the application creates room for disparate information
  - Allow for flexibility due to changing/evolving technology, variations in institutional capacities, and research projects
1. Review Process

- Top-to-bottom review of each section in IDARS
- Open communication, typically through email, with restricted data applicants
- After initial review is complete, applicants are asked to make corrections to application
  - Receive notification through email with requested changes
  - When user goes to My Application page, a blue box will appear with the requested edits
- Re-submit for second review
- If payment is required, payment must be received before data are sent
  - Can be paid at any point during the application process
- When application is ready for approval, electronic confidentiality pledges are sent through the system.
  - Tracks when they are signed. Once all are received system allows final approval
2. Features of a good online management system for restricted data

• Build and implement an online management system with the following features
  • Automatic notification when materials are due or submitted
    • IRB updates
    • Renewing an expired agreement
    • Submission of an annual report
    • Terminating agreement
2. Features of a good online management system for restricted data

- A centralized management system should eliminate burden associated with paper-based restricted data applications
  - Easier to seek corrections/feedback from applicant than a paper-based application
  - Streamline renewal and modification process
  - Reduces costs
    - Online system lowered admin costs 26%
- Provides applicant information on required documentation or sections to be completed
  - Research description
  - Data Justifications
  - Security Plan
  - IRB Upload
  - Annual Reports
  - Final Signatures
2. IDARs

- ICPSR Data Access Request System (IDARS)
- Built to facilitate requests for restricted-use data
- Since 2012
- Continually looking for ways to improve the systems
2. Example: IDARS system

- ICPSR’s online system to manage the processing of applications for restricted data
- In order to access the IDARS system, an applicant must have a MyData account with ICPSR.
  - Free to create through DSDR and ICPSR websites
    - Can be linked with Gmail, LinkedIn, or Facebook accounts
- Investigator on agreement must meet the following requirements
  - PhD, JD, MD, or other terminal degree
  - If graduate student, faculty adviser must sign on as a sponsor
    - Some restricted data agreements do not allow graduate students to be investigators
      - Can be listed as staff, and guaranteed the same access rights to data
2. Navigating to IDARS

- Visit icpsr.umich.edu/dsdr
  - Click on “Restricted Data” tab on the left hand side
2. Navigating to IDARS

- After selecting the study from the Restricted Data Access page, applicants will be taken to the study’s agreement materials page.
- Links to IDARS, Restricted DUA, Payment and Contact Information.
2. IDARS

After clicking the link on the agreement materials page, applicants will be taken to the IDARS welcome screen.

My Application page
- Request Number
- Completion Status
  - Overall application
  - Section of application
- FAQs
- Contact Us
- Download Agreement
- Delete Request
- Submit to ICPSR
3. Remembering administrative cost...

- If you decide to set up a full service shop....
  - Develop cost-effective fee structure(s) to cover administrative costs
    - Figure out how much it actually costs you to manage applications and then establish a reasonable fee structure that covers your costs
    - Benchmark with other large projects that handle restricted data agreements to see what they charge for processing applications
4. How best to handle security plans...

- Security plans require careful review and often take up most of the time in processing an application
- Important to have guidelines that ensure data security, maintain confidentiality, flexible to rapidly evolving technological conditions
  - IDARS---standardize information collected (a series of questions asked)
    - Access information
    - Computer/hardware information
    - Individuals involved in project
    - Handling printed materials, storage of CD/data
  - Supplemental security plan specific to servers/networked/stand-alone computers
    - Not all plans require the same technological specifications
5. Avoiding Common Mistakes

- Discrepancies in information provided by applicant
  - Data access information on research staff page and confidential data security plan
- Laptops and External Hard Drives
  - Although allowed, laptops cannot be used as “mobile” devices
    - Researcher will have to obtain locking cables and provide documentation of the cables via receipt or photo
    - Slows down application approval
    - External HDs must be “desktop” models
      - Plug into wall and computer
- Omitting information in security plans
  - Incomplete information requires additional corrections
    - Providing information on computers and servers (make/model/location)
    - Identifying individuals by name in security plan
    - How printed materials are handled/stored/discarded
- Institutional Representative Signatures
  - Must have signatory power to legally represent institution
    - Typically, through Office of Research or Sponsored Projects
- Research Descriptions
  - We ask for good quality abstract length descriptions that demonstrate how a given research project is grounded in existing theory, and how the restricted data will help answer a specific research question
5. Tips for Applicants

• Ask questions early!
  • Due to high volume, many applications do not receive an initial review immediately upon submission
    • Reviewed in order they are received
    • By asking questions before submission, you guarantee yourself fewer revisions and approval can be made more quickly.
      • Reviewer can work through more applications in less time
  • Dedicated resources to assisting applicants
    • Email and Phone
• Talk with your IT department
  • Parts of the data security plan are technical, especially when the data are going to be housed on a server
• Be thorough when providing information
  • Data sensitivity and maintaining confidentiality are the reasons why the data are restricted, if we are unable to determine that you have taken adequate steps to maintain confidentiality we will require additional revisions to the application
• Plan ahead and take your time on the application
  • A hastily completed application is more likely to require extensive revisions
  • An application cannot be initiated, submitted, reviewed and approved in a week or two
    • If you have a dissertation or grant deadline, start the process early
    • Obtaining the correct signatures and IRB documentation at your institution will also take time
• Read the full agreement prior to applying
  • Graduate students must make sure that they can be investigator
    • If they have signed and uploaded the agreement, they will have to recomplete this with a faculty member signed off as the investigator – might have to obtain institutional representative signature again
6. ICPSR innovations

- Institutional level, umbrella agreements
  - IRB approval, security plans are only necessary documents to obtain restricted data
  - Removes Institutional Representative from the process
    - No language modifications to agreements
- Risk-focused security plans
  - Concentrate on risks related to confidentiality, rather than technology
    - Provide basic recommendations for mitigating each risk
      - Allow applicant to provide alternative method for mitigating risk
- Virtual Data Enclave (VDE)
  - Ensure security in a collaborative environment
  - Access to restricted-use micro data
  - Output vetted for disclosure