

Data Sharing: Creating Agreements

In support of community-academic partnerships

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Summary

This resource was developed in response to an identified need for more developed guidelines for data sharing in community-academic partnerships. It contains:

- Best practices on data sharing, data management plans, and data sharing agreements
- A step by step process for the creation of a data sharing agreement
- Recommendations for what to include in a data sharing agreement
- Information about the creation and support of effective community-academic partnerships – including building trust
- An annotated bibliography of key resources for the support of data sharing in community-academic partnerships
- And more

This resource is intended as a guide to facilitate decision making concerning data sharing agreements between community and academic partners; it is not meant to be comprehensive, nor directive.

Request for Input

The content of this document has been culled from literature and resources on the Internet. To anchor this in more than our own real life partnerships, we want you to be a part of this conversation!

Please provide us with your feedback so we can improve this document to suit your needs by contacting Paige Backlund Jarquín at Paige.Backlund@ucdenver.edu or Julie Marshall at Julie.Marshall@ucdenver.edu. If you want some direction for providing feedback, there is a document feedback form at the end of the document you can use.

Thank You!

Data Sharing: Creating Agreements

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Data Sharing: Creating Agreements

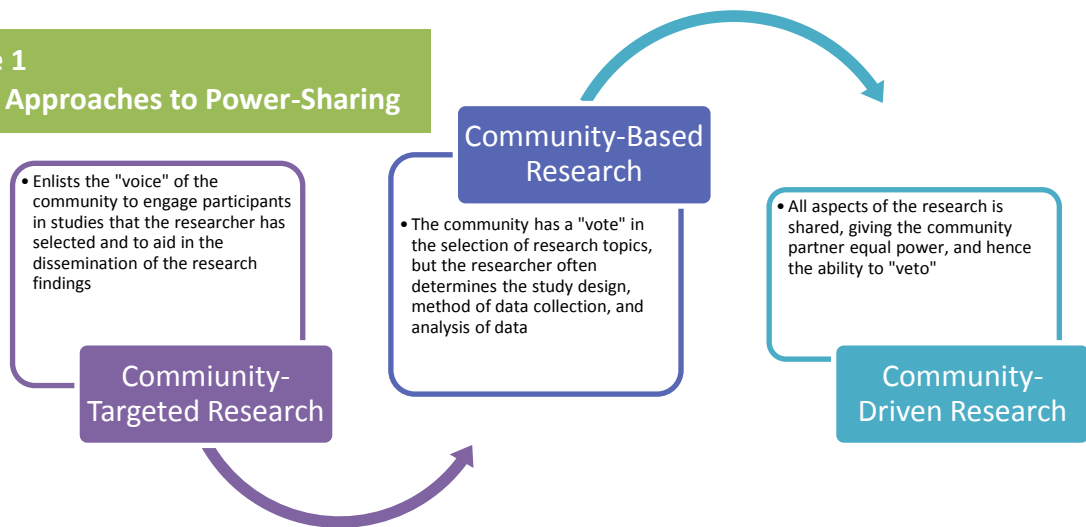
Background

The past 10 years have seen a strong emergence of community-academic partnerships as an approach to conducting participatory public health research. While this approach brings new opportunities for generating knowledge and exchange, it also raises new social, ethical and administrative challenges, particularly around data use. Addressing and surmounting these challenges is critical for transforming community-academic partnerships into sustained enterprises that address health concerns at the community level.

Many funding agencies are attempting to address the challenge of data access, data use and re-use by requiring a thoughtful plan for the data sharing process in research partnerships (Inter-University Consortium for Political and Social Research (ICPSR), 2009). Despite the emphasis on data sharing plans and formal agreements, funders often leave the mechanism for data sharing unspecified (Piwowar, Becich, Bilofsky & Crowley, 2008). There is little guidance for partners on what to include in data sharing agreements and how to facilitate the delicate, yet essential, conversations concerning data use and re-use.

The complex nature of community-academic research projects can further complicate this process. Partnership dynamics between community partners and academic researchers varies based upon the distribution of power between the organizations, and the interweaving of two different organizational systems (Lindamer et al, 2009). There are three main approaches to power sharing in community-academic research partnerships: community-targeted; community-based; and community-driven. Figure 1 demonstrates the three approaches to power sharing in community-academic research partnerships.

Figure 1
Three Approaches to Power-Sharing



(Adapted from: Lindemar et al, 2009)

Each approach to power sharing specifies clear roles of community partners in the research process. Using community-driven techniques is the most effective at reducing power disparities within community and academic partnerships. Developing a data sharing agreement in collaboration with all partners is one tool that can be used to help increase power sharing among partners.

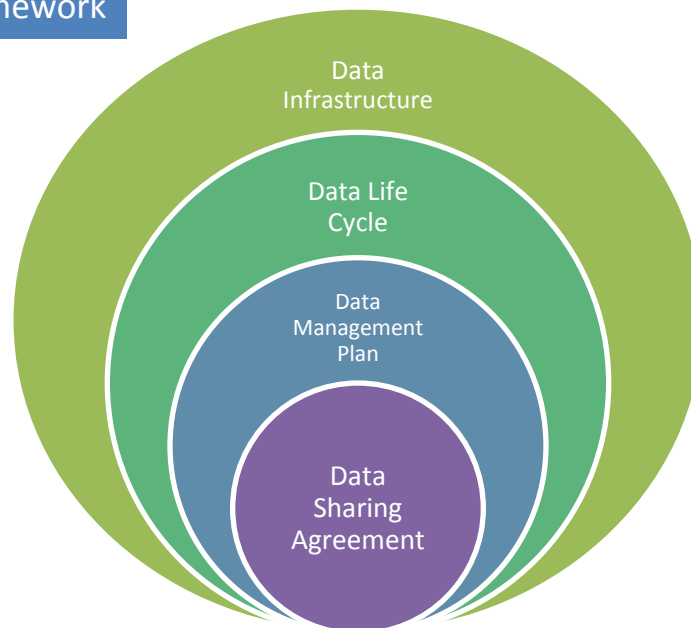
In addition to the navigation of power relations, community-academic partnerships work to combine two very different organizational systems, each with its own goals, values, styles, limitations and pressures (Lindemar et al, 2009). Not only do the types of data differ between partners, but also the needs for re-use, cultivation, analysis and interpretation. This requires shared understanding and open communication, which can be further supported by a well-developed data sharing agreement.

Data, in all its forms, newly created or re-used, should be maximized for use in order to improve health outcomes. Without a strong partnership with good communication, clear direction for a process, and well-developed content as part of a formal agreement, there are risks to the effective use, re-use and generation of meaningful information that is of value to all partners.

Framework

Data sharing is an important piece of an overall data management plan. A data management plan is in turn part of the typical research data life cycle. These are key elements of a wider infrastructure that supports data access, use and sustainability. This guide includes an explanation of the data life cycle, a data management plan, and recommendations for developing a data sharing agreement within community-academic research partnerships. Figure 2 is a depiction of how a data sharing agreement fits into a data management plan, which in turn fits into the overall life cycle of data in a research project. These concepts will be explored in-depth in the following sections.

Figure 2: Framework



If a research partnership has completed a data management plan, much of the administrative work involved in creating a data sharing agreement will be completed and the information specific to data sharing agreements at the end of this document will be especially applicable. If the partnership has not completed a data management plan, it may be helpful or necessary to review the information and resources about the data life cycle and data management plans included in the next sections. The Annotated Bibliography includes helpful resources to support the creation of data management plans and data sharing agreements.

The Data Life Cycle

In order to understand the importance of data management plans and data sharing agreements, it may be helpful to start with an overview of the typical data life cycle. Table 1 identifies the typical steps data take throughout the research life cycle. It is recommended to create a data management plan early on in the cycle.

Table 1: Data Life Cycle						
Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
Proposal Planning & Writing	Project Start-Up & Data Management Plan	Data Collection & File Creation	Data Analysis	Preparing Data for Sharing	Depositing Data	After Deposit: Archival Activities
<p><i>Below are examples of tasks that may be associated with each step in the life cycle of data within research. Some tasks require a specific level of technical skill and tools and each partnership may include some, all or more of these tasks.</i></p>						
<ul style="list-style-type: none"> ▪ Conduct review of existing datasets ▪ Determine whether project will produce a new dataset ▪ Plan for maximizing the usefulness of the data ▪ Describe special archiving challenges, especially informed consent, security procedures and participants' confidentiality, among other human subjects concerns ▪ Identify potential users ▪ Determine costs related to archiving 	<ul style="list-style-type: none"> ▪ Create <i>data management plan</i> ▪ Make decisions about documentation form and content ▪ Conduct pretests and pilot tests of materials and methods 	<ul style="list-style-type: none"> ▪ Follow best practice ▪ For data, address dataset integrity, variable names, labels, and groups; coding; missing data ▪ For documentation explore use of standards; include all relevant documentation elements; document constructed variables 	<ul style="list-style-type: none"> ▪ Manage master datasets and work files (manage how where data is stored) ▪ Set up appropriate file structures ▪ Back up data and documentation 	<ul style="list-style-type: none"> ▪ Address disclosure risk limitation ▪ Determine file formats to deposit ▪ Contact archive for advice 	<ul style="list-style-type: none"> ▪ Complete relevant forms ▪ Comply with dissemination standards and formats 	<ul style="list-style-type: none"> ▪ Collection evaluation ▪ Additional confidentiality review ▪ Data processing ▪ Metadata preparation ▪ Possible preparation for online analysis and data enhancement ▪ Preservation of data ▪ Support for data users
<ul style="list-style-type: none"> ▪ Initiate conversations about a data sharing agreement 	<ul style="list-style-type: none"> ▪ Address communication and trust issues. ▪ Sign data sharing agreement 	<ul style="list-style-type: none"> ▪ Review data sharing agreement, make any necessary changes 	<ul style="list-style-type: none"> ▪ Follow stipulations within the data sharing agreement 	<ul style="list-style-type: none"> ▪ Follow stipulations within the data sharing agreement 	<ul style="list-style-type: none"> ▪ Follow stipulations within the data sharing agreement 	<ul style="list-style-type: none"> ▪ Follow stipulations within the data sharing agreement

(Adapted from: ICPSR, 2009)

Typically, the academic partner of the research project has experience navigating through these steps. In order to share the responsibility, skills development and power, some

community-academic partnerships may decide to include community partners in the process of completing these steps.

Data Management Plan

Planning for data management at the outset is critical to a project's success (ICPSR, 2009). This practice can maximize funding, time, and resources; it builds relationships and meets funding agencies' requirements. In some cases, a data management plan will be directed by funder requirements. It is important to review the stipulations of the funding stream to assure that all requirements are met. If those stipulations are not clearly delineated, the research collaboration will need to set aside ample time to make important decisions about the collection, use, re-use and protection of the data. The Annotated Bibliography included with this document contains a list of helpful resources, including a fillable Data Management Plan template.

In cases where a data management plan is not required by the funder, but the partnership wants to continue with an agreement, reviewing the elements in a data management plan will help formulate a framework upon which to build a data sharing agreement. Taking good notes to capture decisions made about data management will expedite the creation of a data management plan. Following this process also begins to diminish the power differentials by further developing trust and communication pathways within a partnership. Engaging in conversations about each of the elements in Table 2 will help facilitate this process.

Table 2: Elements of a Data Management Plan

Element	Description
Project description	A few paragraphs about the research project. Introduce any terminology
Data description	A description of the information to be gathered or re-used; the nature and scale of the data that will be generated or collected, or re-used.
Existing data	A survey of existing data relevant to the project and a discussion of whether and how these data will be integrated. Search web and data archives for similar datasets. Answer: Why is there a need to create a new dataset?
Format	List data formats, standards, and conventions and apply to each data item. Justify the use of particular formats in terms of usability, longevity, and suitability for archiving.
Metadata	A description of the metadata ("data about data" = means of the creation, purpose, time and date of creation, author, e.g.) to be provided along with the generated data, and a discussion of the metadata standards used.
Data organization	How the data will be managed during the project, with information about version control, naming conventions, etc.

Quality Assurance	Procedures for ensuring data quality during the project.
Storage and backup	Storage methods and backup procedures for the data, including the facilities that will be used for the effective preservation and storage of the research data. Explain backup schedule and process, responsibility and sensitivity levels.
Security	A description of technical and procedural protections for information, including confidential information, and how permissions, restrictions, and embargoes will be enforced.
Responsibility	List owners and stakeholders of the data, and names of the individuals responsible for data management, analysis, interpretation and dissemination in the research project.
Budget	The costs of preparing data and documentation for archiving and how these costs will be paid. Often the time involved in documenting, writing metadata and archiving is underestimated. Also consider equipment and personnel costs.
Intellectual property rights	Entities or persons who will hold the intellectual property rights to the data, and how IP will be protected if necessary. Any copyright constraints (e.g., copyrighted data collection instruments) should be noted.
Legal requirements	A listing of all relevant federal or funder requirements for data management and data sharing. Consider confidentiality issues.
Access and allocation	<i>A description of what data will be shared, how it will be shared, including access procedures, embargo periods, and mechanisms for dissemination and whether access will be open or restricted. A timeframe for data sharing and publishing should also be provided.</i>
Audience	The potential secondary users of the data. List all current and potential future stakeholders.
Selection and retention periods	A description of how data will be selected for archiving, how long the data will be held, and plans for eventual transition or termination of the data collection in the future.
Archiving and preservation	Describe the procedures in place or envisioned for long-term archiving and preservation of the data, including succession plans for the data should the expected archiving entity go out of existence. Also consider secure disposal of data, and backups.
Ethics and privacy	A discussion of how informed consent will be handled and how privacy will be protected, including any exceptional arrangements that might be needed to protect participant confidentiality, and other ethical issues that may arise.
Dissemination	Include format of dissemination (publication, website, etc.), cultural and linguistic needs, principal authors and acknowledgement.

(Adapted from: ICPSR n.d.; Australian National University (ANU), 2010)

Some partnerships may be well past this point, or may not have the need or motivation to complete a full data management plan. This document also provides specific recommendations for the creation of a separate data sharing agreement in the following section.

Data Sharing Agreement

A Data Sharing Agreement is identified as a promising practice mechanism for building and participating in an effective research partnership (Singh & Daar, 2009). A data sharing agreement should supplement and not supplant an overall data management plan. However if both are completed, they will share several elements.

Developing a data sharing agreement is about relationship building, trust building, good communication, compromise, long term planning and finding ways to openly and safely share and maximize the use of the hard earned data from a research partnership. It is about determining culturally and ethically appropriate ways to disseminate the data, meeting funding requirements, improving health outcomes, and adding to the body of scientific knowledge. These are not small tasks, and there are many tools available for partnerships that want to embark on this process.

Successful data sharing agreements in community-academic partnerships have three main elements: 1) strong partnership with clear communication; 2) clear process; and 3) well-developed content. The following are best practice recommendations in each of these elements for developing a data sharing agreement.

Element 1: Strong Partnership with Clear Communication

A strong community-academic partnership requires addressing the aforementioned power differentials (see Background section). It is important to recognize that in some cases power differentials cannot be completely diminished. For example, if an academic researcher has requirements for publication, or community members lack the training or skills to analyze data, this sets up a power differential that requires compromise or investment in changes. Having conversations about these barriers will only strengthen a partnership and may provide the opportunity to improve future collaborative work. The following Principles of Good Community-Academic Partnerships are best practice recommendations for developing strong community-academic partnerships.

Principles of Good Community-Academic Partnerships

- Partnerships form to serve a specific purpose and may take on new goals over time.
- Partners have agreed upon mission, values, goals, measurable outcomes and accountability for the partnership.
- The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment.

- The partnership builds upon identified strengths and assets, but also works to address needs and increase capacity of all partners.
- The partnership balances power among partners and enables resources to be shared.
- Partners make clear and open communication an ongoing priority by developing a common language and striving to understand each other's needs and self-interests.
- Principles and processes for the partnership are established with the input and agreement of all partners, especially for decision-making and conflict resolution.
- There is feedback among all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes.
- Partners share the benefits of the partnership's accomplishments.
- Partnerships can dissolve and need to plan a process for closure.

(Adapted from: Community-Campus Partnerships for Health, 2010)

The process of aligning with these principles should be flexible and mutual, and may happen over an extended period of time. Serendipitously, the development of shared agreements concerning data and resource sharing are primary tools to further strengthen a partnership. Additional tools for analyzing and strengthening community-academic partnerships are included in the Annotated Bibliography.

Element 2: Clear Process

Both community and academic partners should benefit from the outcomes of the research process. Creating and adhering to a clear process for sharing data can help achieve this. A clear process for developing and maintaining a Data Sharing Agreement includes:

1. Develop a data sharing agreement early in the research project.
2. Use the data sharing agreement to develop shared vocabulary to use throughout the research partnership.
3. Formalize the agreement by writing it down and signing it.
4. Meet regularly and include revisiting the data sharing agreement as part of the meeting agenda.
5. Include flexibility within the agreement and make any necessary changes as they arise.
6. Identify clear termination dates within the agreement – termination of data collection, analysis and dissemination, for example.

While this process can direct the overall flow of the creation and maintenance of a data sharing agreement, below is an example of a step-by-step process for facilitating the creation of a data sharing agreement.

Example: Step-by-Step Process for Facilitating the Creation of a Data Sharing Agreement

The process of developing a data sharing agreement in a community-academic research partnership should not further complicate joint efforts to improve health outcomes. It is also important to be timely and efficient when moving through the development of a data sharing agreement. If you have trusting relationships, this can evolve on a more natural level. It may be

necessary to add detail throughout the life cycle of the project. Make decisions, implement them and move on.

Forming and Meeting Preparation	<ol style="list-style-type: none"> 1. Review funding requirements for data management plans or data sharing agreements. Build any requirements into your process. 2. Review work that has already been done. Review your data management plans, meeting minutes, etc. to identify what you already have and content you will have to create. 3. Optional: Hire an external facilitator, which allows all participants to provide input and participate in conversations about the data sharing agreement. <ul style="list-style-type: none"> • The identified “leader” of a group often facilitates meetings and negotiations, making it difficult for them to fully participate. If the resources exist to bring in a facilitator for this process, it may help everyone participate more fully. • If resources are not available, see managementhelp.org for specific information on facilitation, group process and more. 4. Determine and be clear about the decision making process you will use to include or exclude information in the data sharing agreement (consensus, decide and announce, etc.)
Content of Agreement	<ol style="list-style-type: none"> 5. Review Table 3 and decide which <i>Content Areas</i> partners want to incorporate into the agreement (Data Overview, IP/Legal, etc.). You may find some content areas unnecessary to include (for example: a detailed description of the data may be elsewhere). <ul style="list-style-type: none"> • In the discussion of what content areas to include, you may generate important ideas you want to incorporate into the agreement – be sure to take notes. 6. Once content areas have been identified, review <i>What to Consider</i> in each content area and take notes on the discussion. 7. Review the sample agreement templates and find a format you prefer. 8. Fill in the agreement with the content you want to include. 9. Have all partners review the agreement. 10. Make any necessary changes. 11. Review the agreement with any required legal departments or upper management. 12. Agreements should be signed by someone in a decision-making position in relation to the project being proposed. Work with your team to determine the best person to sign the agreement. 13. Get to work!

Element 3: Well-Developed Content

After reviewing the components of a data management plan, partners should have sense of where the data will be housed, legal and ethical requirements to protect confidentiality of participants and partners, responsibilities, funding requirements, and so-on. If documentation has occurred during that process, some of that language can be used directly in a data sharing

agreement. If not, there are multiple agreement templates online for community-academic partnerships to use to develop their own agreement. Direct links to these resources are in the Annotated Bibliography.

Although there may be some overlap, a data sharing agreement will supplement, but should not supplant a general research partnership agreement or a data management plan. Table 4 contains best and good-practice guidelines for data sharing agreement content. Most importantly, the members of the research partnership should determine the content through transparent and agreed-upon communication pathways. Some partners may include all of the information in Table 3; others may only include some of it.

Table 3: Data Sharing Agreement Content	
Content Area	What to Consider
Title	<ul style="list-style-type: none"> ▪ Examples: Memorandum of Understanding, Business Agreement, Data Sharing Agreement
Data Overview	<ul style="list-style-type: none"> ▪ A description of the information to be gathered, used or made available ▪ The nature and scale of the data that will be generated or collected
\$\$/Resources	<ul style="list-style-type: none"> ▪ Funding requirements ▪ Compensation for data management personnel ▪ Other resource sharing and allocation – samples, infrastructure, money, etc.
IP/Legal	<ul style="list-style-type: none"> ▪ IRB ▪ Copyright ▪ Intellectual Property (IP) rights ▪ Ethics ▪ Privacy ▪ Security ▪ Levels of confidentiality ▪ Any site-specific data needs to be cleared by that site before released ▪ Check the need to include tribal, local, state and federal legal requirements, which establish a minimal mandatory framework ▪ Stop-gap for possible confidentiality leaks <ul style="list-style-type: none"> ◆ Site ◆ Individual ◆ Region ▪ Other legal requirements
Ownership	<ul style="list-style-type: none"> ▪ Ownership of the data, example options: <ul style="list-style-type: none"> ◆ Partnership ◆ Consortium ◆ Local communities ◆ Researchers ◆ Research institution ◆ Funder
Storage	<ul style="list-style-type: none"> ▪ Data <ul style="list-style-type: none"> ◆ Data archiving ◆ Data security

Table 3: Data Sharing Agreement Content

Content Area	What to Consider
	<ul style="list-style-type: none"> ◆ Long term preservation strategy ◆ Where is the data housed? ◆ Consider geographic locations of partners and accessibility ▪ Agreement <ul style="list-style-type: none"> ◆ Where will the data sharing agreement be kept? (Online, signed copy, etc.)
Access	<ul style="list-style-type: none"> ▪ How the data will be made available to: <ul style="list-style-type: none"> ◆ Wider community ◆ Scientific community ◆ Research partners ◆ Secondary research/users ◆ Students/Student workers ▪ Revisit confidentiality concerns ▪ Are there any restrictions to access that need to be considered? What? Why?
Approval	<ul style="list-style-type: none"> ▪ The approval process can be determined by the partnership, examples include: <ul style="list-style-type: none"> ◆ Develop a data sharing committee to determine approval for access to data ◆ Develop levels of access for different stakeholders within the agreement
Who/Roles	<ul style="list-style-type: none"> ▪ Who should participate in agreement? ▪ Who are the stakeholders? <ul style="list-style-type: none"> ◆ Ensure equity across the complete spectrum of stakeholders ▪ Data steward – is there a person or people who will be responsible for the data, but not be the actual owner(s) of the data? This may be the same or different from the specific roles below. ▪ Who has responsibility for <ul style="list-style-type: none"> ◆ Data collection ◆ Data storage ◆ Data management ◆ Analysis ◆ Dissemination/publication ◆ Access decisions ◆ Ownership ◆ Acknowledgement ▪ University research teams may have requirements for ownership, authorship, etc. – be clear about these from the beginning and explore options ▪ Keep in mind that partner organizations may have internal policies regarding data, it is imperative to review any policies, take them into consideration when creating an agreement, and address any conflicts that may arise
Training	<ul style="list-style-type: none"> ▪ What training will be available to all partners? <ul style="list-style-type: none"> ◆ Confidentiality, ◆ Human subjects, ◆ De-identifying data, etc. ▪ Identify training needs and requirements for all partners <ul style="list-style-type: none"> ◆ Make sure training is available from start to finish of research partnership ◆ Find ways to make training readily accessible
Analysis	<ul style="list-style-type: none"> ▪ Who will analyze the data? <ul style="list-style-type: none"> ◆ Analysis plan ◆ Review process ◆ Interpretation of results
Dissemination	<ul style="list-style-type: none"> ▪ Determine dissemination procedures

Table 3: Data Sharing Agreement Content

Content Area	What to Consider
	<ul style="list-style-type: none"> ◆ Explore need to release initial findings and how that will be accomplished ◆ Acknowledgements ◆ Who is contact person for more information ◆ How will data use be tracked ◆ How new community or research partners gain access to the data ◆ Role of data committee (if it exists) ▪ Means of release of the data <ul style="list-style-type: none"> ◆ Publications ◆ Media ◆ Educational theater ◆ Word of mouth, etc. ▪ If important findings need to be released before the final data set is completed, include measures to allow this practice ▪ Assure processes so that resulting data resources are clear and reliable ▪ Consider: data access should be openly available when there are no concerns for: <ul style="list-style-type: none"> ◆ IP rights ◆ Recognition confusion ◆ Confidentiality ▪ Assure that data dissemination will be <ul style="list-style-type: none"> ◆ Culturally appropriate ◆ Linguistically competent <ul style="list-style-type: none"> ▪ Translation needs? ▪ Dialect considerations ▪ Determine all mechanisms for dissemination early in the partnership
Timeline	<ul style="list-style-type: none"> ▪ Timeline <ul style="list-style-type: none"> ◆ How long data will be archived & where ◆ When data collection will end ◆ When is the agreement over? ◆ When/how data will be disseminated to the community <ul style="list-style-type: none"> ▪ Timing of release of data ▪ Format of release ◆ Consider timeline restrictions on the release of data

(Sources: Digital Curation Center (DCC), 2010; Rural Economy and Land Use Programme (RELU), 2010; Singh & Daar, 2009; Medical Research Council (MRC), 2005; Piwowar et al, 2008; Wellcome Trust, n.d.)

Creating data sharing agreements and a data management plan are important steps in the Data Life Cycle, support best practices, meet funding requirements and help support strong community-academic partnerships. We hope this guide serves as a resource for research partnerships in developing their own agreements.

Annotated Bibliography of Resources

The following is a list of key resources for data management and sharing in community-academic partnerships and best or good practices in the field. Each resource contains a Map with a link to the appropriate webpage. Because of the changing nature of the internet, Google keywords and instructions have been identified which can be used to access the information.

Agreement Templates

☐ **Community-Campus Partnerships for Health (CCPH) MOUs/MOAs**

Includes both example agreements from multiple community-academic partnerships and links to a skill-building curriculum for “creating the glue” in a partnership.

Map	
Link	http://depts.washington.edu/ccph/commbas.html#MOU
Google Keywords	CCPH, Community Based Participatory Research, MOUs/MOAs
Google Instructions	After the page opens either click on MOUs/MOAs under Overview , or scroll to the bottom of the page.

☐ **caBIG® Knowledge Center – Data Sharing Agreements**

Includes data sharing agreements collected from multiple organizations, and policy/governance documents associated with integrated data repositories.

Map	
Link	https://cabig-kc.nci.nih.gov/DSIC/KC/index.php/Data_Sharing_Agreements
Google Keywords	Data Sharing and Intellectual Capital Knowledge Center, NIH
Google Instructions	After the main caBIG DSIC Data Sharing and Intellectual Capital Knowledge Center page opens, on the left-hand sidebar is the topic area projects ; under this section click on Data Sharing Agreements & Associated Materials .

☐ **University of California San Francisco – Clinical and Translational Science Institute**

Includes model Memoranda of Understanding (MOUs) and agreements between academic researchers and clinical partner sites to serve as models for new projects. Templates and examples are posted as they become available. All identifying information has been deleted.

Map	
Link	http://ctsi.ucsf.edu/research/community-tools#templates
Google Keywords	UCSF, CTSI, community engaged research presentations and tools
Google Instructions	After the page opens either click on Templates for Documents Used in Community-Engaged Research or scroll to the bottom of the page.

Data Management Plan Resources

❑ Digital Curation Center

Comprehensive resource for the creation of a data management plan – includes a [Checklist for a Data Management Plan](#) with a [Data Management Plan Template](#) which can be filled in, and *DMP Online* which allows researchers to populate an online template and save it for further development.

Map

Link	http://www.dcc.ac.uk/resources/data-management-plans
Google Keywords	Data Management Plans, Digital Curation Center
Google Instructions	After the page opens access the different tools by clicking on the links in the body of the text.

❑ UK Data Archive

In the Create & Manage section of this website is a data management plan content area resource with specific information and tools for the following content areas: [Research Data Lifecycle](#), [Starting Your Research](#), [Consent & Ethics](#) (includes information on anonymization, access restriction and more), [Copyright](#), [Documenting Your Data](#) (includes information on metadata, study-level data and more), [Formatting Your Data](#) (includes information transcription, quality control and more), and [Storing Your Data](#) (includes information on backing-up data, security, encryption and more).

Map

Link	http://www.data-archive.ac.uk/create-manage
Google Keywords	UK Data Archive, Create and Manage Data
Google Instructions	After the page opens access the content-area information by clicking on the topic area of interest on the left sidebar of the page.

❑ Inter-University Consortium for Political and Social Research

The Guidelines for Effective Data Management Plans section of this website includes three important topic areas, the first is: [Elements of a Data Management Plan](#). The second is the [Data Management Plan Resources and Examples](#) which is a clearinghouse of resources, templates, tools and guidance for the creation of a data management plan. It also includes examples of university data management websites and general good practice guidance for data management. The final section of importance is the [Other Data Management Plan Examples](#) which include data management plans from multiple different sectors.

Map

Link	http://www.icpsr.umich.edu/icpsrweb/ICPSR/dmp/index.jsp
Google Keywords	Data Management Plans, ICPSR
Google Instructions	When the page opens you can access the different tools by clicking on the links in the body of the text.

❑ Australian National University – Information Literacy Program

The Australian National University hosts a course on data management planning and has two useful downloads: the [ANU DM Manual](#) (chapter 6 has specific information on Writing a Data Management Plan) and the [DMP Template](#) which can be filled in to create a data management plan.

Map

Link	http://ilp.anu.edu.au/dm/
Google Keywords	The Australian National University (ANU) – Data Management
Google Instructions	When the page opens you can access the different tools by clicking on the links in the mauve/pink box on the right-hand side of the page.

Partnership Building Resources

❑ **Developing and Sustaining [CBPR] Partnerships: A Skill-Building Curriculum**

This evidence-based curriculum is intended as a tool for community-institutional partnerships that are using or planning to use a community-driven approach to improving health. It can be used by partnerships that are just forming as well as mature partnerships.

Map

Link	http://depts.washington.edu/ccph/cbpr/index.php
Google Keywords	CBPR Skill Building Curriculum
Google Instructions	After this page opens navigate between sections at the top of the page.

❑ **PARTNER – Social Network Analysis Tool**

The PARTNER tool is designed for use by members of a collaborative (that is, three or more partners) to demonstrate how members are connected, how resources are leveraged and exchanged, the levels of trust, and to link outcomes to the process of collaboration. The tool includes an online survey that you can administer to collect data and an analysis program that analyzes these data.

Map

Link	http://www.partnertool.net/
Google Keywords	Partner Tool, Program to Analyze, Record and Track Networks
Google Instructions	Register as a Manager on the website, follow instructions in the Partner Technical Manual – link at the bottom of the Home page.

❑ **Prevention Institute – Coalition Building**

The Prevention Institute has a special section for tools for Building Cross-Sector Collaboration on their website with links to the following user-friendly resources: [Developing Effective Coalitions – An Eight Step Guide](#), the [Collaboration Multiplier](#), a [Collaboration Assessment Tool](#) and a document called the [Tension of Turf](#).

Map

Link	http://www.preventioninstitute.org/tools/partnership-tools.html
Google Keywords	Building Cross-Sector Collaboration – The Prevention Institute
Google Instructions	After page opens all documents can be accessed either through the links in the left sidebar or by clicking on the links in the body of the text.

References

- Australian National University. (2010, September). *ANU data management manual: managing digital research data at the Australian National University* (2nd Edition). Retrieved from http://ilp.anu.edu.au/dm/ANU_DM_Manual_v10.09.17-63_2010-09-17.pdf
- Cook, J. (2008). *Researchers and their communities: The challenge of meaningful community engagement*. Clinical and Translation Science Award (CTSA) Consortium's Community Engagement Key Function Committee report. Retrieved from http://www.ctsaweb.org/uploadedfiles/Best%20Practices%20in%20Community%20Engagement_Summary_2007-08.pdf
- Community-Campus Partnerships for Health (CCPH). (2010). *Principles of good community-campus partnerships* (Adopted by CCPH board of directors, October 1998). Retrieved from <http://depts.washington.edu/ccph/principles.html#principles>
- Digital Curation Center (DCC). (2010). *MRC Data Plan FAQs: Q3 What about data sharing?* Retrieved from <http://www.dcc.ac.uk/resources/policy-and-legal/mrc-data-plan-faqs#node-1083-question-2>
- Duke Translational Medicine Institute. (2009, May). Best practices in community engaged research. Retrieved from the Duke Center for Community Research website: <https://www.dtmi.duke.edu/about-us/organization/duke-center-for-community-research/community-engagement-consultative-service-cecs/best-practices/best-practices-in-community-engaged-research-version-4.0-may-2009>
- Economic and Social Research Council. (n.d.). Researcher Development Initiative (RDI) <http://www.rdi.ac.uk/>
- Eynden, V.V., Corti, L., Woollard, M & Bishop, L. (2009). *Managing and sharing data: a best practice guide for researchers* (2nd edition). Retrieved from the University of Essex, UK Data Archive: <http://www.dataarchive.ac.uk/media/2894/managingsharing.pdf>
- Inter-University Consortium for Political and Social Research (ICPSR). (n.d). *Elements of a data management plan*. Retrieved from Data Deposit and Findings portion of the ICPSR website: <http://www.icpsr.umich.edu/icpsrweb/ICPSR/dmp/elements.jsp>
- Inter-University Consortium for Political and Social Research (ICPSR). (2009). Guide to social science data preparation and archiving: best practice throughout the data lifecycle (4th Edition). Retrieved from <http://www.icpsr.umich.edu/files/ICPSR/access/dataprep.pdf>
- Kanous, A. (n.d.). *Addressing data sharing obstacles* [PowerPoint slides]. Retrieved from the University of Michigan, Division of Research, Development and Administration Data Sharing Resource Center: http://orci.research.umich.edu/cidays/documents/Data_Sharing_Obstacles_Kanous.pdf
- Lindamer, L.A., Lebowitz, B., Hough, R., Garcia, P., Aguirre, A., Halpain, M., Depp, C. & Jeste, D.V. (2009, March 31). Establishing an implementation network: lessons learned from community-based participatory research. *Implementation Science*, 4(17). Retrieved from <http://implementationscience.com/content/pdf/1748-5908-4-17.pdf>
- Medical Research Council (MRC). (2005, August). Large-scale data sharing in the life sciences: Data standards, incentives, barriers and funding models. Retrieved from <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002552>

- Norris, K.C., Brusuelas, R., Jones, L., Miranda, J., Duru, O.K. & Mangione, C.M. (2007, Winter). Partnering with community-based organizations: An academic institution's evolving perspective. *Ethnicity and Disease*, 17. Retrieved from http://www.nursing.columbia.edu/CIRAR/CIRAR_P20/Carrasquillo_Handout_2.pdf
- Piwowar, H., Becich, M., Bilofsky, H. & Crowley, R. (2008, September). Towards a data sharing culture: Recommendations for leadership from academic health centers (e183). *PLoS Medicine*, 5(9), 1315-1319. Retrieved from <http://www.canprep.ca/library/SharingAcademicCentres.pdf>
- Rural Economy and Land Use Programme (RELU). (2010, September 13). *Data management plan*. Retrieved from the University of Essex, Relu Data Support Service: <http://relu.data-archive.ac.uk/plan.asp>
- Shoultz, J., Oneha, M.F., Magnussen, L., Hla, M.M., Brees-Saunders, Z., Dela Cruz, M. & Douglas, M. (2006, March). Finding solutions to challenges faced in community-based participatory research between academic and community organizations. *Journal of Interprofessional Care*, 20(2), 133-144. Retrieved from <http://www.aapcho.org/altruesite/files/aapcho/Research/Finding%20Solutions....pdf-Shoultz,%20Oneha.pdf>
- Singh, J.A. & Daar, A.S. (2009). Intra-consortium data sharing in multi-national, multi-institutional genomic studies: gaps and guidance [Perspective]. *The HUGO Journal*, 3, 11–14. doi:10.1007/s11568-009-9130-5
- UK Data Archive. (n.d.). *Create and manage data*. Retrieved from <http://www.data-archive.ac.uk/create-manage>
- University of Oxford. (2010, November). *Data management planning checklist*. Retrieved from Research Data Management UAS: <http://www.admin.ox.ac.uk/rdm/dmp/checklist/>
- U.S. Department of Health and Human Services, National Institutes of Health, Office of Extramural Research. (2007, April 17). NIH data sharing policy. Retrieved from http://grants1.nih.gov/grants/policy/data_sharing/index.htm
- U.S. National Institutes of Health, National Cancer Institute, caBIG Knowledge Center, University of Michigan. (2009, September 16). *Decision support tools*. Retrieved from https://cabig-kc.nci.nih.gov/DSIC/KC/index.php/Decision_Support_Tools
- U.S. National Institutes of Health, National Cancer Institute, caBIG Knowledge Center, University of Michigan. (2010, August 27). *The data sharing and security framework (DSSF)*. Retrieved from https://cabig-kc.nci.nih.gov/DSIC/KC/index.php/Data_Sharing_and_Security_Framework
- Wellcome Trust. (n.d.). Guidance for researchers: Developing a data management and sharing plan. Retrieved from <http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/Guidance-for-researchers/index.htm>

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