Accountable Communities for Health
DATA-SHARING TOOLKIT

Produced by:
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How to Use This Toolkit

This toolkit is designed to assist communities working to share data across sectors to improve health. We begin by introducing the Accountable Communities for Health concept, and then provide seven parameters for framing your community’s current data-sharing maturity along a continuum from beginner to advanced. We recognize that not all communities are starting at the same place. Many are at the very beginning stages of contemplating this topic, while others have made initial progress in one or more areas. Progress along the seven parameters will vary and depend on the particular characteristics of a community and the priority health goals that it selects to address. For example, most communities will begin by setting priorities and establishing relationships. Others, however, might begin with a mandate and funding allocation, while still others will have a health information exchange in place with plans to use it for cross-sector data-sharing. We are not aware of any community that has solved all of the problems with data-sharing, thereby rating at the highest level on all parameters of the maturity models.

Myriad resources exist to assist with various aspects of the data-sharing (e.g. setting community priorities, building relationships across sectors, establishing data use agreements, and related functions). Our goal is to help the reader identify the needs within their own community and to point them in the direction of relevant resources. Different communities will be drawn to different resources depending on their own experiences and challenges. And most will find it necessary to obtain expert consultation at some point in the process. Community-based examples are presented to exemplify different communities’ success with various aspects of data-sharing. Though there is no “one size fits all” for many obstacles, we encourage communities to reach out to each other to share resources, support, and best practices throughout their journey towards shared data integration. All of the resources we have compiled are current as of December 2016.

The work of sharing data across sectors to improve health is challenging and requires an investment of time and resources. Even the lowest-tech options of meeting in a room together and sharing static printouts can be challenging if participants from different sectors are mistrustful of one another, or are using different terminology. Technology can solve some problems, while creating others; and the need for human interaction around data-sharing never goes completely away. This interactive toolkit is designed to point the reader toward a variety of resources that will help with this very important but challenging work.
Introduction

The Accountable Communities for Health (ACH) Initiative is one of four key initiatives that form the California State Health Care Innovation Plan. The intent of each ACH is to improve the health of the entire community by linking community prevention activities and health care, with particular attention to achieving greater health equity among its residents. It is a multi-sector alliance that includes multiple payers, health care systems, providers, and health plans, along with public health, community and social services organizations, schools, and other partners serving a particular geographic area.

ACHs will have a broad range of core data needs and will need to define a set of agreed upon metrics, including general population data related to the target geography; community health data; prevalence data for selected conditions; and clinical, utilization, and cost data. Measuring population health improvement in an ACH will require the sharing, aggregation, and analysis of data and information from various clinical and nonclinical services and programs, as well as community and population level data, across a variety of sectors and organizations. Data and information sharing will be needed at all stages of development and implementation, from needs assessment and baseline to ongoing monitoring and evaluation.

However, data-sharing capacity is likely to be highly variable across communities. While health care and community service organizations operate in increasingly data-rich environments, information is generally collected in silos, by individual organizations, funders and payers with constraints on sharing due to compliance with HIPAA and other health information and privacy policies. In response to the need for current data and information sharing practices that would support ACH collaboratives in California, the California Health and Human Services Agency (CHHS) has contracted with the University of California, Berkeley’s Center for Healthcare Organizational and Innovation Research (CHOIR) to develop a toolkit for use by communities in California and beyond. This toolkit provides resources for the steps and processes required to engage in data-sharing across sectors in communities both where data-sharing does not currently exist and where efforts are already underway.

HIGHLIGHT:
Social Determinants of Health

The major determinants of health outcomes are social (e.g. income, education, housing) and behavioral (e.g. smoking, exercise). These social determinants of health (SDOH) are best addressed through community partnerships across sectors (e.g. health care, public health, education, agriculture, housing, transportation, criminal justice, and community development).
ACH Data-sharing: Maturity Along Seven Parameters

We have identified seven parameters of data-sharing that allow a community to assess their maturity along a spectrum from beginner to advanced.

The logic behind these seven components of an ACH data-sharing infrastructure begins and ends with a clear purpose and strong buy-in from a broad array of key community stakeholders. With these components in place, a community is well positioned to secure funding for data-sharing projects to improve community health. With some funding in place, analytic capacity can be expanded (whether high-tech or low-tech) and metrics can be chosen that are specific and actionable. Ultimately, the data can be shared, first within an organization/agency/sector, then across sectors. The entire process is iterative and each of the parameters builds on the others. Each community begins at a different place along each of the parameters, and while progress along one parameter will help speed progress along the others, progress will vary. The rate at which each community works through each of the stages will also differ because major obstacles and barriers will look different in each community. Furthermore, it is very common to move back to a previous stage when incorporating new strategies, technology, and/or partners into an existing system.

Our toolkit uses this overarching framework to organize and describe common barriers to building an ACH data-sharing infrastructure, and to provide recommendations and identify resources to help overcome them. Resources range from continuously updated websites to toolkits, books, templates, and the use of consultants offering technical assistance. Community-based examples are also presented to exemplify each of the seven data-sharing parameters.
Data-sharing to support an ACH should always begin with a clear purpose. What is the aim of the data-sharing? Initially, this may simply be to identify health priorities by asking, for example, what are the leading causes of disability, death, or preventable hospitalization within the community? Or how does the community rank, relative to other communities, on various medical and health conditions?

Sometimes, a clear community priority presents itself. For example, homelessness may be a pressing concern, or the community might be an outlier in rates of opioid overdose or childhood obesity. Certain problems lend themselves to cross-sector solutions. For example, childhood asthma might require input from the education, hospital, and housing sectors, while violence might require input from hospital, mental health and criminal justice sectors. In many communities across the country, we have seen that the problem of high utilizer/high cost patients in emergency departments is intractable when viewed through a narrow healthcare lens.

Once a priority area is established, a goal can be set for improvement. Following initial success in one area, a community may leverage its resources and experience to expand into multiple priority areas. With increased understanding of the need for shared data, the goals of a project can move upstream to focus on early intervention and prevention. Ultimately, the goal is to use data to do predictive modeling across multiple programmatic areas and provide indicators of success in achieving the targeted goals.

**NOTE:**

3four50

Oxford Health Alliance’s message that three risk factors (tobacco use, poor diet, lack of physical activity) lead to four chronic diseases (diabetes, heart disease, lung diseases, and some cancers) that contribute to more than 50% of deaths worldwide is useful to keep in mind.

- How does your community fare with regard to these high-priority risk factors and diseases?
- Do you have the data to assess?

**DEFINITION:**

Predictive modeling

The process of creating, testing and validating a statistical model to forecast outcomes.
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<tr>
<td>Don’t have a purpose or aim for data-sharing</td>
<td>Use resources listed on the following page to browse national goals and objectives that are meant to be relevant at the local level; consider issues that are most pressing for your community.</td>
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<tr>
<td>Don’t know what conditions or situations are most pressing in the community</td>
<td>Look at health profiles for your community. Identify leading causes of mortality/morbidity. Consider complex priorities that cannot be solved within one sector and that will have a return on investment for multiple stakeholders.</td>
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<td>Different stakeholders have different priorities</td>
<td>Find an issue that the whole community can get behind, such as a regional Community Health Needs Assessment, or streamlining services to the homeless, and build upon that.</td>
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<td>Priorities change when leaders and/or funding changes</td>
<td>It is okay to start small and build on small successes. Ultimately, priorities should be based on the needs of the community and the stakeholders involved, not on “pet projects” of leaders or temporary goals of short-term funding sources.</td>
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<td>Trouble identifying cross-programmatic effectiveness, utilizing products/services across multiple sectors</td>
<td>Choose goals/conditions such as childhood obesity reduction that cut across sectors — education, health care, parks and recreation, etc.</td>
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EXAMPLE:
North Carolina Overdose Prevention

Practical Playbook, Lessons Learned from a Grassroots Collaboration Focused on Overdose Prevention

This case study of Project Lazarus in North Carolina describes how a crisis within a community became the purpose needed to develop a strong cross-sector collaborative effort. Project Lazarus incorporates both bottom-up (community-based) and top-down (medically-based) approaches to achieving a unified community goal.

RESOURCES:

Centers for Disease Control and Prevention
http://wwwn.cdc.gov/communityhealth
An interactive web application that produces health profiles for all counties in the US, which can be useful when trying to decide upon a community objective. Multiple key indicators of health outcomes, including social determinants, are provided, as well as comparisons with how each county rates compared among peer counties.

Healthy People 2020
https://www.healthypeople.gov/2020/topics-objectives
The Healthy People initiative provides science-based, 10-year national objectives for improving the health of all Americans. Here you will find information about Healthy People 2020, including over 1,200 measurable health goals and objectives for establishing benchmarks and monitoring progress over time; data; stories; webinars; and information about your state’s Healthy People 2020 plan. Also included are excellent resources on social determinants of health.

Association for Community Health Improvement
Community Health Assessment Toolkit
http://www.assesstoolkit.org
The ACHI Community Health Assessment Toolkit is a guide for planning, leading and using community health needs assessments to better understand, and ultimately improve, the health of communities. It presents a suggested assessment framework in six steps, including but not limited to data collection, and contains task checklists, budget and timeline guides, case examples, as well as additional resource links. Requires membership in ACHI.

American Public Human Services Association
http://www.aphsa.org/content/APHSA/en/resources/GUIDANCE/VALUE_CURVE.html
A toolkit for improving human services outcomes by moving through the human services value curve. This value curve looks at four different stages, or business models: regulative, collaborative, integrative, and generative. The toolkit includes tools and templates to support the focus areas discussed in the toolkit.
We cannot overemphasize the importance of personal relationships and human interaction when it comes to successful data-sharing efforts. Afterall, data-sharing is as much about relationships as it is about technology. The degree to which a community has built collaborations and trust within and across sectors will largely determine its success in sharing data. There needs to be a “readiness” to collaborate. The good news is that it’s perfectly fine to start small. Small successes can lead to increased openness and trust, and to a willingness to pursue further work together.

There is a tendency to start sharing data within healthcare, or within social services, but not to span both. Often there is a desire to “get your own house in order” before connecting with others. Initiating cross-sector collaboration calls for a qualified and enthusiastic leader to champion the project. Sometimes this person is a senior community-leader with established relationships or someone who has time dedicated to convene key stakeholders. For cross-sector projects it is important to establish an inclusive leadership group; buy-in from community leaders — ideally from a diverse range of sectors and local government — along with increased community engagement, can increase the likelihood that programs are sustainable. Individuals may cross-pollinate the boards of community groups that act as the primary stakeholders, which can increase cohesion. Once a forum is established for communicating, the process is often rewarding, but it still can take months to years to establish transparency and trust.

One of the major barriers to building trust around data-sharing, whether within an organization or across sectors, is fear surrounding how the data is controlled, accessed, and shared. This fear stems from a number of sources such as concerns that data will be used to gain market advantage, incompetencies will be uncovered, or privacy laws will be violated. Working collaboratively with other sectors towards a common purpose builds trust and helps temper these fears. Establishing effective data governance is also an important step toward building trust around data-sharing.

**NOTES:**

**Backbone Organization:**
An essential component of an ACH is building a backbone organization, which also requires strong relationships. This section specifically refers to relationships particular to data-sharing; however, the relationships built through the backbone organization can be leveraged to further efforts for data-sharing.

**Vocabulary**
Vocabulary is very important when building relationships. Language/word perceptions can be a barrier with buy-in when certain terms become unacceptable — even seemingly benign words can have negative connotations within a particular community, such as “repository” = place to steal my data. It is important to emphasize value to participants rather than labels.

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“DATA TRAVELS AT THE SPEED OF TRUST”
Understanding what drives each sector’s involvement is key so that incentives can be aligned. If stakeholders understand the value of data-sharing at the start of the initiative, they are more likely to continue interest, participation, and commitment during difficult times. Over time, it is important to build data-sharing relationships among the front-line users who are most familiar with the data. A clear case for the value of data-sharing needs to be made for the leadership (e.g. it will be cost effective) as well as for the front-line data users (e.g. it will improve client/patient services).

Once collaboration begins it is important to keep the momentum going, even if the initial project has ended. Find a new project or reason to meet. Working together over time builds trust and furthers the willingness to collaborate on new projects. New data-sharing projects often spring from these mature collaborations.

Example: Health care data-sharing relationships are encouraged by:

1. Patients moving between health plans and healthcare providers
2. Outside variables (ie., social and behavioral determinants) that impact patient health, but healthcare ultimately becomes responsible
3. Sharing in interventions to reduce the cost of high utilizers (“coopetition”, shared pain point)
4. “Mission-oriented” people who want to “do good” — want to help make community a desirable, vibrant place
5. Value-based payment models (see sidebar below)

**NOTE:**

**The ACA is a Strong Driver of Cross-sector Collaboration**

The federal Affordable Care Act of 2010 accelerated the shift from fee-for-service to value-based payment models in healthcare. Value-based payment models reward quality over quantity, paying for outcomes rather than individual services. As this shift occurs, California healthcare providers such as hospitals and medical groups are increasingly being held accountable for the health outcomes of their defined patient populations, requiring a growing focus on social determinants of health that traditionally lie outside of the realm of healthcare. As incentives align in favor of improved population health, healthcare providers are motivated to establish new partnerships with community organizations and government agencies that have a deeper understanding of community health and the social determinants of health in order to control costs and leverage resources. The power of these new payment policies in driving cross-sector collaboration cannot be overestimated.

**Definitions:**

**Anti-trust Law**

United States antitrust law refers to the federal and state laws that regulate the conduct and organization of business corporations, generally to promote fair competition for the benefit of consumers. Anti-trust concerns are raised when competing health plans or health care organizations are working together across a community in ways that could be interpreted as collusive, in restraint of trade, lessening competition, or abusing monopoly power. Anti-trust law should not be a major barrier to sharing data to improve community health (see resources on page 10).

**Coopetition/Coopertition**

A hybrid of cooperation and competition is the term coined for the teaming up of two rival companies. The whole concept of coopetition is the idea of teams helping each other to compete.
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<td>Absence of a convener that is perceived as “neutral”</td>
<td>Follow the ACH model of establishing a neutral backbone organization</td>
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<tr>
<td>Fear that a competitor will gain market advantage</td>
<td>Focus on the economic advantages of collaborating to solve mutual challenges (e.g. high utilizers or homelessness).</td>
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<tr>
<td>Fear that incompetencies will be exposed</td>
<td>Emphasize value-based purchasing and outcomes; encourage performance metrics to be displayed publicly to encourage improved performance.</td>
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<td>Healthcare organizations are owned and operated by a larger entity outside of the community; compliance review at levels in the larger organization are unknown to local employees and/or the drive to build local systems has low priority in faraway places</td>
<td>Work to build relationships with leaders within the local community and the larger corporate infrastructure. Identify local priorities that will impact the bottom line of the larger organization.</td>
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<tr>
<td>Competition for patients among hospitals and clinics</td>
<td>Set initial priorities that will have mutual benefit, especially around complicated patients that often move between settings.</td>
</tr>
<tr>
<td>Anti-trust concerns</td>
<td>Anti-trust law should not be a major barrier to sharing data to improve community health. Familiarize yourself with the basics (see resources on the following page); set parameters around meetings; obtain legal counsel if necessary.</td>
</tr>
<tr>
<td>Territorialism/primacy in social services (to whom does the client “belong”)</td>
<td>Work to find common ground where everyone’s job is made easier and the clients’ needs are met. Emphasize the increased efficiencies and decreased redundancies.</td>
</tr>
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<td>Regimented systems in county government; bureaucracy</td>
<td>Start small by identifying champions who understand the value of data-sharing to improve community health. If possible, engage leadership at the top; consider the culture/norms of the organization; work to change job descriptions and include in performance appraisal systems so that data-sharing is a priority.</td>
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<td>Disparate grants/projects that often don’t have much impact or longevity, and thus don’t seem worthwhile or like a success</td>
<td>Focus on identifying common goals and priorities, so that over the long haul collaborations are mission-driven rather than driven primarily by a small amount of grant funding; choose projects that are of value to stakeholders and will move the overall community health data-sharing agenda forward. Celebrate small wins. Recognize that the value of a small project may be in identifying priorities and building relationships and gaining experience, even if the impact on health is small at first.</td>
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<tr>
<td>Historic competition or “bad blood” between individuals or organizations</td>
<td>Focus on moving forward; try to find opportunities for small successes; try to find individuals within the organizations that can work together; may be necessary to wait until there is new leadership in one or more of the organizations involved.</td>
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Anti-trust concerns  
Anti-trust law should not be a major barrier to sharing data to improve community health. Familiarize yourself with the basics (see resources on the following page); set parameters around meetings; obtain legal counsel if necessary.
**RESOURCES:**

**Practical Playbook**  
*Sharing Data Fuels Partnerships*  

Adapted from a chapter in The Practical Playbook, this summary explains how sharing data for population health encourages relationships between primary care and public health. We recommend purchasing the book itself, which is simple to read and contains case studies and practical recommendations about how to develop partnerships, and has an entire section on working together, including how to have difficult conversations, group dynamics, the role of early wins in long-term success, challenges of working together, leveraging media, etc.

**A.T. Himmelman White Paper**  
*Collaboration for Change*  

A white paper that defines principles of collaboration and provides a step-by-step guide to collaborative process. Attachments include definitions and assessment of collaborative leadership.

**B.E. Smith White Paper**  
*Population Health Developing a Leadership Workforce That Reaches Across the Continuum*  

A white paper that explains the changing landscape for healthcare leadership. It talks about the need to lead from the top and how executives need to be “strategic innovators” as well as “build and nurture strong community relationships as a foundation for strategic partnerships outside the hospital.”

**Health Affairs**  
*The Culture of Data-sharing Has to Change*  

A blog about the role of data and data-sharing and its significance in transforming the US health care system. It talks about moving away from proprietary data, developing new business models, making strides nationwide, challenges in perceptions, and market approaches.

**Federal Trade Commission, Antitrust Enforcement in Health Care: Proscription, not Prescription**  

In this 2014 speech, Deborah L. Feinstein, Director of the Bureau of Competition at the Federal Trade Commission, explains the Commission’s approach to enforcement in health care markets, describing the types of collaborations that do and do not raise significant antitrust concerns.

**Institute of Medicine, National Academies Press. Legal Issues In Collaboration**  

In this chapter, Clark C. Havighurst, J.D. outlines the rudiments of antitrust law including specific pitfalls to be avoided and describes how antitrust law regards information collection and exchange, in particular.
Humboldt County, California

Humboldt County is a largely rural county over 200 miles north of the San Francisco Bay Area. Though it is almost 3600 square [land] miles, most of the 135,000 residents live near the largest cities, Arcata and Eureka. Demographically, Humboldt’s population is older, predominantly white, and has lower income levels than the California average.

Although geographically isolated with a small, economically poor population, Humboldt has a strong sense of collective accountability. Due to limited resources, important relationships have developed and community members have been able to come together to collaborate to achieve shared objectives. There is a sense that “we’re all in this together” and a desire to “do good” to make the community a desirable, vibrant place to live.

Started in 2006 around a diabetes project, community Care Improvement (CI) meetings are still held every other week. They include representatives from the Humboldt Independent Practice Association, the county Department of Health & Human Services, Federally Qualified Health Centers, the California Center for Rural Policy (at Humboldt State University), and other community services and businesses. These meetings have encouraged engagement from all the people who “should be involved,” and are an active venue for sharing community health information and making practical progress. New projects are chosen through this collaboration. Homelessness, for instance, became a cross-sector platform that everyone could get behind because Humboldt County has the highest rate of homelessness per capita in the nation.

There is also a CEO group, comprised of healthcare CEOs and HHS directors, who are the “leaders of the community driving change.” They are invested both financially and idealistically. Among other challenges, this group has been helpful in engaging the larger hospital groups that are owned outside of the county but operate within.

In this small community with scarce resources, collaboration stems from a desire not to duplicate services. Previous grants (e.g. from Robert Wood Johnson Foundation’s Aligning Forces for Quality and from the Office of the National Coordinator for Health Information Technology) have helped the community better align and work more collaboratively, particularly in bringing in social services as partners with health care and in being able to implement new technology, such as the development of the North Coast Health Improvement and Information Network (NCHIIN) and its HIE. Their current homelessness project, sponsored by AcademyHealth, continues to improve relationships and build communication and trust.

Because of its existing history of strong relationships and buy-in, which began around a single project but has developed into a mainstay in the community, Humboldt County has been able to be proactive in applying for and obtaining valuable grants. The programs from these grants, in turn, have enhanced the collaborative infrastructure within the community. Furthermore, they have been ready and able to participate in national networks, such as the AcademyHealth Community Health Peer Learning Program, which promote data-sharing and provide additional resources. All of this, in turn, enhances and reinforces the strong relationships built.
Lack of funding is often cited as a major barrier to cross-sector data-sharing for community health improvement. Communities will all start in different places with regard to funding, and they will move at different speeds along the maturity model. Individual partnerships/projects within a community may be more or less advanced in terms of funding streams. For example, a county might have dedicated, sustainable funding to integrate its social services data, while the same community has one-time grants for sharing data between emergency departments and the housing sector. Newer projects are more likely to have less mature funding models, although in some cases a mandate and funding allocation (such as a bond measure) might launch an initiative.

Initially, a lot can happen from partners supporting a project with its day-to-day operations, such as shared personnel or meeting spaces. Much can be done by leveraging this type of “in-kind” support. Poorer communities especially benefit from pooling resources across organizations. This requires buy-in at a high-level (CEO) and at the level of front line personnel. Job-descriptions need to include data-sharing so that individuals have protected time to do this challenging work across all seven data-sharing parameters. Many free resources exist to help with the early stages of data-sharing, but community leaders need to have the time and ability to find these resources and utilize them.

Initial funding is typically pieced together from competitive, short-term grants. These types of grants may be siloed (e.g., they may be narrowly focused on a small data-sharing project or partnership). Larger data-sharing initiatives, however, often build on these smaller data-sharing successes.

Writing a successful grant proposal requires proof that relationships are in place and that buy-in is already established which can take a lot of pre-work. Once a community is successful in obtaining grant funding, it is more likely to be able to apply for other grants because some of the building blocks are in place. Once a community becomes part of a collaborative with other communities who are attempting similar efforts, they have access to networks and resources that can also help with securing grant funding.

NOTES:

First Things First
While funding is a major barrier to successful data-sharing, many communities report greater success when an initiative begins with a focused goal and strong relationships and buy-in from community partners, rather than beginning with “a pot of money.” Fund-raising initiatives are more likely to be successful and sustainable when community partners are drawn to the table by a common mission rather than by outside funding.

Successful Grant Writing Requirements

- Thorough knowledge of the organization’s purpose and what it wants to achieve
- Knowledge of funding sources (being networked);
- Dedicated time/space to write a grant (often is not an organizational priority; “not my day job”); and
- Grant-writing expertise
But ultimately, grant funding is piecemeal. Longer term solutions are needed. More mature funding models include bond dollars, county budget allocation, pooled community benefit dollars, or some other sort of financial buy-in by participating organizations, such as a wellness fund (see resources on page 14). These longer term approaches are more likely to happen once there are relationships built and some early successes that lead to trust. The ultimate goal is for the project to be self-sustaining without any need for grant funding.

**QUICK TIP:** Grant funding for cross-sector data-sharing projects can come from local or national foundations, professional organizations, or governmental agencies such as the Office of the National Coordinator for Health Information Technology, the Center for Medicare and Medicaid Innovation, or the Centers for Disease Control and Prevention.

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<td>Not enough funding</td>
<td>Start small; look for opportunities to share and leverage resources; network, both locally and nationally; research grant opportunities; pitch the project to local community-based funders; if enough widespread support, consider a community bond measure.</td>
</tr>
<tr>
<td>No one with time/skill to write a grant</td>
<td>Identify and train within the organization; hire new personnel with relevant skills.</td>
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<tr>
<td>No time to research grants/other funding</td>
<td>Consider the culture/norms of the organization. Make identifying funding sources a priority. Consider re-writing job descriptions to include protected time.</td>
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<tr>
<td>Not sure how to braid or blend funding</td>
<td>Familiarize yourself with the process of braiding and blending (see resources on the following pages).</td>
</tr>
<tr>
<td>Not sure how to leverage current funding or not aware of the funding or opportunities that exist</td>
<td>Seek advice from others. As above, make identifying funding sources a priority. Consider re-writing job descriptions to include protected time.</td>
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**EXAMPLE:**

**Santa Clara Bond Measure**

Santa Clara county is one of the largest and wealthiest counties in California, with a population of just under two million and an average household income of almost $130,000. The Santa Clara Valley Health and Hospital System (SCVHHS) is the largest governmental entity as well as the largest health care network in the county. It is comprised of five departments: Valley Medical Center (VMC), Ambulatory and Community Health Services, Mental Health, Alcohol/Drug Services, and Public Health.

Large integrated health and hospital systems have many challenges, including competing priorities, siloed services and data, and limited analytic capacity. In response to this, the county decided to develop the Center for Population Health Improvement (CPHI). The goal of CPHI is to build analytic capacity and integrate data across agencies within HHS, first data within SCVHHS and then with the community, with strong analytic capability that systematically and effectively links individual clinical health and community-level population health efforts.

Led by the VMC Foundation and the Santa Clara Family Health Foundation and with support from the County Board of Supervisors, Measure A, a 1/8 cent sales tax increase, was put on the ballot and passed in 2012. The goal of the measure was to raise $50 million annually for county programs. There was no organized opposition to Measure A. In 2014, using some of the funds generated by Measure A, the CPHI was established.
RESOURCES:

Practical Playbook Checklist — Pitching your Project to Funders or Partners
https://www.practicalplaybook.org/resources/checklist-pitching-your-project-funders-or-partners
A downloadable checklist of key questions to consider when developing a pitch for funding from key decision makers. Included with each question are tips on how to answer the question.

RWJF County Health Rankings and Roadmaps: Funding Guide
This guide is designed to assist communities in securing additional resources for community health improvement. It provides tools and resources for identifying and accessing funding resources for your community health initiative. It will help you understand how best to apply for outside funds. It includes sections on 1) readiness assessment; 2) developing partnerships; and 3) identifying and accessing funding opportunities.

Prevention Institute: Sustainable Investments in Health: Prevention and Wellness Funds
A primer on prevention and wellness funds including discussion of their structure, function, and potential. Topics include: how funds can generate revenue; how they should be managed and where they should invest; how to assess effectiveness; and how to emphasize health equity.

Prevention Institute: How Can We Pay for a Healthy Population? Innovative New Ways to Redirect Funds to Community Prevention
This publication and webinar describes innovative funding models including: wellness trusts, social impact bonds/health impact bonds; pooled community benefits from non-profit hospitals, and accountable care organizations.

All In: Data for Community Health
All In: Data for Community Health helps communities build capacity to address the social determinants of health through multi-sector data-sharing collaborations. An active push is being made to grow this network by inviting other community-based transformation initiatives to affiliate with All In.

MAPP Network
http://mappnetwork.naccho.org
An online forum for Mobilizing for Action through Planning and Partnerships (MAPP), a strategic approach to community health improvement. The forum is a resource for past, present, and future MAPP communities to converse with community partners, solicit advice from MAPP navigators, connect with other MAPP communities, as well as find other resources.

Trust for America’s Health, Healthy Communities Navigator
http://healthyamericans.org/healthycommunities/#/
A dynamic, searchable, interactive platform that provides stakeholders with community and population health resources, grants and examples. The three core components of the Navigator are: 1) Cross-sector Grants, a searchable database of over 50 public and private community prevention funding sources at the local, state, and federal levels; 2) Success Stories; 3) Community & Population Health Policy Papers.
EXAMPLE:

South Stockton Community Resources

Stockton, the county seat of San Joaquin County, is a large but economically poor city. It is the second largest city in the US to file for bankruptcy, and currently 25.8% of its residents live in poverty. It is a diverse community, with more than half of the population speaking a language other than English in the home.

In the 1990's, the Health Community Coalition (HCC) was formed with the sense that they needed to keep the safety net open and make sure the underserved were helped. Additionally, they wanted to figure out how best to work together without redundancies or gaps. The HCC is currently comprised of about 30 members from local health care, public health, and the community who meet once a month, focusing on collective impact. The HCC decided to focus on the Community Health Needs Assessment (CHNA) as a hub because it’s a 3-year requirement that is mandatory, but not funded. It has become the nucleus for bringing disparate groups together. For the last CHNA, groups from across sectors combined community benefit dollars as well as other funds to hire a consultant, who drew from everyone’s data. By combining their funding efforts, they were able complete this project with no outside help or grants.

The collaborative spirit that has been developed over the years of working together through the HCC has led to the development of other collaboratives as well, such as the HIE. In 2011, County behavioral health, Health Plan of San Joaquin, county hospital and Community Medical Centers decided to develop a regional HIE (the SJCHIE). It established a project budget of approximately $1.3 million. Again, it looked to local resources, obtaining over $800,000, or almost two thirds of the total projected cost, in organizational funds and staff time. The group was then able to secure a grant from Blue Shield of California Foundation for the additional $500,000 needed to implement the project. To further maximize funding resources, in 2013 the SJCHIE joined the Inland Empire HIE (IEHIE), which offered the benefits of a self-funded business model with long-term sustainability and financial durability.

Robert Wood Johnson Foundation, 
*Using Social Determinants of Health Data to Improve Health Care and Health: A Learning Report*

http://www.rwjf.org/content/dam/farm/reports/reports/2016/rwjf428872

A report on the emerging intersection of social determinants of health (SDOH), health care systems, and social and other services. Though aimed at foundations and other major funders, Learning Compendium at the end offers additional information and resources, including a list of major funders, and an annotated list of those interviewed. Also included are examples of programs, mostly across the US but also including an example from Sweden.

Spark Policy Institute, Colorado Guide to Blending & Braiding

http://coactcolorado.org/site_media/media/servee_documents/Blending_and_Braiding_Funding_Guide.pdf

Step by step instructions to develop and expand fiscal coordination, beginning with an explanation on what blending and braiding is. It contains actionable information on how to develop blended and braided models and included templates, both through links and within the document.

Spark Policy Institute, Blending & Braiding Toolkit

http://sparkpolicy.com/tools/overview-blending-braiding/

An online toolkit that begins by explaining the difference between blending and braiding. Five more sections discuss the different phases of establishing blended/braided funding, from identifying vision to tracking and improving an existing setup. Case studies are included, as well as additional resources, such as a self-assessment and planning guide.
Data governance refers to the overall management of the integrity, usability, availability, and security of data. The goals of sound data governance are to ensure data quality; expand knowledge about data and establish a data-driven culture; and maximize data usability so the right data is available to stakeholders and/or end users, all while keeping the data secure and protecting privacy. Getting the right amount of data governance in place can be challenging; healthcare in particular tends to begin with more governance than is necessary which can become unwieldy. That said, data governance has many layers by necessity, from the governing board (strategic goals) to the data analyst (data quality).

Data quality is a key function that aids data governance by monitoring data to find exceptions undiscovered by data management operations. It is a combination of completeness, validity, and accuracy. Every data-sharing project should be discussed with all players involved to ensure that all the data are being collected and analyzed properly, particularly in terms of understanding data sources and definitions. Data-sharing requires a common language, not just with technology in terms of interoperability, but among people as well. This will help avoid miscommunication, poor data collection techniques, and invalid or erroneous data entries, leading to better data analysis and higher quality data. Data quality ultimately is only as good as the data collected and entered into the system.

Building data knowledge consists of the ongoing training and education within the organization or collaborative. This occurs at all levels of the organization, so that everyone involved knows what to do and how to do it. At the “executive” level, this may be training on setting strategic goals or determining what data are needed to support a particular project. At the “administrative” level, the training may include understanding what data should be input into the system and how it needs to be entered.
Once the data consumers are identified, the data needs to be made available. Data should be displayed in a way that’s meaningful but also easy to understand and actionable. Data can also be presented in a way to support and encourage quality improvement, either individually or as an organization or community.

Ensuring data privacy and security also falls under governance. Sharing individual-level data continues to be a major concern, partly because there are no uniform standards. As an example, the rule surrounding use of health care data — the Health Insurance Portability and Accountability Act (HIPAA) — is different from the rule in place to protect the use of educational data — the Family Educational Rights and Privacy Act (FERPA). Even within public health different departments have different regulations surrounding the use of individual-level data. In some cases health care providers have hidden behind their own interpretations of HIPAA to avoid collaboration, but HIPAA does not preclude data-sharing to improve services or improve community health.

Data-sharing agreements such as memorandums of understanding (MOUs) are tools that aid in data governance. Having these agreements in place, combined with solid relationships, goes a long way toward minimizing the risks and fears associated with data-sharing. Data-sharing agreements between stakeholders and other consumers offer an opportunity for increased buy-in by involving them in the process and potentially offering everyone an opportunity to benefit from the results. As initiatives progress and trust develops with clear and open communication, access to data can be increased, eventually moving away from single agency reporting to open data-sharing across sectors and even public access to appropriate data, whether at the aggregate community level or at the individual level for access to services.

One way to set up a system of governance is to begin with deciding what type of data needs to be collected to effectively support the aim of the project. Data-sharing agreements, if needed, should be arranged once the scope of information has been identified. Then a user interface can be designed to support the collection of that data. A workflow plan for the people using the system should be created at the same time to support efficiency and quality analytic output. This would also include a plan to evaluate data quality. Once these other elements have been established, a training program can be established to educate everyone involved.

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**HIGHLIGHT:**

**Engaging Counsel**

Communities have mentioned that there is no agreement until the lawyers say there’s an agreement. Although it’s helpful to involve attorneys in informing contracts and agreements, it’s important to remember that in-house counsel is there to protect the organization. When it comes to data-sharing, it may be valuable to hire outside counsel who specialize in these types of contracts. It is also advisable not to contact attorneys too early, when ideas are vague, but rather when details are relatively finalized.
<table>
<thead>
<tr>
<th>BARRIER</th>
<th>STRATEGY</th>
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<tbody>
<tr>
<td>Data systems siloed</td>
<td>Examine the organizational cultures behind the different systems and work to integrate; consider hiring a neutral facilitator to engage the siloed data systems.</td>
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<tr>
<td>Goals too lofty</td>
<td>Patience. Celebrate small successes.</td>
</tr>
<tr>
<td>Lack of balance between planning and getting the work done</td>
<td>Too much of either can paralyze the process.</td>
</tr>
<tr>
<td>Underestimating the amount of work to be done</td>
<td>Understand that it will probably take more time than anticipated (much like designing and building a new house).</td>
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<tr>
<td>Too much or too little governance</td>
<td>Step back and reevaluate the governance structure, making sure that needed guidelines are in place but that over-regulation is not.</td>
</tr>
<tr>
<td>General fear surrounding collecting, using, and sharing data</td>
<td>Work collaboratively to develop guidelines for how data will be controlled, accessed, and shared.</td>
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<tr>
<td>Lack of knowledge around privacy laws</td>
<td>Become familiar with privacy laws governing data-sharing; consult a legal advisor specializing in the specific privacy issues faced.</td>
</tr>
<tr>
<td>Questionable data quality</td>
<td>Partners need to agree on which aspects of data must be complete, reliable and valid; design tests to determine data quality of the elements deemed to be critical; for those critical elements found not to be sufficiently reliable, partners must agree on an affordable fix.</td>
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RESOURCES:

National Committee on Vital and Health Statistics
A downloadable Toolkit for Communities Using Health Data, specifically explaining how to collect, use, protect, and share data responsibly. Appendices include definitions, federal and state laws, case studies, as well as worksheets and checklists.

HealthCatalyst Demystifying Healthcare Data Governance: An Executive Report
An executive report on best practices of data governance through the lens of the healthcare system. It explains proper governance through organizational layers, common obstacles, specific issues and models within data governance, and gives ideas on how to start.

National League of Cities and Stewards of Change, Sharing Data for Better Results: A Guide to building Integrated Data Systems Compatible with Federal Privacy Laws
A toolkit with information on building integrated data systems that are compatible with federal privacy laws. Chapters address confidentiality and privacy through the lens of different services, such as education, health and mental health, drug and alcohol treatment, among others. More than 20 federal privacy laws are reviewed and a basic, understandable description of the confidentiality issues is provided, along with case scenarios summarizing the opportunities for data-sharing and sample MOUs/MOAs and other documents. Also included are tables outlining each law, explaining the information sharing allowed or prohibited and resolving current myths.

HealthIT.gov, Privacy & Security
A guide to privacy and security of electronic health information. Multiple resources are available, from HIPAA basics to Privacy and Security in Meaningful Use. Also offered is a Sample Seven-Step Approach for Implementing a Security Management Process.

US Department of Health & Human Services
http://www.hhs.gov/hipaa/for-professionals/faq/health-information-technology
A list of FAQs regarding health information privacy as it pertains to health information technology. Sections include Accountability; Collection, Use, and Disclosure Limitation; Correction; Individual Choice; General; Openness and Transparency; and Safeguards — Health Information Technology.

US Department of Education, Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy
A toolkit for civic and community leaders who wish to use shared data to improve academic and life outcomes for students while protecting privacy; includes information and resources, many of which can be applied to any situation requiring cross sector data-sharing and confidentiality. It includes a sample MOU and a sample consent form as well as case studies and checklists.

Actionable Intelligence for Social Policy
http://www.aisp.upenn.edu/resources/legal-agreements-and-other-supporting-documents/
This page explains and has resource links to different types of legal agreements and other supporting documents. Included are sections on working with and understanding “Administrative Data,” Data Use Agreements, the Family Educational Rights and Privacy Act (FERPA), the Health Insurance Portability and Accountability Act (HIPAA), the Privacy Act, as well as additional supporting documents. A section on Memorandum of Understanding (MOU) is coming soon.
RESOURCES (continued):

US Department of Health & Human Services
This site explains business associate contracts and provides sample business associate agreement provisions, breaking down the contract into its component parts. It provides links to additional resources, including guidance on significant aspects of the privacy rule and fast facts for covered entities.

Centers for Medicare and Medicaid Services
This links to a template for a sample business associate agreement.

William T. Grant Foundation Research Practice Partnerships
http://rpp.wtgrantfoundation.org/developing-data-sharing-agreements
This website has work samples and other resources for developing data-sharing agreements. Guiding tips and questions are presented to help define the scope and nature of the agreements. Though the agreements are directed towards Research Alliances, the process remains the same.

CDC
http://www.cdc.gov/cancer/ncccp/doc/SampleMOATemplate.doc
This links to a downloadable sample Memorandum of Understanding template.

EXAMPLE:
The Keys to Governance and Stakeholder Engagement: The Southeast Michigan Beacon Community Case Study
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4371470/
This case study focuses on the Southeast Michigan Beacon Community, a community-based health information exchange. The case study offers lessons learned, insights on challenges faced and accompanying workarounds related to governance and stakeholder engagement. It employs an established Data Warehouse Governance Framework to identify and explain the necessary governance and stakeholder engagement components, particularly as they relate to community-wide data-sharing and data warehouses or repositories. Perhaps the biggest lesson learned through the SEMBC experience is that community-based work is hard. It requires a great deal of community leadership, collaboration and resources. Many of these lessons are relevant to governance of data-sharing projects within an ACH.
Data-sharing can be relatively easy, such as sharing a Google doc or attending a meeting, but it can also be extremely difficult and complex. Organizations should know that it’s ok to begin with simple sharing requests. As relationships grow and need arises, data-sharing partnerships can become more advanced. But an organization or community should look at its current requirements and resources first, then develop a plan based on those. Although the ultimate goal is to be fully integrated across sectors, in the short term not all programs or communities need to jump right into advanced data integration. A lot will depend on the health care priorities the community is attempting to address; for example, the extent to which the priorities require data outside of the health care and public health sectors. Even as communities move along the spectrum, integrating their systems, adding new types of data or new data partners can require stepping back to more basic arrangements. For instance, an integrated data system developed through partnerships between the county public health department and the hospital system may need to request information from behavioral health for a program goal. Initially, this would go back to a lower level of data-sharing. Depending on the needs of the community or program, it may or may not lead to further integration with behavioral health.

When planning for data-sharing, it is important to consider the types of data that can be shared. For example:

- **Aggregate data** are data that are compiled from individual observations to produce summary statistics. Public health departments, for example, typically have easy access to large aggregated datasets. The use of aggregated data has several advantages: they are relatively simple to generate from large datasets; they can provide useful information by categories (e.g., age, geographic region); they do not reveal protected health information; they help detect trends in population health and clusters of disease or unhealthy behaviors.

- **Personally identifiable information (PHI)** is data that, alone or when linked to other data, can be used to identify a specific person. Sharing data that includes personally identifiable information is much more challenging than sharing aggregate data, but is typically the starting place for organizations such

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**DEFINITIONS:**

**Integrated Data System**
Data records from two or more public or private agencies are linked to form a joint database

**Longitudinal tracking**
Repeated data of the same variables over long periods of time

**Master Client Index**
A repository of clients/patients that uniquely identifies and tracks each individual
as hospitals, clinics and schools. Mechanisms to ensure trust are essential to protect the privacy of individuals whose records are being accessed and to protect individuals and organizations that are sharing data. Putting privacy safeguards in place requires an upfront investment of time and resources. Developing a master patient/client index is often a goal when working with PHI. Obtaining consent from patients/clients to have their data shared is also important.

- **Transactional data** are data describing an event such as a healthcare visit or a client referral. This would include such information as wait times, prescriptions for medications classified by formulary categories, claims for workers compensation benefits, complaints regarding services, missed appointments at social service agencies, police incident reports, emergency room visits involving injury, etc.

In addition to variation in type of data shared, there can be variation in the content of the data. For example:

- **Population health data** — often both aggregate and geographically linked, it measures the health outcomes of a group of individuals, including the distribution of such outcomes within the group

- **Clinical data** — data from a variety of clinical sources to present a unified view of a single patient, usually using personally identifiable information

- **Financial** — includes various types of data, such as claims processing, patient-reported outcomes, cost accounting, staffing, and utilization

The function of the data is to answer the questions surrounding the purpose or aim of the program and to hopefully provide actionable answers to those questions. Though the type of data may change depending on the purpose of the program, often all three types of content are used. For instance, when looking at improving homelessness the type of data needed would be PHI (tracking individual cases), but also population health, clinical, and financial data. On the other hand, if looking at the efficacy of preventive services, data would more likely be at the aggregate level.

When beginning, data-sharing can use existing data within an organization or agency. Sometimes “the right hand doesn’t know what the left hand is doing,” and simply integrating the departments can be challenging before progressing to sharing with other sectors/organizations. Conversely, a single branch of an organization, such as in county services, may begin sharing information with other sectors/organizations, then proceed to combine with internal departments/branches.
Data-sharing often begins with static data, either at the level of the individual or at the population level, depending on what is most readily available to answer the questions being asked. Health care tends to start at the individual level, and often has trouble incorporating aggregate data, while county health departments often start at the aggregate level and find integrating PHI difficult. For example, personally identifiable data may be tracked when identifying community solutions for high-utilizers of the emergency department or for homeless members of the community. Alternatively, aggregate population data can be shared, such as census track data on rates of violent crime or asthma hospitalization. Eventually data can be linked from the individual to the aggregate or vice versa, with the ultimate goal that all data be linked and integrated longitudinally.

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<th>BARRIER</th>
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<tbody>
<tr>
<td>Don't know what data are needed to answer the specific question being asked</td>
<td>Identify the specific data needed to meet the objectives of the project.</td>
</tr>
<tr>
<td>Don't know if needed data are available</td>
<td>Build relationships to learn if the data exist, and if the data can be made available to you.</td>
</tr>
<tr>
<td>Data needed for community health improvement is different from data needed for patient care</td>
<td>Identify the specific data needed to meet the objectives of the project (the goal/aim), then create workflows to ensure the data needed is being captured.</td>
</tr>
<tr>
<td>Unfamiliar with data-sharing capabilities of local health department</td>
<td>Learn the extent to which data are integrated vs siloed between agencies within your county health department.</td>
</tr>
<tr>
<td>Don't know how to incorporate an additional type of data (aggregate or individual)</td>
<td>Start small, with specific data requests, and then build from those. Use consultants to help figure out how to adapt software to incorporate new data and legal counsel to clarify issues surrounding PHI.</td>
</tr>
<tr>
<td>Privacy issues surrounding personally identifiable information</td>
<td>Familiarize yourself with the relevant privacy rules (see resources under “Governance and Privacy” on page 18). Obtain legal counsel. Consider partitioned systems, where data are available based on a user’s level of permission for data access.</td>
</tr>
<tr>
<td>Creating a master patient/client index</td>
<td>Familiarize yourself with the issues (see webinar on the following page); obtain consultation with technical experts.</td>
</tr>
<tr>
<td>Consent issues surrounding shared data</td>
<td>Familiarize yourself with the options (e.g. opt-in, opt-out, client engagement). (See resources on the following page.) Obtain legal counsel.</td>
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RESOURCES:

Interoperability Initiative
A Confidentiality Toolkit to guide human service administrators in initiating data-sharing with other systems and agencies. Individual chapters make a different case for sharing, present relevant federal legislation, then present the What, Who, and How of implementation. It includes sample Memoranda of Understandings and data-sharing agreements, as well as a chapter on information technology to support confidentiality.

Center for Care Innovations
http://datadrivenculture.org
A website that offers a set of webinars, assessments, worksheets focused on making data use a central part of an organization’s strategy and goals. Topics are broken down into 1) terms & tools, 2) set your strategy, 3) engaging your team, 4) tactics & technology, and 5) analytics in action. It includes a worksheet that is useful to design an overall data strategy that identifies data needs, data gaps, and planning for data-sharing.

DATA DRIVES School-Community Collaboration,
Seven Principles for Effective Data-sharing
A toolkit designed to support data-sharing between schools, public health, and community services/partners. The toolkit is intended to help leaders implement complex data partnerships, with seven key lessons about how to begin and grow a data-driven initiative. Though focused on the education sector, the principles can also be applied to an ACH. Additional resources are found throughout the toolkit.

Webinar: Considerations for the Development and Use of a Master Person Index (MPI)
During this webinar, hosted by All In: Data for Community Health, presenters gave an overview of Master Person Indexes (MPIs), provide examples of how MPIs are used in practice, and discuss methodologies and tools for record matching versus an overarching MPI strategy.

Webinar: Navigating Consent
During this webinar, hosted by All In: Data for Community Health, presenters gave an overview of consent issues affecting communities (e.g. opt-in vs. opt-out, client engagement, etc.) and discussed questions and use cases from communities.

Webinar: Spotlight on Multi-Sector Data Collaboration
http://dashconnect.org/2016/06/30/webinar-spotlight-on-multi-sector-data-collaboration/
During the June 2016 HealthDoers Monthly Engagement Call, representatives from Data Across Sectors for Health (DASH) and the Community Health Peer Learning Program (CHP) described the current environment for shared data and discussed challenges to and solutions for advancing this work.

Administration for Children & Families, Confidentiality Toolkit: A Resource tool from the ACF Interoperability Initiative
A guide to help human service administrators initiate data-sharing with other systems and agencies, navigating the intersecting laws that give the perception that data sharing is prohibited. The toolkit addresses information sharing for the purpose of individual case planning and decision-making at a program level, specifically looking at personally identifiable data.
NATURE OF DATA EXAMPLES:

**Center for Health Care Strategies, Inc., Improving Care, Ensuring Patient Privacy: Hennepin Health Data-Sharing Case Study**


This case study highlights the work of Hennepin Health, an accountable care organization serving adult Medicaid expansion enrollees with complex needs in Minneapolis, Minnesota. Data-sharing at Hennepin Health includes a common EHR system and an integrated data warehouse for back-end analysis and reporting that brings together health plan claims and enrollment data, EHR encounters, and social service utilization data. Legal issues and patient consent are discussed, along with solutions and lessons learned.

**Center for Health Care Strategies, Inc., Hotspotting: The Driver Behind the Camden Coalition’s Innovations**

http://www.chcs.org/hotspotting-driver-behind-camden-coalitions-innovations/

This case study describes the work of the Camden Coalition of Healthcare Providers in Camden, New Jersey. It explains “hotspotting” — a data-driven process for timely identification of extreme patterns of health care use — and describes the core philosophies of its method, which has evolved over the organization’s 13-year history. A toolkit is provided.
Technology consists of the hardware, software, and storage that is used when working with data. Much of the data-sharing occurring now is still accomplished using methods low on the technology spectrum (“low-tech”), such as reports or spreadsheets that are manually extracted and manipulated in response to ad hoc or informal requests. More “high-tech” methods involve the use of integration technology. Typically, communities that have pioneered a more high-tech approach to data-sharing have had to develop their own technical infrastructure with no uniform standards.

Within a given community, data-sharing is often simultaneously high-tech and low-tech. For example, a community might have a health information exchange in place, but social services data may need to be manually entered. Or data may need to be extracted from an electronic health record into an excel spreadsheet in order to use it for community health improvement.

Many basic technology solutions exist and are perfectly fine for sharing data. Office programs, such as Excel and Access, can store and manipulate data as well as create reports for presentations. Cloud-based solutions, such as Dropbox or Box.net, offer storage at various levels (including free versions) and allow files to be shared. Google Docs is a free Web-based application in which documents and spreadsheets can be created, edited and stored online so that files can be accessed by and shared with multiple users. And the list goes on. For many programs, these solutions may be just fine. However, when data sets become too large or complicated, investing in upgrading software may be a consideration.

Packaged, or off-the-shelf, software solutions, can be a good next step. They are often less expensive than a custom system. They can be easier to use, often set up to have “plug and play” capabilities. However, they usually offer less flexibility and may not provide everything that is needed. Furthermore, they may or may not offer any additional technological support.
Custom software solutions are a more advanced technology option, and may be the best option when dealing with very large and/or complicated data sets. However, it is important not to rush into purchasing a custom system until it is needed or there is the risk of ending up with a system that doesn’t end up being what is required, either because it is not designed correctly or because it has more “bells and whistles” than necessary. Custom software systems often allow greater access to the actual data, which can aid in data manipulation, and often include technological support. However, they are often more expensive and can initially be more complex to learn.

Discovery is the first big step in developing a higher technology infrastructure. Leaders need to know what the community does well, but, more importantly, what it doesn’t do well. What systems are in place and where are the systems fragmented or nonexistent? Once the existing infrastructure is understood, a community can look to its goals and build from there. It is essential to understand the community context and to leverage resources available within the community.

Adopting technology slowly and incrementally is not always bad. Slower implementation allows relationships to build and trust to solidify. As technological solutions are implemented, it is advisable to keep an eye on both the “current reality” of what is possible and useful so that there is some immediate value, while also considering what future capacity may be desired.

Electronic Health Records (EHRs) and Data-sharing

Due to meaningful use and other incentive programs, most healthcare organizations have adopted electronic health records. By now most have figured out that EHRs do not solve all data problems. EHRs have traditionally been designed to input data and use it for patient care; the systems are not designed for data extraction or population health assessment. In the rush for widespread EHR adoption and implementation, there was minimal coordination of efforts, resulting in many providers within a community choosing a different system and creating interoperability issues when trying to share information with each other. Some early adopters have found that their systems don’t stand the test of time and need to be replaced, requiring an additional large investment of time, money and other resources. Others feel there is an emerging movement to bypass an HIE and exchange or store data directly from EHR to EHR. EHR vendors are now offering enhanced services, such as data warehousing, in an effort to capitalize on the growing movement towards sharing data. Though this may sound better initially, the actual process is still cumbersome and limited.
Health Information Exchanges (HIEs) and Data-sharing

HIEs have often been held up as a benchmark of data-sharing; however, HIEs are not necessarily the path towards data-sharing for community health improvement. Currently none of the HIEs in California share data across sectors for population health improvement.

- **Federated Model** — a decentralized organizational form in which the data remains at its source and a record locator service manages data requests between organizations. In this type of model there is no longitudinal analysis.

- **Repository Model** — a centralized organizational form in which data is held in a consolidated data warehouse. Many of these do not have a query function to allow data searching at the population level. Even when a query function is available, it often isn’t set up or available for investigating community health improvement.

Some HIEs are just getting off the ground; others are struggling because the data entered isn’t useable by the organizations inputting the data or because the participating organizations do not recognize the return on investment of the HIE. This is particularly true when the HIE requires additional paperwork and/or data entry. Nonetheless, HIEs are still in their infancy, relatively speaking, and if they evolve to accommodate data-sharing across sectors they represent a powerful tool.

As data-sharing begins across platforms, current data users don’t necessarily need to swap out their existing technology. Instead, tools can be used to allow their different systems to communicate with one another. This is an area that requires working with particular vendors or outside consultants who are familiar with the technological solutions.

✅ **QUICK TIP:**

**Use Notifications**

Use notifications to give people the information when they need it so they don’t have to go looking for the data. Notifications of events or information at the time of events is more useful, does not necessarily include PHI, and can stimulate the process to go look for information that it will be worth the effort.
Want to use an HIE for community health improvement? Make sure it has:

- A centralized architecture model (e.g. clinical data repository)
- Analytics and reporting functionality live or on the roadmap
- Integration of clinical and claims data
- Minimum data requirements and attention to data quality (so that analytics and reporting are based on accurate data)
- Robust data governance
- Care management capabilities (e.g. shared care plans) given the interconnections between analytics and care management
- Experience supporting quality programs and eCQM reporting
- The ability to generate meaningful reports and dashboards (ideally with the ability for participants to generate custom reports)
- Pricing significantly below quotes from stand-alone population health management vendors

— Mark Elson, PhD, Intrepid Ascent

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<tr>
<th>BARRIER</th>
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<tbody>
<tr>
<td>Insufficient human resources capacity for understanding the technological problems. Lack of skills/training to have a conversation about data-sharing</td>
<td>Hire, train appropriate personnel.</td>
</tr>
<tr>
<td>Different organizations/agencies have different formats and content in spreadsheets and/or other low tech data exchange options</td>
<td>Meet with relevant organizations to agree upon standardized format and data elements for the spreadsheets and other data exchange tools.</td>
</tr>
<tr>
<td>EHRs can’t produce data needed for sharing</td>
<td>Work with vendor; hire outside consultant.</td>
</tr>
<tr>
<td>Cannot produce report summaries that other agencies/organizations can read</td>
<td>Find ways to simplify data so that other systems can read them. Face-to-face interaction to determine how to create compatible files.</td>
</tr>
<tr>
<td>HIE not set up to share data for community health improvement or allow queries</td>
<td>See highlight below.</td>
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EXAMPLE:
San Diego

In the area of data-sharing, San Diego has made significant technological advances through three major programs: ConnectWellSD, 211-San Diego and its Community Information Exchange (CIE), and San Diego Health Connect. Each of these programs has implemented high-tech resources to achieve effective exchange of data within its sector, including working towards sharing personally identifiable information (PII). An additional program, Be There San Diego, is the backbone organization for the Accountable Community for Health collaborative. Though smaller and without the high-tech infrastructure that the other, larger programs have, it is currently the only program sharing data across the health care and social services sectors.

ConnectWellSD, is the information technology platform for the County’s Health and Human Services Agency (HHSA) that is connecting 9 separate data systems across social services, public health, behavioral health, and probation in a person-centered model. ConnectWellSD provides an electronic, rule-based information hub with a master client index to enable County staff and County contractors to access relevant client-specific information across multiple program databases to provide more holistic, coordinated services for the more than 1 million clients who use County services each year. Role-based permissions assure that necessary privacy and confidentiality requirements are met. A client portal provides access to selected information for the individual client.

211 San Diego is a 501(c)(3) information and referral service that acts as a “front door for help,” providing emergency assistance and resources to those who call in as well as a searchable online database. HHSA contracts with 211 San Diego to provide selected eligibility services and also to staff a number of 24-hour hotlines. Though currently each call generates a separate electronic record, 211 San Diego is moving toward a person-centered approach with longitudinal record keeping. Sixteen staff people at 211 have “look up” access to ConnectWellSD, with the longer term objective of developing a bidirectional referral system.

In 2016, 211San Diego absorbed the Community Information Exchange (CIE), a trust and technology network created to provide a database for exchanging client-specific social service utilization information across a number of community-based organizations to support better service coordination for clients with complex needs. The CIE focused initially on the homeless population in Central San Diego. The next two cohorts will be the elderly and veterans. Information is self-reported, and medical information is not included, so privacy is less of an issue.

HIGHLIGHT:
San Diego Stats
San Diego is the second largest county in California with a population of approximately 3.3 million and a geographic region just under the size of Connecticut. The average median income, at roughly $64,000, is higher than the state average. The population is majority minority.
San Diego Health Connect (SDHC) is the Health Information Exchange (HIE) for San Diego hospitals, clinics, public health surveillance, and health plans. First created through a Beacon Communities grant from the Office of the National Coordinator for Health Information Technology, the HIE was initially housed at the University of California San Diego (UCSD) during the 3 years of the grant. It has subsequently become a freestanding non-profit and is considered a neutral entity, helping to achieve buy-in in San Diego’s very competitive health market. The HIE is a federated model that includes a master patient index and a record locator system. Data sits for 24-72 hours, but SDHC has no longitudinal database that could support analytics. Data is exchanged through query/response and secure direct messaging, with no patient portal. The HIE holds HIV, mental health, and substance abuse data, among other data, so the governing board is very cautious about connecting or combining this data with other programs. The HIE is collaboratively governed and shares some of the same security and legal officers with 211 San Diego.

Be There San Diego (BTSD) brings various healthcare stakeholders together to collectively impact health outcomes. As a part of this coalition, BTSD acts as a liaison between HHSA Public Health and the hospital and health care system. While currently housed at the University of California San Diego there are plans to migrate the project into a 501c3 entity. Partners share cardiovascular data and best practices to reduce heart attacks and strokes. Aggregate data is collected from electronic health records (EHRs) into Excel spreadsheets. The RAND Corporation analyzes the data, combines it with other community based data, uploads it into a visualization tool (Tableau), and shares it back with the BTSD coalition of healthcare organizations for action. In addition, BTSD is the backbone organization for the CACHI grant in San Diego. As a part of CACHI, BTSD is developing a “Data Portfolio” framework to provide data that would be needed by an Accountable Community for Health. To this end BTSD has engaged Health Management Associates (HMA) to help develop a roadmap for sharing data across sectors. BTSD’s vision is to access and combine data across healthcare, social services, and community settings in a single platform that allows for a deeper understanding of community health, including future predictive analytics and bi-directional referrals.
RESOURCES:

Actionable Intelligence for Social Policy (AISP)
http://www.aisp.upenn.edu
A website that focuses on the development, use, and innovation of integrated data systems (IDS). The purpose of IDS is discussed and the components necessary to establishing an IDS are described. Many resources are available, including legal agreements and best practices, as well as an IDS site assessment tool.

EDM Forum
http://www.edm-forum.org/home
A searchable database of current research around learning health systems. It includes briefs/reports, peer-reviewed publications, and special supplements. Resource topics include analytic methods, clinical informatics, governance, and learning health system.

Public Health Informatics Institute
http://www.phi.org/resources
A list of multiple resources sortable by topic and date. Its 3 toolkits are titles Toolkit for Planning an EHR-based Surveillance Program, Public Health Informatics Profile Toolkit, and Reframing Public Health Informatics: A Communications Toolkit. There are currently 685 other resources (documents/analyses) organized by topic, and it continues to have additions.

nFocus Solutions Guide to Data Collaboration in Communities
A downloadable guide that draws upon successful community initiatives in Boston and Omaha to provide advice and resources for successfully planning, developing, launching and using a collaborative data system. Also available are downloadable assessments and worksheets. Please note that these resources are provided by a software solutions company, though their inclusion is not an endorsement of the company itself.
Analytic Infrastructure

Analytics refers to the manipulation of data: the processes, measures, analysis, reports, and presentation. It combines the technology with the human element. Good analytics is a skill, and include analytics, statistics, program evaluation, as well as information technology (IT). The people involved can work “in-house” or be hired from the outside, and are often titled analysts, software engineers, consultants, implementation specialists, and IT people. Training is also an important element, both during implementation of a new system of workflow as well as ongoing maintenance and improvements.

There are several workforce-related obstacles that emerge when considering analytic capacity for data-sharing. Individuals may lack the skills or training for data-sharing; it may not be part of their job description, or they simply may not have the time, given their other responsibilities; there may be no incentive in place to engage in the challenging and complex work of data-sharing. Within an ACH, the backbone organization will need to either hire and train to build analytics skill within the organization, or partner with other organizations/agencies for this capacity.

An important analytics challenge with data-sharing is to create and share information that is meaningful and useful. Often the problem is that there are too many data available, rather than too few. It is important to remember that more data are not better data. Success often involves focused queries and data reduction in order to share only that data that is key to understanding a problem and marking progress.

Metrics are the method used to measure something, and which data is collected and how it is analyzed is determined by the metrics. Metrics should be actionable and specific. The choice of metrics is important and there are multiple resources to help with identifying metrics that are feasible to collect, valid, and reliable, in addition to being good indicators of improvement in a particular arena.
Once you have the data, you need to know how to analyze it, but you also need to know how to extract the results in a way that it can be shared with others. You need to show the data and describe what it is/what it’s saying. Reports and visual displays, such as charts and graphs, are often the way the data is disseminated. More advanced versions of visual displays are dashboards and scorecards. More advanced analytics can include predictive modeling.

**The Six Rights**
Adapted from Kaiser Permanente

- **Right Question:** Define/refine question(s); actionable
- **Right Action:** Rollout; refinement/revision of current action; additional questions; no action/stop action
- **Right Method:** Data reduction; data visualization; specific to question/decision; timely
- **Right Data:** Ability to identify populations at risk of adverse events in a way that all relevant partners can understand and interpret the summary data
- **Right Team:** Interdisciplinary; cross-sector; data entry, data analysts and data users
- **Right Interpretation:** Specific to question/action; standard definitions; timely; quality assurance
<table>
<thead>
<tr>
<th>BARRIER</th>
<th>STRATEGY</th>
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<tbody>
<tr>
<td>Data-sharing is not in the job description</td>
<td>Evaluate existing job descriptions and revise them as necessary to include data-sharing tasks.</td>
</tr>
<tr>
<td>Lack of training/skills</td>
<td>Create training opportunities throughout the data-sharing process, including on-going support.</td>
</tr>
<tr>
<td>Data-sharing is too time consuming</td>
<td>Evaluate workflows to ensure efficient use of time. If necessary (and able) hire new personnel.</td>
</tr>
<tr>
<td>Lack of incentive/motivation to share data</td>
<td>Consider the behavioral and organizational norms. Is data-sharing aligned with the mission and vision? Is this worked valued and rewarded? Is it built into the performance appraisal system?</td>
</tr>
<tr>
<td>Data on social determinants of health are not routinely captured in healthcare</td>
<td>Begin with sample templates of recommended social determinants of health metrics <em>(see resources on the following page)</em>, then create workflows to ensure that the data needed is being captured.</td>
</tr>
<tr>
<td>Different language/terminology; no standardization</td>
<td>The people that are sharing data must have a personal, human interaction that allows for common understanding of terms and data type, content, function, etc.</td>
</tr>
<tr>
<td>Timeliness of data-sharing</td>
<td>Data should be shared in stages — first small amounts of data and gradually larger amounts as the stakeholders learn about each others data assets. Allow small successes to lead to larger ones.</td>
</tr>
<tr>
<td>Too much data/data overload</td>
<td>Identify the specific data needed to meet the objectives of the project (the goal/aim), evaluate the quality of the data.</td>
</tr>
<tr>
<td>Questionable data quality</td>
<td>Partners need to agree on which aspects of data must be complete, reliable and valid; design tests to determine data quality of the elements deemed to be critical; for those critical elements found not to be sufficiently reliable, partners must agree on an affordable fix.</td>
</tr>
</tbody>
</table>
RESOURCES:

NLADA Increasing Analytics Capacity: A Toolkit for Public Defender Organizations

Though developed for public defenders, this toolkit provides valuable how-to information that can be applied to all sectors of data-sharing and collaboration. The toolkit contains a maturity model for understanding the data analytics capacity of an organization’s system(s), then proceeds to work through their five domains of a quality IT and analytics program: technology, analytics, people and skill, governance and collaboration, and adequate funding. Included are examples and general recommendations for how to advance from one level to the next. Also included are a self-assessment tool, a sample MOU, and glossary.

The Practical Playbook
https://www.practicalplaybook.org/section/expert-insights/working-data

This page contains multiple resources for working with data. Topics range from basic ways to work with data to common data sources, selecting metrics, and tips on how best to display data. Special sections on using data in the digital era are included. Additionally, there are links from page to page with more resources for working with data.

Webinar: The Data Revolution — How You Can Benefit
http://dashconnect.org/2016/02/11/webinar-recording-the-data-revolution-how-you-can-benefit/

Data and information sharing are reshaping the process of setting and acting on community health priorities. In this webinar, Peter Eckart—co-director of the RWJF initiative Data Across Sectors for Health (DASH)—described what’s working in data and information sharing and analysis, steps you can take to benefit from them, the larger networked efforts to expand this work, and what lies ahead.

APHSA Roadmap to Capacity Building in Analytics
http://aphsa.org/content/dam/aphsa/pdfs/NWI/APHSA%20Roadmap%20to%20Capacity%20Building%20in%20Analytics_Dec%202015.pdf

This roadmap provides information on how to effectively implement successful analytic initiatives and the organizational capacities that will be needed to support it. It also provides many real-world examples of how Health and Human Service agencies have achieved cross-enterprise solutions by using analytics to effectively address their business needs as well as a capability assessment tool in the appendix.

National Association of Community Health Centers: PRAPARE Toolkit
http://nachc.org/research-and-data/prapare/

The Protocol for Responding to and Assessing Patients’ Assets, Risks, and Experiences (PRAPARE) is a national effort to help healthcare providers collect data needed to understand and act on their patient’s social determinants of health. This toolkit contains resources, best practices, and lessons learned to help guide interested users in each step of the implementation process, ranging from implementation strategies and workflow diagrams to Electronic Health Record templates and sample reports to examples of interventions to address the social determinants of health.

Webinar: Approaches to Collecting and Using Social Determinants of Health Data

This webinar, hosted by All In: Data for Community Health, addressed various approaches for collecting and using social determinants of health data, provided an opportunity for participants to ask questions of other practitioners, and fostered dialogue around data collection and use.

Children’s Data Network
http://www.datanetwork.org/knowledge/

Links to documents, manuscripts, articles, and studies divided into the following categories: Integrated Data — Commentaries & Reports; Record Linkage — Technical Documents; and Linked Analysis — Research Examples.
EXAMPLE:

Los Angeles

IDS Case Study: Los Angeles County
Collecting Data Across Los Angeles County: the Enterprise Linkages Project

http://www.aisp.upenn.edu/wp-content/uploads/2015/08/LosAngelesCounty_CaseStudy.pdf

A case study of how Los Angeles County developed an integrated data system to answer their questions about the County’s General Relief (GR) Program — a cash assistance program for indigent adults.

Los Angeles County’s Enterprise Linkages Project: An Example of the Use of Integrated Data Systems in Making Data-Driven Policy and Program Decisions


An example of how the effective use of Integrated Data Systems can play a crucial role in generating evidence that can guide important program and policy decisions. The restructure of Los Angeles County’s General Relief Program into an effective IDS provided the type of comprehensive information important for understanding the complex needs of vulnerable populations and for making data-based policy and program decisions that translate into more effective and efficient policies.
EXAMPLE:

**Washington State**

**IDS Case Study: Washington State’s Integrated Client Data Base and Analytic Capacity**


The Department of Social and Health Services Research and Data Analysis Division (RDA) developed and maintains Washington State’s integrated client data base (ICDB). RDA’s integrated client data base makes them uniquely positioned to conduct in-depth analysis of clients who use services from multiple DSHS programs. They are then able to make these de-identified data available to policymakers at all levels as well as the public. The division also houses the Human Research Review Board, which protects the privacy and confidentiality of clients and members of the general public who are subjects in any research project that falls under the jurisdiction of DSHS or the Department of Health (DOH).

**Washington State Department of Social and Health Services: Big Data — Big Discoveries!**

https://www.dshs.wa.gov/sesa/rda/research-reports/big-data-big-discoveries

Revealing patterns of behavior and outcomes using advanced analytical capabilities and predictive modeling. This presentation was prepared for a national ISM conference in Baltimore (IT Solutions Management for Human Services, an affiliate of the American Public Human Services Association). It provides an overview of the data capacity DSHS has established over two decades and gives examples of how the data is used to improve program outcomes and inform policy both administratively and at the state and national level. The content was presented by the Senior Director of Planning, Performance and Accountability in August 2012.
Summary: Getting Started

So how do you get started sharing data across sectors to improve health in your community?

1. Begin with identifying a **purpose or goal**. What are the major health concerns in your community? What is a common purpose that has broad support? What is a high value proposition for key stakeholders — one that will demonstrate a high return on investment?

2. Begin to **build relationships** between key stakeholders. Be sure there is buy-in at a high level (CEOs) and at the front-line (service providers).

3. Secure **funding**, through grants, partnerships, pooled community benefit dollars, bond-measures — whatever is feasible in your environment.

4. Establish the parameters for **data governance** and initiate any data use agreements that may be needed.

5. Consider the **type and content of data** needed to answer the priority questions: identify the data demand.

6. Obtain or build the necessary **technical infrastructure**. Don’t hesitate to start with low-tech solutions and build from there.

7. Hire or partner to obtain **analytical infrastructure** to complete the following major steps:
   
   1. Search, Find, and Review Data
   2. If the Data Look Promising...need to determine:
      
      a. Are they available through Open Data? OR
      
      b. Do you need to acquire data through a data-sharing process? OR
      
      c. Have you identified a data gap (ie. the data do not exist)?
   3. Analyze the data and assess data quality
   4. Develop the narrative: determine how the data should be presented
   5. Disseminate Data
   6. Follow up on any actionable steps; use data to develop new/continuing priorities
Additional Resources: Books Worth Reading

**What Counts: Harnessing Data for America’s Communities**
http://www.whatcountsforamerica.org
Cytron, Naomi, Kathryn L. S. Pettit, G. Thomas Kingsley, David Erickson, and Ellen S. Seidman.
A volume of essays published jointly by the Urban Institute and the Federal Reserve Bank of San Francisco, that addresses the question of how to improve conditions in some of the country’s most distressed places. Its contributors argue that the answers must be data-driven and require better collection, use, and sharing of information across sectors. Supported by the Robert Wood Johnson Foundation, the volume brings together authors from community development, public health, education, and related fields. It outlines opportunities and challenges for the strategic use of data to reduce poverty, improve health, expand access to quality education, and build stronger communities.

**The Practical Playbook: Public Health and Primary Care Together**
https://www.practicalplaybook.org
A roadmap to integrating the work of professionals in primary care and public health with the larger goals of population health. Drawing on the experiences of hundreds of public health and primary care professionals from across the US, this book explains: 1) why population health is important; 2) what the practical steps are that clinicians and public health professionals can take to work together to meet the needs of their community; and 3) what the signs are that you’re on the right track, and that progress can be sustained. It contains case studies, recommendations, and data resources from leaders within both public health and the medical communities on how to integrate primary care and public health

**Actionable Intelligence: Using Integrated Data Systems to Achieve a More Effective, Efficient, and Ethical Government**
http://www.aisp.upenn.edu/resources/aisp-book/
A new approach to promoting more effective, efficient, and ethical intergovernmental decision making and problem solving, called actionable intelligence for social policy (AISP), is presented. Actionable Intelligence (AI) is neither data nor research, although it involves both. It is derived from the combined contributions from executive leaders, practitioners, researchers, and citizens. It requires intergovernmental coordination and collaboration among bureaucracies. It is what is needed to inform disciplined, evidence-based decision making. The AISP model was developed to address the major limitations to traditional approaches to American public administration identified in the literature. AI is a robust integrated data system (IDS) that integrates individual citizens’ data across agencies to provide scientifically sound, intergovernmental information to inform AI. AI can provide a comprehensive picture of the whole person and has the potential of bringing everyone from health, education, and humans service agencies together around one table. Through the use of an IDS, data-sharing agencies can contribute their clients’ data to one collaborative process to achieve a more thorough understanding of a pressing social problem and what to do about it.
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DESIGN: Laura Myers Design

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