TOOLKIT

PROMOTING DATA SHARING APPROACHES

By The Topos Partnership
For the Data Funders Collaborative
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WHAT THIS TOOLKIT IS, AND WHO IT IS FOR

This Toolkit—produced with generous support from the Data Funders Collaborative—is intended to help communicators talk about and promote a wide range of data sharing, with broad audiences. The idea is to identify ways of creating more constructive and supportive dialog with more people. In addition to a review of the underlying research and testing, material in the Toolkit consists of a set of brief, concrete discussions of communications choices and considerations, as well as a set of concrete illustrations of how the recommendations can play out in real-world communications contexts. The Toolkit is designed as a stand-alone document—readers don't necessarily need to dive deeper into the research and rationales behind the material. But anyone interested in doing so is invited to read the accompanying research report.

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"Integrated Data Systems"

The general topic is what many in the field refer to as "integrated data systems," or IDS. Others might call them "data trusts," "information exchanges," "policy labs," "longitudinal data systems" or something else entirely. To borrow a definition from one of the leading initiatives in the field, AISP (Actionable Intelligence for Social Policy, University of Pennsylvania): Integrated Data Systems link administrative data across government agencies to improve programs and practices through evidence-based collaboration. As users of the Toolkit will see, the choice of terminology to describe the topic can be an important one, and the recommended language rarely if ever refers to an "IDS."

Who is the Toolkit for?

Broadly speaking, the Toolkit is intended to be useful to anyone trying to make the case for a data-sharing approach: funders, practitioners, policymakers, community leaders, and so forth. This guide might be for you if you find yourself in the role of a public information officer trying to communicate why a new local data sharing project is valuable; if you're a local funder trying to explain and drum up support for an IDS to promote economic opportunities for system-involved youth; if you're part of a national network providing technical assistance to dozens of local governments about how to use data as a strategic asset, and to build out this kind of data infrastructure. We hope individuals in all these positions and more will find helpful guidance and sample language in the guide.

Communications and Practice

Crucially, nothing in this guide should be misinterpreted as a way of putting positive "spin" on data sharing practices. Communications should be authentic, for both ethical and practical reasons—the goal is to build engagement and trust over time. Many individuals and communities may have legitimate concerns about the safety of their data and/or the uses it will be put to, and communicators should acknowledge those concerns not only through communications, but by continuing to move practices in the right directions, such as developing new mechanisms for community oversight. The Toolkit assumes that any government or partnership pursuing data sharing projects will seek to (a) develop them in order to better serve their community's most vulnerable residents; (b) remain mindful of the possibility for data, badly used, to worsen social exclusion by serving institutional rather than community needs; and (c) therefore to be solicitous of and responsive to community feedback, including criticism. (See documents from Ramsey County for examples of thorough and credible criticism any group developing IDS should be prepared to address.)

The Topos approach involves attention to the "cultural common sense": widely shared perceptions, feelings, values and (mis)understandings that may not be articulated explicitly, but nonetheless drive opinion and action. Many of the most important obstacles to effective advocacy are at this level, and effective communications need to operate there too.

For instance, one piece of Americans' cultural common sense is that business is very competitive, and imposing "unnecessary" costs and restrictions on businesses can ruin them. To one degree or another, this perspective is part of the thinking of Americans across the political spectrum, and easily drives attitudes on many different policy debates.

Successful advocacy means taking account of, and even shifting, this cultural terrain. To have a chance at this, messages must do more than trigger "agreement." (People can agree to statements while interpreting them the opposite of how they were intended!) Successful messaging should provide new perspectives (typically this means connecting the dots for audiences about something they hadn't understood before), must be "sticky" (i.e. must present ideas and terms that people remember and want to think and talk about again), must seem compelling and relevant, and must be presented in terms that people are comfortable using actively with each other, not just responding passively to.

The research and testing for the Toolkit were undertaken with all these considerations in mind.

Research approach

For this effort, Topos used the following methods to assess how people currently think about topics related to integrated data, and to test new messaging strategies for effectiveness. Participants in each method included a cross-section of the American public, unless otherwise specified.

- Review of current expert/practitioner materials: Topos began by reviewing a set of materials shared by DFC and gathered in other ways—both in order to learn about the field and to get a sense of how communicators currently address the topic. (What do they emphasize, what kinds of examples and explanations do they offer, and so forth.)
- Stakeholder interviews: Topos followed up the review of materials with discussions with a set of 10 stakeholders, primarily practitioners, in order to further our learning about the field, and about communications challenges and opportunities.
- "Mini-group" phone discussions: A diverse group of roughly 90 Americans (not in the IDS field) participated in phone discussions in groups of two to four. These conversations allowed the researchers to assess which ideas are clear and compelling, and which end up rising to the top in the course of back-and-forth discussion.
- "ArgumentLab": This unique approach, developed by Topos, focuses on identifying the strongest common-sense rationales for IDS, by engaging roughly 100 participants in a process of friendly argument in an online chat setting.
- "TalkBack" testing: This method, developed by Topos principals, focuses on identifying which elements of a message are clearest and "stickiest." Participants are shown a single message, and then asked a series of questions designed to assess which parts are understood, misunderstood, ignored, exaggerated, etc. Core questions have to do with how participants would pass along the ideas they heard to others. Testing included roughly 20 messages and over 500 participants from around the country.
- "Ethnographic Field Testing": Researchers visited a variety of communities in the Oakland and Dallas areas, with an emphasis on neighborhoods where people are more likely to be represented in agency databases. This form of testing sets a particularly high bar, and also allows for particularly authentic exchanges. It involves conversations in public spaces, workplaces, homes, etc.—with individuals who might ordinarily not participate in research. Roughly 150 individuals participated.
- Stakeholder vetting: Following development of Toolkit materials, Topos conducted a second round of 10 conversations with practitioners, advocates and leaders in the field, to vet the material for helpfulness, accuracy, relevance, etc.

For further detail on research methods, please see the full report.

[1]This Strategic Overview offers a condensed version of the research report for the project.

Why the public?

Research and testing for the Toolkit were conducted largely with public audiences representing a cross-section of non-insiders. Why do research with this audience, and why think about them, as opposed to the insiders that are the audiences for most day-to-day conversations? Guiding assumptions for the project are that:

- An ability to get public audiences on board will be increasingly important. Practitioners have already seen cases where public resistance has stopped IDS projects.
- Even if there were no practical need, there is an increasing sense in the field of *ethical* reasons for including the public in decision-making about data sharing approaches. They shouldn't be in the dark about the work.
- It is misleading to imagine a bright-line distinction between public and insider communications—increasingly, and predictably, materials created for insiders will also end up being seen by the public.
- Leaders need to talk to their own allies, constituents, etc., and therefore will appreciate communications that model effective ways of addressing the topic for these audiences.
- The public may have something to offer! In one case in Oakland, when data findings about children's gross-motor skills were shared with community groups, they suggested parks as an alternative to increased PE classes—which would allow policymakers to bypass questions about how to serve kids in charter schools, private schools, etc.
- Finally, the learning from public audiences is likely to be *relevant to insider communications as well*—e.g. with policymakers and funders. They are people too, and are likely to respond positively to themes that are effective with the public—but to need *additional* details, numbers and arguments, as well.

Key traps/challenges

The research identified a set of key challenges for communicators to keep in mind, and that the material in the Toolkit should help them navigate.

- Lack of trust in government: Widespread skepticism about government's motives and competence are an important aspect of the landscape and can be easily and accidentally triggered.
- Lack of connection to "data systems" conversation: It is easy for references to data sharing, data systems, integrated data, etc., to come across as technical, off-putting and irrelevant to people's concerns.
- Fear of profiling: Many audiences are concerned that personal information will be used (against them and their communities) for negative characterizations and profiling.
- Fear of privacy breaches: High-profile data breaches, especially in the private sector, tend to be top-of-mind when data is the topic.

- Fear of rogue misuses of data: The public is also concerned about individual, malicious misuses of data, related to grudges, revenge, and so forth.
- Fatalism: Finally, it is easy to accidentally reinforce a negative and discouraging sense that "we can't protect our privacy anyway."

Taken together, these concerns often outweigh any sense of the benefits that might come from integrated data approaches.

Key opportunities/recommendations

There are many hypothetical entry points for the conversation—a focus on creating smart/informed policy, on saving (taxpayer) money, improving convenience or efficiency, promoting equity, defining IDS, and so forth. Which of these is most helpful?

The research shows that communicators can effectively navigate and/or inoculate against the many traps on the topic by emphasizing a small set of core organizing themes, which should be used to introduce the topic, and returned to as guiding ideas.

CORE IDEA 1

Helpers (teachers, social workers, etc.) can do a better job if they have all the relevant information about the people, communities they're helping—therefore information should be shared[2]

This concept clarifies the topic and offers the clearest, most basic rationale. It promotes trust and buy-in by painting a concrete, understandable picture, focusing on trusted categories of people, and the goal of *helping* the public.

It is also useful to point out that this information (that helpers need) is currently located in many separate, disconnected places (as in various sample language in the Toolkit).

The idea can also be helpfully linked to motivating values like cooperation, sharing and working together, which are associated with doing a better job.

CORE IDEA 1 CON'T.

Sharing information also leads to better decisions about help: where to put new preschools, what services kids need in a given school or community, etc.

This concept, closely related to the first, is about bigger-picture decision-making—and is a bridge to discussions of research and policy—but still focuses on helping the public. Importantly, this relatively abstract idea must be illustrated through concrete *examples* such as the following. (See later sections for further discussion of how to provide effective proof points.)

> *In Charlotte, North Carolina, when school data was connected with homeless data, it showed there were over 300 homeless children in the schools who had been overlooked by homeless*

[2]While this first message element can sound relatively "top-down" – i.e. implicitly putting practitioners in a position "above" the people and communities they are helping – note that Core Idea 2, below, reasserts the agency of the public.

services. So case workers were sent to the family shelter to talk to them and connect them to other services they needed, and schools offered them additional resources.

CORE IDEA 2

Information should be shared in ways that let people SEE and HAVE A SAY in what's going on.

Even when people buy into the basic rationale for data-sharing, they are still likely to have misgivings along the lines of the key traps and challenges discussed earlier. "Putting people in the driver's seat" is the best way to reassure them and continue to build support—more effective than references to legal safeguards, and so forth.

Importantly, this means the field must continue to consider the question of *how far practices can be pushed in this direction.* Any statements or claims along these lines should obviously be authentic and realistic. If accurate, it is helpful to say that information *IS* being shared in these ways (not just that it *should* be).

Communicators have considerable leeway when it comes to the language they use to express the core ideas, but the research did identify two terms that tend to promote understanding and constructive engagement. These are not terms currently in use, but terms with the potential to strengthen communications if they were to be adopted:

"Information trusts"—defined as collections of relevant information with limits on who can see the information and how it can be used, and *where the public can see and have a say in all of this.*

"Data toolkits"—defined as user-friendly mechanisms (e.g. checklists) for people to learn about their data that's being shared and have a say in who can see it and what it can be used for.

Approaches that miss the mark

The research explored a wide range of lenses for introducing the topic of data integration, of which the recommended approach emerged as the strongest.

Other ways of framing the issue are less effective—when treated as the initial and central focus. Note that this doesn't mean these other angles shouldn't be mentioned. Many of them *should*, but not as the initial organizing theme.

- Making *government* more effective, efficient: People are much more interested in effective help (i.e. the end results and benefits) than they are in government/policy per se. In fact, their distrust of government makes this a problematic starting point.
- *Defining* IDS: The systems and structures themselves aren't the key point.
- Saving money: This is a very secondary consideration for the public, though certainly not a negative.
- Promoting equity: A very important goal for some audiences, less so for others, but in any case not the clearest, most informative way to start out the conversation.

For additional discussion of less effective organizing themes, see the full report.

This section offers guidance for selecting/creating examples that clarify the topic, and make a compelling case for data integration.

- √ Examples should be brief and easy to understand, with little or no technical language or detail.
- √ They should illustrate different kinds of outcomes and benefits, to establish that data sharing can help in a range of ways.
- √ They should emphasize the insights and discoveries made possible only by data sharing.
- √ Initial examples should avoid the realms of law enforcement and (individual) patient care: the first has very problematic associations related to profiling, while the second has many positive associations, but can lead conversations/thinking in irrelevant directions.
- √ If accurate, examples should include reassurances like "information already in the system," "no individuals or families identified in the data."

Except where noted, the following describe actual uses of IDS.

In Charlotte, North Carolina, when school data was connected with homeless data, it showed there were over 300 homeless children in the schools who had been overlooked by homeless services. So case workers were sent to the family shelter to talk to them and connect them to other services they needed, and schools offered them additional resources.

Different agencies in Philadelphia shared data with each other to map where early childhood education programs were located versus where most kids in lower-income families lived. This allowed them to make smarter decisions about where to put new public pre-K slots, so that they were most available to families who needed them.

The state of California linked up hundreds of thousands of child welfare records to birth records to help find out how children end up in the welfare system. One thing they found was that children of teen mothers in foster care were most at risk, and so they made sure to get childcare subsidies and other services to those families.

The state of California uses a "strong start index" to measure basic resources that are available to children when they're born (such as nutrition, healthcare access, stable home environments, childcare subsidies, etc.) Putting information from different sources together helps identify which communities are lower on the strong start index and need additional help and resources for kids.

In order to understand why many kids were chronically missing school, education officials combined data from numerous different sources. They were surprised to see how closely school absence relates to other place-based issues, such as a high proportion of vacant properties, unusually high rents, incidences of violent crime, car crashes, and drug sales. Now officials that work on all of these various issues are collaborating more to help the kids in more comprehensive ways.

In Jacksonville, Florida, researchers looked for patterns in the timing of child abuse reports and found they spiked after the release of report cards, but only when grades were released on Fridays. This prompted a conversation about changing when report cards were released, and also training doctors and teachers to talk to parents about how to support their children to do well in school.

HYPOTHETICAL: In one American city, there is a pilot program where average citizens are able to attend the same training about data access and security that city employees are. And every time a person is asked to provide information—even ordinary information like an address, marital status, employment status, and the like—they are told in simple, straightforward terms how the data will be used and asked to provide their consent about how it can be used and shared.

Have I remembered to...

- √ Start with a focus on how trusted, direct helpers (teachers, social workers, etc.) can be most effective
- √ Bridge to making smart decisions about other kinds of help (where to put pre-schools, etc.)
- √ Point to the kinds of benefits/help that data sharing will lead to (and offer 2-3 concrete examples)
- √ Clarify that information is currently located in many separate places
- √ Emphasize a "we/us" perspective (regarding who benefits, and who's in charge)
- √ Include common sense ideas/values like sharing/collaborating/cooperating
- √ Avoid initial focus on government, policymakers, etc.
- √ To the extent possible, emphasize public's/community's ability to see and have a say in things (what data is shared, who gets to see it, how it is used)
- √ If accurate, mention ways in which data privacy is protected (e.g. aggregated, no individuals associated with data, etc.)

EFFECTIVE LANGUAGE

SAY THIS:

A good way to help teachers, social workers, and other providers do their jobs better is to allow them to see more information about the individuals and families they're helping.

Schools and social service agencies want to collaborate with each other to improve the lives of people in their communities, and sharing ordinary information with each other is a way to do this.

Putting together the information that's already there makes that information more helpful.

Community members should be able to see and have a say in how data is shared and used.

Right now, information is located in separate places, where it can't do as much good.

To boost our families and communities, we need to encourage our schools and services to collaborate more.

We can't make the best choices about where to invest in our communities, unless we have the relevant information to work with.

Helpers need the relevant information in order to make the right choices.

NOT THIS:

When state and local agencies have more of your data in one place, they can access it more easily in order to be more effective.

Data sharing is the pooling of administrative data from different state and local agencies and the connecting of their databases.

The more an agency knows about a person, they more they can help.

Legal safeguards ensure that data won't be misused.

Centralized information sources increase agency efficiency.

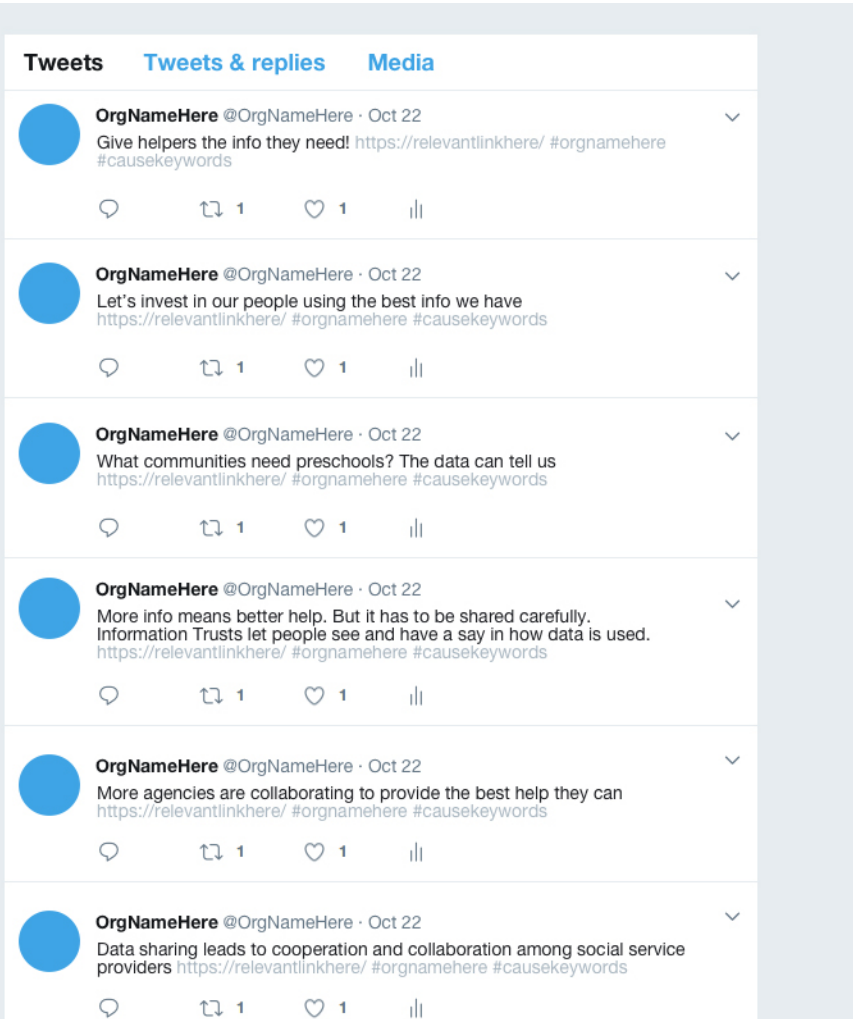
Effective government means creating modern systems for data sharing.

Data integration provides critical input for policymakers.

Data integration allows us to get the fullest picture of an individual or family.

SAMPLE TWEETS

The following are sample ways of expressing relevant points in a brief context like Tweets. Some might be used as introductions to relevant links to news articles, web pages, etc.



STORY TEXT (ORIGINAL)

This section offers an example of how text would look different if the research-based strategy—and some communications best practices—are kept in mind. Note that the comments and revisions assume a broad audience, rather than specialized readers.

Johnson County, IA turns to data for healthcare, justice solutions

According to National Medicaid data, five percent of Medicaid clients account for over fifty percent of all Medicaid expenditures. This scenario in which a small number of individuals account for an overwhelming amount of services used is also common outside of Medicaid. For the Johnson County Police Department, the issue of these "high utilizers" was a familiar one as, when responding to calls, they had encountered the same individuals many times, though they did not have a way to track these individuals efficiently. Information on these individuals was only gathered manually.

In 2014, the Johnson County Police Department tracked four chronically homeless men with substance abuse problems. The study found that over the course of four years these men consumed $2.16 million in social services, and at the end, all were still homeless and had substance abuse problems. In an effort to combat these issues, Johnson County became a founding member of the Data-Driven Justice Initiative (DDJ). DDJ was launched out of the White House in 2016 with a focus on using data to identify individuals with mental illness and substance use disorders who are frequently involved with local criminal justice and healthcare systems.

Johnson County partnered with OpenLattice to attack these issues in three phases. First, there was a foundational need to break down the data silos (police dispatch, jail management, crisis center) and create a holistic view of the current situation. Second, identify high utilizers across these systems and analyze costs of services they required. And finally, collect additional data using OpenLattice's Behavioral Health Report—which gathers information about how individuals with substance and mental health issues behave, how they respond to de-escalation methods, etc.—and share with hospitals and rehabilitation clinics to enable more personalized treatment plans.

With respect to privacy and confidentiality, the OpenLattice data integration platform complies with all HIPAA, CJIS, and 42 CFR Part 2 regulations by implementing industry standard encryption and field level, role-based permissions enabling directional sharing. For example, a health professional who is HIPAA covered viewing the profile of a recovering individual would have access to all information available, while an officer responding to an active incident would only have access to basic historical information.

A spokesman for Johnson County summarized the long-term benefits of the program by saying "We will have a baseline of data, and as we start new services then we can track outcomes to see if they change as a result." The program will give the county a better understanding of the current social services landscape in their community, and key stakeholders such as hospitals and rehab clinics can now bring together a previously fragmented process to stop the cyclical nature of incarceration and reduce recidivism.

Unhelpful focus on "data"

Initial focus on high-utilizer problem misses opportunity to establish general value of IDS

Starts with distancing references to institutions and numbers, as opposed to more relatable ideas

Overall, framed as an administrative challenge

Compelling core case study—about expensive, "failed" services; and a common sense shift from criminal justice to mental health perspective

BUT this core story is relatively buried—mentioned late, and embedded in jargon-filled prose

Helpful to tell a sequenced story (A then B then C)

BUT—too much emphasis on distancing, professional terminology and concepts ("data silos," "holistic view," "Behavioral Health Report")

Good to emphasize concerns that are likely on readers' minds, related to privacy

BUT reassurances come late and are of a very technical nature

Also, should take into account other concerns—potential skepticism about motives—and should imply a more active role for the public

Good to mention benefits

BUT benefits mentioned tilt toward administrative, and benefits to people come last and are framed abstractly ("stop the cyclical nature of incarceration and reduce recidivism")

Johnson County, IA identifies better ways to help with mental illness

Around the country, cities and counties are looking for the best and most cost-effective ways to help individuals with behavioral health issues that lead to run-ins with the law. And they are finding that by putting together information currently held in separate databases, they can offer these people more effective help, and also save money.

It turns out that small numbers of people with the most severe, chronic issues tend to need the most, and most expensive, interventions—a pattern that is familiar across many social services. For instance, data shows that about five percent of Medicaid recipients account for over fifty percent of all Medicaid expenditures nationally. So figuring out how best to work with "high utilizers"—by putting together information that is already in various separate places—leads to better outcomes for both the individuals and the cities and counties they live in.

In 2014, the Johnson County Police Department tracked four chronically homeless men with substance abuse problems—individuals they had encountered many times when responding to calls. The study found that over the course of four years these men required over $2 million in social services, and at the end, all were still homeless and had substance abuse problems. Wanting to improve these outcomes, Johnson County joined a system designed specifically to identify and help just these kinds of troubled individuals (the Data-Driven Justice Initiative, or DDJ, launched out of the White House in 2016).

The effort proceeded in three parts—all of which led to better information for doctors, rehab workers and social service workers, and reduced rates of incarceration. First, information was shared between systems that had interacted with these individuals (police dispatch, jail management, crisis center). Next, the information was used to identify the "high utilizers" and analyze the costs of the current ways of handling them. Finally, additional information was collected—about how the individuals respond to various treatments, how they tend to behave, etc.—using the "Behavioral Health Report" format created by OpenLattice, the creator of the secure information sharing platform used by Johnson County and others.

This system is an example of a growing trend, in fact. Since more information leads to more effective help, increasing numbers of agencies are working on creating "information trusts"—secure, private ways to combine already-collected information, allowing people in the system to see and have a say in how the information is used.

Final results were shared with hospitals and rehabilitation clinics to enable more personalized treatment plans.

SAMPLE BLOG POSTS

The following are examples of how brief pieces like blog posts can frame information in ways consistent with the research.

Information sharing means better help for the homeless

Since 2015, the state of California has been running the Whole Person Care (WPC) program for vulnerable individuals, particularly the homeless. The heart of the program is the sharing of information among helpers like homeless shelters, street outreach, community living facilities, and mental health providers—so that services can be targeted more effectively to those who need them. This collaboration and information sharing also allows service providers to figure out what the outcomes are, to evaluate whether the help is effective and cost-effective. Without this sharing across agencies, it would be difficult or impossible to know who needs what range of services, and what happens once they receive them.

All 25 of the pilot Whole Person Care programs across California are working to build "information trusts" that safely store information in ways that allow people in the system to see how information is used, and that give healthcare providers, care coordinators, and social service providers a fuller picture of the people and communities they are serving.

The WPC pilots are a great example of how data sharing between agencies can be used to help individuals and improve the quality of life in cities, not only for the homeless but for everyone who lives there.

Sharing information to promote economic opportunity

How can a major city help more of its families achieve greater economic security, and reduce the gaps that separate the haves from the have-nots? One important step in that direction is collaboration and sharing relevant information, so that helpers and decision-makers know where programs are needed, which services are working, and where the success stories really are.

In 2014, New York Mayor Bill de Blasio entered office with inequality as the defining core of his agenda, and city agencies prioritized this goal. An important part of the retooling was to create a way for people in different city offices to share more information—bringing together data from multiple sources, to figure out where the inequalities are, where the need was, and how the city's programs were doing at addressing it. The city's Center for Economic Opportunity became a hub, carefully connecting what had been totally separate, isolated data about communities, kids and families, so it could be put to greater use. As a result, kids in many New York neighborhoods are getting the opportunities they want and the services they need. (Adapted from "New York City's Results-Driven Approach to Combating Poverty and Inequality," https://results4america.org/wp-content/uploads/2018/12/NYCCaseStudy_FINAL.pdf)

Better help for kids receiving home visits

Around the country, many thousands of children receive home-visits from various social services, to check on their health and happiness, their readiness for school, the success of other services they may be receiving and so forth. But until recently, the insights and observations from helpers conducting home visits has not been leveraged to benefit kids as much as it could. For instance, that information was kept separate from other information gathered by health providers, meaning that these helpers couldn't collaborate to find the best ways of improving the experience for babies and families. A new national program called SHINE allows us to combine information so home-visit service providers have all the relevant data to offer kids the best help possible, and make sure precious state dollars are being spent in effective ways.

For more information on this program and how it can be used to help kids in our area, visit…

Each sample in this section represents a possible start to an answer, consistent with the research – then, communicators may wish to go on with additional information, detail and so forth. The samples are intended not as full and thorough responses, but as ways to establish constructive ground, from which communicators can then address a variety of topics and challenges.

In particular, the sample responses should not be read as means of steering the conversation away from genuine and legitimate concerns, e.g. on the part of community groups. The goal is not to put a positive "spin" on the topic, but rather to establish some useful, constructive premises to keep in mind in the course of an authentic discussion. (See the section on Communications and Practice in the Introduction to the document.)

From Public/Media:

How does this approach help me?
It's actually all about more effective help for us, our kids and communities. People like teachers or social workers can do a better job helping if they have all the relevant information about the people or communities they're working with. And so can the people making decisions like where we need new preschools or what services a neighborhood needs.

What is the community's role in this effort? Has the public asked for it?
People in the community want the best, most helpful services they can get, AND they need to have a say in what information is shared, who gets to see it and how it is used. This is why some places are talking about creating "data toolkits" that let people voice how they want information used.

Can I see how my data is being used? Will it be sold?
No, it will never be sold. The basic point is that for teachers, social workers, healthcare providers and so on to do the best job they can, having all the relevant information can be helpful and important. But there are very strict safeguards about who can see information and how it can be used, and the public will need to have a say in how this works.

What if I don't want my data included? Can I opt out?
We're talking about basic information that all of us have already agreed to share in various places, not *new information*, so at the moment there is usually no opt-out for individuals. Plus, we know that the more complete our information is the more effective we can be helping people. That said, the public needs to have a say in ALL of this, and in some places they have established what are called "information trusts" to get people more involved in seeing and understanding how their information gets shared and used.

How do I know that my family, my community, or myself won't be profiled?
We share information so those who are trying to help and do good work can do their jobs better, and we need to give them the resources they need, including the best, most relevant data. If anything, this system can be used to promote *greater* fairness in our communities. And history shows collaboration and data sharing makes a huge difference. But it is also true that we need serious oversight to make sure that negative profiling never happens. That's why the public will be able to see and approve this effort and have a say in how it gets done to make sure the help gets to where it is needed.

My kid is more than a number/data point. What about paying attention to the person?
You're exactly right, and that's actually part of the point—right now an educator or service provider might just have a couple numbers about a person, but if information is shared instead of being kept in separate places, helpers can get a fuller picture of the real person they're working with. The same idea applies to planning how to help our communities—when there is sharing and collaboration, we get a fuller picture.

Doesn't putting all the data in one place just make it easier to hack?
That's a very reasonable concern—but this isn't about storing all the information in one place. It's more about making it easy for information

to be shared when it's needed. Like when someone is planning where a new healthcare facility is needed, sharing would give them a fuller picture of the communities they're helping. The information might still "live" in separate places, but be easier to share when necessary.

Our city/state doesn't have a good track record promoting racial equity. Why should I trust them to use our information in positive ways now?
This is a very real concern, and actually one of the reasons that the careful sharing of data, with public input, is so important—to correct some problems that have been created in the past! This information is meant to help the people who are trying to do good work, and we want to give them the resources they need to be most helpful. *And* as we create this safe, collaborative system, the community must have more of a say in how this information sharing happens, so that educators, healthcare providers and city agencies can be held accountable if they are not using the data in helpful ways.

Will data be used to shut down our school/program?
Information sharing should always be done in a way that lets the community weigh in to make sure the goals are right, the results are positive, and so forth. But specifically to your question: The goal of this work is to get the right help to people and communities who need it, not to *eliminate* services. Results of this kind of work in other places have included new pre-schools being put where they're needed, homeless services offered to school kids who weren't receiving them, and getting additional childcare subsidies to young mothers and their families—not taking things away.

From Leaders:

Why should our city/state spend our money on this?
Very simply, having the best information available will allow us to offer the best services for our communities. If different information is kept in separate places, it's not doing as much good. If there are more opportunities for sharing and collaboration, we can be much more helpful with the information we already have.

How can we overcome legal obstacles?
If the goal is to make our teachers, social workers and other critical helpers and decision-makers more effective, there are certainly ways forward that make that possible. That needs to be the starting point for the discussion. From there, legal details can be worked out to allow for the best results for the residents of our city/state.

How can we overcome staffing challenges at the local level? What if we can't afford new staff, or don't have anyone qualified to build/run this system?
What we're really talking about is more sharing and collaboration, so decision-makers have a fuller picture of the people and communities they're working for. We can make progress in that direction no matter what the staffing situation is. [Note that of course this response will then need to more specifically address needs based on the context/proposal.]

OR: There's no avoiding the fact that information systems always need to be updated and, wherever possible, improved. What we are talking about is updating and improving our system in ways that allow information and data sharing so that all of us can do our jobs better. We can make progress in that direction no matter what the staffing situation is.

From allies, the field (about the communications strategy)

Why aren't we putting more focus on equity?
Great question. We all know this effort has the potential to promote greater fairness and equity, which is part of why we value it. And that certainly can and should be part of the conversation. But testing showed that when we *lead* with that goal, audiences new to the topic often don't see the more basic points about what IDS is and what it's for. For some audiences, if equity isn't a top-of-mind concern, it can even be a distancing way to start the conversation. Finally, some practitioners in the field are leery of overpromising in our core messaging, since not all data sharing approaches will necessarily lead to greater equity, even if they have other benefits.

What about clarifying different kinds of IDS?
Depending on audiences, and goals of the conversation, that is the kind of detail that can be added later, once basic principles and understandings are established. The guidance in the Toolkit is primarily about how to get the conversation started on constructive ground. Many audiences will be much more interested in the potential for improved help and effectiveness, and shifting the conversation too quickly to details of data management can prevent them from grasping and engaging with the full potential of IDS.

To what extent do term distinctions matter—depending on the audience, for example?
The main thrust of the research is about concepts – which ones to emphasize, which ones aren't as helpful to emphasize, and so forth. These ideas can be expressed in different terms, and certainly some of that might depend on audience. For instance, practitioners and public officials are obviously comfortable with some language that the public would find confusing or off-putting. The sample material in this Toolkit illustrates language that is clear and straightforward enough to be used in any context.