



# PROMOTING DATA SHARING APPROACHES

By The Topos Partnership  
For the Data Funders Collaborative  
September 2019





This report—as well as the accompanying Toolkit, both 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 goal is to identify ways of creating more constructive and supportive dialog with more people, and to explore ways of navigating challenges so that they don't derail the conversation.

Advocating for more data sharing naturally raises concerns for many people, but our research finds there are also some approaches that can lead to engagement and support—including a focus on the more effective help that data sharing allows, and the possibilities for community members to see and have a say in how data is collected, shared and used.



## Topos Approach

Developed over nearly twenty years of close collaboration between its three principals—a cognitive linguist, a public opinion strategist, and a cultural anthropologist—the Topos approach is designed to deliver communications tools with a proven capacity to shift perspectives in more constructive directions, give communicators a deeper picture of the issue dynamics they are confronting, and suggest the fundamentally different alternatives available to them.

Throughout our unique research process, the focus is on exploring—and ultimately findings ways of shifting—the current “cultural common sense” that shapes thinking on a given issue. In order to make progress, we need to understand the widely shared (mis)understandings, values and perceptions that are currently standing in the way of action and engagement. 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.



## Research Methods

For this project, our methods for exploring these questions included a combination of Stakeholder Interviews, Mini Groups, Talkback Testing, Ethnographic Field Testing, and Argument Lab, with a total pool of almost 900 participants. These individuals were roughly evenly split by gender; Whites represented roughly 55% of the sample, while roughly one third were African-American or Latinx. Roughly 28% of participants had annual incomes under \$50,000.

### Why the Public?

Research and testing for the project 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're 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.

Importantly, over the course of the project, it became clear that addressing the public's concerns and priorities will ultimately be critical for success in promoting IDS approaches.

### Stakeholder Interviews

In order to collect the relevant perspectives of experts and potential voices on the issue, and to identify red flags associated with particular approaches, Topos conducted a round of 9 interviews with relevant leaders and stakeholders, identified and recruited by the collaborative. Topics for the conversations included such areas as possible narratives for talking about the issues, challenges experienced in communicating with diverse audiences, and key policy priorities to be communicated. Topos paid particular attention to the implicit understandings and metaphors stakeholders bring to the conversation. Interviews were conducted October 2018 thru January of 2019 and ranged from 30-40 minutes.

In May through July of 2019, Topos researchers conducted an additional 10 conversations with stakeholders in order to assess and refine the Toolkit that resulted from the research to that point. These stakeholders were identified with the help of DFC and agreed to review material that Topos presented to them.



## Phone Mini Groups

At the heart of a strong narrative are simple, easily embraced ideas that people can readily comprehend and communicate to others. In this testing format, two to four participants join a researcher on the phone for approximately 30 minutes, and respond both to materials and to each other. The process allows researchers to learn about both individual responses to messages, and, importantly, how ideas fare in the course of an interaction—e.g. whether certain ideas stick as important touch points that participants return to. Importantly, these conversations yield insights about current, default attitudes, as well as assessing responses to various message strategies. A sample of participants were drawn from all around the US and were diverse in terms of age, politics, household income and ethnicity.

For this effort Topos researchers conducted 28 mini groups (with a total sample of 92 individuals) between December 2018 and March 2019. The first 14 groups were conducted early in the process to help establish current, default attitudes as well as responses to particular message approaches. The second 14 groups were used later in the process to test core narrative ideas that emerged from other testing and research components.

## Online Talkback Testing

Talkback testing—an approach unique to the Topos Partnership—allows us to draw on a larger sample size in order to identify which ideas are clear, engaging, easily remembered and able to shift attitudes in constructive directions. In this method, each (online) participant is exposed to a single core idea (a paragraph of roughly 100 words), and testing focuses first on whether the message that is heard is the one that was intended. These sessions also probe whether particular terms stick, whether a given idea is helpful for pushing back against opposition, and other questions. The essence of the approach is that participants are asked to remember and talk about the idea in their own words—a surprisingly difficult measure of success, far tougher than simple “agreement” in a survey.

Topos conducted three rounds of Talkback Testing late December 2018, mid January and early April 2019. In total, 19 texts of roughly 125 words each were tested involving 533 subjects from around the country. The full list of texts is included below.

Parameters of success included subjects’ ability to remember, explain, use and repeat the explanatory ideas and key terms. The testing was designed to assess whether a given idea has the capacity to become an organizing principle for thinking and communicating in a new way about the issue—as well as its overall effects on reasoning and engagement.

## Argument Lab

From January to June 2019, 87 subjects from around the country took part in Argument Lab. This method uses text-based, one-on-one exchanges between a researcher and a participant, where the goal is to arrive at particularly compelling points through a process of friendly argument. While researchers are careful to keep the exchanges constructive, the method also takes advantage of the freedom people feel in online exchanges to take strong or provocative positions, and to honestly reflect their feelings rather than repeat expected points. This unique method, developed by Topos, is particularly important for issues facing significant controversy, because it focuses on identifying the key rhetorical points that rise to the top in text exchanges via social media. The approach is designed to assess how ideas and approaches fare in the face of objections and attacks, and whether allies feel empowered to stand up and defend a position.



## Ethnographic Field Testing

Building on learning from the stakeholder interviews, TalkBack testing and mini groups, Topos worked to refine and further develop messages through “ethnographic field testing” with a diverse pool of 153 participants in two field sites: Oakland, CA and Dallas, TX. In mid-April of 2019, ethnographers spoke with 153 people in the two cities.

Ethnographic field testing consisted of conversations between a trained field researcher and individuals encountered in natural settings such as public spaces, workplaces and homes. This type of research can yield a richer picture and more authentic rapport than more artificially structured conversations, and allows us to reach individuals who would not ordinarily participate in research at all, in communities whose voices we need to hear from. Testing focuses on identifying ideas, communications approaches and aspects of a narrative that are clear and compelling to a diverse cross-section of non-experts in natural, conversational settings—based on observation of which ideas and terms are picked up on, engage interest, shift perspectives, are understood or misunderstood, and so forth.



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. Each has the potential to cause audiences to dismiss the topic, to be skeptical of claims, to misunderstand the point of a communication, and so forth.

Some of these are expected, and confirm what was anticipated going into the research. Others are more surprising, or are more important challenges than previously realized.

Understanding



### 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, regardless of the demographics or politics of the person listening. Virtually any mention of "government" or related terms can trigger counterproductive responses.

*"This sounds good. But on the other hand, they always put the good school in rich neighborhood and leave the poor kids behind."*

**52-year-old African-American woman, Coral Springs, Florida**

*"How much power do the other agencies have in gaining access to this information once you've collected it? Collecting the information and utilizing it for what it's intended for is great. Well, creating the knowledge about how to split the atom, that was great, but look at the consequences later on down the line. You have people that are willing to use it properly, and then you have people that are willing to abuse it completely."*

**54-year-old White man, Dallas, Texas**





*“Since humans are looking at the data, it would be almost impossible to avoid the association of stereotypes based on data. I would also have some concerns about say an agency like ICE looking at the data related to a child and finding that an undocumented immigrant was living in the house—would they have the ability to see data even if they were in no way involved in that child’s case and then use that data to somehow target the family?”*

**48-year-old Hispanic woman, Fort Mill, South Carolina**

*“The government is trying to keep an eye on everyone in the U.S. and keep track of everything we do. Giving us no privacy.”*

**27-year-old Hispanic man, Richmond, California**

*“I also fear government Big Brother tactics.”*

**60-year-old White woman, Bronx, New York**

### **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. In this way, broad audiences are obviously quite distinct from the insiders who usually participate in the conversation.

*“It could get really complicated. So that would be a downside because I think it would be, when you do have the specific agencies for a specific service, and they can concentrate on that service. And if it’s too broad, people can also get lost in the mix of everything.”*

**54-year-old Hispanic woman, Glendale, California**



### **Fear of profiling**

Many audiences are concerned that personal information will be used against them and/or their communities for negative characterizations and profiling.

*“I think it’s misused for the wrong purposes, and I think that if you look at what happened to Facebook, they had these algorithms that were singling out minorities, and they were redlining them. And now high tech has moved to racism; they brought that with them...So I don’t trust anything about that, and I think that people should keep their information confidential.”*

**61-year-old African-American man, Oakland, California**

*“You look at redlining in different cities, and how the cities will do these redlinings in different districts and stuff like that, and so in a way, it kinda sets people up for that...Some of these things are not very intentional but some people might not want to invest in that area for that reason.”*

**30-year-old Hispanic man, Dallas, Texas**

*“I would not want landlords, for instance, or even future employers to get this info. Landlords and employers can ASK if a person has had a criminal record, for instance, or see a credit card or report, but I would not want them to...see everything.”*

**48-year-old Hispanic woman, Teaneck, New Jersey**

*“[Information] can be, I don’t know, used against people...I often think that especially social services having the kind of information that they have on people can be demeaning.”*

**57-year-old White woman, Oakland, California**

### **Fear of privacy breaches**

Not surprisingly, high-profile data breaches, especially in the private sector, tend to be top of mind when data is the topic.

*“I feel like a lot of times now it’s like you don’t really know where your data’s going. I mean Facebook was just in front of Congress...People joke about how everyone has their own FBI agent.”*

**24-year-old White woman, Oakland, California**

*“Information being scraped, people just selling your information to advertising agencies to target you, apps just listening in on you. People are more wary, I think, about this more than anything nowadays, you know? You don’t want just any random Joe Schmo and random company just to be having their information.”*

**28-year-old Hispanic man, Oakland, California**



## Fear of rogue misuses of data

The public also tends to be concerned about individual, malicious misuses of data, related to grudges, revenge, and so forth.

*"Perhaps abuse was being investigated, the info gets leaked and someone kills the person who was an alleged abuser. It's very high stakes info potentially."*

**54-year-old White woman, Barbourville, Kentucky**

*"A part of me thinks that some people with power may use that info against someone when it isn't appropriate. For example, a teacher could discuss a student's diagnosis with another parent who is concerned about their child at school. That's not relevant or acceptable."*

**36-year-old African-American woman, Fairfield, California**

## Fatalism

Finally, it is easy to accidentally reinforce a negative and discouraging sense that "we can't protect our privacy anyway." While this attitude might be taken as having positive implications ("Why object to data sharing if there's no privacy?"), the research shows it is connected with a kind of fatalism that prevents engagement or optimism about positive uses of data.

*"Would the information be hack proof? I already know the answer to that!"*

**63-year-old White woman, San Antonio, Texas**

*"They said...the privacy laws will help and all that...I think there's still gonna be a way they can pop up and someone can get your information."*

**55-year-old African-American man, Oakland, California**

*"Nothing is safe anymore and that's something we all have to live with and understand."*

**41-year-old White man, Buckeye, Arizona**

*"I mean think about it. The government says the Russians hacked into the election when Trump won, and that system should be a government system and it got hacked into!"*

**42-year-old White woman, Kenosha, Wisconsin**

*"My question is still how are they going to protect data in this world when big companies still can't protect our data. So I am still concerned with that. You know, and everybody always says something's for the greater good but we all know data is misused and you can fudge data and turn data into anything you want so that would still be my concern."*

**44-year-old White man, Evansville, Wisconsin**



---

The next section of the report focuses on approaches that proved to have significant capacity to steer conversation away from these problematic perspectives, and to promote a more constructive conversation.



There are many hypothetical entry points for a conversation about data sharing—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

The first idea focuses on the idea that information sharing means trusted helpers can be more effective—on behalf of people, families, communities.

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...

*Note that this is an idea, that can be expressed in different terms, though the language above is similar to what worked in testing.*

This concept has the important benefit of immediately clarifying the topic and offering the clearest, most basic rationale. Testing shows that people understand and relate to this idea immediately.

*"I think in our current world we have to be concerned about data security. There are too many breaches not to be concerned. But I can absolutely see how social services having access to a child's school and health records could keep a child safer and maybe save a life."*

**49-year-old White woman, Ashland, Massachusetts**

It also promotes *trust and buy-in*—very important dimensions of the conversation—by painting a concrete, understandable picture, focusing on trusted categories of people, and the goal of helping the public.



### A NOTE ABOUT "HELP"

Communicators should make their own decisions about whether to use this term/concept, or find alternatives.

For broad audiences it is clear, sticky and compelling.

But, to some advocates (and others) it may seem to reinforce a top-down / us-them / active-passive view that ignores communities' own power and agency.

Alternative phrasing might include: "Individuals who work on behalf of the community can be more effective if..."  
"More beneficial decisions can be made when..."



## PUTTING THE CORE IDEAS TOGETHER

Helpers (teachers, social workers, etc.) can do a better job if they have all the relevant information about the people, communities they're helping.



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.



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



Illustrate with one or more examples.

As a related, clarifying point, it is useful to point out that this information, that helpers need, is currently located in many separate, disconnected places. (See sample language on this point and others in the Toolkit for the project.)

*"I mean, the more the better. The more communication we got out there, the more everybody else will be aware of and it won't just be one person trying to do the whole job themselves."*

**24-year-old African-American woman, Dallas, Texas**

*"It's pretty much collaborating on a cause or a problem. Say it's just really hard predicament that you don't really know the answer to, it's better to have the collective thoughts of different people's minds and opinions."*

**19-year-old Asian-American man, Dallas, Texas**

*"Silos of information that do not let the one head speak to another is not in the best interests of anyone."*

**48-year-old White man, Superior, Colorado**

## Values

Besides the value of "helping," Core Idea 1 can also be helpfully linked to motivating values like cooperation, sharing and working together, all of which are associated with doing a better job.

*"Agencies work best when they can cooperate and share information about people they assist."*

**48-year-old White man, Louisville, Kentucky**

*"With all these parties working together, the child will be protected in all cases."*

**45-year-old White woman, Montgomery, Alabama**

## Core idea 2

The second core idea bridges to a bigger picture:

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 *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 the Toolkit for additional examples, and discussion of the best types of examples to select.)

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.

Examples create clarity and confidence, and should be an important part of every communication about data sharing.

*"That would help people a lot because they would be more aware of what's going on. If they're not aware then nothing happens...no action is being taken."*

**18-year-old Hispanic man, Dallas, Texas**

*"I think it is important to share information. One agency could be learning something very valuable that another group could benefit for, but has no knowledge of...The benefits could be in the form of programs. For example, local health agency has good findings. They partner with a school to implement a program to benefit the area's youth. Suicide prevention is a really big topic right now. That would be a topic area where this could benefit."*

**32-year-old White woman, Cincinnati, Ohio**





## Core idea 3

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.

*"As long as it's an open line of communication and people are being honest and forthright . . . If you're taking it and putting it into a database and you're not telling the people what you're doing, you're kind of scamming. But if everything's up front, in your face like,*

*"Hey, we're going to do X, Y, and Z,' then I think that's okay. As long as people know what they're getting into before they just sign they name on something."*

**34-year-old African-American man, Oakland, California**

*"People should be aware of what type of information will be shared. People should also be allowed to choose what of their information they wish to share. But stuff that should obviously be shared are things that could prove useful for all."*

**29-year-old Hispanic woman, Panorama City, California**

Importantly, this means the field must continue to consider the question of how far practices can be pushed in this direction. Any statements or claim 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.



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.*

*"I am not sure the government is there to make people's lives better. Facebook or Google either, for that matter. They are all playing chess and we are the pawns."*

**55-year-old White woman, Mount Juliet, Tennessee**

*Defining IDS—the systems and structures themselves aren't the key point.*

*"The first question would be...the reason for collecting...Most local agencies are looking to prop up their own personal agendas within a certain city or a particular territory outside of the state's control. For me, it's basically finding out what's the root of the matter itself."*

**54-year-old African-American man, Pacific, Washington)**

Saving money—this is a very secondary consideration for the public, though certainly not a negative.

*“Of course there would be wasted money because each agency can’t be as efficient working independently and not sharing important information and data. There will also be unnecessary duplication too... [But] the main issue to me is better care and outcome for the individual as a result of sharing information.”*

**49-year-old White man, Lincoln Park, New York**

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.

*“Treating people with dignity means treating them as individuals—not data. I don’t think the numbers tell a good story usually. I think knowing what someone needs isn’t often a statistical thing...I just think a smaller, more community based world, that we’ll never get back to, is more equipped to help people.”*

**37-year-old White woman, Pittsburgh, Pennsylvania**

## APPENDIX



# research materials

## Sample Stakeholder Interview Questions

---

What is your relationship to the Data Funders Collaborative?

What is your professional connection with Integrated Data Systems?

Why take time out of your day for this conversation? What makes it important enough?

Do you use or know of any other terms for this approach (i.e. besides “integrated data systems”)?

Have you had experience communicating/writing/speaking about the topic? What kinds of audiences?

How would you (do you) tend to make the case for why IDS is important?

What are the most important purposes of communications about IDS? What would be the audiences and goals for communications?

Which “values” come into the conversation, if any?

IDS might hypothetically become a no-brainer, implemented all over the place. What would be the rationale for making that so?

Who are the main beneficiaries of IDS? How do they benefit?

Are there go-to examples you use to illustrate the benefits of IDS?

What are/might be the challenges in communicating about the topic?

What main objections to IDS are you aware of?

Who can be hurt by IDS and how?

How would you respond to these concerns?

Could you comment on the different conversations that happen, or should happen, around case management vs. research and policy?

Specifically, how would you respond to concerns about data privacy?

Do you recall hearing any good metaphors for what IDS is and does?

Are there sources of information you think we should look at? About communications, about case studies, etc.?



# Sample Guide for Argument Lab

## Explanation of Topic

We're talking about any sort of approach that integrates data among public agencies like social service systems, school systems, criminal justice systems and so forth, and brings that information together to be used for either individual case management or for policy making and research purposes.

## Debate Topics

US states and cities should set up systems for integrating their data across agencies.

It's better for us if US states and cities set up systems for integrating their data across agencies.

It's good for individuals and communities if US states and cities set up systems for integrating their data across agencies.

More US states and cities should set up systems for integrating their data across agencies.

More state and local agencies should create secure environments for collaborating with data.

We need to have more say in how ordinary information about us is linked and shared by state and local agencies.

More state and local agencies should create secure environments for sharing data.

## Candidate Pro Arguments

We would only have to enter information one time, updating it occasionally.

State and local governments can use the data to help us.

They already collect a lot of information about us.

We might get to know how much information exists about us.

We might get to evaluate how well the government does its job.

They already have a lot of information about us, this is just using that information smarter.

That holistic perspective allows them to see what's unique about people's lives.

We would benefit from this sharing because governments would use it to solve problems.

It can make government more efficient and make teachers, nurses, social workers, police officers and others more effective at their jobs.

That holistic perspective also allows them to see what's unique about communities and their challenges.

It can get services to people early before problems get too expensive to fix.

They can allocate resources more efficiently to individuals and neighborhoods that need them.

## Candidate Con Arguments

Data breaches happen all the time to companies that can afford computer security.

Data sharing—like what Facebook is doing?

This is intrusive, and we can't trust what the government would do with the data.

Having all the data in one place about a group could be used to discriminate against them.

A rogue user could use the data for the wrong purposes, maybe something unethical or illegal.

Other countries like Russia and China use such systems to keep track of their citizens' every move; that's not what we do in America.

The controls on such data aren't strong enough.

The money these systems would require is better spent going directly to schools or hospitals.

It's better if the government can't collect a comprehensive picture about us—we're safer if they're a little frustrated.

This gives the government too much power over us.

Building these systems and keeping them secure would cost too much money.

If teachers and others were doing their jobs, they wouldn't need data to tell them what's right in front of their faces.

People who use certain services will be represented more in the databases than people who don't, and this isn't fair.



# Sample Interview Protocol: Ethnographic Field Testing

Hi, I'm working on a research project—a sort of public opinion poll about public attitudes. The topic is about some ways to help kids and families.

(We videotape for research purposes, and to show what people have to say on the topic, but it's not for broadcast.)

Now I'd like to read you a paragraph and then get your feedback on it.

## FIRST TEXT

Did you hear that alright or should I read through it again?

- What do you think about that?
- What would you say is the main idea there? If you were going to pass on to a friend what you heard here, what would you say?

Let me give you some examples of the sort of thing they have in mind here.

[Read an example of IDS usage]

- What's your reaction to that?
- If you were going to explain to someone what happened there...
- Think about all the information that different programs or agencies have about your part of town or people you know. Do you ever wish they were better at putting all that data to good use? [probe for what that might mean]

- What about the information about individuals and families? Could that information be put to good use? (if so, how?) [probe for what should and shouldn't be done—what kinds of information are they thinking about]

I'd like to read you just one more paragraph if you have time?

## SECOND TEXT

Did you hear that alright or should I read through it again?

- Before I get to your opinion on that, how would you summarize the main points of that one, like if you were telling a friend what it said?
- And what's your reaction to that?

Some communities have had disagreements about whether it's a good idea for schools, social service agencies and so forth to share data with each other. They say they don't want anyone putting numbers together to try to predict which kids are going to get in trouble, need financial help, and so forth.

- What do you think about that?
- [if on board] In some cases it will cost money to bring all this data together. Would that be worth it? (why / why not?)
- [if not on board] In some cases it will save money to bring all this data together
- Would it be worth it? (why / why not?)

## WRAP UP

- Of the topics that we discussed today, what ideas stand out? Any particular ideas that you remember from the paragraphs I read you?
- How do you think this topic is important for our communities or our country?



# Sample TalkBack Survey Instrument



The topic for today's survey has to do with different agencies doing more to share data and collaborate so they can do a better job, especially on behalf of kids. These might be public agencies like child protective services, public health agencies, schools, welfare agencies, or other social services.

Please read the following statement carefully, because you'll be asked several questions about it.

TEXT



**1** Without going back to read the statement again, what do you remember of the main ideas? Please write at least two sentences in your own words as if you were sharing these ideas with a friend.

**2** How is this topic significant for you or for others you know?

**3** If you had the chance to ask an expert, what would you like clarified about the ideas you read about in the paragraph?

**4** Suppose you were having a discussion about this topic with a friend or relative who said, "I don't want the government having any more information about people than they already do." How would you respond?

**5** If you were explaining to a friend the key idea in the paragraph you read, what would you say?

**6** For each of the following statements, please tell us how strongly you agree, from 1 (Not at all) to 10 (Completely)

**RANDOMIZED ORDER:**

2 statements reflecting the "target perspective" we're trying to move people to:

- It would be good if more cities and states found ways for different departments to share data.
- It would be smart to put money into systems for sharing data better.

2 representing problematic default perspectives we're trying to move people away from:

- The government already has too much power, and putting all our info in one place would make it worse.
- I doubt integrated data would be used in the right ways, and for the right purposes.

4 Irrelevant/distractor

- A \$15 minimum wage would harm too many businesses.
- Reducing global warming should be an important priority.
- It would be a good idea to create a national health insurance program.
- Stricter enforcement of immigration laws would help our communities.



**7** How interested would you be in receiving further information about this issue, or taking a simple action such as sending a postcard to a representative? (Note: This question is purely hypothetical—we will not be following up with you.)

Not | A Little | Very | Extremely

# Messages Used in TalkBack Testing

---

Note: Participants do not see labels, which are for internal convenience.

## 01 Dignity

To treat individuals in communities with dignity, state and local governments need to protect the ordinary information they have collected about people. These agencies also need to share the data with each other to give schools, hospitals and others the best information for helping individuals and communities thrive. If we can make this data useful while protecting it, and if people can have a say in how it's used, that is government treating people with dignity.

## 02 More Useful

One way that state and local governments can make the information they collect about people more useful is by pulling it together and sharing it with each other. Most of the information they have is buried in separate databases and doesn't help as many people as much as it could. But when databases are connected, the information becomes much more helpful, just as doctors often share information about patients to serve them better. This gives a fuller picture of what people need and can be used to predict future needs and make agencies more responsive to their communities. Leaving all this data unconnected is like leaving gold in the ground.

## 03 Our decisions

Right now information about kids and families is spread out in many separate databases collected by schools, hospitals, and social services, which makes it harder for us to make informed decisions about things. How can we, the residents of a given community or state, make the best decisions about how to strengthen our families and our

wellbeing without all the information? If there's no place where this data is all put together, we can't get the big picture on the trends in our communities and where the needs are, or about which institutions are doing well and which need to change course. More integrated data would be a critical step forward for our decision making.

## 04 Collaboration

We all know collaboration can be key to doing a big job well. One form of collaboration that would help lots of people is for state and local agencies to share with each other the information they gather on the people they work with. When local governments collaborate, they can do a better job providing services to individuals and families who need them. And they can more effectively plan for the futures of those communities. As in many other parts of life, collaboration on this issue will lead to better results.

## 05 Compiling the book

When a local or state agency collects information about people they help, it's like they have one page in the book about those lives. Much clearer and more helpful insights are possible when those pages are put together, and when schools, hospitals, and other agencies can see the whole book. At the same time, people should know what's on those pages and have some say about which pages go in the book. Putting the whole book together and sharing data across agencies can help people much better, and the same goes for a community, whose life is hard to see all at once. Putting the whole story together gives local governments a better tool to help people thrive.

## 06 Simpler picture 2

One way for us to get a handle on our complex world is to share information and put it together to make a single, clearer picture. For instance, when schools,

hospitals, and other agencies share the information they have about kids and families and collaborate, they get a clearer picture, instead of working with a bunch of separate data. Combining and sharing the ordinary information about the people they serve would allow decision-makers to see through the complexity and make sense of things, so they can help individuals and communities thrive.

## 07 Efficient spending 2

If we want schools, hospitals, and other state and local agencies to spend their budgets efficiently, they have to do more to share the ordinary information they have about people. That's the only way we can see how many negative outcomes have been prevented and how many positive outcomes have been created, and which programs helped the most. In the US, nearly a trillion dollars a year is spent on providing things like education, social services and health care, and sharing information among these players is an important way to make sure we're spending efficiently.

## 08 Ingenuity 2

Connecting different collections of data uses American ingenuity to solve complex problems. State and local governments end up collecting lots of information about individuals and communities, and we should be using modern approaches to put that data together to help us solve practical problems. Right now much of the information is buried in old, separate databases. But if we figure out smart ways to combine it and affordable ways to keep it secure, we can do a better job of answering questions like how to target services to individuals more efficiently, how to plan for future changes in our communities, and how to measure how well local agencies are doing.

## 09 Getting smarter 2

Using existing data in smarter ways would help communities thrive. State and local governments have a lot of ordinary information about individuals and their communities, and linking and sharing this data would make everyone smarter. This would help agencies provide services to individuals more efficiently, and it would allow them to plan for the future needs of communities. Some of what we criticize about government actually comes from their lack of knowledge, which they can improve by combining information from different places. Governments don't need to collect more information about us, they just have to use the existing data in smarter ways.

## 10 Our convenience 2

If state and local agencies shared more information with each other, we wouldn't have to give the same information about ourselves on forms over and over. Imagine if they shared all the ordinary information about us: where we live, what social services we use, where our children go to school, and so forth. We would only have to give this information once and update it from time to time. This would allow the government to deliver services to individuals more effectively, because they would have a more complete picture of us—and it would also reduce our own paperwork and inconvenience.

## 11 Effective workers

Teachers, social workers, and others who provide services to kids and families, wish there was a unified database with all the information that has been collected about the person they're helping. Having access to all the information in one place would make these helpers much more effective at their jobs. As one social worker said, "To get a clear picture of what services a child might need, what would

## Messages Used in TalkBack Testing continued

---

help most is seeing all the information from social service agencies, mental health, education, and law enforcement." If we just connect existing databases to each other, these providers can do a better job.

### 12 Toolkit

More and more state and local agencies are offering people in their communities a "Data Consent Toolkit." This toolkit shows people all the ordinary information that the government already has about them, and lets them have a say in how it is used. The toolkit tells people how data is protected, and how to have a say in who gets to see the information, and what purposes it's used for. The idea is to protect privacy and also to make sure that information is used in positive ways.

### 13 Health care

Imagine that local and state governments could improve health and well-being in their communities by sharing ordinary information about people between different agencies, just as health care providers share the health records about patients. This allows them to see a whole medical history and to make treatment recommendations that keep the whole patient in mind. Likewise, schools, social services and other agencies also stand to help more effectively by sharing information with each other. Imagine knowing which bridge to salt first because more accidents have happened there. We can apply the same kind of thinking to other situations, like helping schools understand how many of their students may actually need homeless services.

### 14 Effective helpers

Teachers, social workers, and others who provide services to kids and families wish there was one place they could go to see all the information they need to know about the person they're helping. Having

access to that information would make these helpers much more effective at their jobs. As one social worker said, "To get a clear picture of what services a child might need, what would help most is seeing all the information from social service agencies, mental health, education, and law enforcement." If we could connect existing databases to each other, these providers can do a better job.

### 15 More Useful

State and local governments can make the information they already collected about people more useful by pulling it together and sharing it with each other. Most of that information is buried in separate places and doesn't help as many people as much as it could. But when files are connected, the information becomes much more helpful, just as doctors often share information about patients to serve them better. This gives a fuller picture of what people need. It can be used to predict future needs. And it can make agencies more responsive to their communities. Leaving all this data unconnected is like leaving gold in the ground.

### 16 1+1 = 3

When social service or other agencies share data with each other, the effect is like 1+1=3, meaning we get extra value by combining information. Teachers, social service providers and others can understand a lot more, and help a lot more, by putting the information together than they can when it's locked in separate, isolated databases. This "1+1 is 3" effect is the main reason so many organizations are looking for ways to safely combine data from different sources—the ordinary information that gets collected, but not really used to the fullest.

### 17 Data Trusts

More and more places in the US are creating what

are called "Data Trusts." These are arrangements that allow the safe, careful sharing of information between different agencies. Experts have found we can help kids, families, and communities more effectively by putting information together to get a fuller picture of the struggles and opportunities in their lives. They're called data trusts because the information is brought together in extra-careful ways that protect everyone's privacy and dignity, and are only used to promote solutions.

### 18 Information Trusts

"Information trusts" are a new way of combining various information about us in ways that protect privacy and create good outcomes. We all know that having more information leads to smarter decisions. Teachers, nurses, social workers and others wish they had access to more information about the people they're helping. But the question is how to make sure the information is handled in the right ways. "Information trusts" are set up so that regular people can see how the information is used, and have a say in it. For example, if data about you is in an Information Trust, you'd have a say in who can see it, and whether it is used to help and support people like you.

### 19 Collaboration

We all know collaboration can be the key to doing a big job well. One way we could be collaborating more is if different local agencies shared the ordinary information they collect about the people they work with. That might really help lots of people. If local governments collaborate more and share more, they can do a better job supporting communities and providing services to individuals and families who need them. As in any part of life, collaboration will lead to better results.

