



2020 Virtual Symposium: *A Compendium*

DATA
FOUNDATION

About the Data Foundation

The Data Foundation is a non-profit think tank based in Washington, D.C. that seeks to improve government and society by using data to inform public policymaking. Our research and educational activities proactively and rapidly address relevant, emerging data-related needs in the country with the goal of devising realistic solutions, accelerating policy coordination, and advancing innovation. The Data Foundation values diversity and transparency in pursuit of an equitable, data-informed society.

The Data Foundation focuses its non-partisan research, education, and programming in five areas.

- **Culture for Evidence-Based Policymaking.** Changing long-standing practice to use data and evidence for informing key decisions and policy choices requires a supportive organizational culture and political environment. The Foundations for Evidence-Based Policymaking Act of 2018 established new positions and leaders in hopes that these roles would collaborate and succeed in changing culture over time. This pillar focuses on developing insights for enabling an environment that encourages and empowers decision-makers and policymakers to demand evidence and for organizations to supply the data and capabilities to meet this demand.
- **Value of Accessible Government Data.** As past efforts have made more government data accessible and open, articulating the economic and practical value of that information to government and the private sector is an essential element of future success for similar initiatives. Research that allows policymakers, citizens, and private companies to better understand “why data matters” for society can be applied to understand current policies and options for future reforms.
- **Technical Capability for Improving Data Quality.** Cultural dynamics and understanding the value proposition for using data can only succeed in fulfilling the stated goals if the technical capabilities exist to enable high-quality data to be used by society. The application of targeted data standards and requirements for how data are published in particular formats based on modern technology can enhance data quality. Fostering policies and practices that efficiently enable data collection and review can similarly ensure government data are most useful for society.
- **Use of Data in a Responsible Manner.** The value of government data can only be realized if data are actually used in practice. Multiple disciplines and strategies exist for extracting value from data, including policy research, statistics, program evaluation, and data science, among other fields. In each of these domains the ability to link, combine, and share data is increasingly relevant. This pillar focuses on strategies to access and share government data as well as to ensure public trust in protecting confidential and sensitive data.
- **Future Planning for Emerging Technologies and Innovation.** New technologies are constantly emerging that change the nature of how data are collected, managed, accessed, and used. Whether privacy-preserving

technologies or approaches for enhancing transparency in data transactions, the platforms for supporting innovation increasingly rely on the development and deployment of emerging technologies. This pillar focuses on the real-world implications of emerging technologies to develop insights relevant for policymakers in adopting new approaches for government data and policy.

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Forward

When 2020 began, no one could have predicted the scope, scale, and import of the new challenges that would be posed to the United States and the American people during the year. But we could predict that data would have a central role in identifying problems, defining those problems, and supporting the formulation and implementation of solutions.

In many ways, the global pandemic and economic instability facing the United States in 2020 highlights what we have known for years: our country's data infrastructure and capabilities are ill-equipped, under-resourced, and misconfigured to provide perfect answers to every critical question as quickly as we would like. Fortunately, the ingenuity and innovativeness of civil servants, non-profit leaders, academics, and industry continues to rise to meet our collective needs in 2020, setting the stage for vast improvements and new capabilities for years to come.

The Data Foundation's Symposium in 2020 originally intended to present the latest research and plan for emerging trends affecting data policy in our country. With a global pandemic affecting nearly every aspect of our lives this year, we shifted our Symposium to focus more on timely, relevant considerations for applying the latest research in today's policy environment. Our invited speakers certainly did not disappoint, shedding light on the magnitude of the challenges we face while also offering practical solutions to plan for the future. This compendium features short essays from the invited speakers, reflecting their comments from May 20, 2020.

On behalf of the Data Foundation, its board of directors and supporters, I want to offer thanks to all of the expert speakers and participants in the Symposium who also contributed to this compendium. We also appreciate the George Washington University's Trachtenberg School of Public Policy and Public Administration for their partnership on the virtual event.

There is no shortage of room for improvement in ensuring our country's leaders in government and the private sector have the data and insights for making good decisions. Thankfully, we are making considerable progress in advancing secure data sharing capabilities, publishing open data, and organizing institutions to have the capacity and will to advance evidence-informed policymaking. We now have the opportunity to continue that trend in progress.

Nick Hart, Ph.D.
President, Data Foundation

Introduction

As modern society evolves to accommodate new state and federal legal requirements for data sharing, access, and privacy protections, a renewed focus on how to responsibly and ethically manage data has emerged. Despite increased calls for recognizing data as a strategic asset across government, there are considerable challenges for achieving this reality.

During the May 2020 virtual symposium hosted by the Data Foundation, participants learned and engaged in dialogue about developing approaches for implementing new legal requirements and satisfying expectations across the American public for applying data governance models to meaningfully use data for producing insights that benefit society. This report presents the ideas and experiences of the speakers during the symposium, adapted from their remarks.

The opening keynote, “The Potential of Naturally Occurring Data” by Katharine Abraham, former chair of the U.S. Commission on Evidence-Based Policymaking, reflected on the experiences of the commission and focused on the potential for leveraging the use of existing government data by combining it with data available from the private sector. The opening remarks set the stage for the three panelists in the opening session who focused on some aspect of data sharing, both across the federal government and between the federal government and the private sector.

The three panelists for the opening discussion presented different examples of their previous work that focused on increasing the quality of available data in order to increase the shareability of data sets and hence their utility for evidence-based policymaking. Joel Gurin’s “Data Sharing and Privacy Protection” focused on the need to establish standardized personal privacy protection in order to mitigate the threat of the release of personally identifiable information that comes from combining different data sets. In “The Need for More Effective Data Sharing Across Agencies,” Anand Parekh focused on research efforts to identify overall federal funding to address the opioid crisis as a way to address the need for data standardization. Parekh’s research identified 57 separate funding streams and established a methodology to align the available data so that information from those different funding streams could be combined in a single, useable data set. The final panelist in the first session, Charles Rothwell, presented an example of cross-agency data sharing and what he saw as some of the existing challenges in “The Benefits and Challenges of Data Sharing in Public Health.” Together the three speakers provided insights and perspectives about the barriers and limitations to using data from a technical perspective, while also offering suggestions for addressing existing technical limitations based on their experience building productive use cases.

A second keynote from a former federal Chief Data Officer, Kris Rowley, shifted the discussion focus from technical issues to organizational capacity. In “Connecting Data Governance Across Levels of Government,” Rowley identified three main components required for successful executive data governance: (1) working with organizational leaders to establish information needs to drive data driven decisions, (2) working across

functional areas, program offices, and domains to establish data standards and business definitions at the data element level, and (3) establishing a data steward community that facilitates the exchange and sharing of data.

The last panel of the symposium focused more generally on how to encourage and grow an organizational culture conducive for evidence-based policymaking. Each panelist provided their perspective on strategies for engaging in organizational change management in developing a data-driven culture within federal agencies. In “Lessons from Establishing an Evaluation Office,” Demetra Nightingale elaborated on her experience building the evaluation function at the U.S. Department of Labor, with focus on a three-pronged strategy of coordination, collaboration, and capacity building. Terrell Lasane took a more phased view of steps to ensure that the Chief Evaluation Officer, Chief Data Officer, and Chief Statistical Officer can align throughout the different steps of developing a more data driven organization in “Phases to Creating a Culture for Evidence-Based Policy.” Kathy Newcomer’s “Trust as Essential to Establishing an Evidence Culture” returned to some of the themes of Rowley’s keynote address about how to create a value proposition for building on the Evidence Act and establishing a culture of evidence-based policy and data-driven decisions.

Opening Remarks:

The Potential of Naturally Occurring Data

Katharine G. Abraham

Former Chair, U.S. Commission on Evidence-Based Policymaking

Professor of Economics and Survey Methodology at the University of Maryland

The world has changed a great deal even in the short time since this event was planned. One of the consequences of the pandemic currently afflicting the nation is a great need on the part of federal, state and local decision makers for data and evidence to inform the urgent decisions they must make. Decision makers need *timely* and *granular* information about what is happening to both health (number of people infected with the coronavirus, how they are faring) and economic activity (employment, job destruction, job creation, hours, wages, sales). Without that sort of information, it will be impossible to figure out how government responses are affecting key health and economic outcomes. Researchers both within and outside of government are working hard to provide needed evidence as all of this unfolds. Though there are other examples one could cite, our current experience with COVID-19 provides a dramatic illustration of the importance of having appropriate data and evidence to guide the government’s policies and operations.

Across the Federal government and elsewhere, there are people who have long been working in the trenches to improve the evidence base for policy. After years of what have been sometimes lonely efforts, there have been some positive recent developments. Many have pointed to the creation in 2016 of the bi-partisan Commission on Evidence-Based Policymaking as an inflection point of sorts. A big part of the

impetus for the creation of the Commission—and an important focus of its deliberations—was the recognition that lack of access to necessary data, even where those data already exist and are held by the government, has been an impediment to generating evidence about programs on an efficient and ongoing basis.

The Commission's final report contained findings and a set of 22 recommendations, all endorsed unanimously by all 15 members, in three primary areas:

1. Improving access to data for approved evidence-building projects, including program evaluations but also the development of statistical data series that can inform policy and program decisions;
2. Modernizing and strengthening privacy protections for data used in evidence building; and
3. Strengthening the Federal government's capacity for evidence building, through measures such as the appointment of Chief Evaluation Officers, the development of agency learning agendas, and the provision of sufficient resources to support evidence building activities.

Thanks to the strong support of then-Speaker Paul Ryan and Senator Patty Murray, many of the recommendations in the Commission's report were incorporated into legislation ultimately passed by both houses of Congress as the Foundations for Evidence-Based Policymaking Act of 2018. Though there is still much that remains to be done, that legislation contained some enormously important provisions. Among other things, the Act:

1. Clarifies that, unless otherwise prohibited by law, data maintained by federal agencies should be available for evidence-building purposes;
2. Directs the establishment of an advisory council to develop an implementation plan for a National Secure Data Service, an entity that would facilitate the sharing of data across agencies for statistical purposes;
3. Re-authorizes the Confidential Information Protection and Statistical Efficiency Act (CIPSEA) and requires assessments of the risk of re-identification before data are released to the public; and
4. Directs the establishment of Chief Evaluation Officer positions in government agencies and the development of agency learning agendas.

The focus of the Evidence Commission and the Foundations for Evidence-Based Policymaking Act were largely on making better use of administrative data *already collected and held by the government*. Something the Commission did *not* tackle is whether and how the government can make more effective use of the enormous amount of naturally occurring data (big data) generated in the private sector on an ongoing basis. Naturally occurring data come in many forms. They include web-scraped price and product characteristic data; scanner data from retail outlets; credit card transactions data; payroll processing firm records; sensor data such as images from satellites and traffic cameras; GPS tracking data; medical records data; Google search frequencies; Twitter content analyses; and others.

There is a broader point to be made about the contribution that naturally occurring data can make to producing statistical information, but to illustrate, I will focus on their potential role in improving economic statistics. Agencies that produce the nation's economic statistics already are making use of various sorts of naturally occurring data. For example, the Bureau of Labor Statistics uses private data to track prices in certain components of the Consumer Price Index and to make adjustments for changes in item quality; the Bureau of Economic Analysis uses transactions data from several private sources in the production of initial estimates of quarterly GDP; and the National Agricultural Statistics Service uses satellite data as an input to its crop acreage estimates.

As these agencies recognize, there is room to do more. The increased use of naturally occurring private data by the federal government could have significant advantages. These data may:

1. Be less intrusive to collect than survey, census or administrative data;
2. Provide a basis for better measures of change in the quality and variety of goods and services;
3. Provide more granular information (e.g., product, industry, geographic detail); and
4. Provide more timely information.

With all of these potential advantages, however, there are significant challenges that will need to be overcome if naturally occurring private data are to be incorporated into the ongoing production of economic statistics:

1. Naturally occurring data may not be representative of all people or all businesses, and their use will continue to require survey, census or administrative data as benchmarks.
2. There are risks associated with relying on third-party data suppliers:
 - Will the content of the data be consistent over time?
 - Will the data continue to be available?
 - What will the data cost?
3. The data may be highly sensitive, creating challenges in how they are handled, both with respect to the privacy of the data subjects and with respect to the proprietary interests of the data holders.

Despite these concerns, the present crisis brings home the potential value of integrating naturally occurring data to inform our understanding of unfolding events. Official statistics provide an overall picture that, in a normal period, would seem quite timely, but in today's environment seems both much too aggregated and much too slow. Looking at the ways in which researchers are beginning to exploit naturally occurring data to glean insights about the pattern and evolution of economic activity suggests how things could have been different. To cite a few examples of the sort of work that is underway and could perhaps lead to the regular production of useful publicly available statistical information:

- A research team at the Federal Reserve Board has used credit card data from First Data, a large payments processor, to produce near-real-time measures of spending by industry and geographic area that correlate well with published Census statistics.
- A research team at the Harvard Business School has been using data scraped from Yelp postings to study business dynamics.
- Researchers in the College of Engineering at the University of Maryland have compiled GPS location data derived from anonymized phone records to examine travel patterns—trip start and end points, trip duration, trip mode, trip purpose – and ongoing work is assessing the use of these data on trips to track what is happening to employment.

In all these cases, at least in principle, private naturally occurring data are available far more quickly and provide a far larger number of observations than the survey data collected by the federal statistical agencies. Estimates based on these new sorts of information must of course be calibrated to more representative data sources, but they offer potentially significant advantages in terms of *timeliness* and *granularity*. As the coronavirus crisis hit, it would have been terrific had we been at a point where real-time or nearly real-time economic statistics based on these or other sorts of naturally occurring data had been a resource readily available to policymakers.

I do not want to understate the challenges, already mentioned, that will need to be overcome to make the routine use of naturally occurring data for the production of economic statistics possible. Although much has been written about the fact that many of these data sources are not fully representative, this is not what I see as the most daunting challenge. Progress is being made on the development of statistical methods for addressing the representativeness issue through the integration of naturally occurring data with data from more representative sources and I am confident that approaches for producing usable statistics that incorporate non-representative input data can be developed. The bigger challenges, in my view, relate, first, to scaling the process of data acquisition from supporting interesting research projects to supporting the routine production of statistical estimates and, second, to finding ways to use the data that also ensure the privacy of data subjects.

Similar to existing approaches for the acquisition of administrative data, acquisitions of naturally occurring data for statistical exploration presently are occurring on an individually negotiated basis. In many cases, the holders of naturally occurring data view the data as an asset and are looking for a return on that asset. The question, then, is whether the process of data acquisition can be streamlined and scaled at a price the statistical agencies can afford.

In regards to concerns about privacy, I imagine many people would be unhappy about the idea of the government having access to information on their credit card spending or travel histories. The challenge with regard to those concerns is whether there are ways to share information for statistical purposes while providing assurance to data subjects that their privacy is being protected. There are approaches that could work well—e.g., data facilities where computations can be done in a secure environment with only the

results passed along; secure multi-party computing, with the data never leaving the premises of the original owner and only aggregated estimates shared—but it is not yet obvious how best to address this problem.

Businesses have been able to figure out how to use the wealth of information they have about us to market their goods and services. I very much hope we can find a way to use some of that same information—and other naturally occurring information—to better inform the important decisions that must be made in the interest of the public good. Although there are certainly challenges to be overcome, I am optimistic that we will be able to do so.

Value of Data: Cases from Public Health that Demonstrate Why High-Quality, Accessible Data Matter

The following section provides perspectives from three panelists, describing technical challenges and opportunities to overcome barriers for data sharing and use. Each offers perspectives on valuable use cases, from the panel discussion moderated by Rashida Dorsey from the U.S. Equal Employment Opportunity Commission.

Data Sharing and Protecting Privacy

Joel Gurin

President and Founder, Center for Open Data Enterprise

The Center for Open Data Enterprise, or CODE, is a nonprofit organization located in Washington, DC founded in 2015 with a mission to help maximize the value of open government data for the public good. Over more than five years we have held dozens of roundtables with the White House and numerous federal agencies, bringing them together with the people and organizations in academia, business, and the nonprofit sector who rely on federal data. Recently, our work has focused largely on the need for high-quality, accessible data for public health.

Since 2018, CODE has worked with the U.S. Department of Health and Human Services (HHS) and their data users to find new opportunities to apply public and privately held data. We are seeing an explosion in the use of different kinds of health data and the rapid development of sophisticated analytical techniques that can use data to improve prevention, diagnosis, and treatment. There are new opportunities to bring together clinical data, genomic data, and patient-generated data, such as information that people may volunteer about their health for research studies, or from wearing a FitBit. Equally important are data about the social determinants of health, such as income, education, environment, and neighborhood factors that have an increasingly clear impact on individual and community health and illness.

There are also new opportunities to use artificial intelligence (AI) and machine learning to bring together these diverse kinds of data for potentially lifesaving insights. To give you one example, CODE has worked closely with the population health management

company ZeOmega to apply both public and private data sources to address the opioid epidemic. ZeOmega manages medical claims for tens of millions of individuals, which they can analyze in accordance with the protections for privacy around health data. They are finding that they can detect patterns that predict whether an individual is at risk for opioid overdose, by looking not only at strictly clinical factors but at social and behavioral factors as well. For example, they find that the number of visits to the emergency room in a 12-month period is a stronger predictor of opioid overdose risk than a person's prescription medicine history. With that information, they can connect with the health plans that are their clients to design clinical interventions to prevent opioid overdoses.

In our work with HHS on other diseases, we are seeing ways in which novel approaches to data gathering and analysis are emerging as important strategies. For Lyme Disease, there is a tremendous need to accelerate research, because conventional double-blind clinical trials may be too slow for people who are severely impacted and have no alternatives. To help support rapid research, many patients are volunteering blood and tissue samples to go to a biobank for research purposes. With Sickle Cell Disease, there is a lot of interest in the idea of a national patient registry, which could be helpful, for example, for patients who need to demonstrate that they have the disease when they go to the emergency room.

Across all areas of health care – and most recently for COVID-19 – there is a great need and opportunity in the use of data on social determinants of health. Some public health experts have said that your ZIP code may be more important than your genetic code in determining your health. Several groups at HHS, including the Office of Minority Health, are now looking at social determinants that may help explain the very high risk of COVID-19 in minority and low-income communities. Understanding those social factors could pave the way for new interventions to improve prevention, diagnosis, and treatment.

All these advances can only happen if we can figure out how to share health data appropriately and safely. Privacy concerns are a particular conundrum. We know that medical data and data on health-related factors is especially valuable at a granular level: The whole concept of personalized medicine is based on the use of individual data in medical care. But the more granular and individualized the data, the greater the privacy risk.

CODE has had a chance to explore these issues in depth through a two-year project on health data. The project was funded by the Patient-Centered Outcomes Research Institute (PCORI) and conducted in collaboration with the HHS Office of the Chief Technology Officer. It included a series of roundtables, briefing papers, and reports and recommendations that are available at the publications tab of www.odenterprise.org. Privacy was a theme throughout this project, and we had some unexpected findings about attitudes to health data privacy. There is a growing understanding that there is not going to be a technological magic bullet to anonymize or de-identify personal health data with 100 percent effectiveness and no loss in data value. Instead, we will need to look at tradeoffs and creative solutions that respect patients' rights while enabling

researchers to do their jobs. This may include approaches like data enclaves, new initiatives like All of Us and the Million Veteran Program that enable patients to volunteer their own data, and quite possibly reforms to the Health Insurance Portability and Accountability Act (HIPAA) that governs health data privacy.

We saw a striking example of the need for new approaches in our roundtable on data to fight the opioid epidemic, which we held with HHS in mid-2018. We had participants at that roundtable who represented non-profits, communities, and state governments as well as the federal government. Across the board, all these stakeholders were concerned about a particular privacy regulation called 42 CFR Part 2. This regulation was meant to offer special privacy protection for opioid users, out of concern for the risk that they could be stigmatized. But the roundtable participants believed that 42 CFR Part 2 did not actually provide any real protection beyond what is provided by HIPAA, while it had the unintended consequence of making research on the opioid epidemic very difficult to do. HHS is now considering changing this regulation and is looking at potential changes to HIPAA as well.

The lesson is that while individual privacy is very important, it is possible to go too much in the direction of blanket privacy protections that don't allow for appropriate research uses of data. This is going to be a big issue as we continue research on COVID-19, where we are seeing privacy concerns around contact tracing or efforts to analyze data from different kinds of datasets. It is a tricky situation where we have to balance privacy protection with public good. But we have an increasing number of examples to draw on from across healthcare that can help us all chart that course.

The Need for More Effective Data Sharing Across Agencies

Anand Parekh, MD

Chief Medical Advisor, Bipartisan Policy Center

In 2019, the Bipartisan Policy Center (BPC) released the first comprehensive and transparent analysis of federal funding provided to states and localities to address the opioid crisis. Given that there had been no standardization in data definition and data collection around federal funding, BPC designed a methodology to determine the amounts, destination, and purpose (e.g., prevention, treatment, interdiction) of funding for Fiscal Years 2017 and 2018 by reviewing Congressional appropriations and their explanatory statements, agency spending, and www.USAspending.gov data. BPC identified 57 different federal funding streams accounting for \$11 billion over the two fiscal years. Two-thirds of funding came from agencies of the Department of Health and Human Services. BPC also conducted in depth state case studies demonstrating that funding is largely going to areas experiencing the highest number of overdose deaths. An analysis of Fiscal Year 2019 data is currently on-going and will be released in September 2020.

As part of the methodology, BPC needed to make a determination as to which funding streams should be included in the analysis as well as on their categorization based on purpose. BPC relied on expert judgment in its determination and provided a baseline for

future analyses. Following release of BPC's report, the Department of Health and Human Services (HHS) released an Opioids Grant Dashboard which had a similar aim although it was limited to one department.

These types of analyses are critical so that we can ensure that federal investments are being effectively targeted to the communities most affected and to those with the highest overdose deaths. An effective response requires policymakers to know how resources are allocated and to use that information to minimize duplication and maximize the efficiency of limited resources. Unfortunately, this type of analysis had not been conducted prior to BPC's project.

Access to data is critical to evidence-based decision-making especially during public health emergencies. We are seeing this right now with respect to COVID-19. For example, we now know that health inequities are driving a disproportionate number of cases and health disparities are driving a disproportionate number of deaths. Early on, the country did not have a good appreciation of this finding because of a lack of racial and ethnic subgroup data.

With respect to overall data on the trajectory of the epidemic, many experts have relied on private sector data for real-time tracking as opposed to federal sites. For example, the Johns Hopkins Coronavirus Dashboard, the COVID Tracking Project, and the COVID-19 Impact Survey have been invaluable to keep abreast of data such as the number of daily COVID-19 tests nationwide, the positivity rate by state, and the impact of the pandemic on the population. While private sector leadership is helpful, it does beg the question of the role of the federal government in equipping policymakers and the public with the evidence and the data needed for their decision-making.

One critical COVID-19 debate over the last several months has been how quickly to loosen social distancing interventions. In early May, most states started lifting their stay home orders although very few actually met the White House's own gating criteria. Many did not have transparent data and when they did, some chose to ignore their own metrics. Many states were also slow in reinstating social distancing restrictions when it was apparent that COVID-19 cases and hospitalizations were steadily increasing. This speaks to the importance of adhering to a data-driven approach.

Finally, federal leadership around data standards and data collection are so important not only during public health emergencies but also in tackling our most challenging public policy issues. Many of these issues require the actions of multiple stakeholders, and thus at the federal level, the role of the Office of Management and Budget to help with federal data coordination is so important.

I believe both sides of the aisle would agree that one of the core functions of government is to support the most vulnerable populations in this country. All Executive Branch departments support vulnerable populations, whether it is through health insurance or public health programs at HHS, nutrition feeding programs at the Department of Agriculture (USDA), or housing assistance programs at the Department

of Housing and Urban Development (HUD). In many cases, similar populations are being served and yet data are very often siloed within individual departments.

At BPC, we have looked at the intersection of data between these departments, and there are many opportunities for partnership. For example, there is considerable overlap between Supplemental Nutrition Assistance Program (SNAP) participants and Medicaid beneficiaries. Could data-driven efforts between the departments support the decision making of SNAP recipients leading to more nutritious choices, better health outcomes, and lower healthcare costs for the Medicaid program?

As another example, the majority of HUD assisted facilities for older adults are comprised of dual (Medicare and Medicaid) eligible residents with multiple chronic conditions. How could data partnerships between HUD and HHS support the health of these vulnerable individuals to improve outcomes and reduce preventable healthcare costs?

These are the types of questions we could answer with more effective data coordination. Together with more well-defined, reported, and centralized data collection, we will be able to engage in better and faster analysis and evidence building about what works and in what context. From a public health perspective, this can help save lives and improve the quality of life of Americans.

The Benefits and Challenges of Data Sharing in Public Health

Charles Rothwell

Former Director, National Center for Health Statistics

There is a lack of information to make informed surgical-like decisions during this COVID-19 pandemic. It is not just a problem of antiquated systems which are indeed inflexible or not nimble enough to focus on an unanticipated crisis or in this case one we hoped would never come. It is also a problem of siloed thought about data. As we are learning the hard way during this crisis, we are a very connected society dependent on one another for so many services and things of everyday life which we have taken for granted. In that vein, health data is not just about health but the social milieu we find ourselves living in. It is a very connected web of economics, travel, employment, life expectations, living conditions, social status all impacting on our mental and physical health. Health data must be more than just data on health. We must create a connected and protected data environment to bring our existing data together. We need to connect our data just as our society is connected in order to provide the information we need to make policy decisions that actually help and minimize unintended negative consequences of those decisions.

One of the efforts I am most proud of over the years has been the data linkage activities of the National Center for Health Statistics (NCHS). NCHS has linked its survey data to Medicare and Medicaid data as well as data from SSA which in a way could provide a passive longitudinal look at the health of the elderly and economically challenged.

NCHS has worked with the Department of Housing and Urban Development (HUD) by linking its large in-person health survey, National Health Interview Survey (NHIS) and its physical measurement survey, National Health And Nutrition Examination Survey (NHANES) with data on recipients of housing support through HUD. One of the many findings was that children whose families received HUD support had significantly lower blood lead levels than other children of families of comparable socio-demographic backgrounds. It is not just about housing ... it is not just about health ... it is about the intersection of the two.

Yet as proud as I am of this activity, there is a significant problem. It is a one-off effort. It took us years to do the HUD study and the data from linkage with Medicaid and Medicare and SSA are old and not regularly updated. Agencies are not used to, and in many cases abhor, sharing data with each other. Data sharing is not a natural occurrence and thus does not propagate easily. It is not just a systems problem; it is an inappropriate parochial and siloed mission problem within all our agencies. It is a virus not of quick spread, but of quicksand which keeps agencies hunkered down and not building bridges for the betterment of our citizens. COVID-19 has made it clear that health risk and economic risk are inextricably intertwined, yet this was known before! Just a few years ago we had inadequate data to make quick and precise decisions after the natural disasters in Puerto Rico, Texas, and in Paradise CA, but we did not learn from that and we now face and even greater disaster ahead.

There is hope though, for example the Data Foundation worked with NORC to create a survey called the Covid Impact Survey which will report on the physical, mental, and economic health of the American people during the COVID-19 shutdown. And now the Federal Statistical System has come together through what is called the Household Pulse Survey conducted by the Census but a shared activity across the statistical agencies looking at the health both physical and economic of Americans. Also, the Bureau of Labor Statistics (BLS) has added COVID-19 related questions to the Current Population Survey (CPS). But this is still not a natural move in government, yet it should be especially with the passage of the Evidence Act of 2018 and with the current Administration's management agenda of bringing the availability and use of data to the forefront instead of as an afterthought.

Going back to the problem at hand, the lack of data sharing at the national level has a direct impact on those at the local level. Not only are we not providing them with responsive, understandable and useful data for their specific communities, we are actually hurting them by our siloed thought and systems. The agencies supplying the data to these siloed Federal agencies are often the same local data providers dealing with different systems of different agencies which like their agencies do not share data and do not provide useful data back to them for action. For example, for the local Medical Examiner certifying a death, their case management system of the does not share needed data with the electronic death registration system recording the death and many times the certifier does not have access to or is not able to push data from the patient's electronic health record to case management system or the death registration system. Is it any wonder that we do not have as responsive and complete information on COVID-19 related deaths?

Now more than ever we need to look beyond our professional domains. As we are linked together in our society providing for each other, so do our systems and data need to be linked together safely and responsibly in a trusted and protected environment for the betterment of our society. While there are legal and ethical issues that have to be accounted for to ensure the protection of Personally Identifiable Information (PII), at the very least our data need to be constantly linked at the geographic level to provide us with a better grasp of community needs and to take appropriate action at all levels of government. We have the legislation; we have the technology; but do we have the will?

Keynote Remarks:

Connecting Data Governance Across Levels of Government

Kris Rowley

Chief Data Officer, Conference of State Bank Supervisors

Former Chief Data Officer, General Services Administration

Advisor Director, Data Foundation

Typically in talking about data management we focus on two issues – data management and the technical issues involved and leveraging that data for analysis and decision making. In this presentation, three key components to successful executive data governance are broadly identified: (1) working with organizational leaders to establish information needs to drive data driven decisions, (2) working across functional areas, program offices, and domains to establish data standards and business definitions at the data element level, and (3) establishing a data steward community that facilitates the exchange and sharing of data.

The needs for these three key components are being driven by several factors. First, executive expectations for real-time transactional data is increasing rapidly. Second, technology advances are making it possible to create rapid and secure system-to-system connections, but data standards are essential in making them work. Third, the democratization of data is creating cross-function data analytics teams that are driving consolidated information management. Fourth, machine learning and artificial intelligence need high-quality data to perform. Finally, transactional-level reporting at the local level is being aggregated for state and national policies right now. But there are also barriers involved in proceeding down this path. There are a lot of actions will have to be taken in order to make this work well. States and the federal government all have laws, rules, and regulations regarding data collection that are not consistent. State and federal laws will likely need to be adjusted to create greater data standardization across many domains, as will the technological infrastructure that will ensure the ability of different systems to communicate and exchange data in order to fully benefit from increased data integration. States also have different laws, rules, and regulations regarding the protection of privacy and Personally Identifiable Information (PII). Data security standards at both the systems level and the individual level will need to be made stronger and more universal. These are only a few of the issues that will have to be addressed in the long run.

Within this general framework, I focus in on the central question of “How do CDOs add value?” The central theme that runs through these solutions is to engage and help drive organizational change management through the three key components of successful executive data governance restated below:

- Facilitating discussions to help determine and prioritize areas of focus based on value and need.
- Helping to differentiate between cultural issues versus technological challenges and mediate solutions.
- Driving more centralized and reuse of analytics and models to promote consistent use of information by leadership.

We can use a baseball analogy to show an example of data standardization that works. One consistent measure of baseball success has always been the batting average. It works because its components are all well-defined. It also works because the same definition is used world-wide at all levels of the sport.

The question is – “How do CDOs make data sharing and integration work?” A simple first step is to work to establish a formal network between local, state, and federal CDOs. At the federal and state levels networks within those levels of CDOs have been developed. These networks, especially when developed across the different levels of government will allow the governmental CDO community to develop best practices both for their particular level of government as well as best practices that will increase the ability to share data and evidence across the different levels of government.

The next steps are for this network, working across the different levels of government, to focus on solving *very* specific data standardization issues that exist today and are known issues. They should consciously not try to do it all and focus on those specific known issues that may vary in complexity but can be solved. Finally, working within and across the networks of CDOs will help to prevent a duplication of efforts to solve the same problem.

We are making initial steps towards improved data use and sharing within the federal level and across the federal, state, and local levels. The federal government has established a Council of Chief Data Officers as required by the Evidence Act. At the state level, there is a State Chief Data Officer Network based in the Beeck Center for Social Impact and Innovation that has about 25 members. Several cities have CDOs and there have been some efforts at establishing a network of CDOs at the local level. In the future, we should establish a working group of federal, state, AND local Chief Data Officers. A chief goal of that group to start could be to identify specific functional areas that are lacking data standards and governance across the various levels of government. Collectively, this group can start to develop the value proposition for working together, gaining momentum and support to begin solving the problems of increasing data standardization and sharing. There is not a lot of consistency in the definition of what a CDO should do or who they should report to. Learning from each other this network could begin establishing standard roles and responsibilities that are important foundations for CDO success as well as improving data quality and usefulness.

Next Steps for Building the Evidence Act's Intended Culture

The following section provides insights from experts in organizational capacity for data and evidence, offering perspectives about how such evidence-building capacity and culture can be achieved in practice. The panel discussion was moderated by Joe Willey from the Data Foundation.

Lessons from Establishing an Evaluation Office

Demetra Nightingale

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Former Chief Evaluation Officer, U.S. Department of Labor

Building an evaluation office in a federal department requires a multi-faceted approach. At the Department of Labor (DOL), the position of chief evaluation officer (CEO), with Dr. Jean Grossman serving in that post for about a year. The decision to have such a position to elevate the emphasis on and use of high-quality independent research and analysis was made by the Secretary and Deputy Secretary and top officials at the White House and the Office of Management and Budget (OMB). I succeeded Dr. Grossman and served for five years, during which time we were able to staff the office with professional evaluation specialists, expand the learning agenda and evaluation planning processes, and develop an evidence infrastructure in the department. Congress also appropriated specific funds for departmental evaluation purposes and provided the Secretary with authority to set aside funds that could be used for evaluation. The development of the office and the role of evaluation were, therefore, possible because of the support, authority, and resources provided by Congress, the Secretaries, and Deputy Secretaries of Labor and OMB.

The CEO at DOL is responsible for building a culture of evidence at the department. This involves coordinating evaluations throughout the department, raising knowledge and understanding about evaluation and research, initiating rigorous high-quality program evaluations, and collaborating with the performance management and statistical agencies around access to and analysis of quality data. That is, institutionalizing a culture of evidence required coordination, collaboration, and capacity building.

Under coordination, efforts were focused on working together across the department to improve the rigor of evaluations and to increase the number of high-rigor evaluations. With dedicated funding CEO was able to initiate many evaluations directly, as well as coordinate with sub-agencies that also had authority and budgets for research. Strategic learning agendas developed with each of the sub agencies helped identify priorities for studies, gaps in evidence and knowledge that should be filled with new studies, and possible cross-program and cross-agency evaluations.

Collaboration was also important. It was important that the independent evaluation office and the evaluation specialists were not viewed as totally separate from the operational and administrative functions of the department, but that the evaluations and

evaluation-related activities could inform program and management functions and decisions. For example, while the CEO, performance management, and budget preparation were in different offices, we developed processes that ensured that the functions were aligned and that evaluation and evidence were considered when developing performance, strategic, operating, and budgetary plans. At DOL, this same collaborative approach involved aligning statistical and data activities with evaluation, particularly with the Bureau of Labor Statistics. In 2013, the CEO also established the Data Analytics Unit, staffed with highly skilled statisticians who collaborated with programs and agencies to improve the use of administrative data for analytic and evaluation purposes. That unit has now evolved into the office of the Chief Data Officer, a position required by the Evidence Act.

To continuously build evaluation capacity, we worked hard at improving data quality, increasing evaluation knowledge, and expanding access to and use of evaluation results. One of the first things we did was to develop an evaluation policy for the whole department. We adapted and learned from the evaluation policy statement of the Department of Health and Human Services Administration on Children and Families. The five principles in the DOL evaluation policy statement were established to guide all evaluation-related activities in the department: rigor, independence, relevance, transparency, and ethics. The policy statement was not simple to develop, requiring all agency heads to sign off through the formal clearance policy. Their full support was critical, ensuring it became official departmental policy. That policy statement is still in effect. And it is also one that is now incorporated into the implementation of the Evidence Act.

Finally, one of the most important capacity-building efforts at DOL was the development of the evidence-based clearinghouse called Clearinghouse for Labor Evaluation and Research (CLEAR). Like other federal evidence clearinghouses, such as the Department of Education's What Works Clearinghouse, CLEAR has established high methodological standards and expectations for evaluations, including rating of the quality of the studies.

Not all research is high quality. Having transparent standards and publicly available ratings of studies makes it much easier to identify evaluation findings and results that can be reliable and can be trusted. Having reliable and credible findings that can be used to improve public policy and program results is the real reason for doing evaluations. CLEAR serves that very important role in the evidence infrastructure of DOL.

I build upon the work we performed at DOL in my current position at the Urban Institute with the Federal Evaluation Forum where we are providing workshops on federal evaluation issues. The subject matters for these workshops range from the creations of learning agendas to evaluation methods and have started to engage in targeted Training/Technical Assistance engagements to leverage the lessons learned at DOL for other federal agencies.

Phases to Creating a Culture for Evidence-Based Policy

Terell Lasane

Assistant Director, Center for Evaluation Methods and Issues, Government Accountability Office

When OMB released M-14-06 in 2014, it described a process for how data assets could be used to build a stronger base of evaluation evidence for a more effective and efficient government. The excitement around that idea was recently given more gravitas with the recent passage of the Evidence Act and the OPEN Government Data Act. The excitement behind this movement is largely tied to the idea that using data assets (administrative data and what Katharine Abraham described as naturally occurring data) would allow agencies to assess program impact as well as other types of evaluation questions: evaluability assessments, needs assessments, process evaluations, customer experience evaluations, and summative/outcome evaluations. From all of my experiences as an evaluator for the last 26 years in local, state, and the federal government, I am excited by these possibilities. However, I am also with guarded and qualified optimism.

The Evidence Act emphasizes collaboration and coordination among three key players – Chief Evaluation Officer, Chief Data Officer, and Statistical Official – who work in tandem to create solid evidence. I contend that the coordination among these three stewards is *critical* to the success of the legislation's promise. And when I talk about solid evidence here, I use the criteria for high-quality evaluations widely cited in the evaluation field: transparency, independence, ethics, relevance, and rigor.

Phase I: Learning Agendas, Personnel, and Planning Advance Transparency, Relevance, and Rigor

The Evidence Act suggests a thoughtful and logical sequence of activities to achieve the formation of a desired evidence culture. In phase 1, the Chief Evaluation Officer leads agencies in systematically formulating relevant evaluation questions tied to their strategic priorities. The planning process of identifying these questions should be transparent. Evaluation officers must convene the influence of key stakeholders: senior leaders/decision-makers, program staff, program customers, evaluation experts, and data experts.

Evaluation culture can only be built if the most relevant questions that are to be used for program improvement are asked. I caution that those individuals in these positions should ensure that the best questions are asked *before* examining the availability and the quality of the data. If this happens in the reverse order, I believe that there will be natural trap to build evaluation questions that are data-driven and not driven by the program's theory of change or *a priori* as it should. The Chief Evaluation Officer defines relevance, but this individual should also promote transparency, independence, and rigor. The undue influence of asking ideologically driven questions over empirically driven questions of strategic importance should be primarily guarded against by the

Chief Evaluation Officer. I recommend the use of program logic models and learning agendas created by multi-stakeholders to scope questions that are relevant.

Phase 2: Open Data Access and Management Promotes Transparency, Relevance, Ethics, and Rigor

In phase 2 of the Evidence Act, Chief Data Officers (CDOs) will take the lead. The CDO should determine the following: (1) what data are available and (2) are data of sufficient quality (i.e., are the data assets valid and reliable indicators of the information sought out by programs)?

CDOs must also ascertain that all safeguards have been employed to ensure that there are no violations of privacy and confidentiality. Data assets must be managed carefully in the exercise of the modernization of privacy that the Evidence Commission has carefully addressed. Agencies that have successfully navigated the modernization of privacy do so with the custodians of program data—often effectively done so as a part of data communities of practice. These officials also help to guide the development of system security plans, secure platforms for sharing data and transmitting data, and the creation of memoranda of understanding with the Offices of General Counsel when data are analyzed by independent entities.

Because independence is a feature of strong evaluation work, the CDO should encourage program staff to create comprehensive data dictionaries so that data analysts/statisticians analyze these data with a complete understanding of the data's strengths and limitations. These practices ensure transparency, bolster relevance, and uphold ethics. They also advance the rigor of evidence, as the quality of the evidence cannot be greater than the quality of the data used. I will say that this is a particular challenge of federal data sets in my experience because voluminous amounts of data are collected, but often these data are incomplete, of poor quality, lack face validity, are not tied to performance management goals, and are housed in databases and within archaic data systems that few in the organization understand.

Phase 3: Data Access for Statistical Purposes Promotes Rigor, Independence, and Transparency

The third phase of the Evidence Act involves the use of the data identified for statistical purposes. A Statistical Official works closely with the Chief Evaluation Officer and Chief Data Officer to ensure that the statistical analyses required to answer the evaluation questions are conducted with statistical validity. In designing evaluations, methodologists attend to internal and external validity. Statisticians attend to statistical validity. As data assets are used, the Statistical Official must make sure that the data analyses are defensible and are being independently conducted by technically-qualified analysts using the most rigorous analyses free of undue influence in the messaging or suppression of results. Kris Rowley talked about predictive analyses that tell a good story at the Executive level.

Phase 4: Coordination Is the Critical Element for Program Evaluation

Although these roles and responsibilities are spoken about in phases, I contend that it is only when all of these elements are undertaken with a great deal of foresight, coordination among key stewards, and with leadership buy-in that the evaluation evidence resulting will meet the criteria for high-quality standards. This will build the culture intended by the Evidence Act.

So, my guarded and qualified optimism is formulated with this concern: If these phases are done in silos without intentional coordination, I do not believe that we will be able to optimally build the culture intended by the Evidence Act and the OPEN Government Data Act.

With that said, I am very encouraged by the guidance for the Evidence Act issued by the Office of Management and Budget as well as efforts by the American Evaluation Association, academic researchers, thought leaders—many of whom are assembled here today—non-profits, NGOs, and others in the evaluation community. I am especially excited about the resources currently offered and being updated by my team at the Center for Evaluation Methods and Issues (CEMI) in the Applied Research and Methods Team (ARM) at the GAO, and by the Strategic Initiatives Mission Team at GAO.

Trust is Essential to Establishing an Evidence Culture

Kathy Newcomer

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Beyond the “box checking” of establishing the components and infrastructure required by the Foundations for Evidence-Based Policymaking Act and OPEN Government Data Act, creating an evidence-receptive organization requires creating the value proposition for such a culture and its ability to thrive.

There are two main components to making this value proposition – evidence building and trust building. Evidence building requires establishing the key components and infrastructure needed to provide the evidence, but it also entails increasing the motivation necessary for organizational leaders to embrace a culture to help evidence-informed decision-making grow. We need to build the demand that people, the leaders in government, have to address useful questions and come to the providers with their questions. We need to coach those leaders and help them. We also need the infrastructure of the people to collect the data, and to analyze data.

In order to build both demand and supply for evidence to inform decision making, effective knowledge brokering is needed. You need respected leaders who perform intentional strategic knowledge brokering in an organization, develop the questions, and figure out how to construct the answers. For example, the new “Learning Agendas” required by the Evidence Act need to be centrally and strategically developed for each organizational entity by their respected and skilled knowledge brokers. Evaluation

capacity is needed to develop and answer key questions about what the organization is doing and what difference it makes. And that's why evaluative thinking skills – such as framing the right questions to address, and coaching leadership to help them appreciate why and how they can use evidence is so important.

And secondly, trust building is needed to establish and maintain stakeholder buy-in. Trust building can be helped by the stature of the leaders trying to develop an evidence-based culture, but it always requires a collaborative style of leadership. A second piece of trust building is showing concrete examples of progress. Here, the first step is building a useful learning agenda for an organization. A learning agenda requires refining the key evaluative questions that leaders want to answer. What data are needed to answer these questions? What are the theories of change that underlay programs and policies that we need to flesh out? What are the managers' decision making behaviors that we view as important to inform? That is the evaluative value proposition that the Evaluation Officer needs to build on and demonstrate their important role as the key knowledge broker who can work very closely with the Chief Data Officer (CDO), Statistical Official, and Chief Information Officer, among other organizational stakeholders.

Speaking of trust, clarity in roles in evidence building is certainly needed to implement the Evidence Act effectively. For example, the CDO and Evaluation Officer are not the same thing. The CDO is the lead for data brokering; and needs to reach across government agencies and across levels of government, as well as the private sector. Data brokering is extremely important. And data are needed to answer important questions from the Learning Agendas, and that's where data and knowledge brokering meet. Evaluation Officers can ensure we ask not only, "What do we need to know tomorrow?" but "What do we need to know in the next three or five years? A CDO can make sure that needed data are available for answering short-term questions. The Chief Evaluation Officer can help raise and address longer-term knowledge brokering questions.

Cultivating an evidence-receptive organization entails building both motivation and infrastructure. And you cannot get the motivation without the trust building, as well as the data, the data analytics, and the ability to share data. To be able to make linkages between data across agencies and across our federal inter-governmental system is not easy. When I teach about federal policy implementation, I use a pinball machine and suggest that federal policies are like the ball that is released at the bottom. By the time you involve state and local governments and the non-profits that may be involved in the very complex network of service providers in our country, policies and programs may evolve quite differently than anticipated. Implementing policies and programs in our federal system is not for the faint hearted - it is hard and taxing work!

Organizational change management is difficult. Establishing an evidence-receptive culture requires a great deal of trust building both up and down the levels of any organization as well as outwardly to other stakeholders. Trust building can only be established through a great deal of time and effort. It also requires substantial amounts of open and honest communication. Sometimes implementers are worried the data are

going to make them look bad, or that they're going to be used to make their program look bad. These are the kind of issues that take time to address. Having data standards that allow data to be shared and shows how they will be shared is an important first step. In the end, the value proposition of establishing an evidence-receptive organizational culture means that we need to make people less scared of data and more receptive to being informed by evidence.

Conclusion: A Roadmap for Progress in the Data Ecosystem

Nick Hart

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During the Data Foundation's May 2020 symposium, speakers presented the benefits of using data in decision-making along with the persistent challenges for using data to support evidence-informed decision-making. Despite the production of valuable case studies, existing limitations challenge the capabilities to make data use low-cost, efficient, and timely. Katharine Abraham's experience with the Evidence Commission and expansive perspective that alternative data sources offer potential for improving statistical activities highlights the need for continued innovation and capability to acquire and access naturally occurring data. In doing so, data sharing capabilities can provide new opportunities for generating insights that increasingly use multiple data sets and may not be achievable through the use of individual data sets.

While the technical barriers to data sharing are well recognized, achieving the potential benefits means certain technical capabilities must exist. For example, speakers addressed themes related to accessing, linking, protecting, and even standardizing data. While well-understood, these technical barriers continue to challenge efforts in federal agencies, industry, and the research community to access these potential benefits. In order to access them requires intentional efforts to address barriers and establishing enabling conditions for data sharing and use.

Addressing the technical conditions is an aspect of building, organization, and sustaining a culture that promotes effective data management and use practices. The institutional capacity to create and use evidence is a complex, multifaceted endeavor. Former CDO Kris Rowley's framework to identify need, establish collaboration, and build a community shows the need to create an environment that requires both organizational- and individual-level demand and supply for data and evidence. Reinforced by other speakers, Kris' framework shows that the knowledge, skills, and abilities of individuals within an organization, as well as supportive leadership and adequate resources operate nested within an ecosystem built on trust are all required to build a sustainable evidence-based organizational culture. The varied baseline of organizational capacity suggests an iterative and customized process for building capacity that may vary by organization, with no single script or pathway to success. Yet, common core components exist for capacity to be sustained over time.

To overcome the complexities and challenges faced by organizations and individuals promoting more evidence-informed decision-making or data-driven government, some steps are clear and provide an immediate roadmap for creating conditions necessary for progress.

1. ***Organizational leaders must prioritize and commit to establishing enabling conditions for the data ecosystem.*** Little happens within organizations without buy-in from leaders who have the capability to set tone, expectations, and goals. Organizational leadership committed to building and sustaining the data ecosystem means the presence of champions for all other factors. Identifying and empowering such champions in government and the private sector alike, through Chief Data Officers and Evaluation Officers, offers the promise of a new capability and dedicated leaders to prioritize long-overlooked gaps in capacity.
2. ***Organizations and individuals must allocate resources for effectively implementing data priorities.*** Funding, people, and capability are all central to creating the required capacity needed to support a data-driven culture. With leadership support, the allocation of time and funding to support staff with the right knowledge, skills, and abilities can help foster core capacity and growth over time. Such activities should include improved data literacy educational opportunities in addition to more technical aspects of disclosure avoidance, data protection, and data management.
3. ***Organizations must create conditions, expectations, and authorities for individuals to explore, innovate, and progress.*** The activities of conducting data linkage and rigorous analysis require technical skill. Organizations without a history of engaging in such activities need operational conditions, legal authorities or frameworks, and the expectation to pursue such efforts as a default rather than an exception. Better using data in our society to improve decision-making will continue to require innovation and technological advancement ingenuity from those inside organizations with the motivation, willingness, and skill to do so. We should continue to find strategies to empower, enable, and encourage this ingenuity.

Building a more robust data ecosystem in the United States will prove to be an ongoing activity for years to come. But every organization and agency must initiate progress now, starting with leadership, resources, and expectations. The challenges of 2020 demand nothing less of our society – that we apply our best capabilities to ensure information and insights are available to promote responsible decision-making that protects the health of the American people, improves our government’s operations, and equitably strengthens economy.

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